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CE for California Mental Health Professionals

Ethics violations occur in all professions, making the study of ethics a critical issue for all professionals. Professionals in the field of mental health face many complex ethical considerations. Managed care requires practitioners to consider issues of confidentiality, informed consent and multiple relationships with clients in a constantly changing culture with many diverse populations. In an increasingly litigious society, strict adherence to a code of ethics by all mental health professionals and their staffs is essential.

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CE for California Mental Health Professionals

Chapter 1: Ethics in Social Work and Counseling and HIPAA Privacy Rules

6 CE Hours - state required for renewal

By: Deborah Converse, MA, NBCT

Learning objectives

- Describe five primary purposes of the codes of ethics for mental health practitioners.
- Explain the five professional values and related principles that inform ethics for social work practitioners.
- Recognize and discuss problematic nonprofessional behavior that could lead to ethics violations.
- Describe ethical best practices that mental health practitioners use each day to avoid unethical or illegal behaviors.
- Identify issues of multicultural diversity in mental health practice.
- List examples of informed consent as applied to clients, supervisees and other professionals.
- Identify four factors in an ethical decision-making model.
- Explain the impact of technology and a protocol for ethical use in mental health practice.
- Identify five ethical guidelines to follow when filing, managing and storing client data covered by HIPAA.
- Describe confidentiality and privileged communication as it affects ethical practice.
- Describe two current issues that involve the ethical decision-making process in counseling.

Introduction

Those who pay attention will often see ethics violations reported in the media. Teachers, politicians, coaches, physicians, nurses, college presidents and clergy, all professionals in their field, are a few who have made national headlines recently. Ethics violations occur in all professions, making the study of ethics a critical issue for all professionals.

Today, professionals in the field of mental health face many complex ethical considerations. Managed care requires practitioners to consider issues of confidentiality, informed consent and multiple relationships with clients in a constantly changing culture with many diverse populations.

In an increasingly litigious society, strict adherence to a code of ethics by all mental health professionals and their staffs is essential.

Ethics refers to the beliefs individuals hold about what is "right." Ethical conduct refers to the behaviors exhibited by the counselor and social worker. Good ethical conduct is grounded in sound moral principles, understanding the ethical codes, and having the desire to do what is right. Morality informs proper ethical conduct and involves an evaluation of behavior based on standard expectations often influenced by culture and religion.

Laws and ethical codes regulate the practice of social workers and counselors. Professional organizations do not enforce the law; instead, laws are enforced by government definitions of the minimum standards acceptable to society.

To guide professional counselors and social workers, their professional organizations have developed guidelines in the form of a code of ethics. Recent revisions to these codes of ethics will be discussed.

The Standards for Privacy of Individual Identifiable Health Information, (the Privacy Rule) establishes a set of national standards for the protection of health information. The U.S. Department of Health and Human Services (HHS) issued the Privacy Rule to implement the requirement of the Health Insurance Portability and Accountability Act of 1996 (HIPAA). The Privacy Rule standards address the use and disclosure of individuals' health information by organizations subject to the rule (HHS, 1996).

The major goal of the Privacy Rule is to assure that health information is properly protected, while allowing the flow of information to promote quality health care and protect the public health.

The HIPAA Privacy Rule and the codes of ethics for mental health practitioners compliment each other, as both were developed to ensure privacy, confidentiality and the well-being of individuals and society.

Historical perspectives

Standards of practice and the idea of accountability can be traced back to ancient Egypt around 2000 BC as found in the code of Hammurabi (American College of physicians, 1984), which contained a description of physician responsibilities and the consequences and punishments if the patient's health did not improve.

Later, around 400 BC, the Hippocratic oath was an early example of a code of ethics to guide the practice of medical professionals and highlighted obligations to their profession, practice and patients. This oath contains many of the same values and ethical principles that we see today in current codes of ethics (Sinclair et al., 1996).

The writings of Aristotle concluded that ethics provide guidelines for virtuous action. In his rule the "Gold Mean," Aristotle defined ethical choice as one that falls between two extremes. For example, Aristotle believed that trust is a virtue that lies between suspicion and foolish faith (Stanford, 2010).

After World War II, the American Psychological Association (APA) saw the need to develop a code of ethics because of a change in the type of professional activity requested of their members. Psychologists were called upon to address the mental health needs of many soldiers returning home from the war and responsible for developing psychological assessments that would be used to determine eligibility for the draft. A committee was formed to identify ethical issues that would be effective in guiding psychologists' practice as well as their behavior. It covered such concepts as the psychologists' responsibilities when treating clients, their relationships with their clients, students and colleagues and ethical research practices (Hobbs, 1948).

Through the years, the APA and other mental health organizations developed codes of ethics and subsequent revisions to address changes in society and the needs of their clients.

One shared belief among social workers and counselors is that professionals will do the right thing or make the right decision in the best interest of the client.

Trust appears to be the common thread throughout ethical counseling and social work practice. Tremble and Fisher (2006) note that it is not an external force that directs ethical practice; instead the focus is on internal resources such as trust and respect as a foundation for the counselor/client relationship. Ridley (2001) provides an ethical decision-making model based on trust and respect in an effective counseling relationship which is referred to as "goodness of fit." The counselor/client relationship affects ethical decision-making that considers the cultural context of the relationship as applied to general ethical principles.

Confidentiality is essential in developing an effective relationship between mental health practitioners and clients. Some researchers have noted that therapy may not be effective at all without the trust that comes from confidentiality between therapist and client (Epstein, Steingarten, Weinstein and Nashel, 1977). They proposed the ideas that the therapeutic relationship must be based on confidence and trust so clients are willing to openly and honestly communicate emotions, fears, perceptions and actions. The complex, sensitive and serious nature of the information that is shared may be painful or shameful for the individual. If the client believes that this information will be kept confidential, there is a greater possibility of developing an effective relationship with the therapist and therefore a positive outcome for the client.

Over the last decade, ethical issues faced by counselors have received increased attention in counseling literature (Corey, Corey, and Callahan, 2003). Counselors are often faced with situations that require sound ethical decision-making. Determining the appropriate course of action to take when faced with a difficult ethical dilemma can be a challenge.

Codes of ethics were developed by professional associations to provide guidelines for practice by counselors and mental health professionals. These codes are designed to protect the professional practitioner, client and public. In their practice, counselors constantly encounter ethical issues and dilemmas that require decisions and should be not only familiar with ethics codes for their organization but also should know the areas and issues that are problematic for counselors.

Overview

Ethical professional behavior includes (Meara, Schmidt and Day, 1996):

- Understanding and implementing ethical codes.
- Always doing what is best for the client.
- Practicing the four core virtues: prudence, integrity, respectfulness and benevolence.
- Realizing the importance of intuition, integrity, honest self-evaluation and ethical decision-making models.
- Placing client welfare as paramount in all ethical decisions.

Moral principals

Kitchener (1984) identified five moral principles that are viewed as foundations of components that make up ethical decision-making. The guiding moral principles described by Kitchener and adopted by other researchers include the following:

- **Autonomy** – The concept of freedom of choice for the client is stressed. Counselors encourage the client to make decisions that are consistent with their values and to think and act in autonomous ways. The counselor must consider whether the client is capable of making sound choices. If the client is incapable of making sound choices, the counselor will help the client as much as possible.
- **Non-malfeasance** – The concept of "do no harm." Though this language has been recently revised, it reflects the concept of not inflicting pain on others and refraining from actions that risk harm to others.
- **Beneficence** – The counselors' responsibility to contribute to the welfare of the client by preventing harm by being proactive and attempting to benefit the client.
- **Justice** – The principle of providing equal treatment for all clients.
- **Fidelity** – Honoring commitments. Counselors must guard clients' trust and therefore not threaten the therapeutic relationship.

Ethics in counseling focuses on the ideal rather than the obligatory rules and emphasizes the character of professionals and their relationships with clients rather than on solving a specific ethical or legal dilemma. Although ethics codes speak to many issues, counselors must recognize that these codes are broad and do not cover all ethical issues faced by counselors. Professionals' ethical awareness and problem-solving skills will determine how they translate these general guidelines into professional day-to-day behavior. Welfel (2002) concludes that "ethical codes are not cookbooks for all ethical problems, and in fact, the codes are silent on many ethical issues."

Client focus

Counselors need to be aware that their focus must be on putting the client's needs before their own. Counselors must understand their own needs, areas of unfinished business, potential personal conflicts and defenses, and how this may affect the client. Professionals have a responsibility to work actively toward expanding self-awareness and recognizing areas of bias, prejudice and vulnerability.

Right of informed consent

Informed consent is an ethical and legal requirement and is an integral part of both therapeutic processes. Providing clients with information they need to make informed choices promotes the active cooperation of clients in their counseling plan. By educating clients about their rights and responsibilities, the counselor builds empowerment and a trusting relationship.

Confidentiality

Cullar (2001) conducted a study in which clients were questioned to determine what was most important to them in a therapeutic relationship. The survey revealed that the two most critical were "a feeling of safety and security" and "the chance to talk to the therapist in a safe environment without fear of repercussion." Aspects of informed consent and confidentiality included in the in HIPAA Privacy Rule will be discussed later in this course.

Today the social stigma surrounding mental illness and seeking therapy has decreased – but those perceptions still exist in some areas. In the 1996 decision by the U.S. Supreme Court in Jaffe v. Redmond (1996, p.8), the court said, "Disclosure of confidential communications made during counseling sessions may cause embarrassment or disgrace," and "the mere possibility of disclosure may impede development of the confidential relationship necessary for successful treatment."

Confidentiality is also based on our society's belief that individuals have a right to privacy and the right to decide what information they will share and with whom. Confidentiality is an ethical principle, which holds the practitioner responsible for respecting the client's privacy and protecting information disclosed during therapy. Both the code of ethics and the HIPAA Privacy Rule provide explicit, detailed provisions that cover client consent for disclosure of information and which entities can receive information. Privileged communication resulting from a therapy session is a legal concept that protects clients from having confidential information disclosed without their consent.

Confidentiality is the foundation of the professional-client relationship and is consistent with the mission to serve as an advocate for the client and the greater society. Confidentiality as it is addressed in ethics codes and case study examples of violations of confidentiality, will be presented here. The Tarasoff vs. University of California case and the legal action that resulted led to the revisions in the American Counseling Association (ACA) Code of Ethics in 2005.

Some research found that only 1 percent to 5 percent of complaints registered with ethics committees and state licensing boards of counselors and psychologists involved confidentiality violations (Pope and Vasquez, 1998). However, a national study that interviewed psychologists reported that 69 percent revealed they had violated client confidentially unintentionally, and clients may not have known (Tabachnik, & Keith-Spiegel, 1987).

Today, codes of ethics and the HIPAA Privacy Rule must address the use of new technology to prevent unintentional and intentional breaches of confidentiality that may occur in managing therapy notes and patient files electronically.

Multicultural issues

A major focus of the ACA Code of Ethics revision of 2005 was multicultural diversity competency. Cultural bias is an ethical dilemma facing many counselors today. Our culture influences our lives and defines reality for us in many ways. A culturally centered approach recognizes that culture is central, not marginal, to effective counseling relationships. Cultural issues have given rise to a variety of counseling styles that are complex and ever changing.

An ethical dilemma in multicultural diversity may begin with the difficulties with assessment because appropriate evaluation tools may not be available. It is difficult, if not impossible, to locate a culture-fair or culture-free test for all specific cultural contexts. The counselor must be trained to interpret data from tests in ways appropriate to the client's cultural context (Paniagua, 2001).

The counseling theory or methodology must provide a valid explanation for the origin and maintenance of the behavior to inform the counseling process. The racial or cultural identity of both the counselor and the client influences how problems are defined and influences counseling goals and methods. Counselors must expand their repertoire of helping responses to be effective in a variety of cultural contexts.

Problems may also arise when making a diagnosis in a multicultural context when using the Diagnostic and Statistical Manual of Mental Disorders (DSM-IV). There are many cultural beliefs and experiences that are normal for the client's culture, but viewed from a "western" perspective, may seem pathological (Pedersen, 2007).

Revised ethical codes

The American Counseling Association (ACA) developed a professional code of ethics that has been adopted by licensing boards in 22 states that use the code as the basis in counseling decision-making on ethical issues.

A major revision of the ACA Code of Ethics was completed in October 2005 and contains significant changes that will impact professional counselors across all settings and specialties. The code contains new ethical directives in the areas of confidentiality, dual relationships, multiculturalism and diversity, technology, end-of-life care, and the selection of counseling interventions.

Revisions in the ACA code also include obligations for protecting the confidentiality of a deceased client, ethical use of technology in the practice of counseling, permission to refrain from making a new diagnosis and mandates for selecting new or innovative interventions, and the importance of always consulting professional colleagues in the ethical decision-making practice.

A review of the Code of Ethics for the American Mental Health Counseling Association (AMHCA), American Counseling Association (ACA), the American Psychological Association (APA), American Association of Marriage and Family Therapists (AAMFT), and the National Association of Social Workers (NASW) reveals similarities in the values, principals and standards that guide their professions.

All have the mission to enhance human development and well-being, recognize diversity and promote the worth, dignity, potential and independence of all people within their social and cultural contexts. All of these associations have ethics codes that apply to their scientific, educational, and professional roles. They share common terms and definitions and are based on the foundational premise that the client's welfare always has the highest priority.

These codes clarify the ethical responsibilities of the practitioner and identify relevant considerations when professional obligations conflict or ethical uncertainties arise. The code for each organization includes information in the following areas:

- The client relationship.
- Communication and privacy, and confidentiality.
- Professional responsibility.
- Evaluation, assessment and interpretation.
- Training, teaching and supervision.
- Research and publication.
- Relationships and ethical responsibilities to colleagues and other professionals.
- Ethical responsibilities to society.
- Resolving ethical issues, complaints or inquiries.

This course will review and discuss key elements of the codes of ethics for social work and counseling and the application of an ethical decision making process. It is not a comprehensive guide to compliance or a source of legal information or advice.

Terms and definitions

Counseling and social work organizations, including ACA, NASW, APA, AAMFT and AMHCA, have terms and definitions in common, and these are seen throughout their ethics codes. Some of the most commonly used terms and their definitions are:

- **Advocacy** – Promotion of the well-being of individuals, groups and the profession within systems in organizations. Advocacy seeks to remove barriers and obstacles that inhibit access, growth and development.
- **Assent** – To demonstrate agreement when a person is otherwise not capable or competent to give formal consent or informed consent to a plan of service.
- **Client** – An individual or group of individuals seeking services or referred for professional services to help with problem resolution or decision-making.

- **Competency –** Only services that are within the boundaries of social workers' and counselors' education, training, license and certification shall be offered.
- **Culture** – Membership in a socially constructed way of living that incorporates collective values, beliefs, norms, boundaries and the lifestyles that are co-created with others who share similar world views on biological, psychosocial, historical, psychological and other factors.
- **Diversity** – The similarities and differences that occur within and across cultures, and the intersection of cultural and social identities.
- **Document**s – Any written, digital, auditory, visual or artistic recording of the work within the counseling relationship between counselor and client.
- **Multicultural/diversity competence** – A capacity whereby practitioners possess cultural and diversity awareness and knowledge about self and others, and how this awareness and knowledge is applied effectively in practice with clients and client groups.
- **Psychosocial** – Involves aspects of social and psychological behavior and development. Related to the influences of life experiences combined with cognitive and behavioral processes.
- **Student** – An individual engaged in formal educational preparation to be a counselor or social worker.
- **Supervisee** – A professional counselor or counselor in training who is being supervised by a qualified professional in a formal supervisory relationship.

Code of Ethics of the National Association of Social Workers

The NASW approved a Code of Ethics in 1996 at its Delegate Assembly, and the same group revised it in 2008. The Code is based on a set of core values that are the foundations for the principals and standards of the profession. The core values are:

- Service.
- Social justice.
- Dignity and worth of the person.
- Importance of human relationships.
- Integrity.
- Competence.

The NASW Code of Ethics proposed these values, principles and standards to guide social workers' conduct. The code is relevant to all social workers and social work students regardless of the type of work, setting or population they serve.

The NASW Code of Ethics was developed to:

- Identify core values on which social work is based.
- Summarize broad ethical principals that reflect the profession's core values and establish a set of specific ethical standards that guide the social work practice.
- Identify relevant considerations when professional obligations conflict or issues concerning ethics occur.
- Provide ethical standards to which the general public can hold the social work profession accountable.
- Articulate standards that the social work profession can use to assess whether unethical conduct has occurred.
- Introduce new practitioners to the mission, values, ethical principles and ethical standards.

The NASW Code of Ethics is used by individuals, agencies, organizations, licensing and regulatory boards, professional liability insurance providers, courts of law, agency boards of directors, government agencies and other professional groups that choose to adopt it as a frame of reference.

No code of ethics can ensure ethical behavior or resolve all ethical issues and disputes. The NASW code reflects the commitment of all social workers to uphold professional values and to act ethically. Principles and standards must be applied by individuals, who identify moral questions and must make reliable ethical judgments (NASW, 2011).

Ethical principles

The following principles are based on the six core values identified by the NASW and set forth ideals to which all social workers should aspire and are the foundation of the NASW Code of Ethics:

- **Value: Service.**
  Principle: Social workers' primary goal is to help people in need and address social problems. Social workers elevate service to others over self-interest. Social workers are encouraged to volunteer their professional skills with no expectation of significant financial return (pro bono).
- **Value: Social justice.**
  Principle: Social workers pursue social change on the behalf of vulnerable oppressed individuals and groups of people. Efforts of social change may be focused on poverty, unemployment, discrimination and other forms of social injustice. Social workers promote sensitivity and knowledge about oppression and cultural and ethnic diversity.
- **Value: Dignity and worth of the person.**
  Principle: Social workers respect the inherent dignity and worth of the person. Social workers treat each person with care and respect, aware of individual differences and cultural and ethical diversity. They promote clients' social responsibility and self-determination to change and address their own needs.
- **Value: Importance of human relationships.**
  Principle: Social workers recognize the central importance of human relationships. Social workers seek to strengthen relationships among people in a purposeful effort to promote, restore, maintain and enhance the well-being of individuals, families, social groups, organizations and communities.
- **Value: Integrity.**
  Principle: Social workers behave in a trustworthy manner. Social workers act honestly and responsibly to promote ethical practices on behalf of their organization.
- **Value: Competence.**
  Principal: Social workers practice within their areas of competence and enhance their professional expertise. Social workers strive to increase their professional knowledge and skills to apply them in practice. They should aspire to contribute to the knowledge base of the profession.

Ethical standards

Ethical standards concern social workers' ethical responsibilities to their clients, colleagues, the profession as a student or professional, and to the broader society.

These standards cover the following general areas. Contact the NASW for the code of ethics for each section below and procedures for enforcement.

Section 1: Ethical responsibilities to clients.
Section 2: Ethical responsibilities to colleagues.
Section 3: Ethical responsibilities in practice settings.
Section 4: Ethical responsibilities as professionals.
Section 5: Ethical responsibility to the social work profession.
Section 6: Ethical responsibility to the broader society.

Each of the six sections includes extensive and specific details that cover such topics as:

- Privacy and confidentiality.

- Informed consent.
- Competence.
- Multicultural diversity.
- Conflict of interest.
- Disputes, referrals, termination of service.
- Records.
- Supervision.
- Unethical conduct.
- Evaluation and research.
- Education and training.
- Administration.
- Continuing education and staff development.
- Labor management disputes.
- Social welfare.
- Public emergencies.
- Social and political action.

Counselor Code of Ethics

The American Counseling Association (ACA) Code of Ethics was approved by the ACA governing council in 2005. Every section of the code was revised during the three-year process. Since it was first adopted in 1963, the ACA Code has been revised every seven to 10 years. It is currently under revision, and a revised code is planned for publication in 2014.

The American Mental Health Counseling Association (AMHCA) governing board revised its Code of Ethics in 2010.The mission of both counseling associations is to enhance the quality of life in society by promoting the development of professional counselors, advancing the counseling profession, and using the practice of counseling to promote respect for human dignity and diversity.

The ACA and AMHCA serve as educational, scientific and professional organizations whose members work in a variety of settings and serve multiple capacities. Members are dedicated to the enhancement of human development and serve individuals of all ages. Association members recognize diversity and embrace a cross-cultural approach in support of the worth, dignity, potential and uniqueness of people within their social and cultural context.

Professional values represent the ethical commitment of the counseling profession and are the foundation for principles that guide professional behavior and the counseling practice. The practice of the counselor is developed out of personal dedication rather than mandatory requirements of an external organization or legal system.

The codes of ethics for the two counseling associations mirror each other and in purpose and content and will be summarized.

Purpose

The ACA Code of Ethics and AMHCA Code of Ethics outline the following purposes:

1. The code enables the association to clarify to current and future members and to those served by the members the nature of the ethical responsibilities held by all counselors.
2. The code supports the mission of the association.
3. The code establishes principles that define ethical behavior and best practices for counselors.
4. The code serves as an ethical guide to help counselors construct a professional course of action that best serves the client and best promotes the values of the counseling profession.
5. The code serves as a basis for processing ethical complaints and inquiries initiated against members in the counseling profession.

The complete ACA Code of Ethics and the AMHCA Code of Ethics must be reviewed to study the specific guidelines for each section:

- Counseling relationship.
- Confidentiality, privileged communication and privacy.
- Professional responsibility.
- Relationships with other professionals.
- Evaluation, assessment and interpretation.
- Supervision, training and teaching.
- Research and publications.
- Resolving ethical issues.

The ethics code sections above contain specific details covering the following topics:

- Informed consent.
- Professional competence.
- Cultural sensitivity/diversity.
- Advocacy.
- Group work.
- End-of-life care.
- Fees and bartering.
- Termination and transfer.
- Technology services.
- Privacy and confidentiality.
- Shared information.
- Records.
- Parents and guardians.
- Research and publication.
- Continuing education.
- Assessment and evaluation.
- Supervision and training.
- Standards and the law.

American Nurses Association: Code of Ethics for Nurses

The following summary is from the American Nurses Association Code of Ethics for Nurses with Interpretive Statements, published in 2001. Please refer to this document for specifics of the code.

- Nurses in all professional relationships have respect for the uniqueness of every individual, regardless of social or economic status.
- Nurses' primary commitment is to the patient, regardless of the setting for treatment of their health problems.
- The nurse always advocates for the health and safety of the patient.
- The nurse is responsible and accountable for nursing practice to provide optimal patient care.
- Nurses are responsible to maintain competence and personal and professional growth.
- The nurse strives to maintain and improve health care environments and conditions conducive to quality care.
- The nurse participates in the advancement of the profession.
- The nurse collaborates with other health professionals to meet health needs throughout the community.
- Those in the profession of nursing are responsible for articulating nursing values to maintain integrity of the profession, its practice and for shaping social policy.

Public education code of ethics

Most states and local school systems throughout the states have a code of ethics for teachers and counselors. The American School Counselor Association (ASCA) is a professional organization whose members are school counselors, certified or licensed in school counseling with unique qualifications and skills to address all students' academic, personal, social and career development needs.

In their role as school counselors, they are advocates, leaders, collaborators and consultants who work to ensure equity in access and success in educational programs. In all situations, the educational professionals must align their programs with the mission of the school and school district. As with other codes of ethics, the ASCA Ethical Standards were developed to:

- Specify the principles of ethical behavior.
- Maintain high standards.
- Clarify the nature of ethical responsibilities.
- Serve as a guide for ethical practice.
- Provide self appraisal and peer evaluation.
- Inform others, including students, parents, guardians, teachers, administrators, community members and courts of justice, of the best ethical practices in the profession of school counseling.

The following major sections are included in the ethical standards for school counselors. Specific details for each section are included in the document last revised by ASCA in 2010. The sections are:

- Responsibilities to students.
- Confidentiality academic, career/college, post-secondary and personal/social counseling plans.
- Appropriate referrals.
- Danger to self or others.
- Student records.
- Evaluation, assessment and interpretation.
- Technology.
- Student peer support.
- Responsibilities to parents/guardians.
- Parental rights and responsibilities.
- Responsibilities to colleagues.
- Sharing information.
- Collaborating and educating as the counselor.
- Responsibilities to school communities and families.
- Responsibilities to self.
- Multicultural and social justice advocacy.
- Responsibilities to the profession.
- Supervision of school counseling candidates.
- Maintenance of standards.
- Resulting ethical conflicts.

An ethical decision-making model

Ethical decision-making is a process and involves the informed judgment of the social worker or counselor. There are many situations in which simple answers are not available for ethical issues. The practitioner should consider how the issues would be judged in a peer review process where the ethical standards would be applied.

In all cases, practitioners must review all values, principles and ethical standards that are relevant to the situation. They must have thorough knowledge of the code of ethics for their organization or employer.

When codes do not contain information on a particular issue, the practitioner is still responsible for making correct ethical decisions. If practitioners are faced with ethical dilemmas that are difficult to resolve, they are expected to engage in a carefully considered ethical decision-making process. Reasonable differences of opinion can and do exist among individual counselors or social workers about values, ethical principles and ethical standards to be applied when they conflict.

Because there is no specific ethical decision-making model that is most effective, professionals are expected to be familiar with credible models of decision-making that involve the professional team and will stand public scrutiny. In the absence of a clear answer in the particular ethics code or conflicts arise among the team concerning interpretation, they must implement an ethical decision-making model. Through an ethical decision-making process and evaluation of the context of the situation, counselors are empowered to make decisions that help expand the capacity of people to grow and develop.

Cottone and Claus (2000) described nine decision-making models. These models are grounded in Kitchener's five ethical principles. The model that is used most frequently and complements most of the professional codes of ethics is an eight-step model (Corey, Corey, and Callahan (2004). The eight steps are:

1. Identify the problem or dilemma.
2. Identify the potential issues.
3. Look at relevant codes of ethics for general guidance.
4. Consider applicable laws and regulations, and determine how they may have bearing on an ethical dilemma.
5. Seek consultation from more than one source to gain multiple perspectives on the dilemma.
6. Brainstorm various courses of action.
7. Enumerate consequences of various decisions.
8. Implement the course of action.

School counselors must become familiar with an ethical decision-making model such as Solutions to Ethical Problems in Schools (STEPS) (Stone, 2001). This model follows nine steps to help the school counselor work through solutions to ethical problems in schools. It includes the following steps:

- Define the problem emotionally and intellectually.
- Apply the code of ethics for the school system and any school law that applies.
- Consider the student's chronological and developmental level.
- Consider the setting, parental rights and minors' rights.
- Apply the moral principles.
- Determine potential courses of action and their consequences.
- Evaluate the selected action.
- Consult with other professionals and administrators within the school system.
- Implement the course of action.

The implementation of the decision-making model provides a means by which the counselor can implement a standard of care in making ethical decisions (Grant, 2010).

It is important to realize that different professionals may implement different courses of action in the same situation. There is rarely one right answer to complex ethical dilemmas, but if practitioners follow a systematic model, they will be able to give a professional explanation for the course of action they choose.

The decision-making model presents a format for balancing risks and benefits of a course of action. In accordance with professional codes of conduct, the models provide a means for counselors to consult with others and reflect on the process, which minimizes the likelihood of an arbitrary decision. The model will help counselors select an action that includes the rights, responsibilities and welfare of the client (Corey, et al, 2004).

After a counselor or team has selected a course of action, the plan should be reviewed to see whether it presents any new ethical considerations. Stadler (1986) suggests a counselor should apply three simple tests to the course of action selected to be sure it is appropriate. The three tests are:

1. **Justice** – In this test, you assess your own sense of fairness and whether you would treat other people the same way in this situation.
2. **Publicity** – Ask yourself if you want your ethical decision or course of action to be reported by the press.
3. **Universality** – Could you recommend the same decision and course of action to another counselor in the same situation?

If the course of action or decision seems to present new ethical issues, then the counselor will go back to the beginning and re-evaluate each step of the process. The course of action or decision may be incorrect, or the problem, situation or context may have been identified incorrectly.

If the counselor can answer in the affirmative to Sadler's three tests questions above and is satisfied with course of action they selected, he or she is ready to move to implementation.

After implementation the counselor would follow up to assess whether the course of action had the anticipated effect and consequences.

Evaluating ethical practice

Van Hoose and Paradise (1979) suggest practitioners are probably acting in an ethically responsible way with a client if they:
- Maintain personal and professional honesty.
- Clearly have the best interest of the client as a priority.
- Act without malice or personal gain.
- Consult with other professionals in the field.
- Can justify their actions as the best judgment of what should be done based on the current state of the profession.
- Can demonstrate and document their competency in their area or practice.
- Employ a sound decision-making model.
- Follow their code of ethics.

Current ethical issues

Many counselors have consulted ACA staff and leaders about ethics in the practice of conversion therapy. The ACA ethics committee shared its formal interpretation of specific sections of the Code of Ethics concerning the practice of conversion therapy and the ethics of referring clients for this practice in (Whitman, Glosoff, Kocet &Tarvydas, 2011).

Ethics case study 1: Reparative/conversion therapy
During the third session of counseling, a client reports that he is gay and states, "I want to change my way of life and not be gay anymore. It's not just that I don't want to act on my sexual attraction to men. I don't want to be attracted to them at all except as friends. I want to change my life so I can get married to a woman and have children with her."

At the suggestion of a friend, the client had read about reparative/conversion therapy and has researched this approach on the Internet is convinced this is the route he wants to take.

The counselor listens carefully to what the client has to say, asks appropriate questions and engages in a clinically appropriate discussion. The counselor informs the client that although she is happy to continue working with him, she does not believe reparative/conversion therapy is effective and tells him she can find no scientific evidence or support for the approach. She will not offer that as a treatment, and the client says he is disappointed that the counselor will not honor his wishes.

He then asks for a referral to another counselor or therapist who will help him to change his sexual orientation. The ethical question is whether the counselor should make a referral for conversion therapy.

Interpretation
The ACA Ethics Committee considered many factors and derived a consensus opinion that addresses several sections of the Code of Ethics and moral principles of practice presented in this scenario.

Members started with the basic goal of reparative/conversion therapy, which is to change an individual's sexual orientation from homosexual to heterosexual. Counselors who conduct this type of therapy view same-sex attractions and behaviors as abnormal and unnatural, and therefore in need of "curing."

The belief that same-sex attraction and behavior is abnormal and in need of treatment is in opposition to the position taken by national mental health organizations, including ACA, APA and the AMHCA. The ACA Governing Council resolution of 1998 specifically notes that the ACA opposes the portrayals of lesbian, gay and bisexual individuals as mentally ill due to their sexual orientation.

In addition, the resolution supports dissemination of accurate information about sexual orientation, mental health and appropriate interventions and instructs counselors to report research accurately and in a manner that minimizes the possibility that results may be misleading.

In 1999, the ACA Governing Council adopted a statement "opposing the promotion of reparative therapy as a cure for individuals who are homosexual." In fact, in 1973, the American Psychological Association Diagnostic and Statistical Manual (DSM–IV-TR) stated that homosexuality is not a mental disorder in need of being changed. (APA, 2011)

The ACA found the majority of the studies on this topic have been expository in nature with no scientific evidence published in psychological peer-reviewed journals that state the effectiveness of conversion therapy. They did not find any longitudinal studies conducted to follow the outcomes of those individuals who have engaged in this type of treatment. They did conclude that research published in peer-reviewed counseling journals indicates that conversion therapy may harm clients.

Ethical questions
These findings bring several questions to the forefront:
- Is a counseling professional who offers conversion therapy practicing ethically?
- Since ACA has taken the position that it does not endorse reparative therapy as a viable treatment option, is it ethical to refer a client to someone who does engage in conversion therapy?
- If the client insists on obtaining a referral, what guidelines can a counselor follow?
- If professional counselors do engage in conversion therapy, what must they include in their disclosure statements and informed consent documents?

Ethical decision
- ACA committee members agreed that it is of primary importance to respect the client's autonomy to request a referral for services not offered by counselor.
- If counselors determine an inability to be of professional assistance to clients, they must avoid entering or continuing the counseling relationship.
- Counselors are knowledgeable about culturally and clinically appropriate referral resources and suggest alternatives. (ACA, 2005)
- The ACA Code reminds the counselor "to be respectful of approaches to counseling services that differ from their own."(ACA, 2005)
- "The primary responsibility of counselors is to respect the dignity and to promote the welfare of clients." (ACA, 2005)

- "Counselors act to avoid harming their clients, trainees, and research participants and to minimize or to remedy unavoidable or unanticipated harm." (ACA, 2005)

Referring a client to a counselor who engages in a treatment modality not endorsed by the profession and that may in fact cause harm does not promote the welfare of clients and is opposition to the basic purpose of the code.

The ACA Code clearly states that counselors "practice only within the boundaries of their competence based on the education, training, supervised experience, state and national professional credentials, and appropriate professional experience."

It continues, "Counselors practice in specialty areas new to them only after appropriate training, education, and supervised experience. While developing skills in a new specialty area, the counselor takes steps to ensure the competence of their work and to protect others from possible harm." (ACA, 2005)

Any professional engaging in conversion therapy must have received appropriate training in such a treatment modality with the requisite supervision. There is no professional training condoned by ACA, APA, AMHCA or other prominent mental health associations that would prepare counselors to provide conversion therapy.

The ACA Code requires counselors to "recognize history and social prejudices in the misdiagnosis and pathologizing of certain individuals and groups and the role of mental health professionals in perpetuating these prejudices through diagnosis and treatment."

Historically, mental health professions viewed homosexuality as a mental disorder. But with the revision by the APA, removing it from the Diagnostic and Statistical Manual as a mental disorder, professional communities of counseling, social work and psychology no longer diagnose the client who has an attraction to people of the same sex as mentally disordered.

However, within some religious and cultural communities, same-sex attractions and behaviors are still viewed as pathological.

Referring a client to someone who engages in conversion therapy communicates to the client that same-sex attraction and behaviors are disordered and need to be changed. This contradicts the dictates of the 2005 ACA Code of Ethics and APA Diagnostic Manual, so the ethical decision in this case would be to refuse the referral request.

The use of technology

Today, computer networks are used to manage records concerning assessment and evaluation, treatment, billing and payment, and communications between therapist and client. The use of these systems may lead to breaches in confidentiality given the rising use of new technologies such as the computer, e-mail, faxes and cellular phones. Technology in counseling settings requires special security considerations to avoid new risks for unintentional confidentiality breaches. Gelman et al. (1996) advise that secure computer systems be developed that:

- Block unauthorized users from accessing information.
- Provide ongoing security of data to prevent alteration or lost.
- Verify the source of information to confirm authenticity.
- Keep a record of communications to and from the system.
- Recover quickly and effectively from anticipated disruptions.

Koocher and Keith–Spiegel (2008) suggest the following safeguards to manage electronic records:

- Apply encryption software to protect data transmission.
- Protect stored information with complex passwords.
- Apply Internet firewalls.
- Discuss security measures with professionals when storing files with the common server or backing them up on an institutional system.
- Keep removable data storage media in secure places or use complex passwords to encrypt them.
- Protect passwords, changing them frequently and never share passwords with others.
- Be knowledgeable about security measures when using wireless devices.
- Never reveal confidential information in an e-mail or instant messaging without encryption.
- Always use privacy screens to shield monitors or other screens from view.
- Protect the physical security of portable devices such as laptops, small computers, personal digital devices and smartphones.
- Update virus protection software and other security systems.
- Remove all information when disposing of computers or other electronic devices because information may remain after erasing files.
- Consult technology specialists when disposing of information electronically.

Practitioners must always consult their organizations' code of ethics, which address the maintenance, dissemination and disposal of confidential records of professional and research work stored or communicated electronically.

The following cases concern confidentiality issues using modern technology as described by Koocher and Keith–Spiegel. (2008)

Ethics case study 2: Technology breach of confidentiality
A therapist sent a third billing notice to a slow-to-pay client's fax machine in her office. On that day, however, the client did not report to work. The bill was titled "Psychological Services Rendered" and handwritten in large print was "Third Notice – Overdue!!" with the client's name also on the cover. This notice sat in an open access mail tray of the busy office all day.

Analysis: The therapist should have considered that many people would have access to a common fax machine in a business office. Private material should not be faxed unless it is known that the intended recipient will be there to immediately receive the information. In fact, a message relating to billing or payment sent to a client's office might violate debt collection laws as well as confidentiality (Koocher and Keith-Spiegel, 2008).

Ethics case study 3: Technology breach of confidentiality
A therapist updated numerous cases on her laptop computer while on a flight. As she completed a treatment summary on a client, she was directed to turn off all electronic equipment and prepare for landing. She saved the file to a hard disk, backed it up on a removable drive, put the stick in the seat back pocket, and packed up her computer. At that moment, the plane hit some turbulence, which caused her to become anxious and confused. She left the plane without the removable drive and though she called the airline, the drive was not recovered and the confidential material was not retrieved.

Analysis: The use of readily available encryption technology for confidential files would have protected the contents.

Ethics case study 4: Technology breach of confidentiality
A therapist who managed an office bought new desktop computers and donated the old computers to a local community center. She deleted all of the word processing and payment files before donating the computers.

Analysis: Just deleting files on a hard drive will not permanently remove the information, so the confidential files remained on the donated computers. In some cases, reformatting a drive may not prevent some information from being recovered. Professional computer consultation must be considered when disposing of computer equipment containing client data. The counselor must consider special confidentiality issues when using modern technology. The use of encryption technology for confidential files would have protected the contents also.

Ethics case study 5: Technology breach of confidentiality
A mental health practitioner received a faxed complaint release of information form from a counselor in another city. The form requested

information about one of the practitioner's former clients. The practitioner noticed an e-mail address indicated on the new counselor's letterhead to which he transmitted the requested files. During the e-mail transmission, the practitioner was interrupted by a phone call that resulted in him sending the confidential material to the wrong e-mail address – and 3,500 subscribers on the International Poodle Fanciers list server received the confidential client files.

Analysis: When sending information by e-mail, the practitioner must always determine the security and accuracy of the recipient e-mail address and carefully execute the transmission of confidential material by e-mail, fax or any electronic means.

Ethical principles and codes and the HIPAA Privacy Rule remain in place even though technology is constantly changing. Therapists are always responsible for protecting client privacy and information disclosed to them in confidence. They must be especially careful when using electronic communication methods to protect client welfare.

Extra precautions must be taken to ensure confidentiality of information transmitted through the use of computers, electronic mail, fax machines, telephones, voice mail, answering machines, video and audio recording devices, and other electronic or computer technology.

Dual relationships

When reviewing revised codes of ethics, considerable information relates to dual relationships that counselors may have with a client. Gabbard (1994) discussed the need for maintaining boundaries, which requires therapists to set aside their own needs in the service of addressing the patient's needs. Mental health professionals must have guidelines, often referred to as boundaries, that are designed to minimize the opportunity for therapists to use clients for their own gain.

These boundaries can identify a set of roles for those involved in the therapy process and serve as a "limit that promotes integrity." (Katherine, 1991).

Boundaries serve to ensure the well-being of clients who disclose confidential information to their therapist. Dual relationships are sometimes referred to as multiple-role relationships, which occur when the counselor assumes two or more roles concurrently or sequentially that involve the client (Herlihy and Corey, 1997).

The dual relationship may include a second role that could be social, financial or professional. The practitioner may also be a friend, supervisor, teacher, associate or employer.

In all codes of ethics there are key elements in the guidelines relating to dual relationships as summarized below:

- A dual relationship exists when a mental health practitioner is in a counseling relationship at the same time he or she is in a relationship with the client.
- Guidelines also govern a promise or agreement to enter into another relationship in the future with the client or a person associated with the client.
- Mental health practitioners should not take on a dual role with the client if it would impair their assessment, objectivity, competence, effectiveness, communication or confidentiality as a therapist.
- Mental health practitioners should not enter into a dual relationship if the possibility exists that it could exploit or harm the client.
- Mental health practitioners are responsible for establishing clear, appropriate, sensitive and ethical boundaries before entering into any dual relationship with a client.
- If a mental health practitioner becomes aware that potential harm may occur or that unintentional harm has occurred because of a multiple relationship, the practitioner must take immediate action and show evidence of attempting to remediate the harm.

Kitchener and Harding (1990) identified three risk factors that may result in harm to clients involved in multiple or dual relationships with their therapist:

- The more incompatible the expectations in the roles within the dual relationship, the greater the potential harm.
- The greater divergence of responsibilities and obligations associated with the dual roles, the more potential for divided loyalties and loss of objectivity.
- The larger power and prestige differential between a therapist and client in a dual relationship culminates in greater potential for client exploitation because power is generally assigned to the therapist in most societies.

Herlihy and Cory (1997) outlined four problematic and complicated characteristics of dual relationships:

- Dual relationships can be difficult to identify because they develop in a subtle fashion without a clear danger sign alerting the therapist that the behavior in question might lead to an unprofessional relationship.
- The potential for harm broadly ranges from extremely pernicious to neutral or even beneficial. Sexual dual relationships can be extremely harmful to the client, whereas attending a client's graduation may be benign or therapeutic.
- Except for dual sexual relationships, there is little consensus among mental health practitioners concerning the appropriateness of dual relationships.
- Some dual relationships cannot be avoided, such as those facing clinicians living in rural areas and small towns where they are more likely to have social and other relationships with clients.

Within an urban environment, political affiliations, ethnic identities, pastoral counseling and substance abuse status can promote dual relationships because clients may seek a therapist with similar values. (Lerman and Porter, 1990).

Borys and Pope (1989) surveyed 1,600 psychiatrists, 1,600 psychologists, and 1,600 social workers with a 49 percent return rate. They examined a number of the beliefs and behaviors related to dual relationships, such as the practitioners' gender, type of profession, area of residence, marital status, experience, practice setting, practice location, size of the community, therapeutic orientation, and clients' ages. Their results found:

- There was not a significant difference between the three professions relative to sexual intimacy with clients before or after termination, nonsexual dual professional roles, social involvements, or financial involvements with clients.
- More therapists rated each dual relationship behavior as "never ethical" or "ethical under only some rare conditions" than a rating of "ethical under most or all conditions."
- Psychiatrists, as a whole, rated such dual relationships as less ethical than psychologists or social workers.

Herlihy and Corey (1997) developed a decision-making model for therapists faced with a potential dual or multiple relationship. Their model gives following guidelines:

- Determine whether the dual relationship is avoidable or unavoidable.
- If avoidable, the practitioner should explore potential problems and benefits with the client.
- The practitioner must judge whether benefits outweigh the risk or vice versa by assessing issues that establish potential harm.
- The differences in the client's expectations of the therapist in the two roles must be examined.
- The therapist's divergent responsibilities in the two roles must be determined.
- The power differential in the therapist and client relationship must be considered.

- If the practitioner's assessment concludes that client risk of harm is greater than the potential benefits, the counselor should not enter the dual relationship, and if necessary, refer the client to another therapist.
- The client should be informed of the rationale for not participating in the dual relationship.
- If the therapist feels that client benefits are substantial and the risk of harm is minimal or that the dual relationship is unavoidable, then the dual relationship can exist with the following safeguards:
    - Obtain the client's informed consent and initiate the dual relationship. The practitioner and client should discuss potential problems and possible methods of resolution.
    - Seek ongoing consultation because the therapist can lose objectivity in managing a dual relationship's potential for harm to the client.
    - Maintain ongoing communication and monitoring with the client about potential problems and potential resolutions. This step reflects the dynamic and ongoing, rather than static, nature of informed consent.
    - Document the dual relationship and self-monitor throughout the process. If the dual relationship becomes a complaint before a licensure board or court of law, those adjudicating the complaint will expect an open reporting of all information.
    - The practitioner is advised to document the dual relationship, providing evidence of vigilance toward client risks, benefits and protection.
    - Obtain ongoing supervision, beyond simple consultation, during the dual relationship if risks are high, the relationship is complex, or if practitioners are concerned about maintaining objectivity.

Ethics violations related to dual relationship comprise the majority of ethics complaints and licensing board actions (Montgomery and Cupits, 1999; Neukrug, Milliken, and Walden, 2001). Lawsuits and the cost of defending licensing board complaints led to increased liability insurance rates, which affect everyone in the mental health professions.

This would explain the number of revisions and the specificity in the detailed descriptions of dual relationships in mental health organization's current codes of ethics. The above section represents only a brief view of complex dual relationships. Practitioners must carefully study their organization's code of ethics in its entirety.

Ethics case study 6: Dual relationships
A client worked as a records clerk for a community mental health center and a therapist supervised her work. The client experienced some personal problems that she asked the therapist to treat, and he agreed. The client ultimately filed an ethics complaint against the therapist, charging that he blocked her promotion based on the evaluation of her as a client rather than an employee.

Analysis: It is difficult to determine exact cause and effect in this situation, but the client can now interpret the cause of any work-related negative outcomes as related to the therapy. Dual relationships with a client/employee can become problematic in many ways and can produce career and economic hardships for the client. The therapist violated ethical standards because of the clear and foreseeable risk of harm to the client. (Koocher and Keith-Spiegel, 2008)

Ethics case study 7: Dual relationships
A professional artist complained to an ethics committee that the therapist did not carry out her promises. The therapist had treated the artist for more than one year, during which the therapist complemented the client's art work, attended art shows with him and promised to introduce her art gallery contacts to the client. The client stated he began to feel so self-confident that he terminated therapy and expected the therapist's interest in his career to continue. The therapist stopped returning the ex-client's phone calls, which left the client frantic. An ethics committee contacted the therapist, who explained that she always provided unconditional positive regard to her clients, but since this particular individual was no longer a client, she felt no further obligation to him.

Analysis: The ethics committee found in favor of the client. The therapist maintained a dual relationship by entwining their lives together, rendering confusion in the client. The therapist did not resolve the potential consequences of the dependency she established and maintained with the client. Koocher and Keith-Spiegel, 2008)

Ethics case study 8: Dual relationships
A therapist and her ex-client decided they would become friends because the past therapeutic relationship was very harmonious. Unexpectedly, the ex-client perceived the therapist to be controlling and overbearing in the new relationship. She then questioned the therapist's overall competence to the point of distancing herself from the post-therapeutic friendship. The ex-client decided that the therapist was incompetent, causing her to feel exploited and confused. She then consulted another therapist, who told her to press charges against the previous therapist.

Analysis: An ethics committee determined that incompetence could not be conclusively proven, but both the complainant and respondent were surprised at the findings on a dual role violation.

The investigation uncovered that the therapist mistakenly planned their developing relationship and its longer-term continuation while the client was still in active therapy. The therapist had actually presented these facts as a defense against the client's accusations.

This case shows how personas may change from one context to another, and the change may be viewed as negative. The client responded well to the therapist's authoritative personality in therapy but not socially. Also, ex-clients may choose to reenter therapy, and a neutral relationship combined with the positive effects of continuing transference is advised. (Koocher and Keith-Spiegel, 2008)

Bartering: A common boundary issue

Bartering with the client for goods or services is not ethically prohibited but is not recommended as a customary practice. All codes of ethics for mental health practitioners include major sections on regulations surrounding bartering.

There is much disagreement among practitioners regarding whether bartering is ethical as evidenced by Gibson and Pope's (1993) survey finding that 53 percent judged accepting services and 63 percent rated accepting goods instead of payment as ethical. Therapists generally enter bartering arrangements with clients with the good intention of offering services to those with limited finances. However, potential problems exist.

Often, client services do not equal the monetary value, on an hourly basis, to that of therapy (Kitchener and Harding 1990). Therefore clients fall further behind in the amount owed and may feel trapped or resentful.

The quality of barter services might also become problematic as therapist or client may feel short-changed, resulting in resentment and therapeutic damage.

The exchange of goods instead of payment may elicit the same quality issues inherent in service exchange, and negotiating the equivalent number of therapy sessions for the bartered goods can become an issue.

The following list provides general guidelines that are summarized and held in common from the various codes of ethics for mental health practitioners:

- Bartering arrangements create the potential for conflicts of interest and inappropriate boundaries with clients.

- Bartering should occur only in limited circumstances and if it is an accepted practice in the community.
- The mental health practitioner assumes the full burden of demonstrating that this arrangement will cause no harm to the client.
- Bartering arrangements should not put the mental health practitioner at an unfair advantage.
- Bartering agreements should be discussed and a clear written contract should be signed by the counselor and client.

Establishing a friendship or social relationship when bartering with clients produces a conflict of interest that impairs the required objectivity necessary for professional judgment (Pope and Vasquez, 1998.) The friendship dual relationship forms a new set of interests beyond those of the client, namely those of the therapist. For example, a therapist may hesitate to raise a certain issue with the client who is also a friend because of concerns about damaging the friendship.

Ethics case study 9: Bartering
A counselor presented an unemployed landscaper the option of designing and redoing his yard in exchange for psychotherapy. The counselor charged $100 per hour and credited the client with $15 an hour, thus the client worked more than six hours for each therapy session. The client protested to the therapist that the time required for the yard work prevented him from securing full-time employment. The therapist countered that the client could choose to terminate therapy and resume when he could pay the full fee.

Analysis: The therapist calculated a below fair-market value for a proficient landscape artist's labor. The bartering contract is assumed to have contributed to the client's difficulties. The therapist interrupted the agreement and abandoned the client upon hearing the client's complain. The client sued the therapist for considerable damages (Koocher and Keith-Speigel, 2008).

Most professional liability insurance policies exclude coverage pertaining to business relationships with clients (Canter et al., 1994; Bennett et al., 2007). Liability insurance carriers may construe bartering arrangements between mental health professionals and clients as business relationships and therefore refuse to defend covered therapists if bartering complications arise. Koocher and Keith-Spiegel (2008) believe that bartering arrangements have the propensity to be problematic, actually or perceived as exploitive, unsatisfactory in outcome to both parties, and should be used sparingly, if at all.

Sexual dual relationships

One of the oldest ethical mandates in the health care profession is the prohibition of sexual intimacies with health seekers, and it predates the Hippocratic Oath. The ethics codes of mental health professions, however, did not address this behavior until research revealed its prevalence and harm to clients (Pope and Vasquez, 1998). It is estimated that 7 percent of male counselors and 1.6 percent of female counselors reported sexual relationships with former or current clients (Salisbury & Kinnier, 1996; Thoreson, Shaughnessy, & Frazier, 1995).

Holroyd and Brodsky (1997) discovered that 80 percent of psychologists who reported sexual contact also reported sexual intimacy with more than one client.

Approximately 90 percent of clients who experienced sexual intimacies with their therapist are damaged by the relationship. (Bouhoutos, Holroyd, Lerman, Porter, & Greenberg, 1983).

Clients are likely to suffer reactions similar to victims of rape, spouse abuse, incest and post-traumatic stress disorder. Feelings of guilt, rage, isolation, confusion and impaired ability to trust often ensue. Other clients have symptoms of post-traumatic stress disorder, including attention and concentration issues, overwhelming emotional reactions upon sexual involvement with the partner, nightmares and flashbacks.

Such harm is currently well recognized, and there are no credible opinions in the profession that defend therapist-client sexual relationships.

The codes of ethics for all mental health organizations include established moratorium time frames and strict regulations concerning sexual contact with clients. Mental health practitioners must review the sections of their organization's code of ethics that govern sexual contact with clients in their entirety.

The following list contains information held in common among major codes of ethics regarding regulations for sexual contact between mental health practitioners and clients:

- Mental health practitioners do not engage in sexual intimacies with current therapy clients.
- Mental health practitioners do not engage in sexual contact with former clients that according to the limits set in their organization's code of contact.
- Sexual intimacy with former clients is likely to be harmful.
- Even after the appropriate time period allowed in the professional's code of conduct, the burden shifts to the therapist to demonstrate there has been no exploitation or injury to the client or the client's immediate family.
- Whether such contact is consensual or forced, under no circumstances will the counselor engage in sexual activities or sexual contact with current clients.
- Mental health practitioners should not engage in sexual activity with anyone associated directly with a client, such as friends, family members or colleagues.

The indecency of sexual conduct with clients is widely acknowledged, and clients who sue for damages have an excellent chance of winning their lawsuits if allegations are true.

Jorgenson (1995) lists the broad array of causes of action that victimized clients may allege in their civil lawsuits:

- Malpractice.
- Negligent infliction of emotional distress.
- Battery.
- Intentional infliction of emotional distress.
- Fraudulent misrepresentation.
- Breach of contract.
- Breach of warranty.
- Spousal loss of consortium.

Some state legislators have passed laws that automatically make it negligent for certain categories of mental health professionals to engage in sexual relationships with their clients – which encourages victimized clients to sue.

Clients who sue must prove the sexual relationship harmed them, but harm is broadly defined as emotional, financial or physical.

Feeling sexually attracted to a client is not unethical, but acting on the attraction is unethical. Upon feeling a sexual attraction to a client, Remley and Herlihy (2007) recommend various measures, including:

- Consulting with clients.
- Considering client welfare issues.
- Obtaining supervision.
- Self-monitoring feelings.
- Seeking counseling to help the practitioner resolve issues.
- Referring the clients to another therapist.

Confidentiality and duty to warn

Anyone familiar with the previous 1995 ACA Code of Ethics will notice the omission of "clear and imminent danger" and the substitution of "serious and foreseeable harm" in the 2005 revisions. This was a direct outcome from the legal case Tarasoff vs. the University of California.

This case from 1969 concerned a counselor working with a client who confessed an intention to kill a partner (Grant, 2011).

Ethics case study 10: Duty to warn
In this case study, a student named Prosenjit Poddar came from India, where he had been born into the Harijan "untouchable" caste. He came to UC Berkeley as a graduate student in September 1967, and he briefly dated a fellow student named Tatiana Tarasoff.

She was not interested in a serious, exclusive relationship, and during the summer of 1969, she went to South America. Poddar felt betrayed, became depressed and went to a psychologist for counseling at UC Berkeley University's Health Service Department. During counseling, Poddar confided his intent to kill his former girlfriend to his counselor.

The psychologist requested that the campus police detain Poddar, writing that, in his opinion, Poddar was suffering paranoid schizophrenia, acute and severe. The psychologist recommended the defendant be civilly committed as a dangerous person.

Poddar was detained, but then quickly released, because he appeared rational. The psychologist's supervisor then ordered that Poddar not be subject to further detention.

Poddar then befriended Tatiana's brother and even moved in with him. In October, after Tatiana had returned, Poddar stopped seeing his psychologist. Neither Tatiana nor her parents received any warning of the threat he had made as revealed to the counselor. Several months later, on October 27, 1969, Poddar carried out his plan, killing Tatiana Tarasoff by stabbing her with a kitchen knife.

Tatiana Tarasoff's parents sued the psychologist and other employees of the university. Poddar's original sentence was overturned, and he was allowed to avoid a second trial by agreeing to return to India. Some reports indicate he is married and living happily in India today.

Ethical questions
This case brings several ethical questions to mind:

- Should the counselor have informed the police or Tarasoff or her family?
- Does the counselor have a duty to warn or to protect?
- What information concerning cultural contexts existed, and should they have been reviewed?
- Was the counselor competent to deal with the cultural aspects and the mental health diagnoses?
- Was the counselor competent to deal with dangerous or violent clients?
- If confidentiality is the cornerstone of patient-counselor relationships, can the counselor violate this ethical standard if he is no longer seeing the client?
- In what circumstances is breaching the sanctity of confidentiality necessary or allowed?

Interpretation
Resulting court opinions form the basis for general acceptance of the notion that treating professionals have a duty to protect known intended victims. This is important and relates to the general principles of beneficence, meaning "strive to benefit," and non-malfeasance, or taking care to "do no harm."

In Tarasoff v. Regents of the University of California it was ruled that if the patient poses a significant risk of violence to another party, the therapist "bears a duty to exercise reasonable care to protect the foreseeable victim of the danger." States differ in their requirements for identifying foreseeable danger or intended victims and the scope or degree of possible danger. These are important factors to be considered and acted upon to protect individuals and society.

Ethical decisions
Key points resulting from the Tarasoff case: (Grant, 2011).

- A belief that therapists have special knowledge that, when coupled with the "special relationship" of therapist and client, gave rise to the duty to protect in such cases.
- The Tarasoff case and the line of cases that followed do not stand for that proposition that psychotherapists have a duty to warn unknown, intended victims. Instead they have a duty to protect the intended victim.
- Counselors must keep current in methods and procedures to handle violent clients and evaluate the level of danger.
- If a patient poses a significant risk of violence to another party, the therapist "bears a duty to exercise reasonable care to protect the foreseeable victim of danger."
- One standard by which the breach of confidentiality and the duty to warn will be judged is the standard of what a reasonable professional in the community under the circumstances would do.
- Counselors must be competent to work with clients with those diagnoses that may include violent behavior.
- Thorough records are critical to document that the therapist understood the nature of the situation in relation to the client's diagnosis.
- Counselors must take reasonable steps in light of the facts.
- Counselors should consult with colleagues if they unsure of how to proceed according to their code of ethics and the law of their state.
- A therapist is liable for a negative outcome if their actions fall below the expected level of care.

Therapist liability either to the client for slander or defamation or to the person warned for intentional infliction of emotional distress is extremely unlikely under the doctrine of "qualified privilege"(Grant, 2011). Elements of this doctrine are:

- Good faith.
- Legitimate interest in their duty to "protect from harm" to be furthered by statement or action.
- Statements limited in scope to that purpose.
- Proper location and communication in a proper manner and to proper parties.

Subsequent cases

- Some cases have recognized the duty to warn all foreseeable victims, not just those clearly identified.
- Legislative and regulatory bodies have attempted to clarify and define this duty across numerous states.
- In child abuse cases, parents must be notified despite client confidentiality rules.
- All 50 states have mandatory reporting requirements for child abuse.
- In cases of communicable diseases, HIV in the relevant case, the counselor may attempt to diffuse the risks before making an exception to the confidentiality rule if the levels of risk or foreseeable harm allow it. Examples would be to:
    - Have the client present when the partner is notified.
    - Including this in part of the therapy.
    - Have the partner or client voluntarily divulge.
    - Have the parties participate in other partner notification programs.
- States differ in the breathe of requirements concerning the identifiable victim versus the scope of the danger. As stated

throughout all codes of ethics, counselors must be familiar with their state statutes.

Other circumstances dictate the counselor MUST legally report information in the following cases as outlined by law:

- Counselors believe a client under 16 is a victim of incest, rape or some other crime.
- Counselors believe the client needs hospitalization to prevent harm to self or others.
- When information is required as an issue in a court action.
- When clients request that their records be released to themselves or to a third party. (HIPAA, 1996).

Discussing confidentiality laws with a minor or incapacitated client

Federal and state laws mandate reporting of suspected child abuse or neglect, and statutes require the protection of others who may not have the ability to protect themselves, such as elderly individuals or those who reside in institutions.

A report by Taylor and Alderman (1995) included a statement to inform minor clients about the counselor's obligations to report information that may breach confidentiality between the counselor and client. Taylor and Alderman provided an example of the type of statement that could be used in this situation:

> *"Most of what we talked about is private, but there are three kinds of problems that you might tell me about that we would have to share with other people. If I find out that someone has been hurting or abusing you, I would have to tell the police about it. If you tell me you plan to hurt yourself, I would have to let your parents know. If you tell me you have made a plan to hurt someone else, I would have to warn that person. I would not be able to keep these problems just between you and me because the law says I can't. Do you understand that it is okay to talk about things here, but that these are things we must talk about with other people?"*

They further suggest adding a buffer statement along the lines of the following:

> *"Most of what we talked about is private. If you want to talk about any of the three problems that must be shared with others, we will also talk about the best way for us to talk about the problem with others. I want to be sure I'm doing the best I can to help you."*

As previously outlined, the confidentiality requirement does not apply when imminent danger to the client or others exists. This duty to warn from the Tarasoff case in California has been added to many states' laws across the nation. The laws on therapists' obligation vary. Variations across the states include:

- Language such as whether the therapist must warn of imminent danger or may warn of imminent danger.
- Information about which individuals must be given a warning of imminent danger.
- What circumstances warrant the therapist's obligation to warn of imminent danger.

Therapists must know their state laws on their duty to warn, and if they are communicating across state lines in the course of therapy, they must also be knowledgeable of the laws of that state or country.

The requirement that counselors keep information confidential as defined in the code of ethics governing their organization must also be reviewed in relation to state and federal laws, including HIPAA, governing disclosure.

According to the APA, psychologists should disclose confidential information without the consent of the individual only as mandated by law or where permitted by law for a valid purpose such as to:

- Provide needed professional services.
- Obtain appropriate professional consultations.
- Protect the client/patient, psychologist or others from harm.
- Obtain payment for services from a client/patient, in which disclosure is limited to the minimum necessary to achieve the purpose (APA, 2002).

To have thorough knowledge about the above situations, the complete APA Code of Ethics and HIPAA Privacy Rule must be studied.

NASW (1999) highlights on duty to warn include:

- Social workers should protect confidentiality of all information obtained in the course of professional service, except for compelling professional reasons.
- The general expectation that social workers will keep information confidential does not apply when disclosure is necessary to prevent serious, foreseeable, imminent harm to a client or identifiable person.
- In all instances, a social worker should disclose the least amount of confidential information necessary to achieve the desired purpose.
- Only information that is directly relevant to the purpose for which the disclosure is made should be revealed.

This summary above is not compete information, and contains concepts that cannot be fully understood without studying NASW Code of Ethics in its entirety.

The ACA (2005) general requirement that counselors keep information confidential does not apply when:

- Disclosure is required to protect clients or identified others from serious and foreseeable harm.
- When legal requirements demand that confidential information must be revealed.
- The counselor is in doubt as to the validity of the exception and must consult other professionals.
- Additional considerations apply when addressing end-of-life issues (ACA, 2005).

The statements above are addressed in detail in the ACA Code of Ethics, which must be studied in its entirety to understand the complexities of confidentiality between the client and the counselor.

Case study 11: Duty to warn

A PhD and MFT therapist had treated a client, who was a former policeman, for three years. Therapy centered on work-related injuries and the breakup of a 17-year relationship with a woman who had begun to date someone else.

On June 21, 2001, the client allegedly told the therapist that he was having suicidal thoughts. The therapist recommended hospitalization, and he asked for permission to speak with the client's father. The father told the therapist that his son was deeply depressed, had lost his desire to live, and contemplated harming the new man his former partner was dating.

The client checked himself into the hospital as a voluntary patient on the evening of June 21, 2001.

The therapist received a phone call from the client's father the next morning, who said the hospital would soon release his son. The therapist then called the admitting physician and urged him to maintain the client's hospitalization for further observation through the weekend. The psychiatrist disagreed and released the client, who did not contact his therapist after he was released from the hospital.

On June 23, 2001, the client shot the boyfriend of his ex-partner and then killed himself with the same handgun.

The parents of the new boyfriend filed a wrongful death lawsuit naming the therapist as one of the defendants (Ewing v. Goldstein, 2004), claiming he had a duty to warn their son of the risk from the client.

A judge dismissed the case against the therapist, who asserted that his client did not disclose a threat to the new boyfriend directly to him.

Ultimately, the California Court of Appeals reinstated the case, explaining, "When the communication of a serious threat of physical harm is received by a therapist from the patient's immediate family, and is shared for the purpose of facilitating and furthering the patient's treatment, the fact that the family member is not technically the 'patient' is not crucial." The court expressed that psychotherapy does not occur in a vacuum, and that for therapy to be effective, therapists must be aware of the context of a client's history and personal relationships. The court advised that communications from clients' family members in the context comprised a "patient communication."

When therapists must testify in court and their clients request that they not disclose information revealed in therapy, therapists may ask the court not to require the disclosure and explain the possible harm to the therapeutic relationship if such a disclosure is made. If the judge requires the therapist disclose the information, the therapist should only reveal information directly related to the request. Under the circumstances, counselors are not in violation of privacy rules because they are complying with a judge's order. This is a defense against any charge of wrongdoing if the counselor is later sued over a breach of confidentiality (Prosser, 1971).

Confidentiality in group counseling

When counseling groups or families, confidentiality cannot be guaranteed because the counselor cannot control the behavior of group members. In all codes of ethics there are statements that guide the counselor to:

- Inform all clients in the group of the rules of confidentiality.
- Define the parameters of the specific group.
- Identify who the client is in the counseling setting.
- Discuss how confidentiality matters will be addressed.
- Determine how information provided by one member may be disclosed to other members by the counselor.
- Discuss how to disclose information that was previously held as secret in the group counseling session.
- Explain that confidentiality cannot be guaranteed in the group setting.

The ACA suggests that counselors seek agreement and document in writing agreements among all parties involved in the group counseling setting. These documents should include consent agreements concerning the rights of each individual to confidentiality and any obligation to preserve the confidentiality of the information disclosed. (ACA, 2005).

The AAMFT notes that as with other information shared in a counseling setting, marriage and family therapists:

- Do not disclose client confidences except by written authorization, waiver or when mandated by law.
- May accept verbal authorization only in an emergency situation, or when permitted by law.
- Do not disclose information outside the treatment context without a written authorization from each individual competent to execute the waiver.
- Must disclose to clients the nature of confidentiality and the possible limitations of the clients' right to confidentiality.
- Review with clients the circumstances where confidential information may be requested and when it can be disclosed.
- Explain circumstances that may necessitate repeated disclosures.
- May not reveal any individual's confidences to others in the client unit without the prior written permission of that individual (AAMTF, 2001).

As noted above, this information serves as a guideline only. The entire AAMFT Code of Ethics must be reviewed to understand the complex nature of confidentiality in group therapy.

The American Counseling Association offers confidential ethical and professional standards consultation five days a week during business hours. Most inquiries are answered within 24 hours, but may take up to three days when inquiries require specific research.

As noted above, the ACA Code is currently being revised, and one of the newest areas of concern is social media. ACA President Marchetta Evans noted in June 2011, "with Twitter and Facebook, there are some ethical boundary issues just floating out there with counselors."

Evans continued, "Revising our ethics code periodically is part of our professionalization. We want it to be as extensive and as inclusive as it can be while also looking at issues that pop up in the future. The ACA Code of Ethics helps define who we are, how we operate and who we are as counselors." (Glosoff & Kocet, 2011).

Confidentiality in research

There are many ethical standards in the code of ethics for mental health practitioners that govern the confidentiality rights of subjects or clients in research projects. The standards also govern research conduct and the differences between the client-therapist relationship and the participant-researcher relationship.

Therapy clients usually realize that they are receiving services. Research subjects may not always know this. The goal of therapy is healing the client. The goal of research is the dissemination of information. The therapist, because of the close relationship, would probably have a better understanding of what would be harmful to the client than a researcher would. Because of the formal, superficial nature of research, a researcher likely would not know the research subject as well as a therapist does. Information obtained about a participant during a research project must be kept confidential unless an agreement has been made in advance. (Keith-Spiegel and Koocher, 1985).

Some laboratory ethics don't translate well to recent research studies outside the laboratory. New ethical dilemmas may occur when social psychologists use what are called nonreactive methods in which research subjects are not aware they are being observed. This would preclude advanced informed consent and voluntary contracts. People may be observed in a social setting, contrived or changed setting. Without consent, ethical principles allow for only minimal-risk research. Yet, minimal risk may be hard to define, because the invasion of privacy and some level of deception may be involved. Both of these situations may be considered sufficient conditions to cause risk. Ethical problems in these cases may be minimized if the data cannot be linked to those observed.

When participants believe they are in a private setting, such as their own homes, added ethical issues arise when a researcher surreptitiously intrudes into the settings.

The responsibility is solely on the researcher to develop research conditions and procedures that engage in compassionate, sensitive work that provides accurate data. A researcher must also be sure that actually being studied has not harmed the group or subject.

Researchers may deem it necessary to violate the confidentiality of a subject to improve their data to help others. But with sensitive and advanced planning, ethical problems can be minimized. Mental health practitioners are responsible for seeking advice whenever scientific values may cause a conflict and compromise ethical principles. Investigators are also responsible for removing any negative consequences as a result of research-related participation. (Keith–Spiegel & Koocher, 1985).

Ethics case study 12: Research violations

A research article was published concerning a child abuse case. It centered on a videotaped discovery of a reportedly forgotten memory in a child sexual abuse case, which was compared to the childhood interview videotaped 11 years before. The woman, known as Jane Doe, had agreed to this publication of the article (Caridad, 2003).

A psychologist on staff with a university and a private investigator discovered the real identity of Jane Doe. They interviewed her mother, brother, stepmother and foster mother. The investigator also tried to contact Jane Doe, but failed. The psychologist and the investigator did not contact the original publisher of the article or Jane for their consent to confirm her identity or to talk to her caregivers.

As a result of their investigation, two articles were published, entitled "Who abused Jane Doe?"

The psychologist did not respond to the university's Institutional Review Board (IRB) in response to questions about their research of Jane Doe. This was because the psychologist claimed the IRB had given the permission to proceed with the research. The IRB had no record of approval for research in this case. The university decided that the study didn't fall within its scope.

The psychologist believed she was justified in exposing Jane's identity because she believed that the secrecy rules used to protect patients or research subjects should not be used to hide the truth about a child abuse case. The psychologist admitted befriending Jane's mother and that she was largely motivated by the a desire to reunite the mother and daughter.

Jane Doe told the IRB that she disagreed with the psychologist's decision and actions to find her mother and her stepmother for interviews.

Meanwhile, the psychologist's actions damaged her relationship with the university. Her colleagues questioned the methods she used in her challenge of the initial published research. University officials began a 21-month investigation of the psychologist's research in this case.

The dean at the university stated that university rules for research on human subjects were primarily written for medical school examinations. The office of scholarly integrity stated that the psychologist would have had to seek the university's permission to interview people and probably would have been required to give the IRB a list of questions being asked and a form explaining to the subjects the risks of being interviewed. The psychologist would have been required to have the researcher who wrote the initial article get permission to interview Jane Doe and review records. The university cleared the psychologist, but she was required to take an ethics class and to get permission from the IRB before talking to any of the research subjects again.

The psychologist is facing an impending lawsuit filed by Jane Doe. She and several others are accused of defamation, libel, negligent and intentional infliction of distress, emotional invasion of privacy, and damages. Jane Doe alleges that the psychologist's research disclosed her private information and disclosed her identity. Her lawsuit claims that this has subjected her and her family to additional emotional distress from past events. She also claimed that the psychologist did not plan the research with regard for her safety and welfare, and those procedures were not in place for other researchers, or her, to observe the project and report possible problems. Jane Doe states that the psychologist purposefully mischaracterized the records and information they received.

The psychologist in her defense claims she always called the subject Jane Doe in the publication and that the lawsuit was an attempt to stifle her freedom of speech.

Though the psychologist's article did not include names, other details were included that could break confidentiality. This information included Jane's parents' wedding date, name of the hospital Jane was taken to and the emergency room director's name, Jane's age and the date of the incident, details of her injuries and information on a custody case.

This information and other details in the article would make it relatively easy for a researcher to ascertain Jane's identity.

Analysis: In this particular case, it appears the psychologist may have violated at least three ethical codes: research subject confidentiality, informed consent and dual relationships. Psychologists are only allowed to reveal the information with the consent of the person or their legal representative, with the exception of when this information could cause a clear danger to the person or others.

The code of ethics further states that psychologists who present personal information obtained during their professional work are required to obtain adequate prior consent or adequately disguise the information. The psychologist did not get prior consent or adequately disguise the information. (Keith-Spiegel& Koocher, 1985).

The 1992 APA guidelines for disclosure of information say psychologists are only allowed to disclose confidential information without the individual's consent in the following cases:

- To help provide the client services.
- To get appropriate professional consultation.
- To protect clients or others from harm.
- To get payment for services provided, but disclosure is limited to the minimum information necessary.

The psychologist's rationale for violating confidentiality was to expose the truth, but this does not fall under one of the APA's guidelines for violating confidentiality.

However, scientific merit and ethical issues may sometimes conflict. A researcher may deem it necessary to violate confidentiality of the subject to improve the data to help others. But with sensitive advance planning, ethical problems can be minimized.

Psychologists are responsible for seeking advice whenever scientific values may cause a conflict and compromise the APA standards. The investigator is also responsible for removing any necessary negative consequences as a result of research-related participation.

Stricker (1982) defines informed consent as the subject agreeing to participate in research after receiving an explanation of the research and its risks. The elements of informed consent include competency, voluntariness and knowledge.

One issue in the research concerns existing records that were collected for clinical or administrative purposes. Patients may have given initial consent for this data to be collected, but they probably didn't give consent for the data to be used in research. Many records may be old, and a patient's permission would be difficult to obtain. In these cases, retaining patient anonymity is crucial. Permission should be obtained from a person acting on the patient's behalf. The data should not be used in any way beyond that for which permission was granted. Stricker, 1982).

Jane Doe gave consent to the initial study, but she did not give consent for the second study. The psychologist admits she could have contacted Jane Doe to interview her, but chose not to do so. The psychologist did not call the original researcher until the middle of her research of the Jane Doe case.

As previously noted, the psychologist admitted to befriending Jane's biological mother and that she was largely motivated by the desire to reunite the family. Dual relationships are defined as having two or more roles with the client at the same time. In this situation, the psychologist had two or more relationships with research subjects. The psychologist acted as researcher and friend to the mother.

The psychologist's objectivity may have been diminished by her friendship with Jane's mother. The psychologist's desire to unite mother and daughter may have made her biased to the mother's perspective.

A mental health practitioner needs to maintain a certain distance to watch for transference and counter transference issues.

Therapists may not need to be as objective as a researcher when trying to come to a conclusion about the data or clients there they are studying. A researcher is merely observing the subject to obtain accurate data, while a therapist is attempting to help the client make a change.

A researcher must also be sure the group or subject has not been harmed by being studied. A case could be made that because of the breach of confidentiality and intrusion into Jane Doe's private life and the life of her family, Jane's informed consent before research of this case would be ethically mandated. Jane also alleges she was harmed by the research. As noted, it is a researcher's ethical responsibility to ensure such harm is not occurring to anyone during the research.

The right to freedom of speech and academic debate does not allow for the kind of ethical breaches that were made in the Jane Doe case. The violation of Jane Doe's confidentiality without her written consent around such a sensitive issue appears to have been unnecessary and inappropriate.

Furthermore, discussing such a sensitive issue publicly without a person's consent appears to be extremely insensitive. There may have been other ways to contradict the initial case study that would not have necessitated publishing extremely personal details about Jane Doe without her permission.

The hazards and inconveniences that the research caused Jane and her family were not well mediated. The psychologist admitted having a dual relationship with Jane's mother, which shows poor judgment on her part.

The psychologist's excuse that she should reunite the mother with Jane is not strong enough to counteract the possible damage that could result from her dual relationship with the mother (Claridad, 2003).

Summary of the HIPAA Privacy Rule

The U.S. Department of Health and Human Services (HHS) created the Standards for Privacy of Individually Identifiable Health Information, known as the Privacy Rule, to establish a set of national standards for the protection of certain health information. The Privacy Rule was needed to implement the requirements of the Health Insurance Portability and Accountability Act of 1996 (HIPAA).

The Privacy Rule standards address the use and disclosure of individuals' health information called "protected health information" by organizations subject to the rule, which are called "covered entities." HIPAA also includes standards for individuals' privacy rights to understand and control how their health information is used.

Within HHS, the Office for Civil Rights (OCR) has responsibility for implementing and enforcing the Privacy Rule, including voluntary compliance activities and civil money penalties.

A major goal of the Privacy Rule is to assure that individuals' health information is properly protected while allowing the sharing of health information to provide high-quality health care and to protect to public health.

The health care marketplace is diverse, so the rule is designed to be flexible and comprehensive to cover the variety of disclosures that need to be addressed.

The following summary of key elements in the Privacy Rule is not a complete or comprehensive guide to compliance. Covered entities regulated by the rule are obligated to comply with all of its requirements and should not rely on this summary as the source of legal information or advice. To view the entire rule, and for other information about how it applies, review the OCR website included in the resource information section at the end of this course.

Background information

The Health Insurance Portability and Accountability Act of 1996 (HIPAA), Public Law 104-191, was enacted on August 21, 1996, and sections 261 through 264 required the secretary of HHS to publicize standards for the electronic exchange, privacy and security of health information. These are known as the administrative simplification provisions.

HIPAA required the HHS secretary to issue privacy regulations governing individually identifiable health information if Congress did not enact privacy legislation within three years of the passage of HIPAA. Because Congress did not do so, HHS developed a proposed rule and released it for public comment on Nov. 3, 1999. The department received more than 52,000 public comments. The final regulation, the Privacy Rule, was published Dec. 28, 2000.

In March 2002, the department proposed and released modifications to the Privacy Rule. The department received more than 11,000 comments, and the final modifications were published on Aug. 14, 2002.

Covered entities

The Privacy Rule, as well as all of the administrative simplification rules, applies to health plans, health care clearinghouses, and to any health care provider who transmits health information in electronic form in connection with transactions that are called "covered entities."

- **Health plans**
  - Individual and group plans that provide or pay the cost of medical care are covered entities. The plans include health, dental, vision, prescription drug insurers and health maintenance organizations (HMOs).
  - Medicare, Medicaid, Medicare Plus Choice, and Medicare supplement insurers, and long-term care insurers are covered entities.
  - Health plans also include employer-sponsored group health plans, government- and church-sponsored health plans, and multi-employer health plans.
    - There are exceptions; a group health plan with less than 50 participants that is administered by the employer that established and maintains the plan is not a covered entity.
  - Two types of government-funded programs are not health plans:
    1. Those whose principal purpose is not providing or paying the cost of health care, such as food stamp programs.
    2. Those programs whose principal activity is directly providing health care, such as a community health center, or to provide grants to fund the direct provision of health care.
- **Health care providers**
  - Every health care provider, regardless of size, who electronically transmits health information in connection with certain transactions is a covered entity. These transactions include claims, benefit eligibility inquiries, referral authorization requests and other transactions for which HHS has established standards under the HIPAA Transaction Rule.
  - The Privacy Rule covers a health care provider regardless of whether it electronically transmits these transactions directly or uses a billing service or other third party to do so on its behalf. Health care providers include "all providers of services" and "providers of medical or health services" as defined by Medicare and any other person or organization that furnishes, bills or is paid for health care.

Protected information

The Privacy Rule protects all "individual identifiable health information" held or transmitted by a covered entity or its business associate, in any form or media, whether electronic, paper or oral. The Privacy Rule calls this information "protected held information (PHI)."

"Individually identifiable health information" is information, including demographic data, that relates to:

- The individual's past, present or future physical or mental health condition.
- The provision of health care to the individual.
- The past, present or future payment for the provision of health care to an individual.
- Identification of the individual or information for which there is a reasonable basis to believe can be used to identify the individual.
- Individually identifiable health information that includes many common identifiers such as name, address, birth date and Social Security number.

The Privacy Rule excludes from protected health information employment records that a covered entity maintains in its capacity as an employer, and education and other records subject to or defined in the Family Educational Rights and Privacy Act, 20 U. S. C. 1232G.

De-identified health information

There are no restrictions on the use or disclosure of de-identified health information. De-identified health information neither identifies nor provides a reasonable basis to identify the individual. There are two ways to de-identifying information:

- A formal determination by a qualified statistician.
- The removal of specified identifiers of the individual and of the individual's relatives, household members and employers is required, and is adequate only if the covered entity has no actual knowledge that the remaining information could be used to identify the individual.

The following identifiers of the individual or of relatives, employers or household members of the individual must be removed to achieve the "safe harbor" de-identification:

- Names.
- All geographic subdivisions smaller than the state, including street address, city, county, precinct and zip code, except for the initial three digits of the zip code unless the ZIP code is for a geographic unit containing 20,000 or fewer people. In that case, the initial three digits are changed to 000.
- All elements of dates, except a year, directly related to the individual, including birth date, admission date, discharge date and date of death.
- Telephone numbers.
- Fax numbers.
- Electronic mail addresses.
- Social Security numbers.
- Medical record numbers.
- Health plan beneficiary numbers.
- Account numbers.
- Certificate and license numbers.
- Vehicle identifiers and serial numbers, including license plate numbers.
- Device identifiers and serial numbers.
- Web universal resource locators (URLs).
- Internet protocol (IP) addresses.
- Biometric identifiers, including fingerprints and voice prints.
- Photographic images and any comparable image.
- Any other unique identifying numbers, characteristics or code.

In addition to the removal of these identifiers, the covered entity may not have actual knowledge that the remaining information could be used alone or in combination with any other information to identify an individual who is the subject of the information.

Principles for uses and disclosures

Basic principles

A major purpose of the Privacy Rule is to define and limit circumstances in which an individual's protected information may be used or disclosed to covered entities. A covered entity may not use or disclose protected health information, except:

- As the privacy rule permits or requires.
- As the individual who is the subject of the information or the individual's personal representative authorizes in writing.

Required disclosures

- To individuals, or their personal representatives, specifically when they request access to, or an accounting of, disclosures of their protected health information.
- To HHS when it is undertaking a compliance investigation or review of enforcement action. In these cases, refer to the OCR Government Access Guidance.

Permitted uses and disclosures

A covered entity is permitted, but not required, to use and disclose protected health information without an individual's authorization for the following purposes or situations:

1. To the individual, unless required for access or accounting of disclosures.
2. Treatment, payment, and health care operations.
   - ○ Treatment is the provision, coordination, or management of health care-related services by one or more health care providers, including consultation between providers regarding a patient, and referral of a patient by one provider to another.
   - ○ Payment encompasses activities of the health plan to obtain premiums, determine or fulfill responsibilities for coverage, provisions of benefits, and furnish or obtain reimbursement for health care to an individual.
   - ○ Health care operations may include any of the following activities:
     - ■ Quality assessment and improvement activities, including case management and care coordination.
     - ■ Competency assurance activities, including provider or health plan performance evaluation competency assurance activities, credentialing and accreditation.
     - ■ Conducting or arranging for medical reviews, audits or legal services, including fraud and abuse detection and compliance programs.
     - ■ Specified insurance functions.
     - ■ Business planning, development, management and administration.
     - ■ Business management and general administrative activities of the entity, including de-identifying protected health information, creating a limited data set, and certain fund-raising for the benefit of the covered entity.
3. To provide the opportunity to agree or object.
4. Incident to an otherwise permitted use and disclosure.
5. For the public interest and benefit activities.
6. For limited data sets for the purposes of research, public health or health care operations.

Covered entities may rely on professional ethics and best judgment in deciding which of these permissive uses and disclosures to make.

Most uses and disclosures of psychotherapy notes for treatment, payment and health care operations purposes require an authorization as described below:

- Obtaining consent, which is written permission from an individual to use and disclose information for treatment, payment and health care operations, is optional under the privacy rule for all covered entities.
- The content of a consent form and the process for obtaining consent are at the discretion of the covered entity electing to seek consent.
- The counselor should refer to the ethics sections or their organization to determine how to proceed in disclosures of psychotherapy notes.

Informal permission may be obtained by asking the individual outright, or by circumstances that clearly give the individual the opportunity to agree, acquiesce or object.

Where the individual is incapacitated, in an emergency situation or not available, covered entities generally may make such uses and disclosures, if in the exercise of their professional judgment the use of disclosure is determined to be in the best interest of the individual.

Refer to the code of ethics for the counseling or social work organization to address issues in the decision-making process related to these disclosures.

Facility directories

It is common practice in many health care facilities, such as hospitals, to maintain a directory of patient contact information. A covered health care provider may rely on the individual's informal permission to list in its facility directory the individual's name, general condition, religious affiliation and location in the provider's facility. The provider may then disclose the individual's condition and location in the facility to anyone asking for the individual by name, and also may disclose religious affiliation to clergy. Members of the clergy are not required to ask for the individual by name when requiring about patient religious affiliation.

Notification and other purposes.

A covered entity also may rely on the individual's informal permission to disclose to the individual's family, relatives, friends or other persons whom the individual identifies, protected health information directly relevant to that person's involvement in the individual's care or payment for care. This provision, for example, allows a pharmacist to dispense filled prescriptions to a person acting on the behalf of the patient. A covered entity may rely on the individual's informal permission to use or disclose protected health information for the purpose of notifying family members, personal representatives or others responsible for the individual's care, the individual's location, general condition or death.

In addition, protected health information may be disclosed for notification purposes to the public or private entities authorized by law or charter to assist in disaster relief efforts.

Public interest and benefit activities

The Privacy Rule permits use and disclosure of protected health information without an individual's authorization or permission for national priority purposes. These disclosures are permitted, although not required, by the rule in recognition of the important use made of health information outside the health care context. Specific conditions or limitations applied to each public interest purpose, striking the balance between the individual privacy interest and the public interest for this information, are as follows:

- **Required by law** – Covered entities may use and disclose protected health information without individual authorization as required by law, including statute, regulatory, or court orders.
- **Public health activities** – Covered entities may disclose protected health information to public health authorities authorized by law to collect or receive such information for preventing or controlling disease, injury or disability and to public health or other governmental agencies authorized to receive reports of child abuse and neglect.
- **Entities subject to FDA regulations** – Entities involved with FDA regulated products or activities may disclose information for purposes such as adverse event reporting, tracking of products, product recalls and surveillance.
- **Individuals** – When notification is authorized by law, information may be released on people who may have contracted or been exposed to a communicable disease.
- **Employers** – Information on employees about a work-related illness, injury or related medical surveillance may be sought and disclosed because such information is needed to comply with the Occupational Safety And Health Administration (OHSA) and Mine Safety and Health Administration (MHSA) regulations or similar state law.

Victims of abuse, neglect or domestic violence

In certain circumstances, covered entities may disclose protected health information to appropriate government authorities about victims of abuse, neglect or domestic violence.

Health oversight activities

Covered entities may disclose protected health information to help oversight agencies for purposes of legally authorized health oversight activities, such as audits and investigations necessary for oversight of the health care system and government benefit programs.

Judicial and administrative proceedings

Covered entities may disclose protected health information in a judicial or administrative proceeding if the request for the information is through an order from a court or administrative tribunal. Information may be disclosed in response to a subpoena or other lawful process if certain assurances regarding notice to the individual or a protective order are provided.

Law enforcement purposes

Covered entities may disclose protected health information to law enforcement officials for law enforcement purposes under the following six circumstances, and subject to specific conditions:

1. As required by law, including court orders, court ordered warrants, subpoenas and administrative requests.
2. To identify or locate a suspect, fugitive, material witness or missing person.
3. In response to a law enforcement official's request for information about a victim or suspected victim of a crime.
4. To alert law enforcement of a person's death, if the covered entity suspects that criminal activity caused the death.

5. When a covered entity believes that protected health information is evidence of a crime that occurred on its premises.
6. By a covered health care provider in a medical emergency not occurring on its premises when necessary to inform law enforcement about the commission and nature of a crime, the location of the crime or crime victims and the perpetrator of the crime.

Covered entities may disclose protected health information to funeral directors as needed, and coroners or medical examiners to identify the deceased person, determine the cause of death and to perform other functions authorized by the law.

Research

"Research" is any systematic investigation designed to develop or contribute to general knowledge. The Privacy Rule permits a covered entity to use and disclose protected health information for research purposes, without an individual's authorization, provided the covered entity documents:

- That an alteration or waiver of individuals' authorization for the use or disclosure of protected health information about them for research purposes has been approved by an Institutional Review Board or Privacy Board.
- That the use or disclosure of the protected health information is solely to prepare a research protocol or for similar purpose preparatory to research, that the researcher will not remove any protected health information from the covered entity, and that information is necessary for the research.

Serious threats to health and safety

Covered entities may disclose protected health information that they believe is necessary to prevent or lessen a serious and imminent threat to a person or the public, when such disclosure is made to someone they believe can prevent or lessen the threat, including the target of the threat. Covered entities may also disclosed to law enforcement if the information is needed to identify or apprehend an escapee or violent criminal.

Essential government functions

Authorization is not required to use or disclose protected health information for certain essential government functions. These functions include assuring proper execution of a military mission, conducting intelligence and national security activities that are authorized by law, providing protective services to the president, making determinations of medical suitable for U.S. State Department employees, protecting the health and safety of inmates or employees in a correctional institution, and determining eligibility for or conducting enrollment in certain government benefit programs.

Workers' Compensation

Covered entities may disclose protected health information to comply with workers' compensation laws and other similar programs providing benefits for working-related injuries or illnesses.

Limited data set

A limited data set is protected health information from which certain specific direct identifiers of individuals and their relatives, household members and employers have been removed. A limited data set may be used and disclosed for research, health care operations, and public health purposes, provided the recipient enters into a data use agreement promising specific safeguards for the protected health information within the limited data set.

A limited data set excludes the following direct identifiers of an individual or of relatives, employers or household members of the individual:

- Names.
- Postal address information, other than town or city.
- State and zip codes.
- Telephone numbers.
- Fax numbers.
- Electronic mail addresses.
- Social Security numbers.
- Medical records numbers.
- Health plan beneficiary numbers.
- Account numbers.
- Certificate and license numbers.
- Vehicle identifiers and serial numbers, including license plate numbers.
- Device identifiers and serial numbers.
- Web universal resource locators (URLs).
- Internet protocol (IP) address numbers.
- Biometric identifiers, including fingerprint and voice identifiers.
- Full-face photographic images or any comparable images.

Authorized uses and disclosures

A covered entity must obtain an individual's written authorization for any use or disclosure of protected health information that is not for treatment, payment or health care operations, or otherwise permitted or required by the Privacy Rule. A covered entity may not condition treatment, payment, enrollment or benefits eligibility based on whether an individual grants an authorization, except in limited circumstances.

Any authorization must be written in specific terms. It may allow use and disclosure of protected health information by the covered entity seeking that authorization or by a third-party. Example of disclosures that would require an individual's authorization are disclosures to a life insurer for coverage purposes, disclosures to an employer of the results of a pre-employment physical or lab tests, or disclosures to a pharmaceutical firm for its marketing purposes.

All authorizations must be in plain language and contains specific information about the information to be disclosed or used, the persons disclosing and receiving the information, expiration, right to revoke in writing, and other data. The Privacy Rule contains transition provisions applicable to authorizations and other express legal permissions obtained prior to April 14, 2003.

Psychotherapy notes

The covered entity must obtain an individual's authorization to use or disclose psychotherapy notes with the following exceptions:

- The covered entity who originated the notes a may use or disclose the psychotherapy notes for his or her own training with

an individual's authorization, and as part of a defense in legal proceedings brought by the individual.
- For HHS to investigate or determine the covered entity's compliance with the Privacy Rules.
- To avert a serious and imminent threat to the public health or safety.
- To a health oversight agency for lawful oversight of the originator of the psychotherapy notes, for the lawful activities of the coroner or medical examiner or as required by law.

"Psychotherapy notes" are notes recorded in any medium by a health care provider who is a mental health professional documenting or analyzing the contents of the conversation during a private counseling session or a group, joint, or family counseling session and that are separated from the rest of the individual's medical record.

Psychotherapy notes exclude medication prescription and monitoring, counseling session start and stop times, the modalities and frequencies of treatment furnished, results of clinical tests, and any summary of the following items:
- Diagnosis.
- Functional status.
- Treatment plan.
- Symptoms.
- Prognosis.
- Progress to date.

Limiting uses and disclosures to the minimum necessary

An essential aspect of the Privacy Rule is the principle of " minimum necessary" use and disclosure. A covered entity must make reasonable efforts to disclose and request only the minimum amount of protected health information needed to accomplish the intended purpose of the disclosure or requests. A covered entity must develop and implement policies and disclosures to reasonably limit uses and disclosures to the minimum necessary. When the minimum necessary standard applies to a use or disclosure, a covered entity may not use, disclose or request the entire medical record for a particular purpose unless it can specifically justify the whole record as the amount reasonably needed for the purpose.

The minimum necessary requirement is not imposed in the following circumstances:
- Disclosure to order a request by a health care provider for treatment.
- Disclosure to an individual who is the subject of the information.
- The individual's personal representative.
- Use or disclosure made pursuant to an authorization.
- Disclosure to HHS for complaint investigation.
- Compliance review or enforcement.
- Use of disclosure that is required by law.
- Use of disclosure required for compliance with the HIPAA Transaction Rule or other HIPAA administrative simplification rules.

Access and use: For internal uses, a covered entity must develop and implement policies and procedures that restrict access and uses of protected health information based on the specific roles of the members working within the covered entity. These policies and procedures must identify the persons, or classes of persons, in the workforce who need access to protected health information to carry out their duties, the protected health information to which access is needed, and any conditions under which they need the information to do their jobs.

Disclosures and requests for disclosures: Covered entities must establish and implement policies and procedures for routine, reoccurring disclosures or requests for disclosures that limit the protected health information disclosed to that which is the minimum amount reasonably necessary to achieve the purpose of disclosure. Individual review of each disclosure is not required. For nonroutine, nonrecurring disclosures or requests for disclosures that it makes, covered entities must develop criteria designed to limit disclosures to the information reasonably necessary to accomplish the purpose of the disclosure and review each of these requests individually in accordance with established criteria.

Reasonable reliance: If another covered entity makes a request for protected health information, a covered entity may rely, if reasonable under the circumstances, on the request as complying with the minimum necessary standard. Similarly, a covered entity may rely upon request as being the minimum necessary protected health information from:
- A public official.
- A professional, such as an attorney or accountant who is a covered entity's business associates seeking information to provide services to or for the covered entity.
- A researcher who provides the documentation or representation required by the privacy rule for research.

Privacy practices notice

Each covered entity, with certain exceptions, must provide a notice of its privacy practices. The privacy rule requires that the notice contain certain elements:
- The notice must describe the ways in which the covered entity may use and disclose protected health information.
- It must state the covered entity's duty to protect privacy, provide notice of privacy practices, and abide by the terms of the current notice.
- The notice must ascribe individual's rights, including the right to complain to HHS and to the covered entity if the person believes his or her privacy rights have been violated.
- The notice must include a point of contact for further information and for making complaints to the covered entity.
- Covered entities must act in accordance with their notices.
- The Privacy Rule also contains specific distribution requirements for direct treatment providers and all other health care providers and health plans.

Notice distribution: Since April 14, 2003, a covered health care provider with the direct treatment relationship with individuals must deliver a privacy practices notice to patients, as follows:
- Not later than the first service encounter by personal delivery, by automatic and contemporaneous electronic response, and by prompt mailing.
- By posting the notice at each service delivery site in a clear and prominent place where people seeking service may reasonably be expected to be able to read the notice.
- In emergency treatment situations, the provider must furnish its notice as soon as the emergency is resolved.
- Covered entities, whether direct treatment providers or indirect treatment providers such as laboratories or health plans, must supply notice to anyone on request A covered entity must also make its notice electronically available on any website it maintains for customer service or benefits information.
- The covered entity in an organized health care arrangement may use that joint practice privacy notice, as long as each agrees to abide by the notice content with respect to the protected health information created or received.
- The health plan must distribute its privacy notices to each of its enrollees by its compliance date.
- A covered health care provider with a direct treatment relationship with individuals must make a good-faith effort to obtain a written acknowledgment from patients of receipt of the privacy practices notice. The privacy rule does not prescribe any particular content for the acknowledgment. The provider must document the reason for any failure to obtain the patient's written acknowledgment. The

provider is relieved of the need to request acknowledgment in an emergency treatment situation.

Access: Except in certain situations, individuals have the right to review and obtain a copy of their protected health information in covered entities' "designated record set." The designated record set is that group of records maintained by or for a covered entity that is used, in whole or part, to make decisions about individuals, or that is a provider's medical and billing records about individuals or health plan's enrollment, payment, claims adjudication and case of medical management records systems. The rule excepts from the right of access the following protected health information:

- Psychotherapy notes.
- Information compiled for legal proceedings.
- Laboratory results to which the Clinical Laboratory Improvement Act (CLIA) prohibits access to information held by certain resource laboratories.
- For information included within the right of access, covered entities may deny an individual access in certain specific situations, such as when a health care professional believes that access could cause harm to the individual or another. In such situations, the individual must be given the right to have such denials reviewed by a licensed health care professional for a second opinion.
- Covered entities may impose reasonable, cost-based fees for the cost of copying and postage.

A covered entity may deny access to individuals, without providing the individual an opportunity to review, in the following protected situations:

- The protected health information falls under an exception to the right of access.
- An inmate request for protected health information under certain circumstances.
- Information that a provider creates or obtains in the course of research that includes treatment for which the individual has agreed not to have access as part of consenting to participate in the research, as long as access to the information is restored upon completion of research.
- For records subject to the Privacy Act, information to which access may be denied under the Privacy Act.
- Information obtained under a promise of confidentiality from a source other than a health care provider, if granting access would likely reveal the source.

Restriction and request

Individuals have the right to request that a covered entity restrict use of disclosure of protected health information, payment or health care operations, disclosure to persons involved in the individual's health care or payment for health care, or disclosure to notify family members or others about the individuals general condition, location or death. The covered entity is under no obligation to agree to a request for restrictions. A covered entity that does agree must comply with the agreed restrictions, except for the purposes of treating the individual in a medical emergency period.

Confidential communications requirements

Health plans and covered health care providers must permit individuals to request an alternative means or location for receiving communications of protected health information. Health plans must accommodate reasonable requests, especially if the individual indicates the disclosure of all or part of the protected health information could endanger the individual. The health plan may not question the individual statement of endangerment.

Administrative requirements

HHS recognizes that covered entities range from the smallest provider to the largest multistate health plan. The rules are intended to allow covered entities to analyze their own needs and implement solutions appropriate for their environment. This may depend on the nature of the covered entity's business, as well as its size and resources.

Privacy policies and procedures

A covered entity must develop and implement written privacy policies and procedures that are consistent with the HIPAA Privacy Rule.

Privacy personnel: A covered entity must designate a privacy official responsible for developing and implementing its privacy policy and procedures, and the contact person or office responsible for receiving complaints in providing information on the covered entity's privacy practices.

Workforce training and management: Workforce members include employees, volunteers and trainees and may also include other persons whose conduct is under the direct control of the entity. A covered entity must train all workforce members on its privacy policies and procedures as necessary and appropriate for them to carry out their functions. A covered entity must have and apply appropriate sanctions against workforce members who violate its privacy policies and procedures or the privacy rule.

Mitigation: A covered entity must mitigate, to the extent practicable, any harmful effect it learns was caused by the use or disclosure of protected health information by its workforce or associates in violation of its policies and procedures or the Privacy Rule.

Data safeguard: A covered entity must maintain reasonable and appropriate administrative, technical and physical safeguards to prevent intentional or unintentional user disclosure of protected health information. For example, a safeguard might include shredding documents containing protected information before discarding them or securing medical records with a lock, key or pass code, and limiting access to key user pass codes.

Complaints: A covered entity must have procedures for individuals to make complaints regarding its privacy policies and procedures. The covered entity must explain those procedures in its privacy practices. The covered entity must identify to whom individuals can submit complaints to at the covered entity, and advise that complaints also can be submitted to the Secretary of the HHS.

Retaliation and waive: A covered entity may not retaliate against a person for exercising rights provided by the Privacy Rule for:

- Assisting in an investigation by HHS or another appropriate authority.
- Opposing an act or practice that the person believes in good faith violates the Privacy Rule.

A covered entity may not require an individual to waive any right under the privacy rule as a condition for obtaining payment, treatment, an enrollment or benefit eligibility.

Documentation and records retention: A covered entity must maintain until six years after the latter of the date of their creation or last effective date its privacy policies and procedures, privacy practices notices, disposition of complaints and other activities and designations that the Privacy Rule requires to be documented.

Personal representatives and minors

Personal representatives: The privacy rule requires a covered entity to treat a personal representative the same as the individual with respect to uses and disclosures of the individual's protected health information, as well as the individual's rights under the rule. A personal representative is defined as a person legally authorized to make health care decisions on an individual's behalf or to act for a deceased individual or the estate.

The privacy rule permits an exception when a covered entity has a reasonable belief that the personal representative may be abusing or neglecting the individual, or that treating the person as the personal representative could otherwise endanger the individual.

Special case – Minors: In most cases, parents are the personal representatives for their minor children. In those cases, parents can exercise individual rights, such as access to the medical records, on behalf of their minor children. In certain exceptional cases, the parent is not considered the personal representative. In these situations, the Privacy Rule defers to state and other law to determine the rights of the parents to access and control the protected health information of their minor children.

If state and other law is silent on parental access to the minors' protected health information, a covered entity has discretion to provide or deny a parent access to the minor's health information, provided the decision is made by a licensed health care professional in the exercise of professional judgment. For further information, review the OCR Personal Representatives Guidance.

State law preemption

In general, state laws that are contrary to the Privacy Rule are preempted by the federal requirements, which mean that the federal requirements will apply. "Contrary" means it would be impossible for a covered entity to comply with both the state and federal requirements, or that the provision of state law is an obstacle to accomplishing the full purposes and objectives of the administrative simplification provision of HIPAA. The Privacy Rule provides exceptions to the general rule of federal preemption for contrary state laws that:

- Relate to the privacy of individually identifiable health information and provide greater privacy protections or privacy rights with respect to such information.
- Provide for the reporting of disease or injury, child abuse, birth or death, or for public health surveillance, investigation or intervention.
- Requires certain health plan reporting, such as for management or financial audits.

Exception determination: In addition, preemption of a contrary state law will not occur if HHS determines, in response to a request from a state or other entity or person, that the state law:

- Is necessary to prevent fraud and abuse related to the provision of or payment for health care.
- Is necessary to ensure appropriate state regulation of insurance and health plans to the extent expressly authorized by statute or regulation.
- Is necessary for state reporting on health care delivery or costs.
- Is necessary for purposes of serving a compelling public health, safety or welfare need, and if the Privacy Rule provision is at issue, if the secretary determines that the intrusion into privacy is warranted when balanced against the need to be served.
- Has as its principal purpose the regulation of the manufacture, registration, distribution, dispensing or other control of any controlled substance as defined in 21 U.S.C.802, or that is deemed a controlled substance by state law.

Enforcement and penalties for noncompliance

Consistent with the principles of achieving compliance provided in the rule, HHS will seek the cooperation of covered entities and may provide technical assistance to help them comply voluntarily with the rule. The rule provides processes for persons to file complaints with HHS, describes the responsibilities of covered entities to provide records, compliance reports, and to cooperate with and permit access to information for investigations and compliance reviews.

However, she American Recovery and Reinvestment Act of 2009 put new teeth into the laws and penalties for HIPAA violations when it implemented tiered penalties reflecting the circumstanced surrounding the violation. These acknowledged whether the violator did not know about the violation, had reasonable cause, allowed the violation because of willful neglect but subsequently corrected it or allowed the violation because of willful neglect and did not correct it.

- For violations that the entity did not know about, minimum fines are $100 per violation up to $50,000 may be imposed, with an annual maximum of $1.5 million.
- For violations that had reasonable cause and were not due to willful neglect, a minimum fine of $1,000 up to $50,000 may be imposed, with an annual maximum of $1.5 million.
- For violations due to willful neglect that were corrected within the required time period, a minimum fine of $10,000 up to $50,000 may be imposed, with an annual maximum of $1.5 million.
- For violations due to willful neglect that were not corrected, a minimum fine of $50,000 per violation may be imposed, with an annual maximum of $1.5 million.

However, courts have in some cases have treated multiple violations as separate cases, allowing the maximum fines to be much higher than $1.5 million.

In addition, criminal penalties may apply in some cases. A person who knowingly obtains or discloses individually identifiable health information in violation of HIPAA faces a fine of $50,000 and up to one year imprisonment. The criminal penalties increase to $100,000 and up to five years imprisonment if the wrongful conduct involves false pretenses, and up to $250,000 and up to 10 years imprisonment if the wrongful conduct involves the sale, transfer or use of individually identifiable health information for commercial advantage, personal gain or malicious harm. Criminal sanctions are enforced by the Department of Justice.

Compliance dates

All covered entities, except "small health plans," were required to be compliant with the privacy rule by April 14, 2003. Small health plans had until April 14, 2004, to comply.

Small health plans: A health plan with annual receipts of not more than $5 million is a small health plan. Health plans that file certain federal tax returns and report receipts on those returns should use the guidance provided by the small business administration at Number 13 Code of Federal Regulations (CFR) 121.104 to calculate annual receipts. Health plans that do not report receipts to the Internal Revenue Service (IRS), for example, group health plans regulated by the Employee Retirement Income Security Act 1974 (ERISA) that are exempt from filing income tax returns should use proxy measures to determine their annual receipts.

The entire HIPAA Privacy Rule as well as guidelines and additional materials may be found on the government website *http://www.hhs.gov/ocr/hipaa*.

Client Education: Confidentiality and privacy rights

Clients may feel betrayed when therapy records become part of their general medical or health records in an HMO or other managed-care facility and may be disclosed to third-party resources and eligibility compliance. Not all clients understand that submitting a claim for mental health services leads to the provider of services sharing information such as diagnosis, types of services offered, dates of service, duration of treatment and so on.

Sometimes, insurers or companies assigned to manage mental health benefits may be authorized to seek detailed information from case files, such as client current symptoms status, treatment plan specifics or other personal information. Insurance companies may not protect such information as diligently as a provider of services, so confidentiality lies beyond the control of the therapist in this circumstance.

The Council of the National Academies of Practice, which includes medicine, dentistry, nursing, optometry, osteopathic and podiatric medicine, psychology, social work and veterinary medicine, adopted the "Ethical Guidelines for Professional Care in a Managed Care Environment," and confidentiality is one of the five guidelines indicated as a primary concern.

The council recognized that utilization and quality assurance reviews are functional in a health care system, but it also promotes safeguards to protect confidentiality of patient/client data and practitioner clinical materials, and to obtain client consent.

It concludes, "The rationale for this position is founded on the patient's autonomous right to control sensitive personal information. It is further based upon historical recognition of the Oath of Hippocrates, and corroborated throughout the centuries, on the enduring value of preserving confidentiality in order to enhance mutual trust and respect in the patient provider relationship" (1997).

All mental health practitioners, their employees and students must have a thorough and working knowledge of their organization's ethics code and the HIPAA Privacy Rule as it applies to their practice.

In addition, they should inform clients about issues of confidentiality governing their practice and help them gain understanding of the HIPAA Privacy Rule as it may apply to disclosure of their health care information. They should be prepared to answer questions on these issues in a manner best suited for their individual client's needs.

Resources for information

- American Association of Marriage and Family: www.aamft.org/resources/LRMPlan/Ethics/ethicscode2001.asp
- American Counseling Association: *www.counseling .org*
- American Psychological Association: *www.apa. org*
- HIPAA Privacy Rule: *www.hhs.gov/ocr/hipaa*
- National Association of Mental Health Counselors: *www.namhc.org*
- National Association of Social Workers: *www.socialworkers.org*

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ETHICS IN SOCIAL WORK AND COUNSELING AND HIPAA PRIVACY RULES

Final Examination Questions

Select the best answer for each question and then proceed to **SocialWork.EliteCME.com** to complete your final examination.

1. Which of the following definitions is not correct?
    a. Assent - To demonstrate agreement when a person is otherwise not capable or competent to give formal consent.
    b. Competency - Demonstrating excellent skills in many areas of counseling.
    c. Psychosocial - Involves aspects of social and psychological behavior and development.
    d. All of the above.

2. Codes of ethics serve to:
    a. Help mental health professionals construct a professional course of action.
    b. Clarify the nature of ethical responsibilities held by all counselors for current and future practitioners.
    c. Establish principles that define ethical behavior and best practices for counselors.
    d. All of the above.

3. Van Hoose and Paradise suggest that practitioners are probably acting in an ethically responsible way with a client if their behavior includes all of the following EXCEPT:
    a. They have the client’s best interest as a priority.
    b. They act without malice or personal gain.
    c. They maintain personal and professional honesty.
    d. They have a Master’s level or higher degree.

4. Koocher and Keith-Spiegel suggest all of the following safeguards to protect electronic records EXCEPT:
    a. Apply encryption software.
    b. Apply Internet firewalls.
    c. Both you and our client should use pseudonyms.
    d. Consult a technology specialist when disposing of information electronically.

5. Which of the legal points listed below was a result of the Tarasoff case?
    a. The therapist bears a duty to exercise reasonable care to protect the foreseeable victim of danger.
    b. Counselors are not responsible for physically handling violent clients and evaluating the level of danger; an expert must be brought into such a case.
    c. One standard by which the breach of confidentiality and the duty to warn will be judged is: What would a reasonable professional in the community under the same circumstances do?
    d. To avoid privacy law violations, counselors may not consult with colleagues if they are unsure of how to proceed in cases where they suspect there is a potential for violence.

6. Which of the following was not a result of rulings in cases subsequent to Tarasoff?
    a. All 50 states have mandatory reporting for child abuse.
    b. Parents do not have to be notified.
    c. Counselors MUST legally report information as outlined by law if a counselor believes a client under 16 is a victim of incest, rape, or some other crime.
    d. Counselors MUST legally report information if they believe the client needs hospitalization.

7. APA guidelines for disclosure of confidential information without the individual’s consent is allowed in the following cases EXCEPT:
    a. To protect clients or others from harm.
    b. To obtain professional counsel.
    c. To obtain payment for service.
    d. For clinical research.

8. NASW highlights on duty to warn include the following statements EXCEPT:
    a. Therapists must know their state laws on the duty to warn, and those of other states if they are communicating across state lines.
    b. Social workers should disclose all confidential information and patient records in all cases where there is potentially imminent harm.
    c. Only information that is directly relevant to the purpose for which the disclosure is made should be revealed.
    d. The general expectation that social workers will keep information confidential does not apply when disclosure is necessary to prevent serious, foreseeable, imminent harm to a client or identified person.

9. “Individually identified health information” excludes which of the following?
    a. Name, address, birthday and Social Security number.
    b. Present physical and mental health information.
    c. Past, present, and future payment information for the provision of health care.
    d. Health information employment records that a covered entity keeps in its capacity as an employer.

10. The Privacy Rule prohibits disclosure of psychotherapy notes without authorization UNLESS:
    a. The notes are handwritten.
    b. The notes are in electronic form.
    c. The notes are part of a defense in legal proceedings brought by the individual.
    d. The notes are part of a conversation during a counseling session.

Chapter 2: Alzheimer's Disease: Unraveling the Mystery

6 CE Hours

By: U.S. Department of Health and Human Services, National Institute on Aging.

Learning objectives

Upon completion of this course, the learner will be able to:
- Define the anatomy and physiology of the human brain.
- Discuss the effects that aging has on mental function in healthy older people.
- Compare and contrast healthy and diseased neurons.
- Discuss vascular problems and how they relate to AD.
- List and discuss risk factors for AD, including aging itself.
- Recommend changes in lifestyle that may slow, delay or prevent AD.
- Describe recent scientific findings, new technologies, and new treatments.
- Identify early signs and symptoms of AD, and its causes.
- Discuss the methods that can be used to diagnose AD.
- Describe the management of symptoms and the treatment of AD.
- Recommend ways to support for families and other caregivers when a loved one is suffering from AD.

Introduction

Over the past few decades, Alzheimer's disease (AD) has emerged from obscurity. Once considered a rare disorder, it is now seen as a major public health problem that has a severe impact on millions of older Americans and their families. The National Institute on Aging (NIA) is the lead agency for AD research at the National Institutes of Health (NIH). NIA launched its AD program in 1978, and since then, the study of this disease has become one of NIA's top priorities. Several other NIH institutes also conduct and sponsor studies on AD.

Thanks to the work of NIH institutes, other research organizations around the world, and many private-sector research, education, and advocacy groups, the study of AD is moving ahead rapidly. This course explains what AD is, describes the main areas in which researchers are working, and highlights new approaches for helping families and friends care for people with AD.

> *"Never have I loved my husband of 41 years more than I do today.... Though he may not know I'm his wife, he does know that my presence means his favorite foods and drinks are near at hand....I wonder why I can sit daily by his side as I play tapes, relate bits and pieces of news, hold his hand, tell him I love him. Yet I am content when I am with him, though I grieve for the loss of his smile, the sound of my name on his lips."*

This excerpt from *Lessons Learned: Shared Experiences in Coping*, by participants of the Duke University Alzheimer Support Groups, gives a glimpse into what a person with Alzheimer's disease (AD) and a family caregiver might experience as the disease progresses. The gradual slipping away of mind and memory is frightening and frustrating, both for the person with the disease and for family and friends, and can elicit strong feelings of love, grief, anger, and exhaustion.

AD is an irreversible, progressive brain disease that slowly destroys memory and thinking skills, eventually even the ability to carry out the simplest tasks. In most people with AD, symptoms first appear after age 60. AD is caused by a disease that affects the brain. In the absence of disease, the human brain often can function well into the 10th decade of life.

Not so long ago, we were not able to do much for people with AD. Today, that situation is changing. Thousands of scientists, voluntary organizations, and health care professionals are studying AD so that they can find ways to manage, treat, and one day prevent this terrible disease.

AD: A growing national problem

For many older adults and their families, AD stands in the way of the "Golden Years." It also presents a major problem for our health care system and society as a whole. AD is the most common cause of **dementia** among older people. Recent estimates of how many people in the United States currently have AD differ, with numbers ranging from 2.4 million to 4.5 million, depending on how AD is measured. But scientists agree that unless the disease can be effectively treated or prevented, the numbers will increase significantly if current population trends continue.

Our aging society makes AD an especially critical issue. A 2005 Census Bureau report on aging in the United States notes that the population age 65 and older is expected to double in size to about 72 million people within the next 25 years. Moreover, the 85 and older age group is now the fastest growing segment of the population. This is all the more important for a **neurodegenerative disease** like AD because the number of people with the disease doubles for every 5-year age interval beyond age 65.

AD not only affects the people with the disease, of course. The number of AD caregivers—and their needs—can be expected to rise rapidly as the population ages and as the number of people with AD grows. During their years of AD care-giving, spouses, relatives, and friends experience great emotional, physical, and financial challenges. As the disease runs its course and the abilities of people with AD steadily decline, family members face difficult, and often costly, decisions about the long-term care of their loved ones.

The growing number of people with AD and the costs associated with the disease also put a heavy economic burden on society. The national direct and indirect costs of caring for people with AD are estimated to be more than $100 billion a year. A 2004 study provided an equally sobering picture of the impact of AD. It is estimated that if current AD trends continue, total Federal Medicare spending to treat beneficiaries with the disease will increase from $62 billion in 2000 to $189 billion in 2015.

For these reasons, AD is an urgent research priority. We need to find ways to manage and treat AD because of its broad-reaching and devastating impact. We now know that the disease process begins many years, perhaps even decades, before symptoms emerge. Discovering ways to identify AD in the earliest stages and halt or slow its progress will benefit individuals, families, and the Nation as a whole.

About this course
Thinking about AD leads to questions such as: What causes it? What can be done to cure it or prevent it? Will I get it? Scientists ask the same types of questions, and this course describes their search for answers. It is written for people with AD, their family members and friends, caregivers, and others interested in AD.

This Course has four sections:

- **Part 1** gives readers some basics about the healthy brain. Illustrations and text show what a healthy brain looks like and how it works.
- **Part 2** focuses on what happens in the brain during AD.
- **Part 3** talks about current research and the advances that are bringing us closer to ways of managing and eventually defeating AD.
- **Part 4** focuses on issues important to AD caregivers and families, including current research that is finding ways to improve caregiver support.

The end of the course includes a list of publications and resources that people with AD, family members, and caregivers may find useful as they live day to day with the disease.

A course like this is possible only because of the major progress that scientists throughout the world have made. Not long ago, we knew very little about AD other than some facts about its major characteristics. Today, we are beginning to understand more about what AD is and who gets it, how and why it develops, and what course it follows. We are learning about the complex interface between AD and normal age-related changes in the brain. We also are getting much better at diagnosing it early and accurately. Most important, we now have some promising leads on possible treatments. Studies also are beginning to focus on preventive strategies by examining lifestyle factors that might influence a person's risk of developing AD.

Since the 1970s, research supported by NIA and other organizations has deepened our understanding of this devastating disease. It also has expanded our knowledge of brain function in healthy older people and identified ways we might lessen normal age-related declines in mental function. Most importantly, this accumulated research has increased our appreciation for just how complex AD is. It is now clear that many scientific and clinical disciplines need to work together to untangle the genetic, biological, and environmental factors that, over many years, set a person on a course that ultimately results in AD.

Then and now: The fast pace of developments in ad research

As shown in this timeline, we have learned a lot since Dr. Alzheimer presented the case of his patient, Auguste D. The pace of research continues to accelerate as new findings open more and more doors to discovery.

1906
Dr. Alois Alzheimer, a German neurologist and psychiatrist, describes the case of a 51-year-old woman, Auguste D., who had been admitted to a hospital 5 years earlier with a cluster of unusual symptoms, including problems with comprehension and memory, an inability to speak, disorientation, behavioral problems, and hallucinations. After her death, Dr. Alzheimer examined her brain tissue and described two of the hallmarks of AD—numerous globs of sticky proteins in the spaces between neurons (beta-amyloid plaques) and a tangled bundle of fibrils within neurons (neurofibrillary tangles).

1910s - 1940s
Belief persists that "senile dementia" is a normal part of aging.

1950s
Scientists study the biological structure of plaques and tangles.

1960s
Scientists discover a link between dementia and the number of plaques present in the brain. AD is recognized as a distinct disease, not a normal part of aging.

1970s

- Scientists find that levels of acetylcholine, a neurotransmitter important in memory formation, falls sharply in people with AD. This discovery is one of the first to link AD with biochemical changes in the brain.
- "Alzheimer's disease" becomes a common term as recognition of AD as a major public health problem grows.
- NIA is established.

1980s

- Diagnostic criteria for AD are established.
- Genetic links to early-onset AD begin to surface.
- Congress mandates NIA as lead Federal agency for AD research.
- Scientists start to unravel the biological pathways that lead to the development of beta-amyloid plaques in the brain.
- Abnormal **tau** protein in tangles is identified.

1990s

- The U.S. Food and Drug Administration (FDA) approves tacrine (Cognex®), the first drug used to treat AD. This drug has since been replaced by other medications.
- Genetic mutations linked to early-onset and late-onset AD are discovered.
- The first transgenic mouse model of AD is created.
- Additional diagnostic criteria are developed for AD.
- Characteristics of mild cognitive impairment are described and defined.
- NIA launches the Alzheimer's Disease Education and Referral Center, AD Cooperative Study, and other initiatives to conduct and support AD treatment and prevention clinical trials.

2000s

- The FDA approves other AD drugs, including rivastigmine (Exelon®), galantamine (Razadyne®), donepezil (Aricept®), and memantine (Namenda®) to treat symptoms of AD.
- Early work on an AD vaccine begins.
- Many new AD clinical trials, initiatives, and studies are launched, looking at a broad array of translational, treatment, and prevention issues.
- New transgenic mouse models, including one that develops both plaques and tangles, are developed.
- Pittsburgh Compound B (PiB) is developed, allowing researchers to "see" beta-amyloid plaques in the brains of living people.
- The growing sophistication of neuroimaging techniques, genetics, memory and cognitive tests, structured interviews, and other technologies improve our ability to identify people at high risk of AD.

PART 1: THE BASICS OF THE HEALTHY BRAIN

To understand AD, it is important to know a bit about the brain. is part of *Unraveling the Mystery* gives an inside view of the normal brain, how it works, and what happens during aging.

The brain is a remarkable organ. Seemingly without effort, it allows us to carry out every element of our daily lives. It manages many body functions, such as breathing, blood circulation, and digestion, without our knowledge or direction. It also directs all the functions we carry out consciously. We can speak, hear, see, move, remember, feel emotions, and make decisions because of the complicated mix of chemical and electrical processes that take place in our brains.

The brain is made of nerve cells and several other cell types. Nerve cells also are called **neurons**. The neurons of all animals function in basically the same way, even though animals can be very different from each other. Neurons survive and function with the help and support of **glial cells**, the other main type of cell in the brain. Glial cells hold neurons in place, provide them with nutrients, rid the brain of damaged cells and other cellular debris, and provide insulation to neurons in the brain and spinal cord. In fact, the brain has many more glial cells than neurons—some scientists estimate even 10 times as many.

Another essential feature of the brain is its enormous network of blood vessels. Even though the brain is only about 2 percent of the body's weight, it receives 20 percent of the body's blood supply. Billions of tiny blood vessels, or **capillaries**, carry oxygen, glucose (the brain's principal source of energy), nutrients, and hormones to brain cells so they can do their work. Capillaries also carry away waste products.

The Brain's Vital Statistics

ADULT WEIGHT
about 3 pounds

ADULT SIZE
a medium cauliflower

NUMBER OF NEURONS
about 100,000,000,000 (100 billion)

NUMBER OF SYNAPSES
(the gaps between neurons)
about 100,000,000,000,000 (100 trillion)

NUMBER OF CAPILLARIES
(tiny blood vessels)
about 400,000,000,000 (400 billion)

Inside the human brain

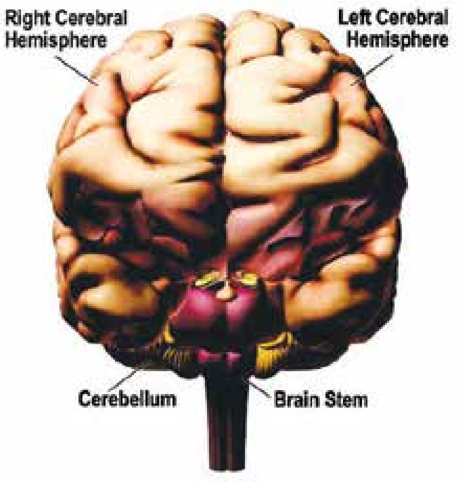
The brain has many parts, each of which is responsible for particular functions. The following section describes a few key structures and what they do.

The main players
Two **cerebral hemispheres** account for 85 percent of the brain's weight. The billions of neurons in the two hemispheres are connected by thick bundles of nerve cell fibers called the **corpus callosum**. Scientists now think that the two hemispheres differ not so much in *what* they do (the "logical versus artistic" notion), but in *how* they process information. The left hemisphere appears to focus on details (such as recognizing a particular face in a crowd). The right hemisphere focuses on broad background (such as understanding the relative position of objects in a space). The cerebral hemispheres have an outer layer called the **cerebral cortex**. This is where the brain processes sensory information received from the outside world, controls voluntary movement, and regulates **cognitive functions**, such as thinking, learning, speaking, remembering, and making decisions. The hemispheres have four lobes, each of which has different roles:

- The **frontal lobe**, which is in the front of the brain, controls "executive function" activities like thinking, organizing, planning, and problem solving, as well as memory, attention, and movement.
- The **parietal lobe**, which sits behind the frontal lobe, deals with the perception and integration of stimuli from the senses.
- The **occipital lobe**, which is at the back of the brain, is concerned with vision.
- The **temporal lobe**, which runs along the side of the brain under the frontal and parietal lobes, deals with the senses of smell, taste, and sound, and the formation and storage of memories.

The **cerebellum** sits above the brain stem and beneath the occipital lobe. It takes up a little more than 10 percent of the brain. This part of the brain plays roles in balance and coordination. The cerebellum has two hemispheres, which receive information from the eyes, ears, and muscles and joints about the body's movements and position. Once the cerebellum processes that information, it sends instructions to the body through the rest of the brain and spinal cord. The cerebellum's work allows us to move smoothly, maintain our balance, and turn around without even thinking about it. It also is involved with motor learning and remembering how to do things like drive a car or write your name.

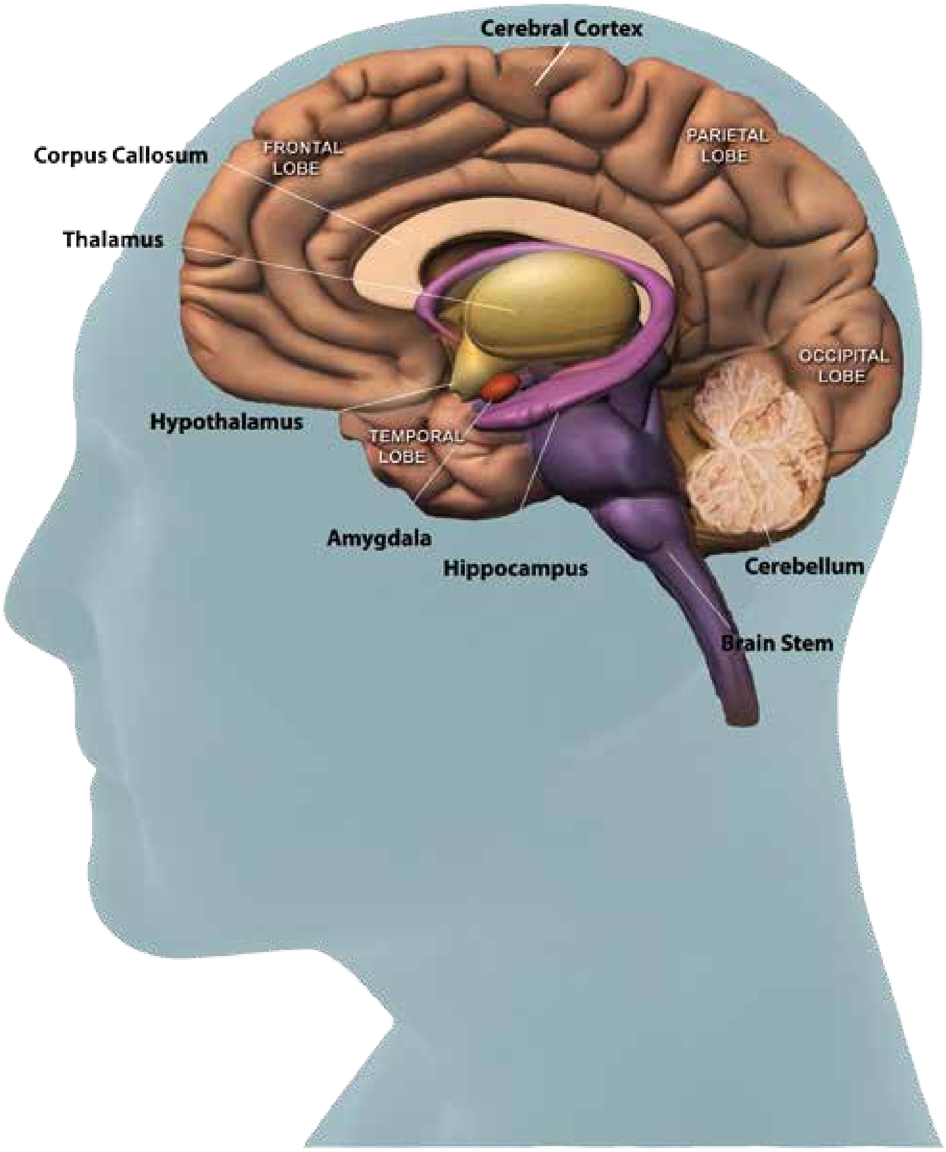
The **brain stem** sits at the base of the brain. It connects the spinal cord with the rest of the brain. Even though it is the smallest of the three main players, its functions are crucial to survival. The brain stem controls the functions that happen automatically to keep us alive—our heart rate, blood pressure, and breathing. It also relays information between the brain and the spinal cord, which then sends out messages to the muscles, skin, and other organs. Sleep and dreaming are also controlled by the brain stem.



Front view of the brain

Other crucial parts
Several other essential parts of the brain lie deep inside the cerebral hemispheres in a network of structures called the **limbic system**. The limbic system links the brain stem with the higher reasoning elements of the cerebral cortex. It plays a key role in developing and carrying out instinctive behaviors and emotions and also is important in perceiving smells and linking them with memory, emotion, and instinctive behaviors. The limbic system includes:

- The **amygdala**, an almond-shaped structure involved in processing and remembering strong emotions such as fear. It is located in the temporal lobe just in front of the hippocampus.
- The **hippocampus**, which is buried in the temporal lobe, is important for learning and short-term memory. This part of the brain is thought to be the site where short-term memories are converted into long-term memories for storage in other brain areas.
- The **thalamus**, located at the top of the brain stem, receives sensory and limbic information, processes it, and then sends it to the cerebral cortex.
- The **hypothalamus**, a structure under the thalamus, monitors activities such as body temperature and food intake. It issues instructions to correct any imbalances. The hypothalamus also controls the body's internal clock.



The brain in action

Sophisticated brain-imaging techniques allow scientists to monitor brain function in living people and to see how various parts of the brain are used for different kinds of tasks. This is opening up worlds of knowledge about brain function and how it changes with age or disease.

One of these imaging techniques is called **positron emission tomography**, or PET scanning. Some PET scans measure blood flow and glucose metabolism throughout the brain. During a PET scan, a small amount of a radioactive substance is attached to a compound, such as glucose, and injected into the bloodstream. This tracer substance eventually goes to the brain. When nerve cells in a region of the brain become active, blood flow and glucose **metabolism** in that region increase. When colored to reflect metabolic activity, increases usually look red and yellow. Shades of blue and black indicate decreased or no activity within a brain region.

In essence, a PET scan produces a "map" of the active brain. Scientists can use PET scans to see what happens in the brain when a person is engaged in a physical or mental activity, at rest, or even while sleeping or dreaming. Certain tracers can track the activity of brain chemicals, for example neurotransmitters such as dopamine and serotonin. Some of these neurotransmitters are changed with age, disease, and drug therapies.

Neurons and their jobs

The human brain is made up of billions of neurons. Each has a cell body, an **axon**, and many **dendrites**. The cell body contains a **nucleus**, which controls much of the cell's activities. The cell body also contains other structures, called organelles, that perform specific tasks.

The axon, which is much narrower than the width of a human hair, extends out from the cell body. Axons transmit messages from neuron to neuron. Sometimes, signal transmissions—like those from head to toe—have to travel over very long distances. Axons are covered with an insulating layer called **myelin** (also called white matter because of its whitish color). Myelin, which is made by a particular kind of glial cell, increases the speed of nerve signal transmissions through the brain.

Dendrites also branch out from the cell body. They receive messages from the axons of other neurons. Each neuron is connected to thousands of other nerve cells through its axon and dendrites.

Groups of neurons in the brain have special jobs. For example, some are involved with thinking, learning, and memory. Others are responsible for receiving information from the sensory organs (such as the eyes and ears) or the skin. Still others communicate with muscles, stimulating them into action.

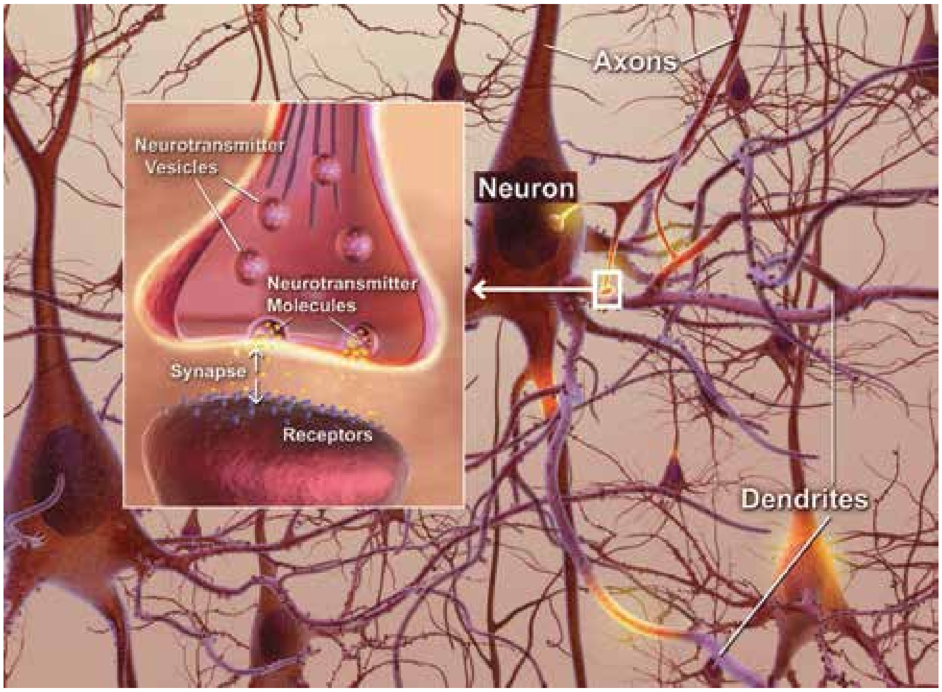
Several processes all have to work smoothly together for neurons, and the whole organism, to survive and stay healthy. These processes are communication, metabolism, and repair.

Communication
Imagine the many miles of fiber-optic cables that run under our streets. Day and night, millions of televised and telephonic messages flash at incredible speeds, letting people strike deals, give instructions, share a laugh, or learn some news. Miniaturize it, multiply it many-fold, make it much more complex, and you have the brain. Neurons are the great communicators, always in touch with their neighbors.

Neurons communicate with each other through their axons and dendrites. When a dendrite receives an incoming signal (electrical or chemical), an "action potential," or nerve impulse, can be generated in the cell body. The action potential travels to the end of the axon and once there, the passage of either electrical current or, more typically, the release of chemical messengers, called neurotransmitters, can be triggered. The neurotransmitters are released from the axon terminal and move across a tiny gap, or **synapse**, to specific receptor sites on the receiving, or post- synaptic, end of dendrites of nearby neurons. A typical neuron has thousands of synaptic connections, mostly on its many dendrites, with other neurons. Cell bodies also have receptor sites for neurotransmitters.

Once the post-synaptic receptors are activated, they open channels through the cell membrane into the receiving nerve cell's interior or start other processes that determine what the receiving nerve cell will do. Some neurotransmitters inhibit nerve cell function (that is, they make it less likely that the nerve cell will send an electrical signal down its axon). Other neurotransmitters stimulate nerve cells, priming the receiving cell to become active or send an electrical signal down the axon to more neurons in the pathway. A neuron receives signals from many other neurons simultaneously, and the sum of a neuron's neurotransmitter inputs at any one instant will determine whether it sends a signal down its axon to activate or inhibit the action of other neighboring neurons.

During any one moment, millions of these signals are speeding through pathways in the brain, allowing the brain to receive and process information, make adjustments, and send out instructions to various parts of the body.



Neurons in the brain

Metabolism
All cells break down chemicals and nutrients to generate energy and form building blocks that make new cellular molecules such as proteins. This process is called metabolism. To maintain metabolism, the brain needs plenty of blood constantly circulating through its billions of capillaries to supply neurons and other brain cells with oxygen and glucose. Without oxygen and glucose, neurons will quickly die.

Repair
Nerve cells are formed during fetal life and for a short time after birth. Unlike most cells, which have a fairly short lifespan, neurons in the brain live a long time. These cells can live for up to 100 years or longer. To stay healthy, living neurons must constantly maintain and repair themselves. In an adult, when neurons die because of disease or injury, they are not usually replaced. Research, however, shows that in a few brain regions, new neurons can be generated, even in the old brain.

The changing brain in healthy aging

In the past several decades, investigators have learned much about what happens in the brain when people have a neurodegenerative disease such as Parkinson's disease, AD, or other dementias. Their findings also have revealed much about what happens during healthy aging. Researchers are investigating a number of changes related to healthy aging in hopes of learning more about this process so they can fill gaps in our knowledge about the early stages of AD.

As a person gets older, changes occur in all parts of the body, including the brain:

- Certain parts of the brain shrink, especially the prefrontal cortex (an area at the front of the frontal lobe) and the hippocampus. Both areas are important to learning, memory, planning, and other complex mental activities.
- Changes in neurons and neurotransmitters affect communication between neurons. In certain brain regions, communication between neurons can be reduced because white matter (myelin- covered axons) is degraded or lost.

- Changes in the brain's blood vessels occur. Blood flow can be reduced because arteries narrow and less growth of new capillaries occurs.
- In some people, structures called plaques and tangles develop outside of and inside neurons, respectively, although in much smaller amounts than in AD.
- Damage by **free radicals** increases (free radicals are a kind of molecule that reacts easily with other molecules).
- Inflammation increases (inflammation is the complex process that occurs when the body responds to an injury, disease, or abnormal situation).

What effects does aging have on mental function in healthy older people? Some people may notice a modest decline in their ability to learn new things and retrieve information, such as remembering names. They may perform worse on complex tasks of attention, learning, and memory than would a younger person. However, if given enough time to perform the task, the scores of healthy people in their 70s and 80s are often similar to those of young adults. In fact, as they age, adults often improve in other cognitive areas, such as vocabulary and other forms of verbal knowledge.

It also appears that additional brain regions can be activated in older adults during cognitive tasks, such as taking a memory test. Researchers do not fully understand why this happens, but one idea is that the brain engages mechanisms to compensate for difficulties that certain regions may be having. For example, the brain may recruit alternate brain networks in order to perform a task. These findings have led many scientists to believe that major declines in mental abilities are not inevitable as people age. Growing evidence of the adaptive (what scientists call "plastic") capabilities of the older brain provide hope that people may be able to do things to sustain good brain function as they age. A variety of interacting factors, such as lifestyle, overall health, environment, and genetics also may play a role.

Another question that scientists are asking is why some people remain cognitively healthy as they get older while others develop cognitive impairment or dementia. The concept of "cognitive reserve" may provide some insights. Cognitive reserve refers to the brain's ability to operate effectively even when some function is disrupted. It also refers to the amount of damage that the brain can sustain before changes in cognition are evident. People vary in the cognitive reserve they have, and this variability may be because of differences in genetics, education, occupation, lifestyle, leisure activities, or other life experiences. These factors could provide a certain amount of tolerance and ability to adapt to change and damage that occurs during aging. At some point, depending on a person's cognitive reserve and unique mix of genetics, environment, and life experiences, the balance may tip in favor of a disease process that will ultimately lead to dementia. For another person, with a different reserve and a different mix of genetics, environment, and life experiences, the balance may result in no apparent decline in cognitive function with age.

Scientists are increasingly interested in the influence of all these factors on brain health, and studies are revealing some clues about actions people can take that may help preserve healthy brain aging. Fortunately, these actions also benefit a person's overall health. They include:

- Controlling risk factors for chronic disease, such as heart disease and diabetes (for example, keeping blood cholesterol and blood pressure at healthy levels and maintaining a healthy weight).
- Enjoying regular exercise and physical activity.
- Eating a healthy diet that includes plenty of vegetables and fruits.
- Engaging in intellectually stimulating activities and maintaining close social ties with family, friends, and community.

ACTIVE Study May Provide Clues to Help Older Adults Stay Mentally Sharp

The phrase "use it or lose it" may make you think of your muscles, but scientists who study brain health in older people have found that it may apply to cognitive skills as well. In 2006, scientists funded by NIA and the National Institute of Nursing Research completed a study of cognitive training in older adults. This study, the Advanced Cognitive Training for Independent and Vital Elderly (ACTIVE) study, was the first randomized controlled trial to demonstrate long-lasting, positive effects of brief cognitive training in older adults.

The ACTIVE study included 2,802 healthy adults age 65 and older who were living independently. Participants were randomly assigned to four groups. Three groups took part in up to 10 computer-based training sessions that targeted a specific cognitive ability—memory, reasoning, and speed of processing (in other words, how fast participants could respond to prompts on a computer screen). The fourth group (the control group) received no cognitive training. Sixty percent of those who completed the initial training also took part in 75-minute "booster" sessions 11 months later. These sessions were designed to maintain improvements gained from the initial training.

The investigators tested the participants at the beginning of the study, after the initial training and booster sessions, and once a year for 5 more years. They found that the improvements from the training roughly counteracted the degree of decline in cognitive performance that would be expected over a 7- to 14-year period among older people without dementia:

- Immediately after the initial training, 87 percent of the processing-speed group, 74 percent of the reasoning group, and 26 percent of the memory group showed improvement in the skills taught.
- After 5 years, people in each group performed better on tests in their respective areas of training than did people in the control group. The reasoning and processing-speed groups who received booster training had the greatest benefit.

The researchers also looked at the training's effects on participants' everyday lives. After 5 years, all three groups who received training reported less difficulty than the control group in tasks such as preparing meals, managing money, and doing housework. However, these results were statistically significant for only the group that had the reasoning training.

As they get older, many people worry about their mental skills getting "rusty." The ACTIVE study offers hope that cognitive training may be useful because it showed that relatively brief and targeted cognitive exercises can produce lasting improvements in the skills taught. Next steps for researchers are to determine ways to generalize the training benefits beyond the specific skills taught in ACTIVE and to find out whether cognitive training programs could prevent, delay, or diminish the effects of AD.

PART 2: WHAT HAPPENS TO THE BRAIN IN AD

The hallmarks of AD

Alzheimer’s disease disrupts critical metabolic processes that keep neurons healthy. These disruptions cause nerve cells in the brain to stop working, lose connections with other nerve cells, and finally die. The destruction and death of nerve cells causes the memory failure, personality changes, problems in carrying out daily activities, and other features of the disease.

The brains of people with AD have an abundance of two abnormal structures—**amyloid plaques** and **neurofibrillary tangles**—that are made of misfolded proteins. This is especially true in certain regions of the brain that are important in memory.

The third main feature of AD is the loss of connections between cells. This leads to diminished cell function and cell death.

Amyloid plaques
Amyloid plaques are found in the spaces between the brain’s nerve cells. They were first described by Dr. Alois Alzheimer in 1906. Plaques consist of largely insoluble deposits of an apparently toxic protein peptide, or fragment, called **beta-amyloid**.

We now know that some people develop some plaques in their brain tissue as they age. However, the AD brain has many more plaques in particular brain regions. We still do not know whether amyloid plaques themselves cause AD or whether they are a by-product of the AD process. We do know that genetic mutations can increase production of beta-amyloid and can cause rare, inherited forms of AD.

From APP to Beta-Amyloid Plaques
Amyloid precursor protein (APP), the starting point for amyloid plaques, is one of many proteins associated with the cell membrane, the barrier that encloses the cell. As it is being made inside the cell, APP becomes embedded in the membrane, like a toothpick stuck through the skin of an orange (Figure 1).

In a number of cell compartments, including the outermost cell membrane, specific enzymes snip, or cleave, APP into discrete fragments. In 1999 and 2000, scientists identified the enzymes responsible for cleaving APP. These enzymes are called alphasecretase, beta-secretase, and gamma-secretase. In a major breakthrough, scientists then discovered that, depending on which enzyme is involved and the segment of APP where the cleaving occurs, APP processing can follow one of two pathways that have very different consequences for the cell.

In the benign pathway, alpha-secretase cleaves the APP molecule within the portion that has the potential to become beta-amyloid. This eliminates the production of the beta-amyloid peptide and the potential for plaque buildup. The cleavage releases from the neuron a fragment called sAPPα, which has beneficial properties, such as promoting neuronal growth and survival. The remaining APP fragment, still tethered in the neuron’s membrane, is then cleaved by gamma-secretase at the end of the beta-amyloid segment. The smaller of the resulting fragments also is released into the space outside the neuron, while the larger fragment remains within the neuron and interacts with factors in the nucleus (Figure 2).

In the harmful pathway, beta-secretase first cleaves the APP molecule at one end of the beta-amyloid peptide, releasing sAPPβ from the cell (Figure 3). Gamma-secretase then cuts the resulting APP fragment, still tethered in the neuron’s membrane, at the other end of the beta-amyloid peptide. Following the cleavages at each end, the beta-amyloid peptide is released into the space outside the neuron and begins to stick to other beta-amyloid peptides (Figure 4). These small, soluble aggregates of two, three, four, or even up to a dozen beta-amyloid peptides are called oligomers. Specific sizes of oligomers may be responsible for reacting with receptors on neighboring cells and synapses, affecting their ability to function.

It is likely that some oligomers are cleared from the brain. Those that cannot be cleared clump together with more beta-amyloid peptides. As the process continues, oligomers grow larger, becoming entities called protofibrils and fibrils. Eventually, other proteins and cellular material are added, and these increasingly insoluble entities combine to become the well-known plaques that are characteristic of AD.

For many years, scientists thought that plaques might cause all of the damage to neurons that is seen in AD. However, that concept has evolved greatly in the past few years. Many scientists now think that oligomers may be a major culprit. Many scientists also think that plaques actually may be a late-stage attempt by the brain to get this harmful beta-amyloid away from neurons.

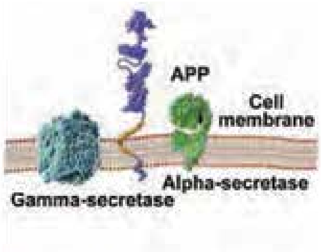


Figure 1

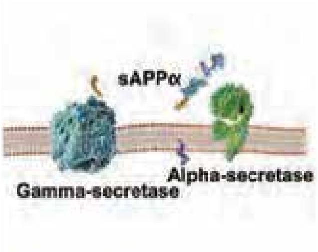


Figure 2

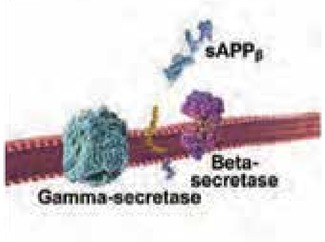


Figure 3

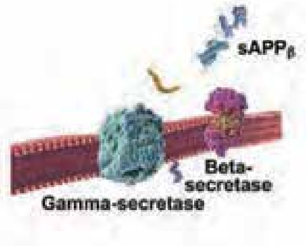
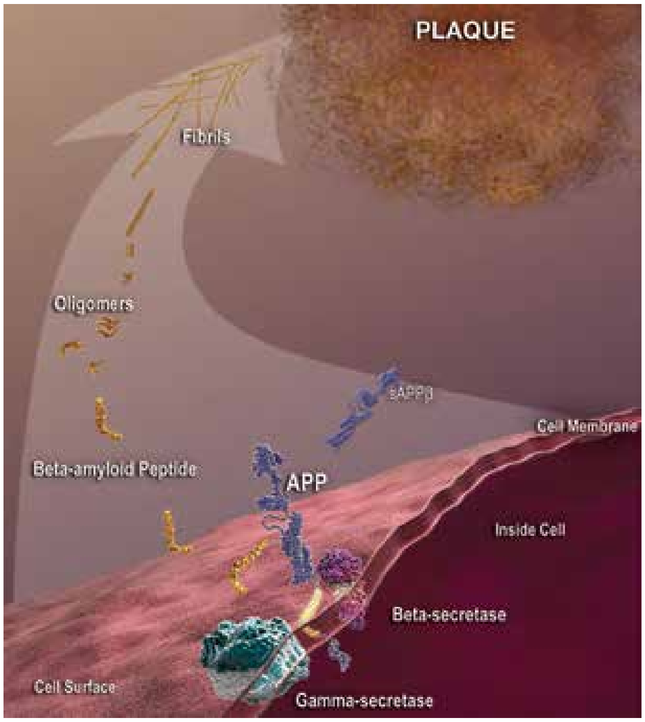
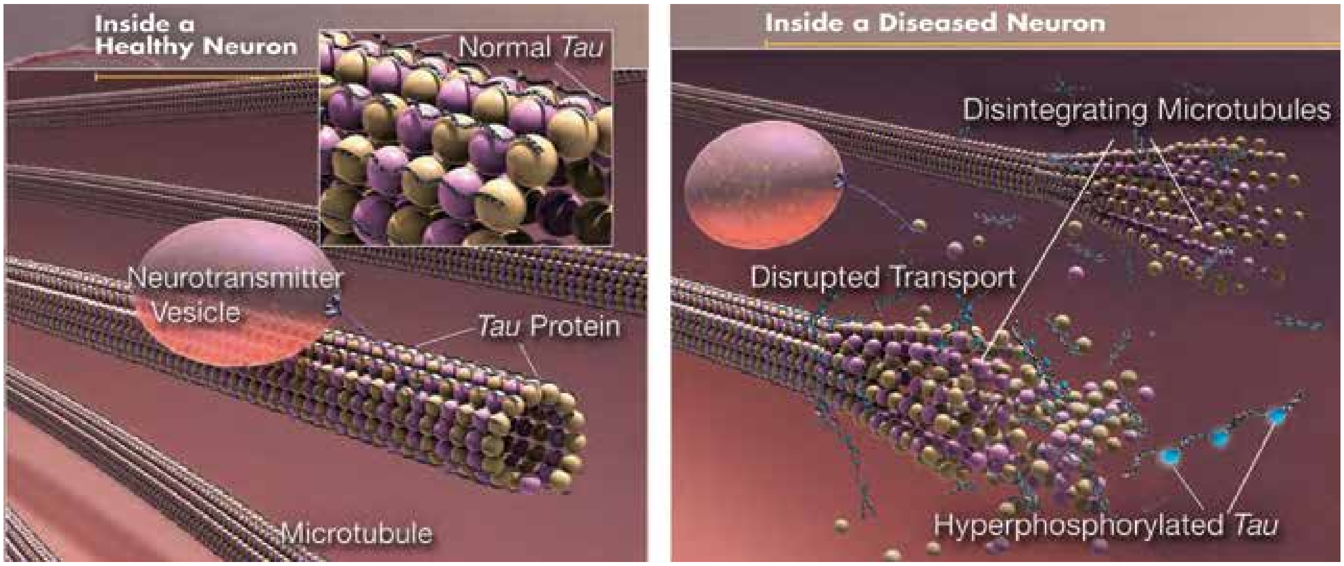


Figure 4



From APP to Beta-Amyloid Plaque



Healthy and Diseased Neurons

Neurofibrillary tangles
The second hallmark of AD, also described by Dr. Alzheimer, is neurofibrillary tangles. Tangles are abnormal collections of twisted protein threads found inside nerve cells. The chief component of tangles is a protein called tau.

Healthy neurons are internally supported in part by structures called microtubules, which help transport nutrients and other cellular components, such as neurotransmitter containing vesicles, from the cell body down the axon.

Tau, which usually has a certain number of phosphate molecules attached to it, binds to microtubules and appears to stabilize them. In AD, an abnormally large number of additional phosphate molecules attach to tau. As a result of this "hyperphosphorylation," tau disengages from the microtubules and begins to come together with other tau threads. These tau threads form structures called paired helical filaments, which can become enmeshed with one another, forming tangles within the cell. The microtubules can disintegrate in the process, collapsing the neuron's internal transport network. This collapse damages the ability of neurons to communicate with each other.

Loss of connection between cells and cell death
The third major feature of AD is the gradual loss of connections between neurons. Neurons live to communicate with each other, and this vital function takes place at the synapse. Since the 1980s, new knowledge about plaques and tangles has provided important insights into their possible damage to synapses and on the development of AD.

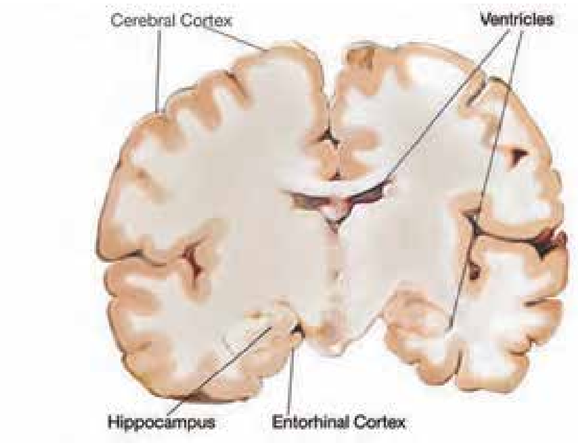
The AD process not only inhibits communication between neurons but can also damage neurons to the point that they cannot function properly and eventually die. As neurons die throughout the brain, affected regions begin to shrink in a process called brain atrophy. By the final stage of AD, damage is widespread, and brain tissue has shrunk significantly.

The changing brain in AD

No one knows exactly what starts the AD process or why some of the normal changes associated with aging become so much more extreme and destructive in people with the disease. We know a lot, however, about what happens in the brain once AD takes hold and about the physical and mental changes that occur over time. The time from diagnosis to death varies—as little as 3 or 4 years if the person is older than 80 when diagnosed to as long as 10 or more years if the person is younger. Several other factors besides age also affect how long a person will live with AD. These factors include the person's sex, the presence of other health problems, and the severity of cognitive problems at diagnosis. Although the course of the disease is not the same in every person with AD, symptoms seem to develop over the same general stages.

Preclinical AD
AD begins deep in the brain, in the **entorhinal cortex**, a brain region that is near the hippocampus and has direct connections to it. Healthy neurons in this region begin to work less efficiently, lose their ability to communicate, and ultimately die. This process gradually spreads to the hippocampus, the brain region that plays a major role in learning and is involved in converting short-term memories to long-term memories. Affected regions begin to atrophy. **Ventricles**, the fluid-filled spaces inside the brain, begin to enlarge as the process continues.

Scientists believe that these brain changes begin 10 to 20 years before any clinically detectable signs or symptoms of forgetfulness appear. That's why they are increasingly interested in the very early stages of the disease process. They hope to learn more about what happens in the brain that sets a person on the path to developing AD. By knowing more about the early stages, they also hope to be able to develop drugs or other treatments that will slow or stop the disease process before significant impairment occurs.



Preclinical AD

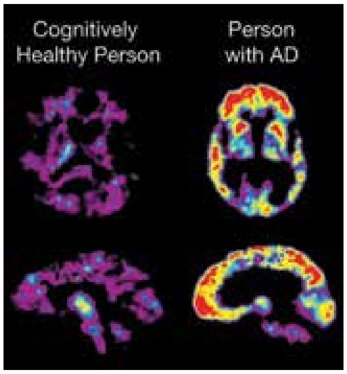
Very early signs and symptoms
At some point, the damage occurring in the brain begins to show itself in very early clinical signs and symptoms. Much research is being done to identify these early changes, which may be useful in predicting

dementia or AD. An important part of this research effort is the development of increasingly sophisticated neuroimaging techniques and the use of biomarkers. Biomarkers are indicators, such as changes in sensory abilities, or substances that appear in body fluids, such as blood, **cerebrospinal fluid**, or urine. Biomarkers can indicate exposure to a substance, the presence of a disease, or the progression over time of a disease. For example, high blood cholesterol is a biomarker for risk of heart disease. Such tools are critical to helping scientists detect and understand the very early signs and symptoms of AD.

PiB and PET

Imagine being able to see deep inside the brain tissue of a living person. If you could do that, you could find out whether the AD process was happening many years before symptoms were evident. This knowledge could have a profound impact on improving early diagnosis, monitoring disease progression, and tracking response to treatment.

Scientists have stepped closer to this possibility with the development of a radiolabeled compound called Pittsburgh Compound B (PiB). PiB binds to beta-amyloid plaques in the brain and it can be imaged using PET scans. Initial studies showed that people with AD take up more PiB in their brains than do cognitively healthy older people. Since then, scientists have found high levels of PiB in some cognitively healthy people, suggesting that the damage from beta-amyloid may already be underway. The next step will be to follow these cognitively healthy people who have high PiB levels to see whether they do, in fact, develop AD over time.



In this PET scan, the red and yellow colors indicate that PiB uptake is higher in the brain of the person with AD than in the cognitively healthy person.

Mild cognitive impairment

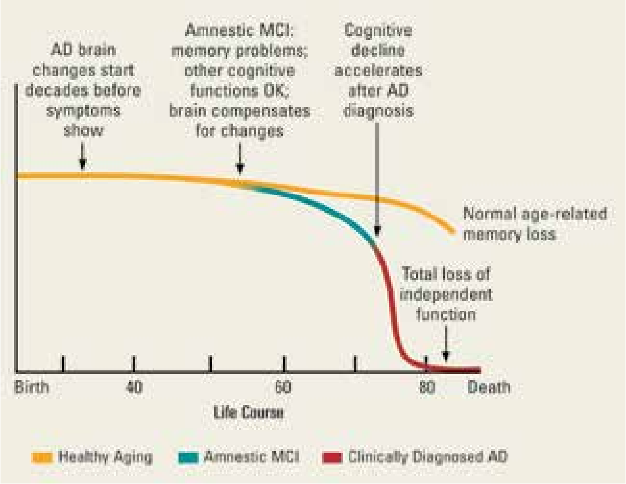
As some people grow older, they develop memory problems greater than those expected for their age. But they do not experience the personality changes or other problems that are characteristic of AD. These people may have a condition called **mild cognitive impairment** (MCI). MCI has several subtypes. The type most associated with memory loss is called amnestic MCI. People with MCI are a critically important group for research because a much higher percentage of them go on to develop AD than do people without these memory problems. About 8 of every 10 people who fit the definition of amnestic MCI go on to develop AD within 7 years. In contrast, 1 to 3 percent of people older than 65 who have normal cognition will develop AD in any one year.

However, researchers are not yet able to say definitively why some people with amnestic MCI do not progress to AD, nor can they say who will or will not go on to develop AD. This raises pressing questions, such as: In cases when MCI progresses to AD, what was happening in the brain that made that transition possible? Can MCI be prevented or its progress to AD delayed?

Scientists also have found that genetic factors may play a role in MCI, as they do in AD. And, they have found that different brain regions appear to be activated during certain mental activities in cognitively healthy people and those with MCI. These changes appear to be related to the early stages of cognitive impairment.

Charting the course from healthy aging to AD

This chart shows current thinking about the evolution from healthy aging to AD. Researchers view it as a series of events that occur in the brain over many years. This gradual process, which results from the combination of biological, genetic, environmental, and lifestyle factors, eventually sets some people on a course to MCI and possibly AD. Other people, whose genetic makeup may be the same or different and who experience a different combination of factors over a lifetime, continue on a course of healthy cognitive aging.



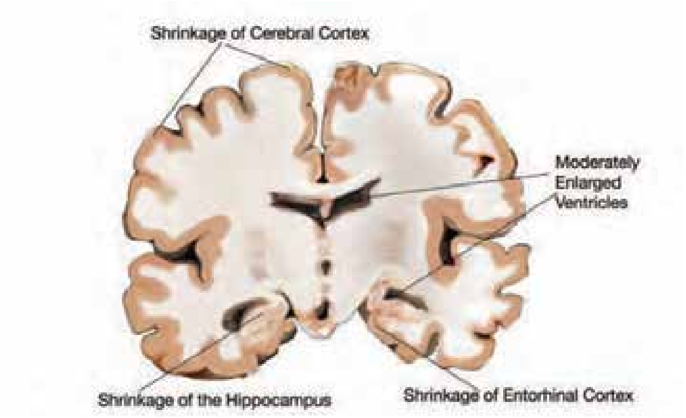
Other signs of early AD development

As scientists have sharpened their focus on the early stages of AD, they have begun to see hints of other changes that may signal a developing disease process. For example, in the Religious Orders Study, a large AD research effort that involves older nuns, priests, and religious brothers, investigators have explored whether changes in older adults' ability to move about and use their bodies might be a sign of early AD. The researchers found that participants with MCI had more movement difficulties than the cognitively healthy participants but less than those with AD. Moreover, those with MCI who had lots of trouble moving their legs and feet were more than twice as likely to develop AD as those with good lower body function.

It is not yet clear why people with MCI might have these motor function problems, but the scientists who conducted the study speculate that they may be a sign that damage to blood vessels in the brain or damage from AD is accumulating in areas of the brain responsible for motor function. If further research shows that some people with MCI do have motor function problems in addition to memory problems, the degree of difficulty, especially with walking, may help identify those at risk of progressing to AD.

Other scientists have focused on changes in sensory abilities as possible indicators of early cognitive problems. For example, in one study they found associations between a decline in the ability to detect odors and cognitive problems or dementia.

These findings are tentative, but they are promising because they suggest that, some day, it may be possible to develop ways to improve early detection of MCI or AD. These tools also will help scientists answer questions about causes and very early development of AD, track changes in brain and cognitive function over time, and ultimately track a person's response to treatment for AD.



Mild to moderate AD

Mild AD

As AD spreads through the brain, the number of plaques and tangles grows, shrinkage progresses, and more and more of the cerebral cortex is affected. Memory loss continues and changes in other cognitive abilities begin to emerge. The clinical diagnosis of AD is usually made during this stage. Signs of mild AD can include:

- Memory loss.
- Confusion about the location of familiar places (getting lost begins to occur).
- Taking longer than before to accomplish normal daily tasks.
- Trouble handling money and paying bills.
- Poor judgment leading to bad decisions.
- Loss of spontaneity and sense of initiative.
- Mood and personality changes, increased anxiety and/or aggression.

In mild AD, a person may seem to be healthy but is actually having more and more trouble making sense of the world around him or her. The realization that something is wrong often comes gradually to the person and his or her family.

Accepting these signs as something other than normal and deciding to go for diagnostic tests can be a big hurdle for people and families. Once this hurdle is overcome, many families are relieved to know what is causing the problems. They also can take comfort in the fact that despite a diagnosis of MCI or early AD, a person can still make meaningful contributions to his or her family and to society for a time.

Moderate AD

By this stage, AD damage has spread to the areas of the cerebral cortex that control language, reasoning, sensory processing, and conscious thought. Affected regions continue to shrink, ventricles enlarge, and signs and symptoms of the disease become more pronounced and widespread. Behavioral problems, such as wandering and agitation, can occur. More intensive supervision and care become necessary, which can be difficult for many spouses and families. The symptoms of this stage can include:

- Increasing memory loss and confusion.
- Shortened attention span.
- Inappropriate outbursts of anger.
- Problems recognizing friends and family members.
- Difficulty with language and problems with reading, writing, and working with numbers.
- Difficulty organizing thoughts and thinking logically.
- Inability to learn new things or to cope with new or unexpected situations.
- Restlessness, agitation, anxiety, tearfulness, wandering—especially in the late afternoon or at night.
- Repetitive statements or movement, occasional muscle twitches.
- Hallucinations, delusions, suspiciousness or paranoia, irritability.
- Loss of impulse control (shown through undressing at inappropriate times or places or vulgar language).
- An inability to carry out activities that involve multiple steps in sequence, such as dressing, making a pot of coffee, or setting the table.

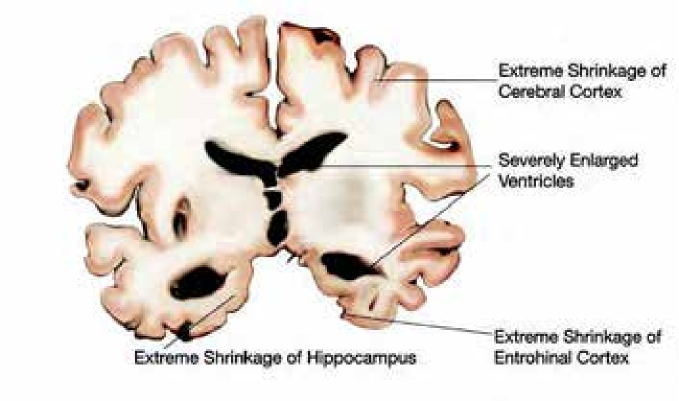
Behavior is the result of complex brain processes, all of which take place in a fraction of a second in the healthy brain. In AD, many of those processes are disturbed, and these disrupted communications between neurons are the basis for many distressing or inappropriate behaviors. For example, a person may angrily refuse to take a bath or get dressed because he does not understand what his caregiver has asked him to do. If he does understand, he may not remember how to do it. The anger can be a mask for his confusion and anxiety. Or, a person with AD may constantly follow her husband or caregiver and fret when the person is out of sight. To a person who cannot remember the past or anticipate the future, the world can be strange and frightening. Sticking close to a trusted and familiar caregiver may be the only thing that makes sense and provides security.

Severe AD

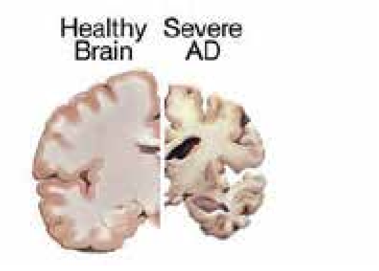
In the last stage of AD, plaques and tangles are widespread throughout the brain, most areas of the brain have shrunk further, and ventricles have enlarged even more. People with AD cannot recognize family and loved ones or communicate in any way. They are completely dependent on others for care. Other symptoms can include:

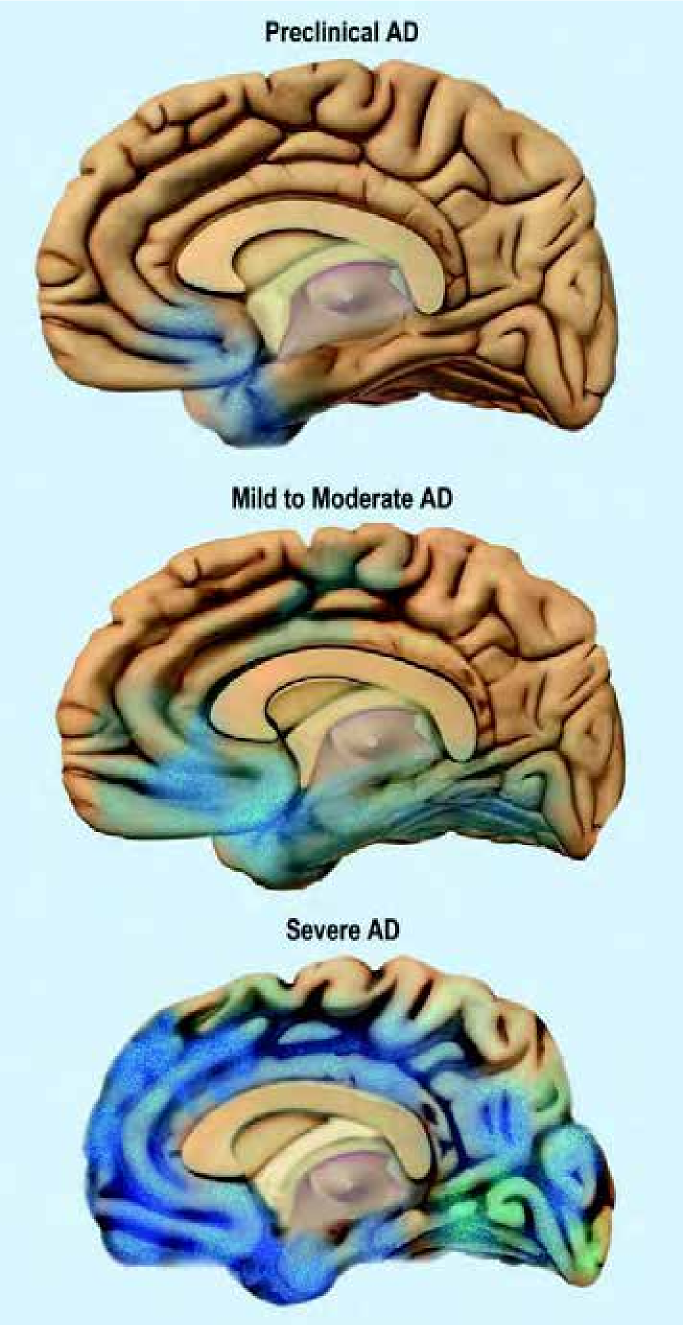
- Weight loss.
- Seizures.
- Skin infections.
- Difficulty swallowing.
- Groaning, moaning, or grunting.
- Increased sleeping.
- Lack of bladder and bowel control.

Near the end, the person may be in bed much or all of the time. The most frequent cause of death for people with AD is aspiration pneumonia. This type of pneumonia develops when a person is not able to swallow properly and takes food or liquids into the lungs instead of air.



Severe AD





AD spreads through the brain

The medical school curriculum demands that students spend enormous amounts of time in the classroom and clinic learning the information and skills necessary for a career in medicine. However, little or no time is set aside for students to be with patients outside the hospital or clinic setting. As a result, it is hard for medical students to get to know the human side of the diseases they are learning about.

The buddy program at Northwestern University

A program at Northwestern University's Cognitive Neurology and Alzheimer's Disease Center is adding just that element to its medical education. The Buddy Program, begun in 1998, matches first-year medical students with people diagnosed with AD or another form of dementia. About 10 to 15 medical students participate every year. They first take a 3-hour orientation course on AD, family issues, and communication skills. Then, for the next year, they spend at least 4 hours a month with a person with dementia in addition to monthly meetings with the program coordinators. Together with the person's caregiver and the program's professional staff, students and their "buddies" choose activities for their visits together. Activities can include shopping, visiting museums, exercising together, or even just sharing a coffee or a meal. The students also are able to observe their buddies' clinical evaluations at the Center. Other medical schools have started similar programs.

The people with AD and their families are selected from Northwestern's Alzheimer's Disease Center and other related programs at the university. Families are contacted about participating, and the people with AD are selected based on their ability to understand the nature of the program and their willingness to spend time every month with the student buddy.

The program has clear benefits for both the medical student and the person with AD. For the medical student, it provides a hands-on way to learn about AD and related dementias, and it helps him or her understand the daily realities and issues involved in caring for and supporting people with AD and their families. It also introduces them to the career path of research and clinical practice in AD and related dementias. For the person with AD, participation in the program provides an opportunity for friendship and socializing and an outlet for sharing their experiences with a sympathetic listener.

For many of the students, the program is a transformative experience. They become very close to their buddies and family caregivers during their year together, and continue the friendship even after the year is over.

PART 3: AD RESEARCH: BETTER QUESTIONS, NEW ANSWERS

Scientists have studied AD from many angles. They have looked at populations to see how many cases of AD occur every year and whether there might be links between the disease and lifestyles or genetic backgrounds. They also have conducted clinical studies with healthy older people and those at various stages of AD. They have done many studies with laboratory animals. They have begun to look at neuronal circuits and networks of cells to learn how AD pathology develops and spreads. They even have examined individual nerve cells to see how beta-amyloid, tau, and other molecules affect the ability of cells to function normally.

These studies have led to a fuller understanding of many aspects of the disease, improved diagnostic tests, new ways to manage behavioral aspects of AD, and a growing number of possible drug treatments. Findings from current research are pointing scientists in promising directions for the future. They are also helping researchers to ask better questions about the issues that are still unclear.

Part 3 of *Unraveling the Mystery* describes what scientists are learning from their search for:

- The causes of AD.
- New techniques to help in diagnosis.
- New treatments.

Results from this research will bring us closer to the day when we will be able to delay the onset of, prevent, or cure the devastating disease that robs our older relatives and friends of their most precious possession—their minds.

Looking for the causes of AD

One of the most important parts of unraveling the AD mystery is finding out what causes the disease. What makes the disease process begin in the first place? What makes it worse over time? Why does the number of people with the disease increase with age? Why does one person develop AD while another remains healthy?

Some diseases, such as measles or pneumonia, have clear-cut causes. They can be prevented with vaccines or cured with antibiotics. Others, such as diabetes or arthritis, develop when genetic, lifestyle, and environmental factors work together to start a disease process. The role that any or all of these factors play may be different for each individual.

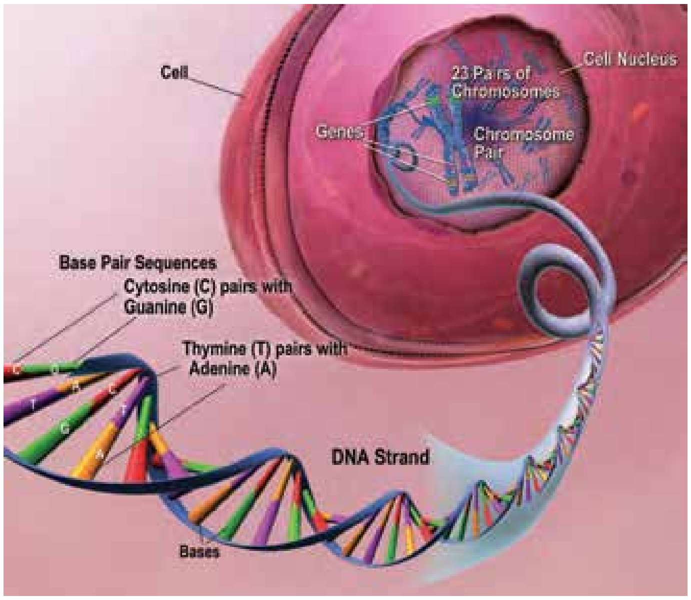
AD fits into the second group of diseases. We do not yet fully understand what causes AD, but we believe it develops because of a complex series of events that take place in the brain over a long period of time. Many studies are exploring the factors involved in the cause and development of AD.

Genetic factors at work in AD
Genetic studies of complex neurodegenerative diseases such as AD focus on two main issues—whether a gene might influence a person's overall risk of developing a disease and whether a gene might influence some particular aspect of a person's risk, such as the age at which the disease begins. Slow and careful detective work by scientists has paid off in discoveries of genetic links to the two main types of AD.

One type is the rare, **early-onset Alzheimer's disease**. It usually affects people aged 30 to 60. Some cases of early-onset disease are inherited and are called familial AD (FAD). The other is **late-onset Alzheimer's disease**. It is by far the more common form and occurs in those 60 and older. Gaining insight into the genetic factors associated with both forms of AD is important because identifying genes that either cause the disease or influence a person's risk of developing it improves our ability to understand how and why the disease starts and progresses.

DNA, chromosomes, and genes: The body's amazing control center

The nucleus of almost every human cell contains an encrypted "blueprint," along with the means to decipher it. This blueprint, accumulated over eons of genetic trial and error, carries all the instructions a cell needs to do its job. The blueprint is made up of **DNA**, which exists as two long, intertwined, thread-like strands called **chromosomes**. Each cell has 46 chromosomes in 23 pairs. The DNA in chromosomes is made up of four chemicals, or bases, strung together in various sequence patterns. The DNA in nearly all cells of an individual is identical.



DNA, chromosomes, and genes

Each chromosome contains many thousands of segments, called **genes**. People inherit two copies of each gene from their parents, except for genes on the X and Y chromosomes, which are chromosomes that, among other functions, determine a person's sex. Each person normally has one pair of sex chromosomes (females are XX and males are XY). The sequence of bases in a gene tells the cell how to make specific proteins. Proteins in large part determine the different kinds of cells that make up an organism and direct almost every aspect of the cell's construction, operation, and repair. Even though all genes are present in most cells, the pattern in which they are activated varies from cell to cell, and gives each cell type its distinctive character. Even slight alterations in a gene can produce an abnormal protein, which, in turn, may lead to cell malfunction and, eventually, to disease.

Any permanent change in the sequence of bases in a gene's DNA that causes a disease is called a **mutation**. Mutations also can change the activation of a particular gene. Other more common (or frequent) changes in a gene's sequence of bases do not automatically cause disease, but they can increase the chances that a person will develop a particular disease. When this happens, the changed gene is called a **genetic risk factor**.

Genes and early-onset Alzheimer's disease
In the early days of AD genetics research, scientists realized that some cases, particularly of the rare early-onset AD, ran in families. This led them to examine DNA samples from these families to see whether they had some genetic trait in common. Chromosomes 21, 14, and 1 became the focus of attention. The scientists found that some families have a mutation in selected genes on these chromosomes. On chromosome 21, the mutation causes an abnormal amyloid precursor protein to be produced (see page 22 for more on APP). On chromosome 14, the mutation causes an abnormal protein called presenilin 1 to be produced. On chromosome 1, the mutation causes another abnormal protein to be produced. This protein, called presenilin 2, is very similar to presenilin 1. Even if only one of these genes that are inherited from a parent contains a mutation, the person will almost inevitably develop early-onset AD. This means that in these families, children have about a 50-50 chance of developing the disease if one of their parents has it.

Early-onset AD is very rare, and mutations in these three genes do not play a role in the more common late-onset AD. However, these findings were crucial because they showed that genetics was indeed a factor in AD, and they helped to identify some key cell pathways involved in the AD disease process. They showed that mutations in APP can cause AD, highlighting the presumed key role of beta-amyloid in the disease. Mutations in pre- senilin 1 and 2 also cause an increased amount of the damaging beta-amyloid to be made in the brain.

A different genetic story in late-onset Alzheimer's disease
While some scientists were studying the role of chromosomes 21, 14, and 1 in early-onset AD, others were looking elsewhere to see if they could find genetic clues for the late-onset form. By 1992, investigators had narrowed their search to a region of chromosome 19. They found a gene on chromosome 19 that they were able to link to late-onset AD.

This gene, called APOE, produces a protein called **apolipoprotein E**. APOE comes in several forms, or alleles—ε2, ε3, and ε4:

- The APOE ε2 allele is relatively rare and may provide some protection against the disease. If AD does occur in a person with this allele, it develops later in life than in those with an APOE ε4 allele.
- APOE ε3 is the most common allele. Researchers think it plays a neutral role in AD.
- APOE ε4 occurs in about 40 percent of all people who develop late-onset AD and is present in about 25 to 30 percent of the population. People with AD are more likely to have an APOE ε4 allele than people who do not have AD. However, at least one-third of people with AD do not have an APOE ε4 allele. Dozens of studies have confirmed that the APOE ε4 allele increases the risk

of developing AD, but how that happens is not yet understood. These studies also have helped to explain some of the variation in the age at which AD develops, as people who inherit one or two APOE ε4 alleles tend to develop AD at an earlier age than those who do not. However, inheriting an APOE ε4 allele does not mean that a person will definitely develop AD. Some people with one or two APOE ε4 alleles never get the disease, and others who do develop AD do not have any APOE ε4 alleles.

Other factors at work in AD

Genetics explains some of what might cause AD, but it does not explain everything. So, researchers continue to investigate other possibilities that may explain how the AD process starts and develops.

Beta-Amyloid

We now know a great deal about how beta-amyloid is formed and the steps by which beta-amyloid fragments stick together in small aggregates (oligomers), and then gradually form into plaques. Armed with this knowledge, investigators are intensely interested in the toxic effects that beta-amyloid, oligomers, and plaques have on neurons. This research is possible in part because scientists have been able to develop transgenic animal models of AD. Transgenics are animals that have been specially bred to develop AD-like features, such as beta-amyloid plaques.

Beta-amyloid studies have moved forward to the point that scientists are now carrying out preliminary tests in humans of potential therapies aimed at removing beta-amyloid, halting its formation, or breaking down early forms before they can become harmful.

For example, one line of research by a pharmaceutical company started with the observation that injecting beta-amyloid into AD transgenic mice caused them to form antibodies to the beta-amyloid and reduced the number of amyloid plaques in the brain. This exciting finding led to other studies and ultimately to clinical trials in which human participants were immunized with beta-amyloid. These studies had to be stopped because some of the participants developed harmful side effects, but the investigators did not give up hope. Rather, they went back to the drawing board to rethink their strategy. More refined antibody approaches are now being tested in clinical trials, and additional research on new ways of harnessing the antibody response continues in the lab.

Another important area of research is how beta-amyloid may disrupt cellular communication well before plaques form. One recent study described how beta-amyloid oligomers target specific synaptic connections between neurons, causing them to deteriorate. Other scientists are studying other potentially toxic effects that plaques have on neurons and in cellular communication. Understanding more about these processes may allow scientists to develop specific therapies to block the toxic effects.

Tau

Tau, the chief component of neurofibrillary tangles, is generating new excitement as an area of study. The recent focus on tau has been spurred by the finding that a mutant form of the protein is responsible for one form of frontotemporal dementia, the third most common cause of late-life dementia, after AD and vascular dementia. This form is known as frontotemporal dementia with parkinsonism linked to chromosome 17 (FTDP17). Finding this mutant protein was important because it suggested that abnormalities in the tau protein itself can cause dementia.

New transgenic mouse models of AD have helped tau research make rapid progress. For example, a recent model, the “triple transgenic” mouse, forms plaques and tangles over time in brain regions similar to those in human AD. Another recent transgenic mouse model, which contains only human tau, forms clumps of damaging tau filaments also in a region-specific fashion similar to AD in humans.

These studies of tau also have suggested a mechanism for tau damage that is different from that previously suspected. With these new insights, scientists now speculate that one reason tau may damage and kill neurons is because it upsets the normal activity of the cell, in addition to forming neurofibrillary tangles.

Other studies of mutant tau in mice suggest that the accumulation of tau in tangles may not even be the culprit in memory loss. Rather, as with beta-amyloid, it may be that an earlier and more soluble abnormal form of the protein causes the damage to neurons.

Protein misfolding

Researchers have found that a number of devastating neurodegenerative diseases (for example, AD, Parkinson’s disease, dementia with Lewy bodies, frontotemporal lobar degeneration, Huntington’s disease, and prion diseases) share a key characteristic—protein misfolding.

When a protein is formed, it “folds” into a unique three-dimensional shape that helps it perform its specific function. This crucial process can go wrong for various reasons, and more commonly does go wrong in aging cells. As a result, the protein folds into an abnormal shape—it is misfolded. In AD, the misfolded proteins are beta-amyloid (the cleaved product of APP) and a cleaved product of tau.

Normally, cells repair or degrade misfolded proteins, but if many of them are formed as part of age-related changes, the body’s repair and clearance process can be overwhelmed. Misfolded proteins can begin to stick together with other misfolded proteins to form insoluble aggregates. As a result, these aggregates can build up, leading to disruption of cellular communication, and metabolism, and even to cell death. These effects may predispose a person to AD or other neurodegenerative diseases.

Scientists do not know exactly why or how these processes occur, but research into the unique characteristics and actions of various misfolded proteins is helping investigators learn more about the similarities and differences across age-related neurodegenerative diseases. This knowledge may someday lead to therapies.

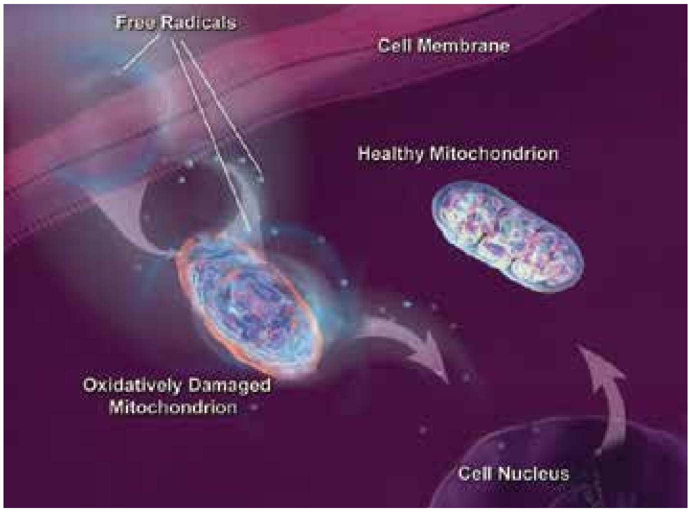
The aging process

Another set of insights about the cause of AD comes from the most basic of all risk factors— aging itself. Age-related changes, such as inflammation, may make AD damage in the brain worse. Because cells and compounds that are known to be involved in inflammation are found in AD plaques, some researchers think that components of the inflammatory process may play a role in AD.

Other players in the aging process that may be important in AD are free radicals, which are oxygen or nitrogen molecules that combine easily with other molecules (scientists call them “highly reactive”). Free radicals are generated in mitochondria, which are structures found in all cells, including neurons.

Mitochondria are the cell’s power plant, providing the energy a cell needs to maintain its structure, divide, and carry out its functions. Energy for the cell is produced in an efficient metabolic process. In this process, free radicals are produced. Free radicals can help cells in certain ways, such as fighting infection. However, because they are very active and combine easily with other molecules, free radicals also can damage the neuron’s cell membrane or its DNA.

The production of free radicals can set off a chain reaction, releasing even more free radicals that can further damage neurons. This kind of damage is called **oxidative damage**. The brain’s unique characteristics, including its high rate of metabolism and its long-lived cells, may make it especially vulnerable to oxidative damage over the lifespan. The discovery that beta-amyloid generates free radicals in some AD plaques is a potentially significant finding in the quest for better understanding of AD as well as for other neurodegenerative disorders and unhealthy brain aging.



Mitochondria and free radicals: Any given cell has hundreds of mitochondria. This illustration shows two–a healthy mitochondrion and an oxidatively stressed and damaged one. The arrows indicate the movement of free radicals, which can spread easily from damaged mitochondria to other parts of the cell.

Researchers also are studying age-related changes in the working ability of synapses in certain areas of the brain. These changes may reduce the ability of neurons to communicate with each other, leading to increased neuronal vulnerability in regions of the brain important in AD. Age-related reductions in levels of particular growth factors, such as **nerve growth factor** and **brain-derived neurotrophic factor**, also may cause important cell populations to be compromised. Many studies are underway to tease out the possible effects of the aging process on the development of AD.

Vascular disease

For some time now, hints have been emerging that the body's vast network of small and large blood vessels—the vascular system—may make an important contribution in the development of dementia and the clinical symptoms of AD. Some scientists are focusing on what happens with the brain's blood vessels in aging and AD. Others are looking at the relationship between AD and vascular problems in other parts of the body.

AD and vascular problems in the brain

The brain requires a constant and dependable flow of oxygen and glucose to survive and flourish. The brain's blood vessels provide the highways to deliver these vital elements to neurons and glial cells.

Aging brings changes in the brain's blood vessels—arteries can narrow and growth of new capillaries slows down. In AD, whole areas of nervous tissue, including the capillaries that supply and drain it, also are lost. Blood flow to and from various parts of the brain can be affected, and the brain may be less able to compensate for damage that accumulates as the disease progresses.

For some time now, study of the brain's blood vessel system in AD has been a productive line of inquiry. One important finding has been that the brain's ability to rid itself of toxic beta-amyloid by sending it out into the body's blood circulation is lessened. Some scientists now think that poor clearance of beta-amyloid from the brain, combined with a diminished ability to develop new capillaries and abnormal aging of the brain's blood vessel system, can lead to chemical imbalances in the brain and damage neurons' ability to function and communicate with each other. These findings are exciting because they may help to explain part of what happens in the brain during the development of AD. These findings also suggest several new targets for potential AD therapies.

AD and vascular problems in other parts of the body

Research also has begun to tease out some relationships between AD and other vascular diseases, such as heart disease, stroke, and type 2 diabetes. It is important to sort out the various effects on the brain of these diseases because they are major causes of illness and death in the United States today.

Much of this evidence comes from epidemiologic studies, which compare the lifestyles, behaviors, and characteristics of groups of people. These studies have found, for example, that heart disease and stroke may contribute to the development of AD, the severity of AD, or the development of other types of dementia. Studies also show that high blood pressure that develops during middle age is correlated with cognitive decline and dementia in later life.

Another focus of AD vascular research is the metabolic syndrome, a constellation of factors that increases the risk of heart disease, stroke, and type 2 diabetes. Metabolic syndrome includes obesity (especially around the waist), high triglyceride levels, low HDL ("good cholesterol") levels, high blood pressure, and insulin resistance (a condition in which insulin does not regulate blood sugar levels very well). Evidence from epidemiologic studies now suggests that people with the metabolic syndrome have increased risk of cognitive impairment and accelerated cognitive decline.

Nearly one in five Americans older than age 60 has type 2 diabetes, and epidemiologic studies suggest that people with this disease may be at increased risk of cognitive problems, including MCI and AD, as they age. The higher risk associated with diabetes may be the result of high levels of blood sugar, or it may be due to other conditions associated with diabetes (obesity, high blood pressure, abnormal blood cholesterol levels, progressive atherosclerosis, or too much insulin in the blood). These findings about diabetes have spurred research on a number of fronts— epidemiologic studies, test tube and animal studies, and clinical trials. The objective of these studies is to learn more about the relationship between diabetes and cognitive problems and to find out in clinical trials whether treating the disease rigorously can positively affect cognitive health and possibly slow or prevent the development of AD.

Lifestyle factors

We know that physical activity and a nutritious diet can help people stay healthy as they grow older. A healthy diet and exercise can reduce obesity, lower blood cholesterol and high blood pressure, and improve insulin action. In addition, association studies suggest that pursuing intellectually stimulating activities and maintaining active contacts with friends and family may contribute to healthy aging. A growing body of evidence now suggests that these lifestyle factors may be related to cognitive decline and AD. Researchers who are interested in discovering the causes of AD are intensively studying these issues, too.

Physical activity and exercise

Exercise has many benefits. It strengthens muscles, improves heart and lung function, helps prevent osteoporosis, and improves mood and overall wellbeing. So it is not surprising that AD investigators began to think that if exercise helps every part of the body from the neck down, then it might help the brain as well.

Epidemiologic studies, animal studies, and human clinical trials are assessing the influence of exercise on cognitive function. Here are a few things these studies have found:

- Animal studies have shown that exercise in- creases the number of capillaries that supply blood to the brain and improves learning and memory in older animals.
- Epidemiologic studies show that higher levels of physical activity or exercise in older people are associated with reduced risk of cognitive decline and reduced risk of dementia. Even moderate exercise, such as brisk walking, is associated with reduced risk.
- Clinical trials show some evidence of short-term positive effects of exercise on cognitive function, especially executive function (cognitive abilities involved in planning, organizing, and decision making). One trial showed that older adults who participated in a 6-month program of brisk walking showed increased activity of neurons in key parts of the brain.

More clinical trials are underway to expand our knowledge about the relationship of exercise to healthy brain aging, reduced risk of cognitive decline, and development of AD.

Diet

Researchers have explored whether diet may help preserve cognitive function or reduce AD risk, with some intriguing findings. For example, studies have examined specific foods that are rich in antioxidants and anti-inflammatory properties to find out whether those foods affect age-related changes in brain tissue. One laboratory study found that curcumin, the main ingredient of turmeric (a bright yellow spice used in curry), can bind to beta-amyloid and prevent oligomer formation. Another study in mice found that diets high in DHA (docosahexaenoic acid), a type of healthy omega-3 fatty acid found in fish, reduced beta-amyloid and plaques in brain tissue.

Other studies have shown that old dogs perform better on learning tasks when they eat diets rich in antioxidants, such as vitamin E and other healthful compounds, while living in an "enriched" environment (one in which the dogs have many opportunities to play and interact with people and other dogs).

Scientists also have examined the effects of diet on cognitive function in people. A very large epidemiologic study of nurses found an association between participants who ate the most vegetables (especially green leafy and cruciferous vegetables) and a slower rate of cognitive decline compared with nurses who ate the least amount of these foods. An epidemiologic study of older adults living in Chicago found the same association. The researchers do not know the exact reason behind this association, but speculate that the beneficial effects may result from the high antioxidant and folate content of the vegetables.

Dietary studies, such as the curcumin study in mice or the vegetables study in nurses, generally examine individual dietary components so that scientists can pinpoint their specific effects on an issue of interest. This approach has obvious limitations because people do not eat just single foods or nutrients. Several recent epidemiologic studies have taken a different approach and looked at an entire dietary pattern.

In one of these studies, researchers worked with older adults living in New York who ate the "Mediterranean diet"—a diet with lots of fruits, vegetables, and bread; low to moderate amounts of dairy foods, fish, and poultry; small amounts of red meat; low to moderate amounts of wine; and frequent use of olive oil. The researchers found that sticking to this type of diet was associated with a reduced risk of AD and that the association seemed to be driven by the whole approach, rather than by its individual dietary components. A follow-up study found that this pattern also was associated with longer survival in people with AD.

All of these results are exciting and suggestive, but they are not definitive. To confirm the results, scientists are conducting clinical trials to examine the relationship of various specific dietary components and their effect on cognitive decline and AD.

Intellectually stimulating activities and social engagement

Many older people love to read, do puzzles, play games, and spend time with family and friends. All these activities are fun and help people feel alert and engaged in life. Researchers are beginning to find other possible benefits as well, for some studies have shown that keeping the brain active is associated with reduced AD risk. For example, over a 4-year period, one group of researchers tracked how often a large group of older people did activities that involved significant information processing, such as listening to the radio, reading newspapers, playing puzzle games, and going to museums. The researchers then looked at how many of the participants developed AD. The researchers found that the risk of developing AD was 47 percent lower in the people who did them the most frequently compared with the people who did the activities least frequently. Another study supported the value of lifelong learning and mentally stimulating activity by finding that, compared with older study participants who may have had AD or who had AD, healthy older participants had engaged in more mentally stimulating activities and spent more time at them during their early and middle adulthood.

Studies of animals, nursing home residents, and people living in the community also have suggested a link between social engagement and cognitive performance. Older adults who have a full social network and participate in many social activities tend to have less cognitive decline and a decreased risk of dementia than those who are not socially engaged.

The reasons for these findings are not entirely clear, but a number of explanations are possible. Among them:

- Intellectually stimulating activities and social engagement may protect the brain in some way, perhaps by establishing a cognitive reserve.
- These activities may help the brain become more adaptable and flexible in some areas of mental function so that it can compensate for declines in other areas.
- Less engagement with other people or in intellectually stimulating activities could be the result of very early effects of the disease rather than its cause.
- People who engage in stimulating activities may have other lifestyle qualities that may protect them against developing AD.

Describing scientific findings: The type of study makes an important difference

These days, the media are full of stories about scientific studies. It can be hard to know what to conclude about their findings. Knowing how the study was conducted can help put the results into the right perspective.

One main type of research is the epidemiologic study. These studies are observational—they gather information about people who are going about their daily lives. Study participants follow many behaviors and practices. It is difficult, therefore, to determine the exact benefits or risks of one particular behavior from among all the healthy or harmful behaviors followed by the participants. That is why, in epidemiologic studies of AD, scientists only say that a finding is "associated with" AD, or not. The epidemiologic evidence linking a behavior and AD is, at best, suggestive, but we do not know that the behavior by itself actually helps to cause or prevent AD.

Other types of research—test tube studies and studies in animals— add to the findings from epidemiologic studies. Scientists use them to examine the same issue but in ways in which the various factors that might influence a result are controlled to a greater degree. This element of control allows scientists to be more certain about why they get the results they do. It also allows them to be more definitive in the words they use to describe their results. Of course, showing a cause-and-effect relationship in tissue samples or even in animal studies still does not mean that the relationship will be the same in humans. Clinical trials in humans are the gold standard for deciding whether a behavior or a specific therapeutic agent actually prevents or delays AD.

New techniques help in diagnosing AD

A man in his mid-60s begins to notice that his memory isn't as good as it used to be. More and more often, a word will be on the tip of his tongue but he just can't remember it. He forgets appointments, makes mistakes when paying his bills, and finds that *he's often confused or anxious about the normal hustle and bustle of life around him. One evening, he suddenly finds himself walking in a neighborhood he doesn't recognize. He has no idea how he got there or how to get home.*

Not so long ago, this man's condition would have been swept into a broad catch-all category called "senile dementia" or "senility." Although we now know that AD and other causes of dementia are distinct diseases, in the early stages it is difficult to differentiate between the onset of AD and other types of age-related cognitive decline. We have improved our ability to diagnose AD correctly, and doctors experienced in AD can diagnose the disease with up to 90 percent accuracy. A definitive diagnosis of AD, however, is still only possible after death, during an autopsy, and we are still far from the ultimate goal— a reliable, valid, inexpensive, and early diagnostic marker that can be used in any doctor's office.

Early diagnosis has several advantages. For example, many conditions cause symptoms that mimic those of AD. Finding out early that the observed changes in cognitive abilities are not AD but something else is almost always a relief and may be just the prod needed to seek appropriate medical treatment. For the small percentage of dementias that are treatable or even reversible, early diagnosis increases the chances of successful treatment. Increasing early diagnosis and improving treatment are among NIA's most important goals.

Even when the cause of a loved one's dementia turns out to be AD, it is best to find out sooner rather than later. One benefit of knowing is medical. The drugs now available to treat AD can help some people maintain their mental abilities for months to years, although they do not change the underlying course of the disease.

Other benefits are practical. The sooner the person with AD and the family have a firm diagnosis, the more time they have to make future living arrangements, handle financial matters, establish a durable power of attorney and advance directives, deal with other legal issues, create a support network, and even consider joining a clinical trial or other research study. Being able to participate for as long as possible in making personal decisions is important to many people with AD.

Early diagnosis also gives families time to recognize that life does not stop with a diagnosis of AD. The person is still able to participate in many of the daily activities he or she has always enjoyed, and families can encourage the person to continue with them for as long as possible. Finally, early diagnosis gives family caregivers the opportunity to learn how to recognize and cope with changes over time in their loved one as well as to develop strategies that support their own physical, emotional, and financial health.

Scientists also see advantages to early diagnosis. Developing tests that can reveal what is happening in the brain in the early stages of AD will help them understand more about the cause and development of the disease. It also will help scientists learn when and how to prescribe the use of drugs and other treatments so they can be most effective.

Current tools for diagnosing AD

With the tools now available, experienced physicians can be reasonably confident about making an accurate diagnosis of AD in a living person. Here is how they do it.

They take a detailed patient history, including:

- A description of how and when symptoms developed.
- A description of the person's and his or her family's overall medical condition and history.
- An assessment of the person's emotional state and living environment.

They get information from family members or close friends:

- People close to the person can provide valuable insights into how behavior and personality have changed; many times, family and friends know something is wrong even before changes are evident on tests.

They conduct physical and neurological examinations and laboratory tests:

- Blood and other medical tests help determine neurological functioning and identify possible non-AD causes of dementia.

They conduct neuropsychological testing:

- Question-and-answer tests or other tasks that measure memory, language skills, ability to do arithmetic, and other abilities related to brain functioning help show what kind of cognitive changes are occurring.

They may do a computed tomography (CT) scan or a magnetic resonance imaging (MRI) test:

- **CT** and **MRI** scans can detect strokes or tumors or can reveal changes in the brain's structure that indicate early AD.

Exams and tests may be repeated every so often to give physicians information about how the person's memory and other symptoms are changing over time.

Based on findings from these exams and tests, experienced physicians can diagnose or rule out other causes of dementia, or determine whether the person has MCI, "possible AD" (the symptoms may be due to another cause), or "probable AD" (no other cause for the symptoms can be found).

Causes of dementia

Dementia is the loss of cognitive functioning—thinking, remembering, and reasoning—to such an extent that it interferes with a person's daily life and activities. It is not a disease itself, but a group of symptoms that often accompanies a disease or condition. Some dementias are caused by neurodegenerative diseases. Dementia also has other causes, some of which are treatable.

Neurodegenerative diseases that cause dementia

- Alzheimer's disease.
- Vascular dementia.
- Parkinson's disease with dementia.
- Frontotemporal lobar degeneration, including:
    - Frontotemporal dementia.
    - Frontotemporal dementia with parkinsonism linked to chromosome 17 (FTDP-17).
    - Pick's disease.
    - Supranuclear palsy.
    - Corticobasal degeneration.

Other causes of dementia

- Medication side effects.
- Depression.
- Vitamin B12 deficiency.
- Chronic alcoholism.
- Certain tumors or infections of the brain.
- Blood clots pressing on the brain.
- Metabolic imbalances, including thyroid, kidney, or liver disorders.

Exciting new developments in AD diagnosis

Scientists are now exploring ways to help physicians diagnose AD earlier and more accurately. For example, some studies are focusing on changes in mental functioning. These changes can be measured through memory and recall tests. Tests that measure a person's abilities in areas such as abstract thinking, planning, and language can help pinpoint changes in these areas of cognitive function. Researchers are working to improve standardized tests that might be used to point to early AD or predict which individuals are at higher risk of developing AD in the future.

Other studies are examining the relationship between early damage to brain tissue and outward clinical signs. Still others are looking for changes in biomarkers in the blood or cerebro-spinal fluid that may indicate the progression of AD.

One of the most exciting areas of ongoing research in this area is neuroimaging. Over the past decade, scientists have developed several highly sophisticated imaging systems that have been used in many areas of medicine, including AD. PET scans, **single photon emission computed tomography** (SPECT), and MRI are all examples. These "windows" on the living brain may help scientists measure the earliest changes in brain function or structure in order to identify people who are at the very first stages of the disease—well before they develop clinically apparent signs and symptoms.

To help advance this area of research, NIA launched the multi-year AD Neuroimaging Initiative (ADNI) in 2004. This project is following about 200 cognitively healthy individuals and 400 people with MCI for 3 years and 200 people with early AD for 2 years. Over the course of this study, participants undergo multiple MRI and PET scans so that study staff can assess how the brain changes in the course of normal aging and MCI, and with the progression of AD. By using MRI and PET scans at regularly scheduled intervals, study investigators hope to learn when and where in the brain degeneration occurs as memory problems develop.

Another innovative aspect of ADNI is that scientists are correlating the participants' imaging information with information from clinical, memory, and other cognitive function tests, and with information from blood, cerebrospinal fluid, and urine samples. Results from these samples may provide valuable biomarkers of disease progress, such as changing levels of beta-amyloid and tau, indicators of inflammation, measures of oxidative stress, and changing cognitive abilities.

An important ADNI achievement is the creation of a publicly accessible database of images, biomarker data, and clinical information available to qualified researchers worldwide.

Biological samples also are available for approved biomarker projects. NIA hopes that this initiative will help create rigorous imaging and biomarker standards that will provide measures for the success of potential treatments. This would substantially increase the pace and decrease the cost of developing new treatments. The ADNI study is being replicated in similar studies by researchers in Europe, Japan, and Australia.

These types of neuroimaging scans are still primarily research tools, but one day they may be used more commonly to help physicians diagnose AD at very early stages. It is conceivable that these tools also may someday be used to monitor the progress of the disease and to assess responses to drug treatment.

New technologies help people participate in ad research at home

Traditionally, AD scientists have collected data by asking people to come to a clinic once or twice a year over a period of years. They give the participants a physical exam and ask them to take a series of memory, language, and other cognitive function tests.

These studies collect much useful information, but they have their limitations. For one thing, participants are seen only once or twice during the year, so the data collected represent only a "snapshot" in time. The studies cannot effectively capture day-to-day fluctuations in behaviors and cognitive abilities. Another limitation is that participants are seen in a research setting, not in their natural community environment. For many, coming to the clinic can be inconvenient, difficult, or both.

Advances in technology, as shown in the two research projects described here, offer some hope for dealing with these challenges by bringing research to people right in their own homes.

Motion detectors tell an interesting story
Scientists who are trying to develop methods for diagnosing AD as early as possible continually grapple with two challenges in conducting their research. First, they need to find easy and accurate ways to collect data from older people, who often have physical, emotional, or cognitive problems. Second, they need to find ways to assess accurately the very early changes in physical or cognitive abilities that could indicate that AD is progressing.

Under an NIA grant, the Oregon Center for Aging and Technology (ORCATECH) at Oregon Health & Science University is exploring the use of unobtrusive, simple technology and intelligent systems to detect and monitor subtle changes in movement that may indicate age-related cognitive changes. This project is building on research that has suggested that motor-function changes may arise before memory changes become apparent.

All of the 300 study participants are 80 years or older or have a spouse of a similar age, and live independently in Portland-area retirement communities. Wireless, infrared motion sensors, like those used to automatically open grocery store doors, have been placed strategically throughout the participants' homes to gather data about changes in their walking or dressing speed over time. Special software also has been installed on each participant's home computer to measure motor skills and speed in typing or using a mouse. The sensors and computer software collect data about motion, not what the volunteer is actually doing. Privacy is largely not a concern therefore, because the volunteers are not directly observed and no video or photographs are taken.

The 3-year study began in early 2007, so results are not yet available. However, a small pilot study using the same type of sensors showed a clear difference in the walking speeds of people age 65 and older who had MCI, compared with cognitively healthy people of the same age, over time periods of nearly a year. These data suggest that a remote sensing system like this is a feasible technology and is potentially sensitive enough to distinguish accurately between affected and unaffected people.

Using technology to collect data at home
Researchers at nearly 30 sites nationwide are comparing various ways of collecting data, including the use of an in-home "kiosk" that combines a touch-screen computer monitor with a telephone handset, an interactive voice-response system, and traditional mail and telephone. All three methods gather the same data about several areas known to be important in early detection of cognitive decline: memory; language skills; attention and concentration; activities of daily living; quality of life; health care and resource use; and changes in "global" well-being as measured by self-rating of health, cognition, and mood. This study is looking at questions such as how likely people are to complete the questions using each method, which method is the most efficient, and how sensitive each method is.

Having a data collection system that is easy to use and that collects data accurately and completely may encourage wider participation in AD clinical trials. It also may reduce the expense and burden of conducting AD research. Early results from this study show that the older participants were skeptical at first about using the kiosk, but once they learned how to use it, they became enthusiastic and excited about participating.

The search for new treatments

More and more, scientists are able to think about ways to treat, slow, or perhaps even prevent AD at a number of possible points during the years-long continuum of disease progression. This continuum begins with the very earliest disease stage, even before symptoms are evident, moves to the first signs of memory and cognitive problems, then continues through the mild and moderate stages, and ends with the very late stages and the person's death.

As a result, researchers who focus on developing AD treatments think a lot about the importance of timing: When would it be best to intervene and what interventions are most appropriate at which time? These questions are similar to those asked with other conditions, such as heart disease. For example, a physician would prescribe different treatments for a patient who is seemingly healthy but who is at risk of having future heart disease than for a patient who is actually having a heart attack or whose heart disease is well established. The same decision process now can be applied to AD.

It has become clear that there probably is no single "magic bullet" that will, by itself, prevent or cure AD. Therefore, investigators are working to develop an array of options from which physicians can choose. For people who already have AD, the most immediate need is for treatments to control cognitive loss as well as problem behaviors, such as aggression, agitation, wandering, depression, sleep disturbances, hallucinations, and delusions. Safe medications that remain effective over time are needed to ease a broad range of symptoms and to improve a person's cognitive function and ability to carry out activities of daily living. Scientists also are investigating treatments that combine medications with lifestyle strategies to lessen the risk of developing cognitive decline or AD. Eventually, scientists hope to develop treatments that attack the earliest manifestations and underlying causes of AD, thereby slowing, delaying, or preventing the disease from progressing and damaging cognitive function and quality of life. Scientists use **clinical trials** to pursue all these goals.

Today, NIA, other NIH institutes, and private industry are conducting many clinical trials of AD interventions. These studies focus on several key areas:

- Helping people with AD maintain their mental functioning.
- Managing symptoms.
- Slowing, delaying, or preventing AD.

Helping people with AD maintain their mental functioning

In the mid-1970s, scientists discovered that levels of a neurotransmitter (a chemical that carries messages between neurons) called acetylcholine fell sharply in people with AD. This discovery was one of the first that linked AD with biochemical changes in the brain. Scientists found that acetylcholine is a critical player in the process of forming memories. It is used by neurons in the hippocampus and cerebral cortex, which are areas of the brain important to memory function. This discovery was an important initial breakthrough in the search for drugs to treat AD.

Four medications, tested in clinical trials, have been approved by the FDA for use in treating AD symptoms. Donepezil (Aricept®), rivastigmine (Exelon®), and galantamine (Razadyne®) are prescribed to treat mild to moderate AD symptoms. Donepezil was recently approved to treat severe AD as well. These drugs, known as cholinesterase inhibitors, act by stopping or slowing the action of acetylcholinesterase, an enzyme that breaks down acetylcholine. They help to maintain higher levels of acetylcholine in the brain. In some people, the drugs maintain abilities to carry out activities of daily living. They also may maintain some thinking, memory, or speaking skills, and can help with certain behavioral symptoms. However, they will not stop or reverse the underlying progression of AD and appear to help people only for months to a few years. The newest approved AD medication is memantine (Namenda®), which is prescribed to treat moderate to severe AD symptoms. This drug appears to work by regulating levels of glutamate, another neurotransmitter involved in memory function. Like the cholinesterase inhibitors, memantine will not stop or reverse AD.

Managing symptoms

> *"My father is often agitated. He paces up and down, wringing his hands and crying. I know he's sad or anxious about something but he can't tell me what's bothering him. Asking him about it just makes him more upset."*
>
> *"Last week, I visited Mom in the nursing home. We had a great time. Then yesterday, I went to see her again. When I walked into her room, she didn't know me. She thought I was her sister."*
>
> *"My husband used to be such an easy going, calm person. Now, he suddenly lashes out at me and uses awful language. Last week, he got angry when our daughter and her family came over and we sat down to eat. I never know when it's going to happen. He's changed so much—it scares me sometimes."*
>
> *"Gran hums all the time. She used to be a singer. Is she trying to relive her past?"*

As AD begins to affect memory and mental abilities, it also begins to change a person's emotions and behaviors. Between 70 and 90 percent of people with AD eventually develop one or more behavioral symptoms. These symptoms include sleeplessness, wandering and pacing, aggression, agitation, anger, depression, and hallucinations and delusions. Some of these symptoms may become worse in the evening (a phenomenon called "sundowning") or during daily routines, especially bathing.

The damage of AD affects many different parts of the brain. This presents a problem because even small tasks require the brain to process signals that often involve more than one region of the brain. If this processing is disrupted because of AD, the person may not be able to do the task or may act in a strange or inappropriate way.

In light of our growing understanding about the effects of AD on the brain, behaviors like the ones highlighted above suddenly make sense or even provide a loving opportunity for caregivers:

> *For a man who can no longer distinguish between past and present, the anguish caused by the death of a parent may be as real today as it was many years before.*
>
> *Sitting down to a family meal may produce intense anxiety when a person has no idea what to do with the knife and fork in front of him and all the conversation and activity feel overwhelming.*
>
> *Memories of favorite songs from long ago resurface and provide a compelling link to a happy time in the past.*

Behavioral symptoms, often emotional and upsetting, are one of the hardest aspects of the disease for families and other caregivers to deal with. They are also a visible sign of the terrible change that has taken place in the person with AD. Researchers are slowly learning more about why behavioral symptoms occur and are conducting clinical trials on new treatments—both drug and non-drug—to deal with difficult behaviors.

Slowing, delaying, or preventing AD

AD research has developed to the point where scientists are looking beyond treating symptoms to addressing the underlying disease process. Slowing the progress of AD could do much to maintain the functioning of people with AD and reduce physical and emotional stress on caregivers. Delaying AD's effects also could help to postpone or prevent placement in an assisted living facility or nursing home, and reduce the financial costs of the disease. Preventing AD altogether is, of course, the ultimate long-term goal.

NIA and pharmaceutical companies support treatment clinical trials that are aimed at slowing, delaying, or preventing AD. The advances in our knowledge about the mechanisms and risk factors associated with AD have expanded the types of interventions under study. These trials are examining a host of possible interventions, including cardiovascular treatments, hormones, type 2 diabetes treatments, antioxidants, omega-3 fatty acids, immunization, cognitive training, and exercise, among others.

For example, NIA funds pilot trials to learn whether treating one or another aspect of type 2 diabetes will affect cognitive health and AD progression. A pilot trial is a relatively small clinical trial that collects initial data on the safety, effectiveness, and best dosage of a potential treatment. This information helps investigators decide which treatments should be tested in larger, full-scale trials. One 4-month pilot trial has examined the effects on AD of administering a nasal-spray form of insulin. This trial is founded on evidence that AD is associated with reduced levels of insulin in cerebrospinal fluid and that treatment with insulin improves memory performance. The trial will provide useful data on the safety, feasibility, and potential effectiveness of this innovative treatment approach. Investigators may be able to use the results to plan future full-scale clinical trials.

Beyond pilot studies, investigators also are conducting full-scale AD clinical trials of various interventions. One of these trials, the Alzheimer's Disease Cooperative Study (ADCS), is testing whether one omega-3 fatty acid (DHA), found in the oil of certain fish, can slow the progression of cognitive and functional decline in people with mild to moderate AD. During the 18-month clinical trial, investigators will measure the progress of the disease using standard tests for functional and cognitive change. Researchers also will evaluate whether taking DHA supplements has a positive effect on possible physical and biological markers of AD, such as brain atrophy and proteins in blood and spinal fluid. The ADCS is a federally established consortium conducting clinical trials on AD, with sites across the United States and Canada.

Full-scale AD prevention trials are underway as well. One such trial, Prevention of Alzheimer's Disease with Vitamin E and Selenium (PREADVISE), is being conducted in conjunction with a National Cancer Institute-funded trial called the Selenium and Vitamin E Cancer Prevention Trial (SELECT). SELECT is evaluating whether taking selenium and/ or vitamin E supplements can prevent prostate cancer in healthy men older than 60 years. PREADVISE is evaluating whether these supplements can help prevent memory loss and dementia by protecting brain cells from oxidative damage. About 6,000 of the more than 30,000 men enrolled in SELECT are participating in PREADVISE.

Participating in a clinical trial

Rapid advances in our knowledge about AD have led to the development of many promising new drugs and treatment strategies. However, before these new strategies can be used in clinical practice, they must be shown to work in people. This means that clinical trials–and volunteer participants–are an essential part of AD research. Advances in prevention and treatment are possible thanks to volunteers who participate in clinical trials.

Clinical trials are the primary way that researchers find out if a promising treatment is safe. Clinical trials tell researchers which treatments are the most effective and for which people they may work best. Trials can take place in various settings, such as private research facilities, teaching hospitals, specialized AD research centers, and doctors' offices. FDA approval is necessary before scientists can begin a clinical trial.

Participating in a clinical trial is a big step for anyone, including people with AD and their caregivers. That is why physicians and clinical trials staff spend time talking with participants about what it is like to be in a trial and the pros and cons of participating. It is also why they get a signed informed consent form before a person enrolls in a trial. Here are some facts that potential participants might want to know about clinical trials.

What kind of trials are there?
Treatment trials with existing drugs or behavioral strategies assess whether an intervention already approved for other purposes may be useful in treating age-related cognitive decline or AD. For example, trials have tested whether drugs used to lower cholesterol help slow progression of AD.

Treatment trials with experimental drugs or strategies show whether a new drug or treatment approach can help improve cognitive function or lessen symptoms in people with AD, slow the progression to AD, or prevent it. Interventions tested in these trials are developed from knowledge about the mechanisms involved in the AD process. Experimental drugs, for example, are first tested in tissue culture and in animals to determine their actions in the body. Safety and effectiveness studies are also conducted in animals before the compounds are tested in humans.

What are the phases of clinical trials?
During Phase I trials, a research team gives the treatment to a small number of participants and examines its action in the body and its safety. The main goals of Phase I trials are to establish the highest dose of a new drug that people can tolerate and to define the dose at which people may begin to experience harmful side effects. These trials generally last only a few months.

If results show that the treatment appears to be safe, it will go on to Phase II and Phase III clinical trials. Phase II trials involve larger numbers of people studied over longer periods of time than Phase I trials. In these trials, the study team wants to know whether the treatment is safe and effective at changing the course of the disease. Phase II trials occasionally also involve the use of a placebo (an inactive substance that looks like the study drug). Results from Phase II trials give study staff an indication of the effective dose to take into Phase III trials. Phase III trials are large studies that compare an experimental treatment with a placebo or standard treatment to determine safety and efficacy (whether the treatment has the power to produce an effect).

After these phases are complete and investigators are satisfied that the treatment is safe and effective, the study team may submit its data to the FDA for approval. FDA experts review the data and decide whether to approve the drug or treatment for use in patients with the disease under study.

What happens when a person signs up for a clinical trial?
First, it is important to learn about the trial. Staff at the clinical research center explain the trial in detail to potential participants and describe possible risks and benefits. Staff also talk about the participants' rights as research volunteers, including their right to leave the trial at any time. Participants and their family members are entitled to have this information repeated and explained until they feel they understand the nature of the trial and any potential risks.

After all questions have been answered, participants who are still interested in joining the trial are asked to sign an informed consent form. In some cases, a participant may no longer be able to provide informed consent because of problems with memory and thinking. In such cases, it is still possible for an authorized representative (usually a family member) to give permission for the person to participate. Laws and regulations regarding informed consent differ across States and research institutions, but all are intended to ensure that participants are protected and well cared for.

Next, people go through a screening process to see if they qualify to participate in the trial. If they qualify and can safely participate, then they are enrolled in the trial.

What happens during a trial?
If participants agree to join the trial and an evaluation process shows they meet all the criteria for participation, then a "baseline" visit is scheduled with the trial staff. This visit generally involves cognitive and physical tests. This gives the team information against which to measure future mental and physical changes.

In most clinical trials, participants are randomly assigned to different study groups so that each study group has people in it of about the same average characteristics (such as age, sex, educational level, or cognitive ability). One group, the test group, receives the experimental drug or intervention. Other groups may receive a different drug, a placebo, or a different intervention. Comparing results for different groups gives researchers confidence that changes in the test group are the result of the experimental treatment and not some other factor, such as the placebo effect (this is when people feel an effect because they think they are getting the test medication even though they are really getting a placebo). In many trials, no one—not even the research team—knows who is getting the treatment and who is getting the placebo or other intervention. This means that the participant, family member, and the staff are "blind" to the treatment being received. This kind of trial is called a double-blind, placebo-controlled trial.

As the trial progresses, participants and family members usually must follow strict medication or treatment instructions and keep detailed records of symptoms. Every so often, participants visit the clinic or research center to have physical and cognitive exams, give blood and urine samples, and talk with trial staff. These visits allow the investigators to collect information on the effects of the test drug or treatment, see how the disease is progressing, and see how the participant and the caregiver are doing.

What should people consider before participating in a clinical trial?
People who have participated in AD clinical trials say that it's a good idea to consider the following issues before deciding to join a trial.

- **Expectations and motivations.** The test drug or treatment may relieve a symptom, change a clinical measurement, or reduce the risk of death, but clinical trials generally do not have miraculous results and participants may not receive any direct benefit. With a complex disease like AD, it is unlikely that one treatment will cure or prevent the disease. Some people choose not to participate or decide to drop out of a study because this reality does not meet their expectations. Others choose to stay in a trial because they realize that even if they get no or only a slight benefit, they are making a valuable contribution to knowledge that will help people in the future.
- **Uncertainty.** Some families have a hard time with the uncertainties of participation—for example, not knowing whether the person is taking the test treatment, a placebo, or a control treatment, not being able to choose which study group to be in, or not knowing for a long time whether the study was successful. Ongoing and open communication with study staff can help to reduce this frustration.
- **Finding the right clinical trial.** Some clinical trials involve participants who are cognitively healthy or have only mild symptoms because they are testing a drug that might delay a decline in cognitive function. Other trials involve participants who have more advanced AD because they are testing a treatment that might lessen behavioral symptoms. Or, a trial may be testing new strategies to help caregivers. Even if a participant is not eligible for one trial, another trial may be just right.
- **The biggest benefit of all.** Many families find that the biggest benefit of participating in a clinical trial is the regular contact with the study team. These visits provide an opportunity to get state-of-the-art AD care and to talk regularly with AD experts who have lots of practical experience and a broad perspective on the disease. The study team understands and can provide advice about the emotional and physical aspects of the person with AD and the caregivers' experience. Team members can suggest ways to cope with the present and give insights into what to expect in the future. They also can share information about support groups and other helpful resources.

For more information
To learn more about AD clinical trials, visit the Alzheimer's Disease Education and Referral (ADEAR) Center's Clinical Trials Database website (www.nia.nih.gov/alzheimers/clinical-trials). This NIA website includes a list of AD and dementia clinical trials currently in progress at research centers throughout the United States. It also provides information about the phases of clinical trials and how to participate, explains the drug development process, and provides links to other useful websites.

Also, visit the clinical trials websites of the National Institutes of Health (www.clinicaltrials.gov) or the Alzheimer's Association (www.alz.org).

PART 4: IMPROVING SUPPORT FOR FAMILIES AND OTHER CAREGIVERS

One of the greatest costs of AD can be the physical and emotional toll on family members, caregivers, and friends of people with the disease. The changes in a loved one's personality and mental abilities; the need to provide constant, loving attention for years on end; and the demands of bathing, dressing, and other caregiving duties in the later stages of the disease can be hard to bear. Many caregivers must assume new and unfamiliar roles in the family, and these changes can be both difficult and sad. Not surprisingly, caregivers of people with dementia spend significantly more time on caregiving tasks than do caregivers of people with other types of illnesses.

One of the hardest decisions that many families face is whether and when to place a loved one with AD in a nursing home or other type of care facility. Once this decision is made, families must decide what type of care is best for the person and the family. Many investigators are working to identify strategies that can lead to improved quality of care in various facilities, including adult day care centers, assisted living facilities, continuing care retirement communities, nursing homes, and special care units (separate areas within nursing homes or assisted living facilities designed especially for people with dementia).

Who Are AD Family Caregivers?

Many primary caregivers are family members, and NIA-funded research has shown that the value of informal family caregiving of people with cognitive impairment adds up to billions of dollars every year. Who are these family caregivers?

- **Spouses:** This is the largest group of caregivers. Most are older, too, and many have their own health problems.
- **Daughters:** The second largest group of primary caregivers is daughters. Many are married and raising children of their own. Juggling two sets of responsibilities is often tough for these members of the "sandwich generation."
- **Daughters-in-law:** Many women in this group help take care of an older person with AD. They are the third largest group of family caregivers.
- **Sons:** Although many are involved in the daily care of a parent with AD, sons often focus on the financial, legal, and business aspects of caregiving.
- **Brothers and sisters:** Siblings may assume primary responsibility for care if they live close by. Many of these caregivers also are older and may be coping with their own frailties or health problems.
- **Grandchildren:** Older children may become major helpers in caring for a grandparent with AD. Grandchildren may need extra support if their parents' attention is heavily focused on the ill grandparent or if the grandparent with AD lives in the family's home.

Research findings benefit caregivers

Although research on family caregiver support is still in its early days, we have already learned much about the unique aspects of caregivers' personalities and situations. For example, it is well established that AD caregivers often experience stress, anxiety, depression, and other mental health problems as a result of the continuing and demanding nature of AD care. This chronic stress can have detrimental effects on the physical health of caregivers. The physical and emotional effects of AD caregiving can last a long time, even after the death of the person with AD.

On the other hand, research also has shown that caregiving can have important positive effects, including:

- A new sense of purpose or meaning in life.
- Fulfillment of a lifelong commitment to a spouse.
- An opportunity to give back to a parent some of what the parent has given to them.
- Renewal of religious faith.
- Closer ties with people through new relationships or stronger existing relationships.

AD caregivers do not all have the same psychological and physical response to caregiving. For example, caregivers who have strong support systems and well-developed coping skills may be able to weather the stresses of caring for a loved one with AD. Others who have few breaks from caregiving responsibilities and/or have preexisting illnesses may be more vulnerable to the physical and emotional stresses associated with dementia care. Caregiver research is beginning to discover effective ways to ease the burden of caregiving. Researchers have learned that:

- **The information and problem-solving needs of caregivers evolve over time as AD progresses.** Therefore, support programs should be tailored to the needs of the caregiver at various stages of caregiving. Programs can respond by offering services and information geared to different stages of the disease.
- **Traditions and attitudes about caregiving vary across cultural groups.** For example, some researchers have found that African-American caregivers use fewer formal in-home services than do white caretakers. Some populations may find it difficult to publicly admit that a family member has AD and may be reluctant to seek help with caregiving issues. Therefore, programs and services for caregivers must be culturally appropriate and sensitive to factors that positively and negatively influence caregivers' attitudes and ability to carry out their responsibilities.
- **Use of multiple types of support over an extended period of time helps caregivers.** For example, the Resources for Enhancing Alzheimer's Caregiver Health (REACH) clinical trial showed that caregivers who received 6 months of intensive help with caregiving strategies had significant improvements in overall quality of life. They also had lower rates of clinical depression compared to caregivers who did not participate in the program. The caregiving strategies included information sharing, instruction, role plays, problem-solving, skills training, stress-management techniques, and telephone support groups. Caregivers reported that taking part in REACH helped them feel more confident in working with their loved ones, made life easier for them, improved their caregiving ability, improved the care recipient's life, and helped them keep their loved one at home.
- **Developing ways to help caregivers become educated about AD, improve flexibility in responding to caregiving demands, and learn a variety of practical strategies can help.** Studies are teaching caregivers how to read the emotional and physical cues of the person with AD and to understand the sequence of events that often leads to inappropriate behaviors. They are also helping caregivers respond to the needs of the person with AD in a variety of creative ways, such as maintaining flexibility in the face of many demands, becoming educated about the disease, learning practical strategies, using available resources, involving other family members and friends, and balancing the needs of the person with their own needs.
- **Helping caregivers deal with the complicated issue of whether and when to place a loved one in a nursing home is an important aspect of caregiver support.** People with dementia are at much greater risk of nursing home placement than are other older people of the same age. Placing a loved one in a nursing home may relieve some of the burden of caregiving, but it does not necessarily reduce caregiver stress or emotional distress. Moreover, nursing home costs now average more than $70,000 per year.

  One clinical trial tested the effects of an enhanced counseling and support program on nursing home placement and caregiver health. This program for caregivers consisted of six sessions of individual and family counseling, support group participation, and on-demand telephone counseling. Participants in the program were able to delay placement of their loved ones in nursing homes by about 18 months. Researchers attributed the effects of the program to greater tolerance for memory and behavior problems in the person with AD, improved satisfaction with the support provided by family and friends, and fewer symptoms of depression. Moreover, it appears that the extra time at home did not come at the expense of the caregivers' sense of well-being.
- **Helping caregivers stay physically active has big benefits.** Researchers have found that regular moderate exercise is an important stress reliever for caregivers. Exercise helps to reduce blood pressure increases due to stress, improves sleep quality, and reduces psychological distress and depression.

Where are people with Alzheimer's disease cared for?

- Home.
- Assisted living facilities (those in the early stages).
- Adult day care centers.
- Nursing homes.
- Special care units.

Early-stage AD support groups: A vital source of help

For families and friends who care for a person with AD, talking with others who are going through the same experience can be a vital lifeline. AD support groups provide a place where caregivers can seek respite, express concerns, share experiences, get tips, and receive emotional comfort. NIA-funded Alzheimer's Disease Centers, the Alzheimer's Association, and many other organizations sponsor in-person and online AD support groups all around the country.

Improved diagnostic tests and increasing awareness of AD mean that more and more people are now being diagnosed at early stages of AD. People in the early stages often still have good coping skills and are intensely aware of themselves and their symptoms. They also may feel considerable distress, embarrassment, and isolation because of a perceived stigma associated with the disease. As a result, a growing number of people with early-stage AD and their family members are looking for coping strategies, meaningful activities, and mental stimulation. They are eager to educate themselves about AD, share common experiences, and break the potential barriers and isolation caused by their diagnosis. This has led to the formation of early-stage support groups specifically designed to meet their needs.

Some early-stage support groups follow a structured model, with 1- to 2-hour sessions scheduled over 6 to 8 weeks. The sessions are led by a facilitator and discussion topics are determined in advance. Guest speakers provide information and help on specific topics such as legal and financial planning. In some programs, the person with AD and the caregiver meet in separate groups; in others, people with AD and their caregivers are together for part of the session and apart for the remainder.

Other types of early-stage support groups are less structured. Members discuss topics of their own choosing, and the groups meet regularly over an extended time. Members with AD may stay in the group as long as they are able to meaningfully take part in the discussion and activities.

Early-stage support groups are not for everyone. Some people with early AD and their families may not benefit because of family conflict, denial, cognitive impairment, or discomfort with the intimacy of a group experience. However, most participants report positive outcomes, such as a greater sense of control over their lives and feelings that they are not alone. Many participants find early-stage support groups helpful because they instill a spirit of camaraderie, build coping skills, and forge relationships and emotional support that continue to help the person with AD and the caregiver even after the sessions end.

Taking care of mom or dad at a distance
Taking care of a parent with AD who lives hundreds of miles away is a real worry facing many adults. “How can we make sure Mom gets the best care possible if we’re not there all the time?” “What can I do to help Dad live at home for as long as possible?”

That was the dilemma facing Ken Nixon and his two brothers in 2001. Their mother lived in an Arkansas farming community and wanted to stay there. Ken and his brothers lived 3 to 5 hours away—close, but not close enough.

With funding from NIA, Ken and his brothers created a multi-purpose, Internet-based system called AttentiveCare that is currently available to others faced with the same long-distance caregiving challenges. Back in 2001, broadband Internet service had just become available in their mother’s community, so the brothers decided to see whether videoconferencing could be a way to keep in touch with her. They installed a computer with a video camera in her home so they could check on her daily, helping fulfill her wish to continue living independently on the family farm while assuring themselves that she was faring well.

“We had a need, and we patched the system together at first,” says Ken. “It exceeded our expectations in being able to keep our mother independent and connected to the family. We could call and have coffee with her every morning, and it got her day started off right. She had something to look forward to every day—one or two of her boys was going to visit.”

After 6 months of using the home-grown system, Nixon decided to develop it to help other caregivers. In 2003, he applied for and received a grant from NIA to refine the AttentiveCare prototype and test its feasibility in providing informal, long-distance care to people with AD.

He later received another grant to evaluate the software, services, and caregiver usage and benefits of the system in a variety of caregiving situations. The participants in this study are distance caregivers of persons with early- to moderate-stage AD who had the AttentiveCare system installed in their own homes and the homes of their family members with AD.

AttentiveCare now features videoconferencing, multimedia reminders to help care recipients function independently, and slide shows to keep care recipients connected with family. The system’s journal and data logging capability also allows family caregivers to maintain and share information about the care recipient’s health and well-being, whether they are across the street or thousands of miles away.

Conclusion

The future builds upon the events and experiences of the past. That’s certainly true of AD research. Our knowledge of AD is advancing rapidly, and we have much to celebrate in our scientific successes.

At the same time, we cannot forget that AD remains an urgent problem for our Nation. The challenge is to continue building on these discoveries so that we can create a brighter future in which the potential of successfully managing AD or even preventing this terrible disease can become a reality.

Glossary

Acetylcholine - a neurotransmitter that plays an important role in many neurological functions, including learning and memory.

Amygdala - an almond-shaped structure involved in processing and remembering strong emotions such as fear. It is part of the limbic system and located deep inside the brain.

Amyloid plaque - a largely insoluble deposit found in the space between nerve cells in the brain. Plaques are made of beta-amyloid, other molecules, and different kinds of nerve and non-nerve cells.

Amyloid precursor protein (APP) - the larger protein from which beta-amyloid is formed.

Apolipoprotein E - a protein that carries cholesterol in blood and that appears to play some role in brain function. The gene that produces this protein comes in several forms, or alleles: ε2, ε3, and ε4. The APOE ε2 allele is relatively rare and may provide some protection against AD (but it may increase risk of early heart disease). APOE ε3 is the most common allele and appears to play a neutral role in AD. APOE ε4 occurs in about 40 percent of all people with AD who develop the disease in later life; it increases the risk of developing AD.

Axon - the long extension from a neuron that transmits outgoing signals to other cells.

Beta-amyloid - a part of the amyloid precursor protein found in plaques, the insoluble deposits outside neurons.

Brain-derived neurotrophic factor (BDNF) - a growth factor that stimulates survival, growth, and adaptability of some neurons.

Brain stem - the portion of the brain that connects to the spinal cord and controls automatic body functions, such as breathing, heart rate, and blood pressure.

Capillary - a tiny blood vessel. The brain has billions of capillaries that carry oxygen, glucose (the brain’s principal source of energy), nutrients, and hormones to brain cells so they can do their work. Capillaries also carry away carbon dioxide and cell waste products.

Cerebellum - the part of the brain responsible for maintaining the body’s balance and coordination.

Cerebral cortex - the outer layer of nerve cells surrounding the cerebral hemispheres.

Cerebral hemispheres - the largest portion of the brain, composed of billions of nerve cells in two structures connected by the corpus callosum. The cerebral hemispheres control conscious thought, language, decision making, emotions, movement, and sensory functions.

Cerebrospinal fluid - the fluid found in and around the brain and spinal cord. It protects these organs by acting like a liquid cushion and by providing nutrients.

Chromosome - a threadlike structure in the nucleus of a cell that contains DNA. DNA sequences make up genes. Most human cells have 23 pairs of chromosomes containing approximately 30,000 genes.

Clinical trial - a research study involving humans that rigorously tests safety, side effects, and how well a medication or behavioral treatment works.

Cognitive functions - all aspects of conscious thought and mental activity, including learning, perceiving, making decisions, and remembering.

Computed tomography (CT) scan - a diagnostic procedure that uses special x-ray equipment and computers to create cross-sectional pictures of the body.

Corpus callosum - thick bundles of nerve cell fibers that connect the two cerebral hemispheres.

Dementia - a broad term referring to a decline in cognitive function to the extent that it interferes with daily life and activities.

Dendrite - a branch-like extension of a neuron that receives messages from other neurons.

DNA (deoxyribonucleic acid) - a long, double-stranded molecule within the nucleus of the cell that forms chromosomes and genes.

Early-onset Alzheimer's disease - a rare form of AD that usually affects people between ages 30 and 60. It is called familial AD (FAD) if it runs in the family.

Entorhinal cortex - an area deep within the brain where damage from AD often begins.

Enzyme - a protein that causes or speeds up a biochemical reaction.

Free radical - a highly reactive molecule (typically oxygen or nitrogen) that combines easily with other molecules because it contains an unpaired electron. The combination with other molecules sometimes damages cells.

Gene - the biologic unit of heredity passed from parent to child. Genes are segments of DNA and contain instructions that tell a cell how to make specific proteins.

Genetic risk factor - a variant in a cell's DNA that does not cause a disease by itself but may increase the chance that a person will develop a disease.

Glial cell - a specialized cell that supports, protects, or nourishes nerve cells.

Hippocampus - a structure in the brain that plays a major role in learning and memory and is involved in converting short-term to long-term memory.

Hypothalamus - a structure in the brain under the thalamus that monitors activities such as body temperature and food intake.

Late-onset Alzheimer's disease - the most common form of AD. It occurs in people aged 60 and older.

Limbic system - a brain region that links the brain stem with the higher reasoning elements of the cerebral cortex. It controls emotions, instinctive behavior, and the sense of smell.

Magnetic resonance imaging (MRI) - a diagnostic and research technique that uses magnetic fields to generate a computer image of internal structures in the body. MRIs are very clear and are particularly good for imaging the brain and soft tissues.

Metabolism - all of the chemical processes that take place inside the body. In some metabolic reactions, complex molecules are broken down to release energy. In others, the cells use energy to make complex compounds out of simpler ones (like making proteins from amino acids).

Microtubule - an internal support structure for a neuron that guides nutrients and molecules from the body of the cell to the end of the axon.

Mild cognitive impairment (MCI) - a condition in which a person has memory problems greater than those expected for his or her age, but not the personality or cognitive problems that characterize AD.

Mutation - a permanent change in a cell's DNA that can cause a disease.

Myelin - a whitish, fatty layer surrounding an axon that helps the axon rapidly transmit electrical messages from the cell body to the synapse.

Nerve growth factor (NGF) - a substance that maintains the health of nerve cells. NGF also promotes the growth of axons and dendrites, the parts of the nerve cell that are essential to its ability to communicate with other nerve cells.

Neurodegenerative disease - a disease characterized by a progressive decline in the structure, activity, and function of brain tissue. These diseases include AD, Parkinson's disease, frontotemporal lobar degeneration, and dementia with Lewy bodies. They are usually more common in older people.

Neurofibrillary tangle - a filamentous collection of twisted and hyperphosphorylated tau found in the cell body of a neuron in AD.

Neuron - a nerve cell.

Neurotransmitter - a chemical messenger between neurons. These substances are released by the axon on one neuron and excite or inhibit activity in a neighboring neuron.

Nucleus - the structure within a cell that contains the chromosomes and controls many of its activities.

Oxidative damage - damage that can occur to cells when they are exposed to too many free radicals.

Positron emission tomography (PET) - an imaging technique using radioisotopes that allows researchers to observe and measure activity in different parts of the brain by monitoring blood flow and concentrations of substances such as oxygen and glucose, as well as other specific constituents of brain tissues.

Single photon emission computed tomography (SPECT) - an imaging technique that allows researchers to monitor blood flow to different parts of the brain.

Synapse - the tiny gap between nerve cells across which neurotransmitters pass.

Tau - a protein that helps to maintain the structure of microtubules in normal nerve cells. Abnormal tau is a principal component of the paired helical filaments in neurofibrillary tangles.

Thalamus - a small structure in the front of the cerebral hemispheres that serves as a way station that receives sensory information of all kinds and relays it to the cortex; it also receives information from the cortex.

Transgenic - an animal that has had a gene (like human APP) inserted into its chromosomes. Mice carrying the mutated human APP gene often develop plaques in their brains as they age.

Ventricle - a cavity within the brain that is filled with cerebrospinal fluid.

Vesicle - a small container for transporting neurotransmitters and other molecules from one part of the neuron to another.

Information and support resources

Alzheimer's Disease Education and Referral (ADEAR) Center
P.O. Box 8250 Silver Spring, MD 20907-8250
1-800-438-4380 (toll-free)
www.nia.nih.gov/alzheimers

This service of the National Institute on Aging (NIA) offers information and publications on diagnosis, treatment, patient care, caregiver needs, long-term care, education and training, and research related to Alzheimer's disease. Staff members answer telephone, email, and written requests and make referrals to local and national resources. The ADEAR website offers free, online publications in English and Spanish; email alerts and online Connections newsletter registration; an AD clinical trials database; and more.

Alzheimer's Association
225 North Michigan Avenue, Floor 17 Chicago, IL 60601-7633
1-800-272-3900 (toll-free)
www.alz.org

The Alzheimer's Association is a national, non-profit organization with a network of local chapters that provide education and support for people diagnosed with AD, their families, and caregivers. Chapters offer referrals to local resources and services and sponsor support groups and educational programs. Online and print publications are also available. The Association also funds AD research.

Alzheimer's Foundation of America
322 Eighth Avenue, 7th Floor New York, NY 10001
1-866-232-8484 (toll-free)
www.alzfdn.org

The Alzheimer's Foundation of America provides care and services to individuals confronting dementia and to their caregivers and families, through member organizations dedicated to improving quality of life. Services include a toll-free hotline, consumer publications and other educational materials, and conferences and workshops.

Dana Alliance for Brain Initiatives
505 Fifth Avenue, 6th floor New York, NY 10017
1-212-223-4040
www.dana.org/danaalliances

The Dana Alliance for Brain Initiatives, a non-profit organization of more than 265 leading neuroscientists, helps advance public awareness about the progress and promise of brain research and disseminates information about the brain.

Caregiving support and services

Caregiver Action Network
2000 M Street NW, Suite 400 Washington, DC 20036
1-202-772-5050
www.caregiveraction.org

The Caregiver Action Network helps educate and support people who care for loved ones with chronic illness, disability, or the frailties of old age. The Network offers an online library of information and educational materials, workshops, and other resources.

Eldercare Locator
1-800-677-1116 (toll-free)
www.eldercare.gov

Eldercare Locator is a nationwide, directory-assistance service helping older people and their caregivers locate local support and resources. It is funded by the U.S. Administration on Aging, whose website at *www.aoa.gov* also features AD information for families, caregivers, and health professionals.

Family Caregiver Alliance
785 Market Street, Suite 750 San Francisco, CA 94103
1-800-445-8106 (toll-free)
www.caregiver.org

The Family Caregiver Alliance is a nonprofit organization that offers support services and information for people caring for adults with AD, stroke, traumatic brain injuries, and other cognitive disorders.

National Hospice and Palliative Care Organization
1731 King Street, Suite 100 Alexandria, VA 22314
1-800-658-8898 (toll-free)
www.nhpco.org

This nonprofit organization works to enhance the quality of life for people who are terminally ill. It provides information, resources, and referrals to local hospice services, and offers publications and online resources.

Well Spouse Association
63 West Main Street, Suite H Freehold, NJ 07728
1-800-838-0879 (toll-free)
www.wellspouse.org

The nonprofit Well Spouse Association gives support to spouses and partners of people who are chronically ill and/or disabled. It offers support groups and a newsletter.

Research and clinical trials

Alzheimer's Disease Cooperative Study
University of California, San Diego
9500 Gilman Drive M/C 0949 La Jolla, CA 92093-0949
1-858-622-5880
www.adcs.org

The Alzheimer's Disease Cooperative Study (ADCS) is a cooperative agreement between NIA and the University of California, San Diego, to advance research in the development of drugs to treat AD. The ADCS is a consortium of medical research centers and clinics working to develop clinical trials of medicines to treat behavioral symptoms of AD, improve cognition, slow the rate of decline caused by AD, delay the onset of AD, or prevent the disease altogether. The ADCS also develops new and more reliable ways to evaluate patients enrolled in clinical trials.

Alzheimer Research Forum
www.alzforum.org

The Alzheimer Research Forum, an online community and resource center, offers professionals and the general public access to an annotated index of scientific papers, research news, moderated discussions on scientific topics, libraries of animal models and antibodies, and directories of clinical trials, conferences, jobs, and research-funding sources.

ClinicalTrials.gov
www.ClinicalTrials.gov

ClinicalTrials.gov is a registry of federally and privately supported clinical trials conducted in the United States and around the world. Users can search for clinical trials and find information about each trial's purpose, who may participate, locations, and phone numbers for more details.

Recommended reading

The ADEAR Center offers fact sheets; easy-to-read materials; booklets about topics such as being diagnosed with early-stage AD, caregiving, home safety, and comfort and care at the end of life; and more. See the ADEAR Center listing under "Information and Support Resources" above for contact information.

Consumers and professionals interested in AD also may wish to refer to the following materials:

Ballard, E.L., & Poer, C.M. ***Lessons Learned: Shared Experiences in Coping***. Durham, NC: The Duke Family Support Program, 1999. Available for $8 from the Duke Family Support Program, 3600 DUMC, Durham, NC 27710; 1-800-672-4213; *www.dukefamilysupport.org*. This book documents the experiences of people caring for loved ones with AD. Filled with short stories and advice, it is intended for caregivers who wish to take comfort and learn from the experiences of others. Caregivers discuss the caregiving process, such as getting a diagnosis, finding support services, making decisions about treatment and living arrangements, and coping with stress and caregiver burden.

Dash, P., & Villemarette-Pittman, N. A***lzheimer's Disease***. New York: American Academy of Neurology, 2005.

This concise volume provides an overview of recent findings regarding the causes, diagnosis, and treatment of AD. It is designed to help caregivers and family members gain a better understanding of AD and the available options for coping with and managing this illness. Sixteen chapters answer questions about topics such as the definition of AD and dementia, AD versus other causes of dementia, treatments for behavioral symptoms and other complications of AD, and practical issues for the patient and family. Illustrations, a glossary, and a list of resources are also included.

Doraiswamy, P.M., & Gwyther, L., with Adler, T. ***The Alzheimer's Action Plan***. New York: St. Martin's Press, 2008.

This book, by a physician and social worker at Duke University, offers information about how to get an early and accurate AD diagnosis and why it matters, life after the diagnosis, state-of-the-art treatments, coping with behavioral and emotional changes through the early and middle stages of AD, accessing the latest clinical trials, and understanding the future of AD.

Kuhn, D., & Bennett, D.A. ***Alzheimer's Early Stages: First Steps for Family, Friends and Caregivers***, 3rd ed.; 2013 Alameda, CA: Hunter House Publishers, 2013.

With increased awareness of the symptoms of AD and improved diagnostic techniques, more people are learning that they or a family member have a memory disorder. This book, written by experts at Rush University Alzheimer's Disease Center in Chicago, helps readers understand and find ways to cope with the early stages of the disease. It also includes an extensive resource list of websites, organizations, and references to consumer and professional literature.

Mace, N.L., & Rabins, P.V. ***The 36-Hour Day: A Family Guide to Caring for People With Alzheimer's Disease, Related Dementias, and Memory Loss in Later Life***, 5th ed.; 2011 Baltimore: Johns Hopkins University Press, 2011.

This book offers guidance and comfort for families caring for loved ones with AD, other dementias, and memory loss in later life. The fourth edition includes chapters on topics such as getting medical help for the person with dementia, behavioral symptoms of dementia, nursing homes and other living arrangements, and research in dementia. New information discusses diagnostic evaluation, caregiver resources, legal and financial information, nursing homes and other communal living arrangements, and the latest updates on research, medications, and the biological causes and effects of dementia. Available in a large-print version.

Messer, M. ***Pressure Points: Alzheimer's and Anger***. Durham, NC: Duke Family Support Program, 2000. Available for $10 from the Duke Family Support Program, 3600 DUMC, Durham, NC 27710; 1-800-672-4213; *www.dukefamilysupport.org*.

In simple, easy-to-read language, this book addresses issues such as setting boundaries, managing anger positively, and risk factors for anger in AD care. It offers tangible action steps for responding appropriately, rather than abusively, when feeling angry. Participants in Alzheimer's support groups share helpful techniques and coping mechanisms, as well as enlightening anecdotes about caring for a loved one with AD. Caregivers, family members of AD patients, clergy, and health professionals all may benefit from this publication. Two companion booklets are also available from the ADEAR Center: "Hit Pause": Helping Dementia Families Deal with Anger (for health professionals; $3.00) and Wait a Minute! When Anger Gets Too Much (for families and caregivers; $2.00).

Perry, G., ed., ***Alzheimer's Disease: A Century of Scientific and Clinical Research***. *Journal of Alzheimer's Disease*, book edition, Fairfax, VA: IOS Press, Inc., 2006.

This volume brings together the important discoveries in the AD field since the disease's original description by Dr. Alois Alzheimer a century ago. It traces how the importance of AD as the major cause of late-life dementia came to light and narrates the evolution of the concepts related to AD throughout the years. Fifty papers are organized into sections on historical perspective, neuropathology, synaptic changes, amyloid, tau, disease mechanisms, genetics, and diagnosis and treatment.

Petersen, R., ed. ***Mayo Clinic Guide to Alzheimer's Disease: The Essential Resource for Treatment, Coping and Caregiving***. Rochester, MN: Mayo Clinic Health Solutions, 2009.

This guide is designed to help nonprofessionals understand dementia and its effects on the mind, the differences between dementia and changes associated with normal aging, and how to improve memory and maintain good mental function. It includes information about changes that occur in normal aging; the process of diagnosing dementia; non-AD forms of dementia; how AD develops, and AD stages, diagnosis, and treatment. New information about mild cognitive impairment, ways to stay mentally sharp, and research trends, along with an action guide for caregivers, are also included.

Restak, R. ***The Secret Life of the Brain***. Washington, DC: Joseph Henry Press, 2001.

This companion to the PBS documentary takes the reader on a fascinating journey through the developing brain, from infancy and childhood through adulthood and old age. The author examines brain disorders and mechanisms of brain repair and healing.

Shenk, D. ***The Forgetting. Alzheimer's: Portrait of an Epidemic***. New York: Random House, Inc., 2003.

An eloquent and moving description of AD, The Forgetting is an exploration of, and meditation on, the nature of memory and perceptions of self. It is a readable, accessible description of the history of AD, research, and the human impact of the disease. Calling AD a "death by a thousand subtractions," the author describes the science of AD in clear and easy-to-understand terms.

Snowdon, D. ***Aging With Grace: What the Nun Study Teaches Us About Leading Longer, Healthier, and More Meaningful Lives***. New York: Random House, Inc., 2002.

This book describes the participants and findings from the Nun Study, a long-term project examin- ing aging and AD in a unique population of 678 Catholic sisters. The nuns gave Dr. Snowdon access to their medical and personal records and agreed to donate their brains upon death. The book discusses the relationship of early linguistic ability to risk of AD, the association of stroke and depression with AD, and the role of heredity and lifestyle in healthy aging.

Tanzi, R.E., & Sisodia, S.S. ***Alzheimer's Disease: Advances in Genetics, Molecular and Cellular Biology***. New York: Springer Publishing Company, 2007.

This book examines every major aspect of AD— clinical, epidemiologic, structural, chemical, genetic, molecular, and therapeutic. This edition includes expanded coverage of related dementing disorders, including prion diseases, Pick's disease, frontotemporal disorders, an in-depth discussion of transgenic models, and the biochemistry of presenilins. It also discusses treatment of symptoms with therapeutic drugs and AD clini- cal trials. The broad coverage of AD in this book will be of special interest to clinicians, educators, investigators, and health administrators.

Uetz, D., & Lindsay, A. ***Into the Mist: When Someone You Love Has Alzheimer's***. Philadelphia: Xlibris Corporation, 2005.

This book combines information from researchers, experts, and families in a comprehensive guide for AD caregivers. It offers personal accounts of three families caring for a loved one from the earliest stages to the last stages, illustrating the commonalities and differences among AD patients and the ways their families handle the most difficult challenges. It also provides information to help families cope with the psychological aspects of AD, behavior problems, and communication difficulties. The book covers such topics as the stages of AD, Medicare, Medicaid, long-term care insurance, geriatric care management, the diagnosis of AD, causes and prevention, and drug treatments.

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ALZHEIMER'S DISEASE: UNRAVELING THE MYSTERY

Final Examination Questions

Select the best answer for each question and then proceed to **SocialWork.EliteCME.com** to complete your final examination.

11. As a person gets older, changes occur in all parts of the body, including the brain. An example of this might be that:
    a. Certain parts of the brain become enlarged, especially the prefrontal cortex and the hippocampus.
    b. In certain brain regions, communication between neurons can increase because white matter is repaired or replaced.
    c. Damage by free radicals decreases.
    d. Inflammation increases.

12. As neurons die throughout the brain, affected regions begin to shrink in a process called _________.
    a. Hyperphosphorylation.
    b. Oligomer atrophy.
    c. Brain atrophy.
    d. Brain neurofibrillary.

13. Initial studies showed that people with AD take up more ________ in their brains than do cognitively healthy older people.
    a. Cerebrospinal fluid.
    b. Positron Emission Tomography (PET).
    c. Pittsburgh Compound B (PiB).
    d. Hyperphosphorylated Tau.

14. Another neurodegenerative disease like AD is:
    a. Parkinson's disease.
    b. Fibromyalgia.
    c. Attention Deficit Disorder.
    d. Gastroenteritis.

15. Research has begun to tease out some relationships between AD and other vascular diseases such as __________________.
    a. Kidney failure, heart disease and stroke.
    b. Heart disease, stroke and type 2 diabetes.
    c. Stroke, type 2 diabetes and fibromyalgia.
    d. Type 2 diabetes, fibromyalgia, and epilepsy.

16. A definitive diagnosis of AD is only possible during __________.
    a. A CT scan.
    b. An MRI.
    c. Radiation therapy.
    d. An autopsy.

17. With the tools now available, experienced physicians can be reasonably confident about making an accurate diagnosis of AD in a living person. They may __________.
    a. Take a detailed patient history.
    b. Get information from other patients at the same stage of AD.
    c. Conduct gastrointestinal testing.
    d. Do a cardiac catheterization.

18. Dementia also has other causes, some of which are treatable. This includes _________.
    a. Attention Deficit Hyperactivity Disorder.
    b. Iron deficiency.
    c. Chronic alcoholism.
    d. Blood clots in the left leg.

19. Four medications, tested in clinical trials, have been approved by the FDA for use in treating AD symptoms. This includes:
    a. Lamotrigine.
    b. Alprozalam.
    c. Rivastigmine.
    d. Gabapentin.

20. Giving care to a loved one with AD can have important positive effects, including:
    a. Access to previously inaccessible medications.
    b. Increasing employer FMLA benefits.
    c. A renewal of religious faith.
    d. Extending COBRA insurance coverage.

SWCA06AZE16

Chapter 3: Cultural Competence in Mental Health Practice

6 CE Hours

By: Deborah Converse, MA, NBCT with Kathryn Brohl, MA, LMFT and Rene' Ledford, LCSW, BCBA

Learning objectives

- Explain three strategies to strengthen communication in a multicultural setting.
- Describe three methods to avoid becoming "affectively charged" and build cultural competence.
- List strategies to create cultural awareness and competence in therapeutic intervention.
- Discuss four common cultural missteps and three strategies for remediation.
- Identify two forms of cultural competence self-assessment.
- Explain the continuum of cultural competence and progress toward proficiency.
- Discuss the impact of multicultural competence on the supervisory relationship.

Introduction

Demonstrating cultural competence is an integral part of mental health service delivery. On the national level this issue has received greater support as the United States government recognizes the influence and impact of converging nationalities and cultures. Because divisions of race, ethnicity and culture exist in the United States, there is an increasing awareness of cultural competence and how it can eliminate disparities in care for people of diverse racial, ethnic and cultural backgrounds.

While the population in the United States continues to diversify, the U.S. Department of Health and Human Services (DHHS, 2001) has continued to report disparities in mental health services for ethnic minorities. Ethnic minorities are less likely to have access to and receive mental health services, often receive a poorer quality of services, and are under-represented in mental health research (DHHS, 2001).

In addition, ethnic minorities experience higher disability rates compared to European Americans (Smart and Smart, 1997). Disability and chronic illness often co-exist with mental disorders, such as depression and anxiety (Bairey-Mertz et al., 2002; Falvo, 2005). This points to the need for clinicians' competency in addressing mental health concerns of minority clients with disabilities. However, many clinicians are inadequately prepared to serve ethnically diverse populations (DHHS, 2001) or to address disability issues in counseling (Sue and Sue, 2003).

Given the consistent mental health service disparities, a lack of clinical cultural competencies poses a significant problem that needs to be addressed in the counseling field. Because of the significant role that training programs can play in enhancing the cultural competency of clinicians, DHHS recommends clinicians complete training programs that address the impact of culture on mental health and mental health services so they can provide culturally responsive services for minority clients.

The American Counseling Association in its 2005 Code of Ethics defines culture as membership in a socially constructed way of living that incorporates collective values, norms, boundaries and lifestyles. These elements are created with others who share similar worldviews including biological, psychosocial, historical, psychological and other factors (ACA, 2005).

The ACA states that multicultural/diversity competence comes when counselors possess cultural diversity awareness, knowledge about self and others, and how this awareness and knowledge is applied effectively in practice with clients and their client groups. This type of counseling recognizes diversity and embraces approaches that support the worth, dignity, potential and uniqueness of individuals and their historical, culture, economic, political and psychosocial context (ACA, 2005).

The National Association of Social Workers (NASW) notes in its revised Code of Ethics (2008) that social workers should understand culture and its function in human behavior in society, which requires recognizing the strengths that exist in all cultures. The counselor should have a knowledge base of the client's culture or be able to demonstrate competence in the provision of services that are sensitive to the client's culture and to differences among people and cultural groups (NASW, 2008).

There is no specific form of counseling that is multicultural because "we are all multicultural individuals, and everyone lives in a multicultural society" Arredondo et al., 1996). All counseling is multicultural. This does not mean that mental health professionals need different counseling theories and practices for all the possible groups in the society. No mental health counselor can be prepared to counsel every possible client specific to his or her ethnic group.

Mental health counselors will need special preparation to work with clients from a particular group. It is here that knowledge of the backgrounds of particular clients is necessary. Such knowledge provides a basis for understanding clients, colloquially, knowing "where the client is coming from." (Patterson, 2004). Multicultural competencies simply provide a compendium of the elements of this knowledge. The knowledge is acquired not from specific academic courses but instead by living in the community with the kind of clients mental health counselors serve in their practice.

The assumption that simply having knowledge of the culture of the client will lead to more appropriate and effective therapy has not been established. Sue and Zane (1987) stated that "recommendations that admonished therapists to be culturally sensitive and to know the culture of the client have not been very helpful." They continue:

> The major problem with approaches emphasizing either cultural knowledge or cultural-specific techniques is that neither is linked to particular processes that result in effective psychotherapy. Recommendations for knowledge of culture are necessary but not sufficient for effective treatment. The knowledge must be transformed into concrete operations and strategies.

Several researchers on multicultural counseling have gone beyond counseling as a matter of knowledge and skills and have listed a number of practitioner characteristics or attitudes necessary for effective practice. Wohl (1976) noted that the healing function includes a caring and concern on the part of the healer, and that therapy promotes a special, close relationship.

Pederson (1976) identified the "expectations of troubled contrasting culture clients and the personal qualities of a counselor as being closely related to healthy change, accurate empathy, and non-possessive warmth and genuineness that are essential to effective mental health care."

Vontress (1976) emphasize the importance of rapport as "the emotional bridge between the counselor and the counselee. Simply defined, rapport constitutes a comfortable and unconstrained mutual trust and confidence between two persons."

Over time, it was recognized that professional confidence is inherent in the personal qualities of the mental health practitioner. The competent mental health counselor is one who provides an effective therapeutic relationship. The nature of this relationship has long been known and is the same regardless of the group to which the client belongs.

In the list of multicultural competencies developed by Arrendondo in 1996, there is not a specific list of groups or specific treatments or techniques appropriate for each. Those therapeutic decisions are left to the mental health practitioner. Pederson (1976) wrote that "each cultural group requires a different set of skills, unique areas of emphasis, and specific insights for effective counseling to occur." In one early review, Peterson reported that:

> Native American Indian culture presents unique requirements for an effective counseling. When counseling Native American Indian youth, the counselor is likely to be confronted by passively nonverbal clients who listen and absorb knowledge selectively. A counselor who expects clients to verbalize their feelings is not likely to have much to do with Native American Indian clients.

Several researchers have proposed that clients from ethnic minority groups desire a structured relationship in which the mental health practitioner gives advice and solutions to problems (Sue and Sue, 1990; Sue and Morishima 1982; Vontress, 1981). However, cultural groups are not pure and discrete, but overlapping. The process of globalization is blurring the differences. The only workable product of a multicultural society is a society of individuals who must ultimately absorb different cultures into themselves. In the current global society, few discrete classifications are possible.

If classifications were possible, because every client belongs to a number of combinations and permutations of these groups, the number would be staggering. Attempting to develop different theories, methods and techniques for each of these groups would be an insurmountable task. This approach is not only impossible, but also irrelevant and harmful when counseling individual clients (Patterson, 2004).

Differences among clients fall into two kinds, accidental and essential. Cultural, ethnic and racial differences are accidental. The accident is the place of birth. But all clients are alike in one basic, essential way in that they are all human beings (Patterson, 2004).

Pinker (1997) notes that "surveys of the ethnographic literature show that peoples of the world share an astonishingly detailed universal psychology." The nature of all human beings provides the basis for a solution to the problem of multicultural counseling. What is needed is a system of counseling or psychotherapy therapy based upon these common characteristics.

A universal system of counseling or psychotherapy

The essence of a universal system of mental health counseling (Patterson, 1995) has long been known. It is what is known as client-centered therapy. There are five basic counselor qualities in this system (Rogers, 1957):

1. **Respect for the client** – This includes having trust in the client and assumes that the client is capable of taking responsibility for himself or herself, and capable of making choices and decisions to resolve problems. Moreover, he or she should be given the right to do so.
2. **Genuineness** – Counseling is a real relationship. The counselor does not assume a role as an all-knowing expert, is not impersonal and cold, but a real person.
3. **Empathic understanding** – Empathic understanding is more than knowledge based on the group to which a person belongs. It requires that the mental health counselor be able to use this knowledge as it applies to the unique client, which involves entering the client's world and seeing it as he or she does. "The ability to convey empathy in a culturally consistent and meaningful manner may be the crucial variable to engage the client" (Ibrahim, 1991). The only way mental health counselors can enter the world of the client is with the permission of the client, who communicates the nature of his or her world to the practitioner through self-disclosure. Plus, client self-disclosure is the essence of counseling. The mental health practitioner's respect and genuineness facilitates client self–disclosure (Patterson, 2004).
4. **Communication of empathy, respect and genuineness to the client** – This must be perceived, recognized and felt by the client if the counselor is to be effective. This perception becomes difficult with clients who differ from the therapist in culture, race, socioeconomic class, age and gender. Understanding of cultural differences in verbal and nonverbal behaviors can be very helpful. Sue and Sue (1990) explain:

   > *"Qualities such as respect and acceptance of the individual, unconditional positive regard, understanding the problem from the individual's perspective, allowing the client to explore their own values, and arriving at an individual solution are core qualities that transcend culture."*

5. **Structuring** – There is another element in all counseling that is of particular importance in intercultural counseling. Vontress (1976) says:

   > *"On the whole, disadvantaged minority group members have had limited experiences with counselors and related therapeutic professionals. Their contacts have been mainly with people who tell them what they must and should do. Relationships with professionals who placed major responsibility upon the individual for solving his own problems are few. Therefore, the counselor working within such a context should structure and define his role to client. Counselors should indicate what, how, and why they choose to proceed in a certain way. Failure to structure early and adequately in counseling can result in unfortunate misunderstanding." (Sue and Zane, 1987)*

   Failure to structure may also result in failure of the client to continue counseling. Structuring is necessary whenever the client does not know what is involved in the therapeutic relationship, how that mental health counselor will function, what is expected of the client, or if the client holds misconceptions about the process (Patterson, 2004).

These professional qualities are not only essential for effective counseling, they are also the elements of all facilitated interpersonal relations. They are neither time-bound nor culture-bound.

Reviews of recommendations and suggestions for specific methods and techniques for counseling multicultural clients indicate there is no evidence for the appropriateness or effectiveness of such methods. Other methods suggested for counseling clients from other cultures are generally recognized, inextricable methods for which there is evidence. It follows that we do not need specific competencies for multicultural clients, but we need methods and approaches that are effective with all kinds of clients. These methods constitute a universal system of counseling (Patterson, 2004).

The universal nature of counseling is reflected in the code of ethics for all mental health organizations. The National Association of Social Workers' primary mission is to enhance well-being and help meet the basic needs of all people, with particular attention to the needs of those who are vulnerable, oppressed and living in poverty. The historic and defining feature of social work is the profession's focus on the individual's well being in a social context and the well-being of society (NASW, 2008).

NASW states that the social work profession is rooted in a set of core values. These core values, embraced throughout the profession's history, are the foundation of social work's unique purpose and perspective:

- Service.
- Social justice.
- Dignity and worth of all people.
- Importance of human relationships.
- Integrity.
- Competence.

These core values must be balanced within the context and complexity of the human experience. The ACA Code of Ethics Preamble states that the American Counseling Association serves educational, scientific and professional organizations whose members work in a variety of settings and serve in multiple capacities. ACA members are dedicated to the enhancement of human development throughout the lifespan. Association members recognize diversity and embrace a cross-cultural approach in support of worth, dignity, potential and uniqueness of people within their social and cultural context (ACA, 2005).

In the 21st century, cultural competence includes recognizing historical and social prejudices in assessment, misdiagnosis and inference of pathology; minimizing bias; respecting diversity; support network involvement; communication; privacy; sexual orientation; environmental adaptation; social advocacy; and ethics competence.

The continued growth in the number of individuals and families from diverse backgrounds challenges counselors' ability to meet the needs of a growing and diverse society. In 1994, Sue, Arredondo and McDavis published what became known as the multicultural counseling competency framework. These competencies provide a foundation for all counselors to focus on the cultural makeup of the counselor and client as well as how culture affects daily living in a diverse society.

Cannon (2008) reported that the changing demographics of the United States population demand that counselor education programs provide training experiences that facilitate the development of multicultural competent counselors. The growing population of diverse individuals in the United States will put more pressure on counselors to be culturally competent in their service delivery.

During the American Counseling Association (ACA) 2010 conference, the Multicultural Social Justice Leadership Development Academy (MSJLDA) was held to open a dialogue about the many issues in multicultural competence and social justice advocacy. The academy presented information about the development of multicultural competence and offered suggestions to help participants improve their applications of multicultural competence.

What is multicultural competence?

The definition of multicultural competence means in part to approach the counseling process from the context of the personal culture of the client (Sue, Arrendondo and McDavis, 1994; Sue and Sue, 2007). Professional ethics compel counselors to ensure that their cultural values and biases do not override those of the client (ACA, 2005).

Presenters at the MSJLDA conference shared personal examples of their individual cultures and how these impacted their personal and professional lives, including professional self-awareness, knowledge and skills.

They also shared experiences that included several variables of discrimination. For example, one of the presenters, an immigrant from India, also shared personal experiences of sexism as a woman. Another presenter, an African-American male raised in the United States, represented racism and how it continues to affect how societies view people of color (Lodge, 2010).

A third presenter, a woman of multiple heritages, represented a group that receives less attention from counselors and offered a self-assessment tool to determine attendees' individual competence as a socially just, multicultural counselor. She also presented a theory on how to help unlink one's personal ego from functioning in the role of multicultural counselor. The final presenter, a male with multiple heritages, submitted written materials for participants, focusing the discussion on the development of multicultural competent leaders.

The conference was based on multicultural competence as outlined by the American Counseling Association (ACA, 2005) and the Association for Multicultural Counseling and Development (ACMD, 1992). These organizations focus on the development of multicultural competence in professional counseling organizations. The conference presentations served as a way to extend the dialogue of multicultural competence from the unique perspective of individual counselors from around the world.

Barriers and challenges

The need for cultural competence became more evident during the 20th century when the American population tripled. This rapid growth was due to an increase in immigration (Urban and Orbe, 2010) and the birthrates of racial/ethnic groups currently present in U.S. communities.

During this time it was noted that there were barriers and challenges faced by counselors who belong to a minority community. Some counselors described a feeling of culture shock and inadequacy. The challenges and struggles indicated that they were not adequately prepared to assimilate into the white culture.

Counselors often sought to consult colleagues, books and research literature. Many counselors found that while there was a strong focus on the challenges faced by counselors with clients from ethnic backgrounds different from theirs, there was less focus on the challenges that a minority counselor faces in meeting the needs of clients who are culturally different (Consoli, Kim, and Meyer, 2008).

According to Pederson (1997), the main features of cultural competence are counselor self-awareness, knowledge about culture, and skills. This belief is consistent with the multicultural counseling competencies developed by Sue, Arrendondo, and McDavis (1994).

These studies noted that to become culturally competent, it is imperative to have cultural knowledge that is perceived as a coalition of theoretical concepts and life experiences (Kiselica and Maben, 1999). Therefore, counselors from another culture must make genuine efforts to integrate their knowledge of culture and life experiences from their country and the United States. Knowledge about two cultures and the experiences from living in both cultures provided scope for reflection and promoted counselor self-awareness (Zalaquett, 2011).

The next important ingredient for multicultural competence, according to the research, was cultural skills. A skilled counselor uses interventions that are client-based and serve client needs (Chung and Bemak, 2002). This study discussed the significance of updating knowledge about various counseling techniques, becoming more knowledgeable about the indications and contraindications of the techniques, and emphasized the significance of establishing collaborative relationships between the counselor and the client.

In multicultural counseling, the counselor and the client need to discuss which techniques will be beneficial to the client. While adhering to the normal counseling and ethical practices in multicultural counseling, counselors need to be more aware of the limitations in their counseling skills in the multicultural context. It is vital to have cultural skills in order to serve multicultural populations in the most productive way to facilitate rapport.

Being culturally aware and recognizing how culture will affect the counseling process helps counselors develop empathetic understanding toward clients (Pederson, 1991). Ridley (2002) stresses the importance of empathic understanding in multicultural counseling based on self-experiences, self-awareness and knowledge of culture. Cross-cultural awareness facilitates the counselor's knowledge, understanding and respect for culturally diverse clientele (Fukuyama and Niemeyer, 1985).

While being cognizant of one's own culture, beliefs and values, it is crucial that counselors do not become culturally encapsulated. Cultural encapsulation puts counselors at risk of using stereotypes, becoming judgmental, and imposing their values on their client.

Counselors are encouraged to respect and accept their clients and their lifestyles, receiving them as who they are, non-judgmentally. However, immigrant counselors are faced with many challenges. They must first educate themselves about the new culture and learn more about the beliefs and values of the people around them. Counselors might need to ask clients to better educate them about their cultures. It is especially important for counselors to establish trust with clients and to demonstrate unconditional positive regard (Zalaquett, 2011).

Stereotypes and perception of other groups

Stereotypes, perceptions and beliefs that counselors hold about groups that are culturally different could hinder their ability to form helpful and effective relationships. Collaborative relationships might be difficult to form in the presence of such hindrances. Counselor educators must prepare counselors to become culturally competent through:

- Revamping training programs.
- Developing multicultural competencies as core standards for the profession.
- Providing continuing education for current service providers.

Culturally competent counselors do not see their group's cultural heritage, history, values, language, tradition or parts as superior to that of others. Culturally competent counselors are open to the values, norms and cultural heritage of clients, and do not impose their values or beliefs on clients (Sue and Sue, 2007).

Perceiving clients from other cultures in a negative way might lead clients to believe that the counselor is superior to them, impairing the collaborative relationship between the counselor and the client. A sincere effort must be made by counselors to remove the "invisible veil" (Sue, 2004). People are all products of cultural conditioning, and their beliefs, values and worldview represent the invisible veil that operates outside the level of consciousness.

As a result, people assume that everyone, regardless of race, culture, ethnicity or gender, shares the nature of reality and truth. This universal assumption is erroneous, but it is seldom questioned because it is firmly ingrained in the individual's worldview. Counselors must make a sincere effort to remove that invisible veil (Sue, 2004).

Qualities of a multicultural counselor

There are several common qualities seen in multicultural competent counselors, not unlike those listed in the section above on the universally shared view of counselor competence. The qualities below have a particular focus on recognition of aspects of multiculturalism (Zalaquett, 2011;Ahmed (2011):

- **Credibility,** which may be defined as the constellation of characteristics that makes one appear worthy of belief, capable, entitled to confidence, reliable and trustworthy.
- **Competence,** which includes credentials and qualifications and on how well informed, capable or intelligent others perceive the person to be. Mental health professionals practice within their areas of competence and develop and enhance their professional expertise. They continually strive to increase their professional knowledge and skills and apply them in practice. In addition, they should aspire to contribute to the knowledge base of their profession.
- **Trustworthiness/integrity,** which is confidence clients hold in a counselor's ability to make valid assertions. All mental health practitioners must act honestly and responsibly and promote ethical practices on the part of the organizations with which they are affiliated.
- **Awareness and sensitivity,** which includes cultural meanings of confidentiality and privacy. Counselors must respect differing views toward disclosure of information and have ongoing discussions with clients on how, when and with whom information is to be shared. Sensitivity also includes recognition that culture affects the manner in which clients' problems are defined. Clients' socioeconomic and cultural experiences should be considered when diagnosing mental disorders. Counselors should recognize that historical and social prejudices can lead to the misdiagnosis of certain individuals and groups, and that mental health professionals may play a role in perpetuating these prejudices through diagnosis and treatment. Counselors may refrain from making and reporting a diagnosis that they believe would cause harm to the client or others.
- **Proper assessment.** Counselors must be cautious when selecting assessment instruments for culturally diverse populations so they avoid the use of instruments that lack appropriate psychometric properties for the client population. Counselors should seek techniques that represent the norms of the population similar to those of a client. They must recognize a client's culture during test administration and interpretation, and place test results in proper perspective with other relevant factors (ACA, 2005).
- **Nondiscrimination** (see next page).
- **Commitment to clients.** All mental health practitioners' primary responsibility is to promote the well-being of clients, which includes respecting cultural diversity.
- **Self-determination.** Mental health practitioners must respect and promote the right of clients to self-determination and help them identify and clarify goals and cultural perspectives that may impact their goals.
- **Privacy, confidentiality and informed consent.** Mental health practitioners should use clear and understandable language to inform clients of the purpose of their service, risks related to service, limits to service, costs, the client's right to refuse or withdraw consent, and the HIPAA Privacy Rules that govern sharing of information. Mental health practitioners must respect

the client's right to privacy. Once private information is shared, standards of confidentiality apply; therapists may disclose confidential information when appropriate, with valid consent from the client or a person legally authorized to consent on behalf of the client. When providing counseling services to families, couples or groups, they should seek agreement among the parties involved on each individual's right to confidentiality. The culture and language of the client may dictate how counselors convey these aspects of multicultural competence.

How can counselors provide validation for others and for themselves?

In the context of multicultural counseling, validation can mean confirming what another person says. It can also mean having respect for other another person's communication by acknowledging the experiences, opinions and thoughts of that person as legitimate. These definitions describe validation as the confirming and affirming action, but convey nothing about being right or wrong. There are many ways to use validation with clients to let them know their counselor respects what they are saying.

Validation is vital to gaining respect and increasing the therapeutic alliance between mental health service professionals and their clients. When clients affirm that the validation process is working, counselors also feel validated for their efforts to positively connect with the client's lives, feelings, struggles and thoughts.

The validation process is viewed as a way of allowing clients to help their counselors gain confidence and growth through the clients' verbal or nonverbal communication of "a job well-done" (Wilson, 2006). It may be less complicated to validate situations with people who have cultural backgrounds similar to our own (Gamez, 2009). Validation has nothing to do with agreeing with others, just letting others know that what they have conveyed has meaning.

In reviewing many studies of ethnic and racial minorities in counseling services, it becomes clear that there are many other reasons why disparities exist. One reason is that some racial and ethnic minorities spend less time in psychotherapy, for example, in the case of European American human service workers who perceive a lack of validation. Perhaps outcomes would improve if human service workers learned how to employ the awareness, knowledge and skills of multicultural competence (Zalaquett, 2011).

It is also important to apply the multicultural competences when social issues arise. In fact, many people do not react to situations that are damaging to clients and peers alike because of:

- Fear of isolation.
- Not knowing what to do to advocate.
- Fear of lost wages, a job, or both.

Evaluating and expanding multicultural competences

Validating justice when speaking out against injustice is about affirming and confirming action, not about being right or wrong.

When people do not feel validated in their workplaces, they struggle with low levels of self-confidence. This low self-confidence negatively impacts the counseling process as well as their personal lives. Learning to become more culturally competent is an active process; it requires less lecture and more active involvement in the learning process. It requires collaboration and teamwork. A counselor's validation of clients' feelings and perceptions will benefit the clients' self-efficacy and self-confidence (Cormier, Nurius, and Osburn, 2009).

Studies of multicultural competency are often grouped into several identified themes. These themes are discrimination, validation, multicultural competence, and the sharing of knowledge. Each of these themes is discussed below:

Discrimination

Counselors must not condone or engage in discrimination based on age, culture, disability, ethnicity, race, religion/spirituality, gender, gender identity, sexual orientation, marital status, partnership, language preference, socio-economic status or any other basis prescribed by law (ACA, 2005).

Counselors must not discriminate against clients, students, employees, supervisees or research participants (ACA, 2005).

The Ethical Standards for School Counselors states that counselors must respect students' values, beliefs and cultural background and not impose their personal values on students or their families (2010).

In addition, it notes that school counselors must develop competencies and understand how prejudice, power and various forms of oppression – disability, age, class, familiarity, gender, gender identity, immigration status, language, racism and religion – affect them, students and all stakeholders.

The National Association of Social Workers (2008) states that social workers should not practice, condone, facilitate or collaborate with any form of discrimination on the basis of race, ethnicity, national origin, color, sex, sexual orientation, gender identity or expression, age, marital status, political beliefs, religion, immigration status, or mental or physical disability.

In addition, social workers should promote conditions that encourage respect for cultural and social diversity within the United States and globally. Social workers should promote policies and practices that demonstrate respect for difference and the expansion of cultural knowledge and resources. They should be advocates for programs and institutions that demonstrate cultural competence, and promote policies that safeguard the rights of and confirm equity and social justice for all people. The organization concludes that social workers should act to prevent and eliminate domination of, exploitation of, and discrimination against any person, group or class on the basis of race, national origin, color, sex, sexual orientation, gender identity or expression, age, marital status, political beliefs, religion, immigration status, or mental or physical disability (NASW, 2008).

Although overt discrimination has diminished, it has been replaced by a more subtle discrimination called micro-aggression that is often hard to identify and address. Micro-aggressions are insults to people who are not in the" dominant" group (Constantine, 2007) and are many times unconscious. Is vital that counselors work as a profession to spearhead community change designed to eliminate this in society.

Mental health professionals often have to address micro-aggression in advocacy work in the community. Helping non-diverse communities become more open and embracing of difference and supportive of change can be challenging, but is essential. Reducing micro-aggression is a collective responsibility of counseling professionals. Counseling professionals might better address social environmental issues, such as sexism and racism, that bring many counselors to counseling, by increasing public awareness and by changing work cultures to be more inclusive (Zalaquett, 2011).

Multicultural awareness

Multicultural competent counselors are culturally self-aware, aware of clients' culture, and willing to bring culture into the discussion during interaction with clients (Sue, Arrendondo, and McDavis, 1994). They are open to listening to and helping clients with goals and objectives without imposing their own cultural values on clients.

They are respectful of the counselor-client relationship and of the client's uniqueness, and meet clients where they are, go on the journey with them, and provide them with the assistance they seek.

Multicultural competent counselors do not judge clients by their own values and their own core cultural beliefs, and do not engage in negative stereotyping.

Being culturally competent is an ongoing process. It is having the awareness that none of us ever knows everything there is to know, and so are always engaged in becoming more competent. It is indeed about being a true advocate for the client.

Sharing knowledge

Multi-culturally competent counselors must be prepared to teach their peers and students about the importance of multicultural competence and willing to stand up to their colleagues and speak out against micro-aggression. They must ask important questions about why some people hesitate to take a stand, allowing subtle aggressions to continue.

Much work is needed to encourage more therapists and counselors to become more open-minded in their professional and personal lives. To become a truly multicultural competent counselor means a person must want to help all mankind. To do so, counselors must challenge the "I" centeredness of their society and the assumptions or myths that breed fear and a sense of self-preservation over others, and assert regard and respect for all mankind (Ahmed, 2011).

Technology offers counselors new and exciting ways to challenge their centeredness. To succeed, they must increase communication and decrease isolation. They must learn about one another and adopt a more global focus.

Counselors must seek to become sensitive to and help clients become aware of family, work and community differences, and factor those in their decision-making. Counselors must develop the ability to hear and understand the basis for client goals and their values and concerns, and offer alternatives in ways that support and respect clients' cultural values.

Counselors must learn to speak in the language of their listeners. They must help clients engage their significant others, family, friends and colleagues in more constructive conversations. Counselors must be as concerned with the wellness of the environment as they are about their own well-being. They must ask open-ended questions upfront, reflective questions about tradition, spiritual centering and other aspects of their own as well as the client's personal cultures to help clients focus on issues and solutions in relationship to their culture (Arrendondo, et al., 1996).

PROMOTING THE BALANCE OF POWER AND MUTUAL RESPECT

Boundaries in a dual relationship

A boundary can be visualized as a frame or membrane surrounding the therapeutic process that identifies a set of roles for those involved in the therapy. (Smith and Fitzpatrick, 1995; Kathryn (1991) defined boundaries as "limits that promote integrity." Boundaries protect the well-being of clients when the mental health practitioner assumes two or more roles, either concurrently or sequentially, with the help-seeker (Herlihy and Corey, 1997).

The second role commonly is social, financial, as friend or teacher. Role-blurring ethics charges constitute the majority of ethics complaint and licensing board action (Bader, 1994; Nuekrug, Milliken and Walden 2001; Sonne, 1994).

Bartering

In the past several decades, licensing boards that protect consumers from therapists' harm and abuse have more vigorously pursued issues such as bartering of professional services. California licensing boards, for example, sent a pamphlet to all therapists in the state noting that "hiring a client to do work for the therapist or bartering goods or services to pay for therapy" represented "inappropriate behavior and misuse of power" (California Department of Consumer Affairs, 1990).

A larger power and prestige difference between therapist and client exist in dual relationships, and a greater potential for client exploitation; power is generally assigned to healers in most societies (Smith and Fitzpatrick, 1995).

Some inherent concerns with multiple-role relationships include:

- Your relationship can deteriorate the professional nature of the therapeutic bond, which is based on predictable boundaries.
- The essential professional nature of the therapeutic relationship is altered and compromised when the therapist is also the client's employer, friend or teacher.
- Dual relationships may establish conflicts of interest, jeopardizing the objectivity and neutrality required for professional judgment.
- Clients do not have equal power in a business or secondary association because of the nature of the therapist-client relationship.

  A client who feels mistreated in a financial or social change with the therapist faces barriers in legal redress because therapists can use client-shared secrets to create a defense. Further, therapists can use diagnostic labels to discredit clients (Pope, 1998).

The ACA (2005) Code of Ethics contains a section on bartering that is considered a dual financial relationship. Counselors may barter only if the relationship is not exploitive or harmful and does not place the counselor in an unfair advantage, if the client requested it, and if such arrangements are an accepted practice among professionals in that community or culture.

Bartering with the client for good or services is not ethically prohibited but it is not recommended as the customary practice. Therapists generally enter bartering arrangements with good intentions. They may barter to offer services to those with limited finances; however, the potential for problems often exists. Often, client services do not equal the monetary value, on an hourly basis, to that of therapy (Kitchener and Harding, 1990).

It should be noted that most professional liability insurance policies exclude financial and other business relationships with clients. Counselors must consider the cultural implications of bartering, discuss relevant concerns with clients and document such agreements in a clear written contract.

In addition, ACA Code of Ethics contains a section on receiving gifts. "Counselors understand the challenges of accepting gifts from clients and recognize that in some cultures, small gifts are a token of respect and show gratitude. When determining whether to accept a gift from a client, counselors must take into account the therapeutic relationship, the monitory value of the gift, the client's motivation for giving the gift, and the counselor's motivation for wanting or declining the gift" (ACA, 2005).

The American Psychological Association's (APA) Ethical Principals of Psychologists and Code of Ethics 2010 amendments addressed bartering as well.

"Barter is the acceptance of goods, services, or other nonmonetary remuneration from clients/patients in return for psychological services. Psychologist may barter only if it is not clinically contraindicated, and the resulting arrangement is not exploitive." The APA also classifies bartering as a multiple relationship that the psychologist should refrain from entering if the relationship could reasonably be expected to impair the psychologist's objectivity, competence, effectiveness in performing his or her functions as a psychologist, or otherwise risks exploitation or harm to the person with whom the professional relationship exists (APA, 2010).

Case study: Bartering

A counselor presented an unemployed farm worker the option of doing yard work in exchange for psychotherapy. Bartering was an accepted practice in the client's home country. The counselor charged $100 per hour and credited the client with $15 an hour, thus the client had to work more than six hours for each therapy session. The client protested to the therapist that the time required for the yard work prevented him from finding full-time employment. The therapist countered that the client could choose to terminate therapy and resume when he could pay the full fee.

The therapist calculated a below-fair-market value for the client's labor. The bartering contract contributed to the client's dissatisfaction as did his difficulty with the English language and understanding monetary value. The therapist interrupted the agreement and abandoned the client upon hearing the client's complaint. The client sued the therapist for considerable damages (Koocher and Keith-Spiegel, 2008).

Attitudes and beliefs

Counselors must be open to having leaders in their organizations who represent diverse political viewpoints and in the definition of social action. No one viewpoint can serve as the dominant viewpoint because counselors potentially serve all members of society and must be viewed as open to viewpoints held by others.

Knowledge

Counselors must gain knowledge about many different political perspectives so they can open a dialogue of mutual respect that leads to openness and respect of differences. Many counselors hold viewpoints that are not necessarily representative of the public at large. Is very difficult to serve others and open up leadership positions if one is not aware of others' views and how they come to hold them. Knowledge about the worldviews of others is at the core of the development of multicultural competent counselors and will form the basis for opening up professional organizations to leaders from a wide variety of backgrounds (Zalaquett, 2011).

Skills

Counselors must seek ways to help that do not place values held by the counselor onto clients, so the clients can find their own way of growth and development. Counselors must seek out opportunities to gain insight into their own views and motivations as well as the views and motivations of those they serve.

Counselors must develop new ways to engage in discussions of the many multicultural and social justice issues that mental health professionals and society face. To this end, counselors must familiarize themselves with the research on social justice and multicultural issues that address the wide spectrum of viewpoints that exist.

Counselors must stop trying to force one particular viewpoint onto others, and when others reject that viewpoint, must not label them as not supporting multicultural and social justice issues.

Difference is what leads to compromise, and it is the skill of compromise that will lead to the balance of power and mutual respect. Reflecting on personal growth, one author pointed out that his grandmother once said, "All who care about the welfare of others must first care about themselves. We cannot help others if we are blind to our own views and the effect they have on others" (Hazier and Wilson, 2010).

Group-specific and multicultural approaches

Over the past two decades, the counseling profession has underscored the importance of multicultural counseling training, which has become an integral part of counselor education (Ridley, Mendoza, and Kanitz, 1994). Sue and his associates (Sue, Arrendondo, and MacDavis, 1992) proposed a tripartite conceptualization of multicultural counseling competencies, which became a major force when multicultural counseling gained significant attention in the field.

The tripartite model has three components, awareness, knowledge and skills:

1. **Awareness** refers to the counselor's awareness of his or her own worldview and cultural biases.
2. **Multicultural knowledge** requires counselors to be knowledgeable about various cultural factors that might influence the counseling process.
3. **Skills** include a counselor's ability to form rapport with culturally diverse clients and to implement culturally responsive interventions.

The tripartite model has stimulated research along with the development of instruments that purport to measure the multicultural counseling competencies (Worthington et al., 2007). While the tripartite model made much contribution to the field, it also received criticism.

One criticism noted by some researchers was the lack of empirical support for the model and almost exclusive focus on for racial and ethnic groups in the U.S.; African-Americans, Asian Americans, Latino Americans, and native Americans. Constantine, Gloria and Ladany (2002) evaluated the factor structure of multicultural counseling competency measures and did not find support for the theoretically proposed three-factor structure. With the exception of the Cross-Cultural Counseling Inventory, Revised (CCCR-I), other competency measures use self-report (CCC I-R; LaFramboise et al., 1991).

Content analysis of multicultural counseling competency research noted a theory-research gap in the multicultural counseling literature, which led to debate on what cultural aspects should be included in divining multicultural counseling competencies (Worthington et al., 2007).

The original multicultural competency model focused exclusively on racial and ethnic issues (Sue et al., 1982), although the second paper in 1992 attempted to define the multicultural counseling competencies more inclusively by considering other diversity factors, including sexual orientation, disability, gender, religion and socioeconomic status, but with the major emphasis still on race and ethnicity. In addition, while the inclusive approach avoids becoming exclusive, there has been the argument that such an all-inclusive approach obscures the understanding of each factor as a powerful dimension of human experience (Sue and Sue, 2003).

Helms and Cook (1999) argued that such all-inclusive definitions lack precise conceptualization to understand the role of race in the counseling process and its sociopolitical implications on clientss' mental health. With the emphasis on specificity, Helms and Richardson (1997) suggested that researchers and professionals address the question of which competencies work best for what aspects of diversity.

To emphasize the significance of race, Helms and her associate developed racial identity development models for European Americans and African Americans as well as instruments to measure the racial identity statuses. Those racial identity development models generally assume that individuals begin developing with a racially unaware state, then going through racial awakening and psychological dissonance to move toward a fuller acceptance and awareness of racial issues. The models lead to a body of research that related racial identity with various psychological constructs, including defense mechanisms (Utsy and Garnet, 2002), racism (Pope-Davis and Ottavi, 1994), and self-reported multicultural counseling competencies for counselors (Constantine, 2002).

There are other group-specific models of focus on the identity and development of specific socio-cultural groups, such as gays and lesbians (Cass, 1979) and feminists (McNamara and Rickard, 1989). Group-specific models often provide rich information specific to the group and a more explicit operational definition of the construct.

Group-specific models render themselves suitable for yielding instruments and large-scale quantitative research. Because of the specificity, the group-specific approach produces more research and a better understanding of the impact of each socio-cultural factor on people. However, this specificity approach does not consider salience of group membership for individuals and the interaction effects of multiple socio-cultural factors.

Pederson (1991) emphasized individuals' multiple identities, such as a person who is a Latino gay man with a disability, and argued that all counseling relationships are essentially cross- or multiple–cultural. In highlighting the complexity of multicultural counseling, he asserted that because such multiple identities within a client are affected by contextual factors, it is important for counselors to assess which identity is more salient for the client in a given context.

From a social constructionist perspective, Collins (2000) described the concept of intersectionality that suggests complex and dynamic interactions between social oppression and individuals' identity and everyday experience. According to conceptualization, different social categories, race, social class, gender, sexuality and so forth create different oppression systems that interact and intersect each other and influence individuals' social positioning in a given context. It is much like a matrix; for instance, although women's social proximity may be close to the context of experiencing sexism, it becomes distant in the context of dealing with mobility issues if such a women has a spinal cord injury. In contrast to the single-dimensional approach to multiculturalism, those views attempt to theorize the impact of multiple socio-cultural factors on individuals and the interactions among different socio-cultural factors (Collins, 2002).

Clinical values of the multidimensional approach to can be supported by the data that show a high concentration of risk factors among certain socio-cultural groups as well as high co-morbidity rates in clinical populations. For example, because ethnic minorities are less likely to receive effective treatment, they bear higher rates of disability burden than European Americans (DHHS, 2001). Demographic variables, such as having a disability, being a woman, African-American, Latino American, or having less education, have been associated with an increased likelihood of living in poverty (Kruse, 1998).

Focusing on wide-ranging impacts of poverty, Evans (2004) suggested that poverty does not occur in isolation and that it is the accumulation of multiple social and environmental risk factors that make chronic poverty more detrimental to the individual's physical and psychological well-being. The data point to the need for counselors to consider interrelations among physical, psychological and social factors that may affect clients presenting issues.

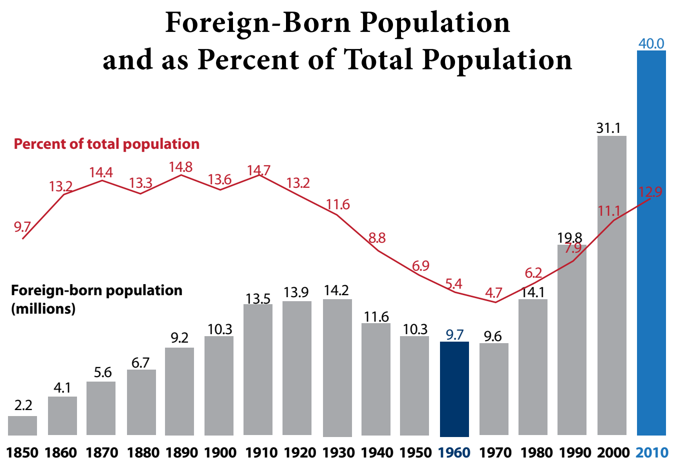
The multidimensional approach can provide more realistic conceptualization in practice because it addresses the intersectionality among different socio-cultural factors and the complexity inherent in multicultural counseling. On the other hand, because of the complexity, the multi-dimensional approach is less likely to be research-friendly to quickly generate empirical data (Ishii, 2012).

A review of single and multidimensional approaches to multiculturalism can be compared with landmark research on the multicultural counseling competency model (Sue et al., 1992). The single-dimension approach advanced research and understanding of the impact of specific socio-cultural factors on clients. The multidimensional approach provides clinically useful concepts that help better understand the salience and intersectionality of different socio-cultural factors for a given client.

Given the emphasis on a universal or holistic approach in counseling, researchers suggest that multicultural counseling research and practices use knowledge gained from the group-specific approach and move toward a multidimensional approach in addressing multicultural issues in counseling (Ishii, 2012). To foster empirical endeavors, researchers are encouraged to incorporate a multidimensional nature of social-cultural identity and the interactional effect of different socio-cultural factors in their research. In particular, the development of instruments or assessment strategies to measure the multidimensional, socio-cultural factors will facilitate much needed research.

Similarly, counselors are encouraged to become confident in addressing various socio-cultural issues in counseling, including ethnicity, race, gender, disability, sexual orientation, age, socio-economic status and religion. In addition, counselors must understand the concept of saliency and intersectionality to conceptualize socio-culturally diverse clients.

Statistics



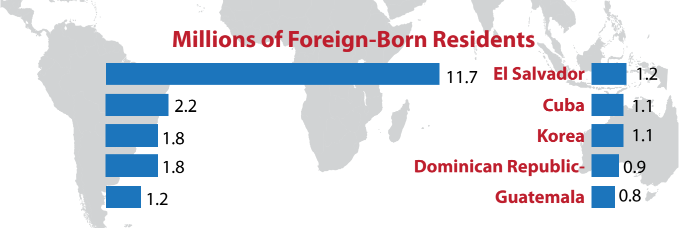
Source: U.S. Census Bureau, 1850-2000 Decennial Census; 2010 American Community Survey

The need for multicultural competent counselors is increasing as the population of various ethnic groups grows. Current and projected 21st century demographic changes in the United States are a major factor.

For example, immigration patterns and increases among racially, ethnically, culturally and linguistically diverse populations are rapidly changing. A 2010 Census Bureau survey reported that one in every eight persons in the United States is foreign born. Currently, the U.S. foreign-born population comprises a larger segment than at any time in the past five decades. This trend is expected to continue.

The Children's Defense Fund predicted that in the first decade following 2000, there would be 5.5 million more Latino children, 2.6 million more African-American children, 1.5 million more children of other races and 6.2 million fewer white, non-Latino children in the United States. (NCCC).

Cultural competence can increase the overall quality of life for everyone and supports best practice in mental health as well as decreases the likelihood of liability and malpractice claims. (NCCC Policy Brief)



Source: U.S. Census Bureau, 2010 American Community Survey.

Child discrimination reports

Discrimination is the denial of equal treatment. Although improvements have occurred, serious problems still exist with children and discrimination. Racial injustice is particularly noted in juvenile justice systems. Youths of color are treated more harshly than white youths for the same detention processing in juvenile court, transfer to adult criminal court, and sentencing and incarceration in juvenile and adult facilities.

Courts commit African American youths with no prior drug offenses to state institutions 48 times as often as white youths with no prior drug offenses. African American youths are sentenced 90 days longer for violent offenses than white youths, and Latino youths are incarcerated 150 days longer. (Child Welfare League of America, CWLA, 2002)

In a Child Welfare League of America study in 2002, 48 percent of children ages 8 to 11 and 67 percent of children 12 to 15 stated that children at their schools were treated badly because they were "different," and that discrimination was a big problem for their peers at school.

As reported in 1999, 7,876 hate crimes were reported in the United States. Nearly two-thirds of all known perpetrators were teenagers or young adults. (CWLA, 2002)

The National Center for Cultural Competence policy brief, Rationale for Cultural Competence in Primary Care, states that there are additional compelling reasons to become culturally and linguistically competent. They include:

- **Eliminating long-standing disparities in the mental health status of people of diverse racial, ethnic and cultural backgrounds.** There are continuing disparities in the incidence of illness and death among African Americans, Latino/Hispanic Americans, native Americans, Asian Americans, Alaskan natives and Pacific Islanders as compared with the U.S. population as a whole (U.S. Department of Health, 1998).
- **Improving the quality of services and health outcomes.** Fundamental differences among people arise from nationality, ethnicity and culture in addition to family background and individual experience. These differences affect the health, beliefs and behaviors of both clients and mental health practitioners and their interaction.
- **Understanding critical factors in the provision of culturally competent mental health services.** These include:
  - Knowledge of beliefs, values, traditions and practices of a culture.
  - Culturally defined health-related needs of individuals, families and communities.
  - Culturally based belief systems of the etiology of illness and disease and those related to health and healing.
  - Attitudes toward seeking help from health care providers
- **Meeting legislative, regulatory and accreditation mandates.** The federal government has a pivotal role in ensuring culturally competent mental health care services. State and federal agencies increasingly rely on private accreditation entities to set standards and monitor compliance with these standards. Both the Joint Commission on the Accreditation of Healthcare Organizations, which accredits hospitals and other health care institutions, and the National Committee for Quality Assurance, which accredits managed care organizations and the behavioral health managed care organizations, support standards that require cultural and linguistic competence in health care.
- **Gaining a competitive edge in the market place.** The provision of publicly financed health care services is rapidly delegated to the private sector. The potential for improved services lies in state managed-care contracts that can increase retention and access to care, expand recruitment and increase the satisfaction of individuals seeking health care services. To reach these outcomes, managed care plans must incorporate culturally competent policies, structures and practices to provide services for people from diverse ethnic, racial, cultural and linguistic backgrounds.
- **Decreasing the likelihood of liability/malpractice claims.** Insensitivity and ignorance about cultural competence could create liability under tort principles in several ways. For example, providers may discover they are liable for damages as a result of treatment in the absence of informed consent. Also, health care organizations and programs face potential claims that their failure to understand health beliefs, practices and behavior on the part of providers or patients breaches professional standards of care. In some states, failure to follow instructions because they conflict with values and beliefs may raise a presumption of negligence on the part of the provider.

In addition, the ability to communicate well with patients has been shown to be effective in reducing the likelihood of malpractice claims. A 1994 study appearing in the Journal of the American Medical Association indicates that the patients of physicians who are frequently sued had the most complaints about communications. Physicians who had never been sued were likely to be described as concerned, accessible and willing to communicate.

Effective communication between providers and patients may be even more challenging when there are cultural and linguistic barriers. Health care organizations and programs must address linguistic competence – ensuring for accurate communication of information in languages other than English. (National Center for Cultural Competence).

Defining culture, competence and diversity

Cultural and linguistic competences are at the base of cultural competence. They are defined here.

Culture – An integrated pattern of human behavior, which includes:
- Thought.
- Communication.
- Languages.
- Beliefs.
- Values.
- Practices.
- Customs.
- Courtesies.
- Rituals.
- Patterns of interaction.
- Roles.
- Relationships.
- Expected behaviors of a racial, ethnic, religious, social, or political group, and the ability to transmit the above to succeeding generations.

Culture is dynamic in nature. It defines us as individuals and makes us who we are. Everyone has culture that influences how each of us sees others. And organizations or systems have distinct cultures that are developed by their mission and goals. Communities have different cultures influenced by their members, the environment and socioeconomic conditions. Culture is a framework for making human connections, as we see things from our own perspective.

Intervening factors that influence culture include:
- Level of education.
- Level of income.
- Geographic residence.
- Place of birth.
- Age.
- Gender.
- Identification with community groups.
- Length of U.S. residency.
- Personal experiences.

Competence – The ability to incorporate values, knowledge, attributes and skill sets in order to work effectively cross-culturally.

Diversity – A range of human perspectives, backgrounds and experiences reflected in characteristics such as age, class, ethnic origin, gender, nationality, physical and learning ability, race, religion, sexual orientation and veteran's status. Other diversity variables include but are not limited to:
- Education.
- Marital status.
- Employment.
- Geographic background.
- Cultural values, beliefs and practices.

Cultural competence – In general, the ability of individuals and systems to respond respectfully and effectively to people of all cultures, classes, races, ethnic backgrounds, sexual orientation, and faiths or religions in a manner that recognizes, affirms and values the worth of individuals, families, tribes and communities and protects and preserves the dignity of each.

Demonstrating cultural competence is an ongoing process that emphasizes cultural strengths of others and integrates their unique abilities and perspectives into our lives. It is a vehicle that can be used to broaden our understanding of individuals and communities, and is reflected in how people in a community relate to and interact with mental health providers. Cultural competence addresses how to understand cultural implication issues and then integrate this knowledge into an optimal therapeutic interaction. (CWLA)

Acculturation – The adaptation of one's own cultural values to existence within another cultural context. It is a process that occurs when two distinct cultural groups have continuous first-hand contact, resulting in subsequent changes in the original cultural patterns of either or both groups. How does your client or client's family deal with conflicting values of their traditional culture and that of the dominant culture?

Assimilation – Adoption of another culture's values and way of life.

Bigotry – A set of attitudes characterized by hate of a cultural group often based on generalized misjudgments of cultural behavior and on a belief in the inferiority of the other group.

Central tendency – The belief that everyone within a culture is exactly alike, shares the same values, beliefs and attitudes.

Cultural competence – The ability of individuals and systems to respond respectfully and effectively to people of all cultures, classes, races, ethnic backgrounds and religions in a manner that recognizes, affirms and values the worth of individuals, families and communities, and protects and preserves the dignity of each.

Ethnicity – Of or pertaining to a social group within a cultural and social system that is based on variable traits including religious, linguistic, ancestral or physical characteristics.

Ethnocentrism – The belief that one's values, standards and world are the best. ("If they are not like me, they are deviant.") Misinterpretation and misjudgment based on looking at another person's behavior from your own cultural reference point.

Genocide – The severe dynamics of difference in which one group regards another group as subhuman and seeks to destroy that group or their culture.

Institutional racism – A condition in which the structures and systems of a society restrict access to rights or resources from groups or individuals based on racial differences. No single person need do anything that is racist. (Guide: Achieving Cultural Competence, 2001)

Five essential cultural competence elements

Five major elements comprise cultural competence. They include valuing diversity, conducting cultural self-assessment, managing the dynamics of difference, acquiring and integrating cultural knowledge and adapting to diversity and cultural contexts:

1. Valuing diversity embraces behaviors, practices, policies and attitudes as well as larger systems and structure.
2. Conducting cultural self-assessments challenges mental health professionals to assess for personal as well as professional proficiency in cultural competence.

3. Managing the dynamics of diversity occurs within natural, formal or informal support, and facilitates networking within clinical and neighborhood settings, ethnic-social-religious organizations and spiritual communities.
4. Acquiring and integrating cultural knowledge prompts mental health practitioners to seek out consultation, coaching and mentoring and from a variety of sources. For example, in some cultures it would be appropriate to request an interview with the religious leader before working with the community as a whole.
5. Adapting to diversity and cultural contexts challenges mental health practitioners to formulate and practice new behaviors and beliefs that might include:
    - Revisiting policies and procedures that are no longer relevant and, in fact, could be counterintuitive to providing culturally competent mental health services.
    - Restructuring systems and methodologies to more appropriately meet the needs of the people served.
    - Enhancing and adopting different values with the commitment to provide culturally competent, evidence-based practice.
    - Revising service practice to incorporate culturally sensitive mental health protocols. Applying cultural competence to mental health practice.

The majority of mental health practitioners are culturally sensitive. When missteps occur, it is usually because there is lack of cultural awareness, communication, perception or other disconnects between a mental health provider and client, especially when a provider becomes "affectively charged." For example:

> *Janet, a licensed clinical social worker, has been seeing 6-year-old Annette for several weeks. Annette was traumatized when she witnessed her parents' fighting, which eventually sent her mother, Tilda, to the hospital with a concussion and broken arm. Annette's grandmother looked after Annette while her daughter was recuperating, and when Tilda was released from the hospital, she moved into her mother's home with Annette. Annette had already been seeing Janet and was soon joined by her mother, engaging in dyadic therapy.*
>
> *In subsequent weeks, Annette appeared to be more anxious and often argued and fought with her teachers and other students. In counseling sessions, Janet struggled to communicate to Annette's mother that Annette was reenacting her traumatic experience with her teachers and classmates. Tilda, on the other hand, felt that Annette was being blatantly disobedient. During one session, Janet became "affectively charged" by Tilda's comments that Annette could overcome her behavior through punishment and reprimands.*

Being "affectively charged" causes therapists to stick to a message that, at the moment, cannot be heard. The message is usually more solution focused rather than strength-based focused.

Because Janet felt passionately about trauma and how it affects children, she forgot to "check-in" with Tilda and ask about Tilda's mother's perception that children could be curbed through corporal punishment as well. Janet was unaware that Tilda's mom had a powerful influence on her daughter and vicariously used her to express her own feelings, even though she wasn't in the session room with her daughter or granddaughter.

Janet was also unaware that even if Tilda felt differently, her upbringing taught her not to question her own mother's authority. In addition, her guilt about leaving her marriage was overwhelming due to her cultural orientation toward marriage. Had Janet asked Tilda about Tilda's culture and also examined her own professional agenda, Janet would have been equipped to communicate her message more effectively to her client.

Janet's orientation toward her role as a child advocate is not unusual. Circumstances such as hers often initiate professional discussion of what is best for children and how to handle seemingly resistant parents when they are at odds with the therapist about a child's health and well-being.

In their own words

A lot has been written about cross–cultural environments from the viewpoint of Americans. However, how often have natural-born Americans stepped back to appreciate the challenges, frustrations, emotions and sometimes amusing experiences that immigrants have faced as they tried to assimilate. The following stories are unique experiences of people who came to work and live in the United States. These stories are in their own words, with few grammatical changes (Lindsell-Roberts, 2011):

Jürgen from Germany
In the workplace we do not use the word "problem." There is just a challenge. The word problem seems to be restricted to life-threatening conditions only.

It was difficult to adjust to working in a cubicle with no natural light. In Germany, it was a law that every permanent office workplace has daylight access.

I had to adjust to women's liberation. At one time I opened the door and a woman was walking behind me, so I held the door open for her. She rudely yelled at me, "I can open the door myself. " So I just did what I felt like: slamming the door in her face.

Robin from Germany
I found it difficult when I came to America to have a conversation without having to speak of Nazis. My first challenge was and still is to meet as many Americans as possible to talk about my country and let them know that Germans are human beings like everybody else, and in each country there are good and bad people. I met a lot of Jewish people who did not like me at the beginning and became good friends of mine after long talks and disagreements. I have a few memories of Jewish families I became friendly with through strange circumstances, and they learned to have a better understanding of Germans.

My second challenge was this: Most Americans have always been aware of Germans being good mechanics, keeping good records, and making sure everything is accurate. When I came to this country, I was shocked when I read letters and other documents written by Americans and saw numerous mistakes in their writings. In Germany we were taught grammar until it came out of our ears. We disliked our English teachers because they were very strict, but after coming to the states, I thanked him 1000 times for making sure we would always speak, talk, and write correctly.

My third challenge, if you want to call it that, was to learn how to smoke and chew gum at the same time. There was a lady in my department who was always chewing gum and smoking at the same time. I thought it was absolutely fascinating the way she made noise and blew bubbles at the same time with a cigarette in her mouth. I succeeded after a while, and it drove my family crazy but I was proud of myself. This was my way of becoming "more of an American."

Ari from Israel
I grew up in Israel in an Orthodox Jewish family. I went to an all-boys school and after my Bar Mitzvah I wasn't allowed to have any physical contact with females, except my mother, sisters, grandmother, then later my wife and daughters. That meant no hugging, kissing, or even shaking hands. When I moved to the United States, I started my own consulting company. I dressed in regular street clothes but I still wore my yarmulke, I found it uncomfortable to shake the hands of women because of my religious upbringing. I do shake women's hands to be polite but it is very uncomfortable for me.

Suzie from Taiwan
I would like to share my challenges with you when I came to America. I'm from Taiwan. The challenges I have faced are as follows:

- English – I learned English from my Taiwanese English teacher, so the pronunciation was way off from standard. I spent so much time to correct it and I'm still trying.
- Religion –Here the churches are all about Jesus. Mine are Confucian and Taoist temples.
- Background – I was taught the more humble you are the better you are. Here you have to express yourself, speak out, otherwise people won't understand you or respect you.
- Culture – I've learned to accept gay marriage, living together, and having children without marriage.
- Dress – Showing your body here is very wild. I've been taught the more you cover up the safer you will be.

April from China
My Chinese name is Chunlin but I adopted the American name April. Chunlin means "forest in the spring," and my parents wanted me to be lively, just like the trees that bloom in the spring time. When I lived in China I got my degree in English language and culture and I taught English there. So I was very well prepared to live in the U.S. I did find some cultural differences and was prepared for most of them.

People here talk very fast and it took me a while to get used to that too.

In China it is commonplace to ask people personal questions about their families, their children, and their income. It shows that you care about them. In the U.S., information like that is very private.

People here are much more direct. In China we would not disagree with you to your face because we wouldn't want to make you feel bad. We try to show disagreement through body language and in other discrete ways.

Jianyao from China
There are some things you may call cultural differences. For instance, Americans usually offer compliments on what you have done well. The Chinese don't, because there is always room for improvement. We do not jump up and down when the boss tells you "You did a good job" because he may just mean it is not too bad. In contrast, if someone in Chinese said that you could do a much better job you would not be upset.

Another difference is how people address others. Here in the states, everyone uses first name even if you are the president of the company, a respected professor, or a grandfather. You don't do this in China unless you are talking to a sibling or friend of the same or younger generation. Otherwise people will think you are rude and disrespectful. To the older generation or to people in higher positions, you better say their title first, then their last name, for example, Uncle Chen, or Manager Chou.

Aman from India
Having grown up in India I came to the U.S. with a very strong English accent and lingo. I tried very hard to lose the accent and the lingo because I wanted to blend in. But I realized I wouldn't blend in, because I look different. I wear a turban. People at work were very welcoming, but I noticed that people in my neighborhood didn't talk to me, maybe because I was different.

My life in the U.S. was good until 9/11 when I became a victim of a hate crime. The perpetrators saw my turban and mistook me for a Moslem. As they victimized me, they shouted, "Go back to Osama bin Laden." As a result, I am now part of an organization based out of New York called Sikh Coalition. It is a nonprofit organization born in the aftermath of the bigotry, violence, and discrimination against New York Sikh population following the terrorist attacks of 9/11. We go to schools to help children understand Sikh traditions such as why we never cut our hair and why we wear turbans. The goal of the organization is to teach understanding and tolerance.

Simon from England
Going out for a "pie and a pint" at lunchtime is somewhat of a tradition during the workday in England. Across the nation many white- and blue-collar workers find themselves in a local pub at lunchtime downing a pint of their favorite beer. I'm sure there are some who follow one pint with the second or even third, no doubt to help them slide through the afternoon with ease, though hopefully not literally! When I joined the ranks of corporate America in San Francisco I started to navigate my way around the different work culture to the one I was familiar with in London, England.

On my first day at work in the U.S., after my boss took me out for my "welcome lunch," along with my New York colleagues, I was promptly called in to her office for a "chat." She told me, in no uncertain terms that drinking alcohol during the workday would not be tolerated, and that the beer I had ordered at lunch not be acceptable under normal circumstances! Oh boy, that put away those work afternoon sliding by with ease, and I wondered what other little cultural gems I was to discover.

As it turns out, I have never been pulled up on such a cultural nuance again, but working in corporate America has shown some other more painful differences to those I was used to in dear old England.

The most challenging one, that I still struggle with on occasion, is that of the "work-life balance." The thought of having two weeks of vacation a year to reinvigorate and rejuvenate oneself after the stresses and strains of 50 weeks of work seems like a tall order. In my native England, and even across the rest of the European continent, where six weeks of vacation is typical, this thought would make people break out in a sweat. It would likely incite some to civil unrest.

Big issue gets compounded if those 40 hours of work a week, for which one is contracted and paid, routinely ends up being closer to 60 hours or more, spilling into evenings and weekends. I have often been asked to work late or finish some work up over the weekend to meet a timeline, with no consideration given to other plans I may have. After numerous times missing a theater performance, being late for a friend's birthday dinner, or disappointing myself or someone else, as I allowed work time to dictate my personal time, I realized that I had to set my own boundaries. This has not always been easy, as one can often be perceived as not being a "team player," and with the knowledge that it's far easier to be fired in the U.S. than the UK, I have seen the softening of my own boundaries.

This is the reason why the U.S. is one of the wealthiest countries in the world! Americans spend much of their time at work being productive. And when they are not talking about it, even when they are not there, they are often thinking about it.

In England I am not always asked, within a minute or two of meeting someone new, what I do for a living. This extends to social settings also, and trying to use British humor to make light of this invariably falls flat. Americans often misunderstand satire. Warning: do not use satire in the workplace!

Fortunately I enjoy my work so I don't mind answering those questions sometimes. I do wonder how easy it ends up being for those of us working in the U.S. to genuinely turn off from our heavily defined work roles, and turn our attention to the many other rich facets of American life. Now I know it's possible with that wonderful American "can-do" attitude that puts many other countries' work culture to shame.

Mohammed from Iran
I came to the U.S. from Iran to attend the University. After I got my PhD I got a job at a biotech company and got along well with my colleagues. Then 9/11 hit. A few people started making comments in front of me about those "blank, blank Moslems," and they made other comments that made me feel uncomfortable. Things quieted down after a few months, but every time there's an international terrorist

incident, I noticed people looking doubtfully at me. I came here with my family and we all became American citizens. I don't know why people don't trust my loyalty to this country. I love America.

Nalini from India
My biggest challenges were the American accent and colloquialisms. Although I knew English, I was unfamiliar with most phrases commonly used in a work setting including something as simple as "wrapping up a meeting." Even if I knew the phrases, they meant different things to me.

I also noticed that people would ask questions that did not sound like questions to me. I often did not realize I was expected to respond until people looked at me. I frequently ask people to repeat things they said just to understand the accent but I did not have the nerve to ask people to explain colloquialisms. After hearing them a few times, I interpreted what they meant by the context.

I also thought people spoke a lot, not always related to the topic of discussion. I sometimes struggle with trying to figure out if the speaker was saying something important.

My communication issues made me feel intimidated, and I didn't socialize or talk to anyone much, other than on work issues. I think people thought I was unfriendly, but I'm not.

Also, time was the problem at first. In India, maybe because the roads are so crowded, getting places on time isn't easy and it isn't important. Instead of saying when we'll arrive, we say when we'll leave. I had to train myself to be places on time because that's important here.

Keiko from Japan
I came to the U.S. to work for a pharmaceutical company that my Japanese company purchased. Everyone was very nice to me. A lot of the U.S. managers made many trips to Japan and they counted on me to help them understand Japanese customs and traditions, which I'm always glad to do.

Marita from Sweden
I was in for a few shocks when I came from Sweden to work in the U.S. as a graphic designer. My first job was at a small advertising firm that had a small in-house staff and a lot of "on-the-road" salespeople. The owners were very unprofessional, immature, and downright mean to people. It was a very stressful place to work. The two owners would brag about how they had reduced someone to tears or how they had turned down job applications because they weren't Caucasian or weren't good looking enough. I found that if you looked good and didn't oppose anything, then you are less likely to be harassed or fired. Good work ethics were not valued at all, this was something I had a very hard time understanding. I still don't understand it and I didn't stay there very long.

I interviewed at a publishing company and I was told that I could "work with other women and it would be less technical." That didn't sit well with me. I did take the job though, because it came the closest to my job in Sweden, but even there I felt that it was a little sexist, starting with my job interview.

The overall biggest difference I noticed in the U.S. would be the sense of teamwork, or rather, lack of teamwork. It doesn't seem like employees work together as a team, instead of what can we do together as a team to make our products and services better. I definitely feel less valued as an individual at any of these jobs than I ever felt at any of my jobs in Sweden.

Akram from Pakistan
When I arrived here I had a very hard time finding a job. I had a bachelor's degree in chemistry from Pakistan, and every company I contacted would not accept my degree. I went to college for four years in the U.S. and got a degree in chemical engineering. After that I got a job quickly. I got an entry-level job with low pay, but over the years I worked my way up to a nice job.

John from Darfur
I'm one of the "lost boys of the Sudan." I saw my mothers and sisters raped and killed and my brothers and father killed. I was wounded and still walk with the bad limp. They thought I was dead or they would have killed me too. I lived in a camp in Darfur for several years and I changed my name to John. A charity brought me to America and found me a place to live with three other boys from my country. After all the horrors we went through the black community shunned us. We didn't fit in because we were too black.

The people from the charity were very nice. Help me get into community college, and I worked in a grocery store stocking shelves to help pay for my food and clothes. The people are treating me well. Many white people have invited me to their homes for Thanksgiving and Christmas, and I like that. When I finish my education, I want to move back to Darfur to help the people were still there. Maybe I'll even find some living relatives.

Tony from Johannesburg
I came to the U.S. from South Africa when I was in my 20s and made an easy transition. This happened because English was my first language and students are educated to know that because of ongoing political strife in South Africa they'll be leaving the country when they graduate. I came to the U.S., had a family, and became an American citizen.

It wasn't until my children were in their teens that I learned I wasn't "an American." My son came home from school one day and announced, "Dad, I'm going to teach you how to be an American. First, you can't leave your cars in the garage. The garage has to be full of junk. Second, you can't be so in the serious about us. We smoke and drink, so don't think we are innocent. American fathers already know that about their kids." Then when my son went off to college and my wife and I visited him, he said, "American fathers always empty their pockets before they leave." So this is what it takes to be an American, I wondered?

Claudio from Brazil
I trying hard to learn better English and take classes after work. The people I work with know I'm taking English classes, and one person always correct my English. I get embarrassed, but I guess she's just trying to be helpful.

In my country we would stand close together when we speak. In the U.S. I found that people like what I learned is called "more personal space." That worked for me because I work with someone who smells of garlic. Now I have a good reason to stand far away from her. Maybe I give her too much personal space, but that's okay.

Anonymous from the United States
I guess because I'm an African-American, a minority, and I'm used to my race being highly visible to myself and others, it just never occurred to me that white Americans wouldn't be equally aware of their race or hardly think of it at all. Many white Americans seem to be frustrated and angry that black Americans attribute racial causes as the root of a lot of social problems for the African-American population. Many black Americans don't necessarily feel it's normal to be black, because throughout the history of the U.S. they have been made to feel anything but normal.

An example of how an initial impression can be a barrier to seeing the real person happened during my diversity class. Our instructor said that her first impression of me was an intimidating one. Initially she said it was because of my height and size but, when we got right down to it, her feeling was because of the darkness of my skin. She found something about dark brown skin anxiety inducing. Conversely, the instructor didn't feel intimidated by a fellow African American male student who had lighter skin that I did.

As a counseling student, I think "good counseling" takes into consideration the contents of the client's ethnic background and keeps them in full view at all times. I think this would be valuable for anyone to do in his or her daily lives.

Lessons learned

Cheryl Lindsell-Robert notes that the United States has always drawn its strength and greatness from diversity, and a lot can be learned from the challenges and experiences of others. Although the stories told above are a sampling of people Roberts interviewed, they contain many lessons we can learn as we strive to understand others. Some of those lessons follow:

- **Check stereotypes at the door.** Many stereotypes have been passed on by families and sometimes by the individual themselves. Stereotypes may seek to create order or systems from observations, but they are destructive because they lead to invalid conclusions and rob people of their individuality. The counselor must always remember they are communicating with a person, not a stereotype.
- **Never correct people in English unless they ask you to.** People whose English is a second language are trying to speak correctly, and they are made to feel uncomfortable by correcting them. If they say something offensive because of a problem with translation, mention it privately. Even people whose primary language is English make mistakes.
- **Allow for cultural differences.** People from different cultures often have challenges in terms of language, etiquette, work practices, and behavior. These differences must be respected, and the counselor has an obligation to manage communication so that the individuals can work together productively and cohesively.
- **Learn about gestures and other body language** and all you can about others' personal space, cultural norms, eye contact and facial expressions.
- **Don't judge a book by its cover.** People may act certain ways because of cultural differences and experiences. For example, although some people may naturally be shy and reserved, others may just feel out of place or intimidated. Some may feel that being reserved and quiet is a sign of respect. Counselors must work to seek them out to and get to know them.
- **Avoid humor and jokes.** Some people in Western cultures try to build rapport through humor, but this is not universally appropriate. Many cultures don't appreciate humor and jokes and may see laughter as a sign of disrespect.
- **Sequence your message strategically.** People from different cultures encode and decode messages differently. This increases the chances of being misunderstood. Recognizing this, think of a logical order in which to present information.
- **Be attuned to timing.** People in the U.S. are concerned with schedules and the consequences of arriving late and missing appointments. People from other cultures may not see or understand the significance of time.

Cultural influence on practice

Culture is considered to be "the configuration of learned behavior and results of behavior whose components and elements are shared and transmitted by the members of a particular society" (Linton, 1945). Culture exerts its influence in every part of one's life. Therefore, it is not a surprise that it affects one's health and health-seeking behaviors.

Because culture has a strong sway on mental health, there is a growing need to conduct more studies to ascertain the extent of its influence. It is very closely intertwined with mental health and the counseling field, so much so that multicultural and diversity considerations are included in the codes of ethics of all professional mental health organizations.

Influence of the client's culture

As counselors incorporate a greater awareness of their client's culture, they must realize that historically, cultural differences have been viewed as deficits (Romero, 1985). Adherence to white cultural values has brought about a naïve imposition of narrowly defined criteria for normality on culturally diverse people (Peterson, 1986). Multicultural counseling, however seeks to rectify this imbalance. Although the variety of cultures is vast, the following examples indicate the types of cultural issues and their effects on the counseling situation.

In the cultural value system of Chinese Americans, passivity rather than assertiveness is revered, quiescence rather than verbal articulation is a sign of wisdom, and self-effacement rather than confrontation is a model of refinement (Ching and Prosen, 1980). Because humility and modesty are so valued, it is difficult for counselors to draw out a response from a Chinese-American in a group setting.

The reticence, which reinforces silence and withdrawal as appropriate ways of dealing with conflict, may be interpreted as resistance by an uneducated counselor. Democratic counselors may also be uneasy with the role of the "all-knowing father" that the Chinese respect for authority bestows on them (Ching and Prosen, 1980).

Africans place great value on social relationships, with a great emphasis on the community and their place in it. In this context, social conflict resolution becomes important so that peace and equilibrium may be restored to the community, while personal conduct becomes secondary (McFadden and Gbekobov, 1984).

In a discussion of counseling the northern natives of Canada, counseling is seen as cultural racism when it does not fit native values. These values are cooperation, concreteness, lack of interference, respect for elders, the tendency to organize by space rather than time, and dealing with the land as animate, not inanimate, objects (Darou, 1987).

Bernal and Flores-Ortiz (1982) point out that Latin cultures view the family as the primary source of support for its members. Any suggestion that the family is not fulfilling this obligation can bring shame, stress, and increase reluctance to seek professional services. Involving the family in treatment will most likely ensure successful counseling outcomes with Latinos.

Mental disorders such as schizophrenia, depression and bipolar disorders are seen in people from all across the world. However, the manifestation varies greatly according to age, gender, culture, race and ethnicity. It has been found that clients from different cultures tend to be selective in expressing their symptoms in a more culturally accepted way. The clinician needs to have multicultural competence to be able to overcome this challenge.

Research has shown that culture influences the treatment-seeking behavior of clients. It has been noted that members of certain minority groups tend not to seek the help of mental health specialists; they prefer informal sources of care like the clergy, traditional healers, family and friends.

Findings also show that members of some minority groups have a feeling of mistrust that can have cultural and racial roots. The method of communication also varies widely from culture to culture and must be taken into account.

Influence of the health professional's culture

A major assumption for culturally effective counseling and psychotherapy is that counselors must acknowledge their own basic tendencies, the ways they comprehend other cultures, and the limits culture places on comprehension. It is essential to understand our own cultural heritage and worldview before we set about understanding and assisting other people (Ibrahim, 1985; Lauver, 1986). This understanding includes an awareness of one's own philosophies of life and capabilities, a recognition of different structures of reasoning, and an understanding of their effects on communication and counseling style. Lack of such understanding may hinder effective intervention.

Part of this self-awareness is acknowledgement that the counselor culture has at its core a set of white cultural values and norms by which clients are judged (Katz, 1985; Lauver, 1986). Assumptions about a cultural group, personal stereotypes and traditional counseling approaches may all signal acquiescence to white culture. Identification and awareness of the specific influences of white cultural values and bias on counseling will help counter the effects of this framework (Katz, 1985).

"The Invisible Whiteness of Being" (Gibson, 2006), proposes that white Americans do not think about race or have a need to think about it because their race or skin color has never been a problem for them psychologically, and therefore, their skin color is invisible to them. It is something that no one makes them aware of in a negative way. Many unconsciously feel it is normal to be white and have no reason to be aware of it.

The clinician has his or her own culture and worldview and brings this personal culture into the therapeutic setting. The intercultural and worldviews of the clinician and client are different, and they may also have different assumptions of each other's roles, pathology of the illness and the appropriate treatment options.

Clinicians can also harbor certain stereotyped ideas and bias about the minority community, which can lead to misdiagnosis and poor counseling outcomes. Therefore, it is imperative that clinicians have multicultural competence.

Adherence to a specific counseling theory or method may also limit the success of counseling. Many cultural groups do not share the values implied by the methods and do not share counselors' expectation for the conduct or outcome of the counseling session. To counter these differences, counselors must investigate their clients' cultural background and be open to flexible definitions of "appropriate" or "correct" behavior (LaFromboise, 1985).

Culture has a very strong influence on the counseling process and influences the mental health professional as well as the client. Researching growing knowledge in this field has produced substantial results, such as the inclusion of the outline for cultural formation in the DSM-IV. This deals with five aspects of the cultural context of mental illness and their applications to diagnosis and interventions. The DSM-IV now includes culture-bound syndrome, which is a combination of psychiatric and somatic symptoms considered to be recognizable disease only within a specific culture (APA, 2010).

The following five contexts are considered in the diagnosis of a culture-bound syndrome in the DSM-IV:
- Categorization as a disease in the culture (not a voluntary behavior or false claim).
- Widespread familiarity in the culture.
- Complete lack of familiarly on the condition to other cultures.
- No objectively demonstrated biochemical or tissue abnormalities (symptoms).
- The condition is usually treated by folk medicine of the culture.

Therefore, it is imperative that the health care professionals have multicultural competences to provide mental health services to the highest standard.

Individual differences

There is always a danger of stereotyping and confusing other influences such as race and socio-economic status with cultural influences. The most obvious danger in counseling is to oversimplify clients' social systems by emphasizing the most obvious aspects of their backgrounds (Pederson, 1986). While universal categories are necessary to understand human experience, losing sight of specific individual factors would lead to ethical violations (Ibrahim, 1985).

Race, ethnicity, national origin, life stage, educational level, social class and sex roles influence individual clients. Counselors must view the identity and development of culturally diverse clients in terms of multiple, interactive factors instead of a strictly cultural framework (Romero, 1985). A pluralistic counselor considers all facets of clients' personal history, family history, and social and cultural orientation (Arcinega and Newlou, 1981).

Although it is impossible to change backgrounds, counselors can avoid the problems of stereotyping and false expectations by examining their own values and norms, researching client backgrounds and finding methods to suit clients' needs.

Clinical sensitivity toward client expectations, attributions, values, roles, beliefs and themes of coping and vulnerability is always necessary for effective outcomes. Three questions that counselors might use in assessing their approach are (Jereb, 1982):
1. Within what framework or context can I understand this client, and what assessment can I use?
2. Within what context do the client and counselor determine what changes in functioning and what goals are desirable?
3. What techniques can be used to affect the desired change, and what interventions would be effective?

Examining the counselor's assumptions, acceptance of the multiplicity of variables that constitute an individual's identity, and development of a client-centered, balanced counseling methods will help the multicultural counselor providing effective help.

Defining linguistic competence

The verbal and nonverbal communication of the health professional influences the counseling session and its success. According to Romero (1985), language barriers impede the counseling process when clients cannot express the complexity of their thoughts and feelings or may resist discussing affectively charged issues.

Counselors, too, may become frustrated by their lack of bilingual ability. At worst, language barriers may lead to misdiagnosis and inappropriate treatment (Romero, 1985). Communication in a manner that is sensitive to the client's culture will be very beneficial.

Linguistic competence is the capacity of a mental health professional to communicate effectively and convey information in a manner that is easily understood by diverse audiences, including persons of limited English proficiency, those who are not literate or have low literacy skills, and individuals with disabilities.

In positive communication climates, trust is established and reaffirmed, allowing freedom to explore sensitive issues and express disagreements. (Shirley Pinder Cook)

Positive talk climates are:
- Descriptive rather than evaluative.
- Oriented towards problems rather than control.
- Spontaneous rather than manipulative.
- Empathic rather than neutral.
- Express equality rather than superiority.
- Provisional rather than certain or dogmatic.

Janet, continued …

> *Janet evaluated Tilda's comments without delving into them more deeply. Instead, she implied they were not "correct" by her remarks, such as, "Annette is simply acting out her personal traumatic experience. See if you can understand."*
>
> *While Janet was probably right about what caused Annette's fighting, failing to acknowledge the inappropriateness of Annette's behavior fueled Annette's mother and grandmother's contention that spanking was the direction to go.*

Janet's well-intentioned remarks fell on deaf ears. She struggled to control the session and drive home her message while superficially addressing Tilda's recent past and assuming that Tilda would agree that corporal punishment was wrong. Had she probed more deeply about Tilda's terrifying abuse and marital separation first, it may have been less challenging to advocate for Annette. And had Janet acknowledged Tilda's normal grief responses to her own marriage and move, Tilda might have heard Janet's powerful message that both the mother and her daughter had courageously shared and survived a terrifying experience.

Effective cross-cultural communication includes respect, understanding of the other's point of view, openness, flexibility, tolerance of ambiguity, curiosity and appropriate humor. Other examples of linguistic competence are demonstrated through:

- Identifying foreign language interpretation and sign language interpretation services.
- Providing print materials that are in easy-to-read and low literacy formats, such as symbols and pictures.
- Identifying cultural brokers (bridge builders or mediators of different cultural backgrounds who work to reduce conflict or produce change).
- Providing service materials in alternative formats such as audiotape, Braille or enlarged print.
- Understanding varied approaches to share information with clients who experience cognitive disabilities.
- Identifying other mental health professionals proficient in working with specific client needs.
- Providing translated documents, such as consent forms, confidentiality, patient rights statements, release of information, applications, health education materials and public awareness materials and campaigns.
- Asking clear questions, avoiding those that start with "Isn't it?" or "Aren't you?" Questions like that do not exist in many other languages and can be confusing to people whose English is a second language.
- Being patient. When someone is trying to put an idea into words, the counselor must listen patiently because it may take longer.

Different gestures

Very few gestures are universally understood and interpreted. What is acceptable in the U.S. maybe rude, offensive or obscene in other cultures. Here are a few gestures to be aware of:

- **Giving the thumbs-up.** In the U.S. and Europe the thumbs-up means something good. It's considered rude in many Asian and Islamic countries and a sign of displeasure in Spain.
- **Placing your hand up to indicate "stop."** In some Asian countries, this means you are requesting permission to speak or go ahead.
- **Placing your hands on your hips.** In the U.S. and Europe, placing a hand on the hip means being open and is a confident gesture. In many Asian countries, it is considered arrogant.
- **Forming a circle with your fingers.** In the U.S., this means okay. In Japan, it means money. In France, it means worthless or zero. In Brazil and Germany, it's considered obscene.

Respecting personal space
Generally, Germans, Chinese and Japanese appreciate more personal space than Americans, and Americans prefer more personal space than Latin Americans, Italians, French and middle Easterners. Americans, Canadians, and Europeans often like a field of about 18 inches. If you get too close, they will try to back away.

Shaking hands
Some cultures do not shake hands, and others may prefer a soft or firm handshake, The Japanese keep the arm fully extended; it often bows. Middle Easterners place their free hand on the forearm of the other person. Orthodox Jewish men will not shake the hand of a woman.

Smiling
Although smiling is universally understood as a pleasant gesture, in parts of Asia, people smile when they're confused, angry or embarrassed.

Showing the soles of your shoes
Americans often cross their legs and let the soles of their shoes show. In Thailand, Japan, France, the Middle East and the near East, this is a sign of disrespect because you're exposing the lowest and dirtiest part of your body.

A linguistic competence checklist for organizations

The following checklist was designed by the National Center on Cultural Competence (NCCC) to help primary health organizations develop policies, structures, practices and procedures that support linguistic competence. According to the NCCC, health care organizations have been slow to develop and implement policies and structures to guide the provision of interpretation and translation services, which remain at the practitioner and consumer level. The following checklist can help mental health organizations develop policies, structures, practices and procedures that support linguistic competence.

The organization should have:

- A mission statement that articulates principles, rationale and values for providing linguistically and culturally competent health care services.
- Policies and procedures that support staff recruitment, hiring and retention to achieve the goal of a diverse and linguistically competent staff.
- Position description and personnel performance measures that include skill sets related to linguistic competence.
- Policies and resources to support ongoing professional development and training of linguistic competence.
- Policies, procedures and fiscal planning to ensure translation and interpretation services.
- Policies and procedures on the translation of patient consent forms, educational materials and other information in formats that meet the literacy needs of patients.
- Policies and procedures to evaluate the quality and appropriateness of interpretation and translation services.
- Policies and procedures to periodically evaluate consumer and personnel satisfaction with interpretation and translation services provided.
- Policies and resources that support community outreach initiatives to persons with limited English.
- Periodic reviews of the current and emergent policies, procedures and demographic trends for the geographic area served to determine interpretation and translation requirements. (NCCC).

Mental health practitioner responsibility

When mental health professionals successfully incorporate the five culturally competent areas into their work, they can better identify and address client issues and provide best-practice treatment.

Cultural competence requires that they be proficient in:

- Defining a set of values and principles and demonstrate behaviors, attitudes and policies that enable them to work effectively cross-culturally. In other words, when they approach their work with the intention of being culturally sensitive and self-aware, mental health practitioners become better listeners and observers.
- Demonstrating a capacity to value diversity, conduct self-assessments, manage the dynamics of difference, acquire cultural knowledge and adapt diversity to the cultural contexts of clients they serve. Many mental health supervisors drive home the message that actions speak louder than words, but both action and verbal communication are needed to manage the dynamics of difference.
- Designing and implementing services that are tailored or matched to the unique needs of their clients. Providing mental health services tailored to the needs of clients sometimes means that mental health practitioners may have to make a referral to someone else with the capacity to communicate more effectively because they simply speak the client's language or use sign language. In addition, mental health practitioners must remain mindful of any professional gaps when working with age-specific populations, such as youth or elders.
- Incorporating all of the above in service delivery and seeking out consultation at appropriate times. A variety of networking opportunities provide mental health practitioners with referral sources in addition to ongoing supervision or coaching and mentoring with a person from a different cultural or ethnic background.

Richardson and Molinaro (1996) have suggested that self-awareness is a prerequisite for multicultural competence. Self-awareness often develops from personal and professional socializations to divergent cultural experiences. (Helms & Cook, 1999) When this self-awareness is integrated into clinical roles, mental health professionals are likely to develop complex perspectives on cultural influences in their role. (Inman, 2006)

In addition to self-awareness, mental health professionals also need to recognize unique client variables, such as cultural membership and socialization, that affect client problems. If mental health practitioners do not have self-confidence in their abilities to integrate this information and perform a set of multicultural skills and behaviors, they are likely to experience decreased competence. (Constantine & Ladany, 2001)

Janet, continued …

> *Janet is an excellent clinical social worker and passionate about domestic violence and traumatic exposure, particularly for children. Her career had been ignited by a personal childhood experience that involved her best friend. She was extremely committed to helping traumatized adults and children. Even though she shared the same ethnic and racial background as Tilda and Annette and understood intellectually, it was difficult for her to accept why a mother could suffer from domestic violence and still hit her own children.*
>
> *Janet's family had emigrated from the same country as Annette's, but Janet's family had moved to the U.S. years earlier. In contrast, Annette's mother and grandmother had arrived in the past few years and were still adapting to their new country. Janet had become acculturated, adopting and integrating Western social norms and rules into her worldview and daily life. She hadn't given much thought to the fact that Annette and her family were still quietly engaged in their familiar and different cultural practices.*

Janet was forced to examine her personal motivations and previous session interactions after Annette's mother began to cancel their sessions. As Janet revisited her past discussions with Annette's family, she recognized that she had not fully acknowledged Tilda's courage when she left her abusive marital relationship.

In addition, Janet also recognized that Annette's grandmother could potentially be a powerful ally and invited her to family sessions, asking for her help to better understand the grandmother's culture. Janet also made a point of learning more about her own family's country of origin, revisiting its cultural norms, especially as they revolved around women's issues. Janet also translated trauma information into Tilda's primary language so that Tilda and her mother were able to read the information on their own. She spent time in session facilitating a discussion between grandmother and mother about the role of women in their culture and how adjusting to another could be daunting. They even exchanged recipes.

Janet became more reflective with her clients and explained the Western perspective on corporal punishment more compassionately as a teacher and coach. And as trust grew between the women, she was able to help Tilda to redirect Annette's behavior as they both worked on reprocessing and integrating both their traumatic experiences.

Common areas of cultural and social class differences

Dominant and non-dominant cultures, while often similar, can also be in conflict. Dominant culture often creates the overall set of rules, rituals and laws that override other cultural norms and routines within a larger society. It is important to distinguish the differences created by intervening factors that influence culture.

Miscommunication can occur when mental health practitioners, oriented to dominant culture norms, conduct mental health assessments and provide treatment for people oriented to a non-dominant culture. Miscommunication can occur with these issues:

- Concept of time.
- Relationship of individual to others.
- Role of their community.
- Religious or spiritual beliefs.
- Sex roles.
- Work ethic.
- Respect and deference.
- Worldview.
- View of helping relationships.
- Parenting practices, such as responsibility delegated to children, the degree of adult dominance and methods of discipline.
- Privacy and personal space.
- Communication such as direct or indirect style of language and conversational conventions.

Even while the dominant culture may share common physical traits, language or religious backgrounds there are still distinct factors that influence culture even within this larger population that also determine how people think and behave. Some of these factors include educational and income levels, geographic residence, identification with community groups such as political or religious membership, personal experiences, age, gender and length of residency in the U.S.

Mental health professionals need to ask themselves: As a culturally competent mental health practitioner, am I capable of interacting positively with people who do NOT:

- Look like me.
- Talk like me.
- Think like me.
- Believe like me.
- Act like me.
- Live like me.

Common cultural competence missteps

In general, the more common mental health cultural competence mistakes include:

- Unintentional racism.
- Miscommunication.
- Lack of personal awareness.
- Insensitivity to nonverbal cues.
- Lapse in discussion of racial/ethnic issues.
- Gender bias.
- Overemphasis on cultural explanations for psychological difficulties.
- Lapses including appropriate questions within the context of acquiring background information.
- Inability to appropriately present questions that elicit valuable information or feedback.
- Nonparticipation in multicultural activities that facilitate cultural awareness, including interactions with people of similar and different racial identities.
- Little or no processing of cultural difference in supervision.
- Inability to identify multiple hypotheses and integrate this information in a culturally competent manner into a client's presenting problem.

While cultural competence often references ethnic or racial cultural missteps, it is also important to note that cultural competence should address other diverse populations, such as youth and the system of care for children's mental health. The National Institute of Mental Health emphasizes the importance of addressing cultural issues in serving children with emotional disturbances and their families.

In addition, certain cultural issues exist for subgroups of young people, such as bi- or transgender youth.

Cultural competence proficiency continuum

Understanding and practicing cultural competence is learned. The cultural competence proficiency continuum ranges from destructive to proficient and includes more subtle areas of demonstrating cultural proficiency in between. It generally goes like this:

1. Cultural destructiveness.
2. Cultural incapacity.
3. Cultural blindness.
4. Cultural pre-competence.
5. Cultural competence.
6. Cultural proficiency.

Continuum feelings and behaviors include fear, denial, minimization, relativism, empathy and integration. The most destructive end of the cultural proficiency continuum encompasses fear. Fear occurs where a person views others with trepidation, avoids contact, and eventually simply denies the existence of others. Superiority occurs when someone sees another person as inferior. Minimization happens when a person is acknowledged, but her or his importance is minimized.

As the proficiency continuum progresses toward cultural competence and proficiency, relativism occurs when a person recognizes and appreciates and values differences, and exhibits empathy with a full understanding of how others perceive the world and how they are treated. Cultural competence proficiency is demonstrated when there is integration of assessment, and appropriate actions are taken in situations involving members of other cultures.

Cultural awareness and cultural sensitivity

When mental health professionals demonstrate cultural proficiency, they've incorporated cultural and linguistic knowledge, awareness and sensitivity into their work. Cultural knowledge, cultural awareness and cultural sensitivity all convey the idea of improving cross-cultural capacity, but they are defined differently.

- **Cultural sensitivity** is defined as knowing that cultural differences as well as similarities exist, without assigning values such as better or worse, right or wrong to those cultural differences. (National Maternal and Child Health Center on Cultural competency, 1997)
- **Cultural knowledge** is familiarization with selected cultural characteristics, history, values, belief systems and behaviors of the members of another ethnic group (Adams, 1995).
- **Cultural awareness** is developing sensitivity and understanding of another ethnic group. This usually involves internal changes in terms of attitudes and values. Awareness and sensitivity also refer to the qualities of openness and flexibility that people develop in relation to others. Cultural awareness must be supplemented with cultural knowledge (Adams, 1995).

STRATEGIES TO PROMOTE DIVERSITY AND CULTURAL COMPETENCE

Cultural competence self-assessment

Cultural competence begins with an awareness of one's personal cultural beliefs and practices, and recognition that people from other cultures may not share them. Cultural competence travels well beyond speaking another language or recognizing cultural icons. It encompasses transforming prejudgments or biases about beliefs and customs.

Cultural competence is rooted in respect and validation towards someone different. Mental health practitioners can benefit from a personal check-in while acquiring client background information. The following questions may appear deceptively simple, but can be surprisingly helpful:

Ask yourself:

- Am I open to working with other ethnic and cultural groups?
- Do I have personal biases, and can I challenge myself to understand and overcome them?
- Am I willing to take the time to learn about my clients' culture?
- Do I have a strategy to monitor my reactions and feelings to avoid imposing my values on others?
- Am I able to give up control to empower my client?

Self-assessment sample

Different types of cultural competency self-assessments have been developed that address specific areas of cultural competence. The following example is an assessment developed by the Georgetown University Center for Child and Human Development, titled Self-Assessment Checklist for personnel providing services and supports to children with disabilities and special health needs and their families. The assessment was broken down into three areas that include physical environment, communication styles and values and attitudes. There is no answer key with correct responses. However, mental health practitioners who often respond with "C" may want to learn more about how to engage in more culturally sensitive service delivery.

Self-assessment checklist for personnel providing services and supports to children with disabilities and special health needs and their families

(Adapted from "Promoting Cultural Competence and Diversity in Early Intervention and Early Childhood Settings – Georgetown University Center for Child and Human Development University Center for Excellence in Developmental Disabilities Education, Research and Service.)

Directions: Please select A, B, or C for each item listed below.

A = Things I do frequently. **B** = Things I do occasionally. **C** = Things I do rarely or never.

Physical environment, materials and resources

___ 1. I display pictures, posters and other materials that reflect the cultures and ethnic backgrounds of children and families within my practice.
___ 2. I ensure that magazines, brochures and other printed materials in reception areas are of interest to and reflect the different cultures of children and families served.
___ 3. I ensure that toys and other play accessories in reception areas and those, used during assessment are representative of the various cultural and ethnic groups within my practice.
___ 4. When using videos, films or other media resources for health education, treatment or other interventions, I ensure that they reflect the cultures of children and families served by my program or agency.
___ 5. When using food during an assessment, I ensure that meals provided include foods that are unique to the cultural and ethnic backgrounds of children and families served by me.

Communication styles

___ 6. For children who speak languages or dialects other than English, I attempt to learn and use key words in their language so that I am better able to communicate with them during assessment, treatment or other interventions.
___ 7. I attempt to determine any familial colloquialisms used by children and families that may impact assessment, treatment or other interventions.
___ 8. I use visual aids, gestures and physical prompts with clients who have limited English proficiency.
___ 9. I utilize bilingual staff or trained/certified interpreters for assessment, treatment sessions, meetings and for other events for families who would require this level of assistance.
___ 10. I use bilingual staff or trained/certified interpreters for assessment, treatment and other interventions with children who have limited English proficiency.
___ 11. When interacting with parents who have limitations in English proficiency I always keep in mind that:
    ___ *Limitations in English proficiency is in no way a reflection of their level of intellectual function.
    ___ *Their limited ability to speak the language of the dominant culture has no bearing on their ability to communicate effectively in their language of origin.
    ___ *They may or may not be literate in their language of origin or English.
___ 12. When possible, I ensure that all notices and communiqués to parents are written in their language of origin.
___ 13. I understand that it may be necessary to use alternatives to written communications for some families, as word of mouth may be a preferred method of receiving information.
___ 14. I understand the principles and practices of linguistic competency and:
    ___ *Apply them within my program or agency.
    ___ *Advocate for them within my practice, program or agency.
___ 15. I understand the implications of health literacy within the context of my roles and responsibilities.
___ 16. I use alternative formats and varied approaches to communicate and share information with children and/or their family members who experience disability.

Values and attitudes

___ 17. I avoid imposing values that may conflict or be inconsistent with clients.
___ 18. In group therapy or treatment situations, I discourage racial and ethnic slurs by helping them understand that certain words can hurt others.
___ 19. I screen books, movies, and other media resources for negative cultural, ethnic or racial stereotypes before sharing them with children and their parents served by my agency or myself.
___ 20. I intervene in an appropriate manner when I observe other staff or parents within my program or agency engaging in behaviors that show cultural insensitivity, bias or prejudice.
___ 21. I understand and accept that "family" is defined differently by different cultures.
___ 22. I accept and respect that male-female roles in families may vary significantly among different cultures (i.e. who makes major decisions for the family, play and social interactions expected of the eldest male in families).
___ 23. I recognize and accept that individuals from culturally diverse backgrounds may desire varying degrees of acculturation into the dominant culture.
___ 24. I understand that age and life cycle factors must be considered in interactions with individuals and families (i.e. high value placed on the decisions of elders or the role of the eldest male in families).
___ 25. Even though my professional or moral viewpoints may differ, I accept that family/parents are the ultimate decision makers for services and supports for their children.
___ 26. I recognize that the meaning or value of medical treatment, health care and health education may vary greatly among cultures.
___ 27. I recognize and understand that beliefs and concepts of emotional well-being vary from culture to culture.
___ 28. I understand that beliefs about mental illness and emotional disability are culturally based. I accept that responses to these conditions and related treatment/interventions are heavily influenced by culture.
___ 29. I accept that religion and other beliefs may influence how families respond to illnesses, disease, disability and death.
___ 30. I recognize and accept that folk and religious beliefs may influence a family's reaction and approach to a child born with a disability or later diagnosed with physical/emotional disability or special health care needs.
___ 31. I understand that traditional approaches to disciplining children are influenced by culture.
___ 32. I understand that families from different cultures will have different expectations of their children for acquiring toileting, dressing, feeding, and other self-help skills.
___ 33. I accept and respect that customs and beliefs about food, its value, preparation and use are different from culture to culture.
___ 34. Before visiting or providing in-home services I seek information on acceptable behaviors, courtesies, customs and expectations that are unique to families of specific cultures and ethnic groups served by my agency or me.
___ 35. I seek information from family members or other key community informants that assist in service adaptation to respond to the needs and preferences of culturally and ethnically diverse children and families served by my program or agency.
___ 36. I advocate for the review of my program or agency's mission statement, goals, policies and procedures to ensure that they incorporate principles and practices that promote cultural diversity and cultural competence.

Improving communication with clients

It is helpful to keep this communication checklist in mind when building cultural competency:

- Build collaboration through reflective listening, inquiry and coaching.
- Invite your client to tell you what feels comfortable or uncomfortable, safe or unsafe, within your practice environment.
- Make no assumptions. Remember the old saying, "You can't tell a book by its cover?" Try this exercise: When you're introduced to someone new, before beginning a conversation imagine how the person speaks, based on his or her appearance. For example, one mental health practitioner remarked that because she and someone she'd just met shared the same ethnic background, she imagined they would speak with the same accent. She was surprised when her new friend spoke quite differently.
- Cultural differences are valid. Communication, beliefs and daily practices become imprinted in children and have been developed from input from caregivers living out their cultural experiences.
- Assess for style or substance communication patterns and then match behavior and communication with those patterns.
- Self-observe and self-assess before reacting to someone who might prompt an "affectively charged" response.
- Learning cultural competence is challenging, and people make unintentional mistakes. So remember the phrase, "All the saints I know are dead." Keep trying.
- Expand your cultural horizons by eating at a different restaurant, taking a foreign language class, asking for some coaching from a friend who shares a different life experience, or spending time volunteering with a more diverse population.
- Understand the differences between individuals and their personalities, and their broader cultural traditions. For example, people will very often adjust their language and conversation based on with whom they are speaking.
- Appreciate diversity and multiculturalism by buying something beautiful from another country.

The following questions can facilitate greater recognition and understanding about your clients when they or their parents have emigrated from another country. Mental health practitioners should present these questions in a timely manner and a culturally sensitive way:

- **What was your migration history?** Migrating to a country can place people in different locations for periods of time before they eventually settle in an area. For example, many immigrants have spent time in other countries before eventually migrating to the United States. What did your client's family experience? How long has your client lived in this country?
- **What is your kinship network?** Are your clients and your client's family members able to contact extended kin and other family members? Do they seek to be reunited with distant or lost kin? How do they define kinship? Does their kinship network include friends?
- **Have you lived through traumatic experiences?** Has your client or your client's family suffered violence, hardship, exploitation or humiliation before or as a result of relocation? Mental health practitioners must be extremely culturally sensitive when introducing this topic.
- **Have you had to make any unusual living adjustments?** How did your client or your client's family adjust to language, status, values, foods, employment opportunities, racism or child care?
- **How is your health?** What does your client or client's family believe about illness and health care?
- **How do you cope with stress?** How has your client or your client's family coped with hardships and challenges? What traditions and beliefs offer them comfort, strength and meaning?
- **Have you experienced racism?** What types of institutional or informal prejudice has your client or your client's family experienced and how have they dealt with it?
- **What are your supports?** How do your clients view support? What types of support or help are available to your client or client's family? Are they community- or family centered?

Current Issues in multicultural counseling

Bullying, a unique problem in the field of multicultural counseling, affects school-age children and adolescents within marginalized groups, such as students of diverse cultures or students new to the United States. Because their cultures and backgrounds fail to mirror mainstream American society, these diverse, marginalized students are innocent targets for bullies. Not only do the bullies victimize them, but adults who often ignore bullying also leave them to their own resources.

By illuminating factors that stress marginalized groups of students, research exposes the danger of such adult attitudes. The factors that are stressors include students' socioeconomic status, identity development, language, physical characteristics, skin color and type of hair (Merrill-James, 2006).

They also include school and community factors, such as pervasive attitudes of denial, justification, avoidance, racism and other forms of prejudice. Together these factors affect students' peer group affiliations through name-calling and ostracism, and their self-esteem through verbal bullying, all of which perpetuate negative stereotypes, lower academic performance and school attendance, and contribute to a climate of violence (Merrill-James, 2006).

Best practices for addressing and putting an end to bullying include professional development and training for students and staff, group and individual counseling, and zero tolerance policies for verbal and other forms of bullying in schools. Additional research is needed about stressors that ensue from lower and middle class comparisons and intraracial bullying.

Future projections indicate that by the year 2020, a majority of school-age children attending public schools will be children of color or from diverse cultural, ethnic and linguistic backgrounds (Holcomb-McCoy and Moore-Thomas 2004). The current racial/ethnic distribution among students in public schools in the United States is about 1.2 percent native American, 4 percent Asian Pacific American, 15.6 percent Hispanic/Latino, 17.2 percent African-American, and 62.1 percent European/white American (National Center for Educational Statistics 2001).

Along with diversity are the increasing reports of bullying incidence among school-aged children and adolescents linked to cultural, ethnic, gender or linguistic differences. There are various definitions of bullying in the literature; however, a commonly cited definition is the repeated, aggressive, physical, psychological or sexual behavior a person directs toward another individual (Batsche and Knoff 1994; Olweus, 1993).

Some statistics on bullying indicate that 60 percent of students report bullying on the basis of appearance or body size, 57 percent on the basis of gender expression, 53 percent on ability, 52 percent on real or perceived sexual orientation, 40 percent on race/ethnicity, and 33 percent on religion or family income (Gordon 2001; Scott, 2002).

Reports indicated that 45 percent of all students said they feel unsafe at school because of some real or perceived personal characteristic, 9 percent of all students have skipped a class in the past month because they felt unsafe in school, 7 percent skipped an entire day of school, 29 percent of gay students skipped a day of school in the past month because of feeling unsafe (four times greater than in the general population) and 60 percent of all students who have been harassed or assaulted did not report the incident to faculty or staff (Gordon, 2001; Scott, 2002).

Addressing diversity as a bullying issue is one of the challenges facing school and mental health counselors. The counseling process must validate and affirm children from marginalized groups and recognize the contextual dimension of race, culture, class, gender, religion, sexual orientation and geography. A marginalized group includes children and adolescents whose cultures and backgrounds do not necessarily mirror the cultural dictates of mainstream American society (Holcomb-McCoy and Moore-Thomas, 2004). Culturally responsive counseling practices require an ethic of caring and understanding in an effort to build bridges between different ethnic groups.

Although all forms of bullying are of significance when addressing the concerns of students, school-aged children, adolescents and adults, counselors must develop techniques to address bullying within marginalized groups, including intraracial bullying (Merrell-James, 2006). Intraracial bullying is a unique problem in the field of multicultural counseling because this form of bullying occurs between people of the same ethnic or racial group. Making it unique are the racial, social, political and educational factors that this form of bullying embodies. The bully selects certain characteristics or attributes common to the ethnic group that becomes the target for abuse. These characteristics include hair type, skin color, intellectual ability, economic background, material items and physical characteristics.

Suggested best practices to address bullying

The following list contains suggested strategies that multicultural counselors can use to address bullying in the school and community:

- Be aware of the various forms of bullying.
- Develop a zero-tolerance policy for bullying.
- Be prepared to host professional development workshops for parents, students, staff and the community on the issue of bullying. The workshops will focus on defining the problem and working on suggestions for addressing the behavior in the school and the community.
- Include bullying intervention strategies in all work plans against bullying and violence in schools and community organizations.
- Multicultural counselors should encourage students to research their ethnic heritage by reading selected literature, attending cultural events, and interacting with experts on the history and culture of their heritage.
- Form multicultural groups for students to address ethnic identity, exploration, and to develop awareness and understanding of ethnic groups other than their own.
- Help students manage the impact of others negative perceptions. Coping with others' faulty perceptions based on stereotypes is an ongoing and difficult path that will likely impact the adolescents' lives (Holcombe–McCoy and Moore–Thomas, 2001).
- Use case scenarios depicting problems, including racism, gender and classism, as catalysts for discussion. During these discussions, it is important for counselors to take a non-expert role so adolescents feel comfortable expressing their feelings. Counselors may ask questions that provide youths with an opportunity not only to articulate their feelings about racism but also to brainstorm new ways of challenging and managing racist encounters.
- School counselors and educators must encourage the development of self-acceptance by reminding youth of their inner as well as outer beauty and the significant aspects of their heritage.
- Consult with diversity agencies and organizations in the community to help answer questions on racial identity and development.
- Develop a list of professionals from diverse cultures to contact for assistance as you address diversity in your counseling.

Golden (2004) suggests multicultural counselors and educators also keep this in mind:

> *Parents sometimes fail to warn students about bullying because of their ethnicity or help them develops coping strategies. In addition, it is rare that parents will warn their children about hateful name-calling from within their own ethnic group. Parents should teach their children not to tease or judge their peers on the basis of outward appearance, which has nothing to do with beauty or identity.*

Multicultural competent supervision

Supervision is a primary method of clinical training, and clinicians rely on their supervisors to guide them as they seek to become culturally competent in providing treatment. A study conducted at Lehigh University investigated the direct and indirect impact of marriage and family therapy trainees' perceptions of their supervisors' multicultural competence on the supervisory working alliance and two outcome variables, trainees' multicultural competence and perceived supervision satisfaction. Trainees who are able to differentiate cultural information, identify multiple hypotheses and integrate this information about clients are considered more proficient at their work (Blocher, 1983).

Research evidence supports the positive relationship between supervisor multicultural competence and the supervisory relationship. Factors such as the supervisors' openness and attention to cultural factors and guidance on culture-specific issues have been deemed important to a culturally responsive supervisory relationship.

In the Lehigh study, a supervisory working alliance served as a significant positive mediator in the relationship between supervisor multicultural competence and supervision satisfaction. In addition, a supervisory relationship that involves an implementation of cultural competence through a mutual agreement on goals and tasks with a focus on multicultural issues may provide for greater supervision satisfaction.

Although trainee satisfaction is crucial to achieving their goals (Heppner & Hadley) little attention has been given in the past to the issues of supervisor multicultural competence in building a working alliance. Another study (Constantine) on multicultural differences in supervisory relationships at 22 internship programs revealed that many participants reported that supervision would have been greatly enhanced if they had spent more time processing issues surrounding cultural differences in supervision.

Supervisors should have the capacity to model behavior that is culturally responsive; facilitate cross-cultural communications; and identify and bridge cultural gaps in both staff development and client service delivery. In their supervisory role, they have opportunities to develop and present culturally enriching activities that stimulate cultural awareness. Assertiveness and direction guide appropriate behavior among staff.

Cultural responsiveness in mental health systems of care

A paradigm shift from ethnocentrism to multiculturalism in mental health systems is accomplished when cultural competence is seen as one of the primary goals of the entire system. In addition, on-going evaluation of internal bias in policies, practices and personal philosophies is necessary to implement and sustain effective treatment protocols.

Three main components of program design for a mental health system that can facilitate the development of culturally responsive services are:

1. Organizational structures, policies and procedures.
2. Training curricula.
3. Supervisory and staff roles and responsibilities.

Cultural responsiveness can be enhanced when:

- Non-dominant-culture staffers are used as consultants and coaches.
- Clear expectations and guidelines for staff exist regarding cultural responsiveness as a job requirement.

- Forms and processes pertaining to cultural bias, stereotypes and stigmatizing are regularly reviewed, monitored and revised.
- Cultural responsiveness training is required for all employees.
- Job expectations and supervisory responsibilities are established on service delivery and workplace interactions.

Overall, training on cultural competence should be presented as an enriching activity. Training in cultural responsiveness (competence) should include first, listing cultural responsiveness as an expectation and providing more details and practice opportunities for cross-cultural communication and ethnographic interviewing techniques. In addition, training should also include stressing cultural self-assessment for trainees as a cultural responsiveness tool.

Training must focus on building skills that aid in differentiating the limitations in mental health functioning due to culture and cultural adaptation to life experience. Regular discussion and information-sharing on additional impacts of regional culture, the culture of economics in addition to other drug, gender or sexual cultures on assessment factors, case planning and case management issues should occur.

Community-based resources as reliable contacts for culture-specific information and services should be included within the training as well as case examples through a variety of teaching methodologies. Within the context of training on cultural competence, trainers should remain sensitive to and gently confront culturally insensitive statements (National Respite Network).

Conclusion

Cultural competence in mental health practice incorporates culture, competence and diversity as well as language. Five elements of cultural competence include valuing diversity, conducting cultural self-assessments, managing the dynamics of difference, acquiring and integrating cultural knowledge, and adapting to diversity and cultural contexts that include policy, structure, values and services.

Linguistic competence is the ability to communicate effectively, in a manner easily understood by diverse clients, including clients of limited English proficiency, those who are not literate or have low literacy skills, and individuals with disabilities.

There are a variety of cultural competence strategies available to mental health practitioners that promote cultural competence in the workplace, and they all build on the five elements of cultural competence. Mental health practitioners have a responsibility to incorporate the five cultural competencies into their work, and according to social researchers, self-awareness is a prerequisite for multicultural competence.

When working with diverse populations, mental health practitioners should keep in mind dominant and non-dominant culture practices and expectations, and avoid unintentional error through various cultural competence missteps that include unintentional racism.

A supervisory relationship that involves an implementation of cultural competence through a mutual agreement on goals and tasks with a focus on multicultural issues may provide for greater supervision satisfaction. (Inman, 2006)

Paradigm shifts from ethnocentrism to multiculturalism can occur in larger mental health systems when cultural competence is seen as one of the primary goals of the entire system.

Training on cultural competence should also be presented as an enriching experience for staff in mental health organizations and include stressing cultural self-assessment as a cultural responsiveness tool.

The most important work for every counselor and mental health professionals is to become more culturally responsive and respectful. Cultural competence is first and foremost a commitment to take the next step, and the next, and the next toward offering accessible and appropriate services for the diverse clients and communities being served. Counselors need to learn to ask questions sensitively and to show respect for different cultures (Ahmed, 2011).

Looking forward

Multiculturalism has been referred to as the “fourth force” in counseling alongside the traditional psychodynamic, cognitive-behavioral, and humanistic approaches (Ivey, Ivey, &Simek–Morgan, 1997; Pederson, 1991). Given the data suggesting the continuing disparities in mental health services for diverse socio-cultural populations, organizational efforts to enhance multiculturalism in multicultural counseling competency need to be continued in the counseling field.

At the close of the 2010 Multicultural Social Justice Leadership Development Academy, a number of strategies were developed as listed below (Zalaquett, 2011):

The first strategy was to develop a support system for counselors and counselor educators who might feel they are “lone wolves” in their working environments. This support might help counselor educators feel empowered to stand strong and move forward in their work as advocates for social multicultural justice. This would help counseling professionals find and use their own voices, and help them balance the “I” with the “we.” Empowering activities should be implemented to help individuals feel connected.

The second strategy was to provide more “bottom-up” rather than “top-down” training. Training should be more participatory, integrating experiential components into workshops. Promoting group dialogue and reducing lecture-style presentations will help participants become more aware of the problems within society. Assistance should be provided to aid the development of groups that work as a collective unit to bring about social justice.

Additional strategies included promoting change that is based on kindness and consideration, being less politically correct, and offering more authenticity in communication. Individuals should listen before engaging, be more patient, and embrace differences. All states should participate in the development of multicultural social justice, and this should include the provision of workshops focused on meeting the social justice needs in schools and communities.

The development of programs to provide more time to participate should be encouraged. Training programs should be expanded to include a wide variety of presenters who are not primarily ethnic/racial minorities and should include more participants from the dominant racial/ethnic group.

Training activities could include self-discovery activities, reacting to cultural values that differ from their own, and role-playing. Workshops could also be developed for teachers, children and parents and could be provided in the schools when possible.

Mentoring for graduate students should also be provided, and as a long-term goal, multicultural social justice training should become a requirement for licensing or certification.

At the close of the session, participants in the conference felt that work was needed to encourage more therapists and counselors to become open-minded, and validated the need for social justice. Speaking out against injustice is about affirming and confirming action – not about being right or wrong (Zalaquett, 2011).

If we look to this future of counseling from a multicultural and social justice perspective, it is important that we open our eyes to the many different perspectives held by diverse people in our society. We must all be willing to see the world from the view of those who are different and have insight into how we view the world from our own phenomenological perspective. Using the multicultural counseling competencies (Sue et al., 1994), counselors can look at themselves and begin to see and conceptualize multicultural counseling competencies and learn about themselves and diverse clients their attitudes and beliefs, knowledge and skills. Applying this knowledge is essential if we are to develop counselors who are multicultural, competent and oriented towards social justice (Zalaquett, 2011).

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CULTURAL COMPETENCE IN MENTAL HEALTH PRACTICE

Final Examination Questions

Select the best answer for each question and then proceed to ***SocialWork.EliteCME.com*** to complete your final examination.

21. Knowledge of the culture of a client:
    a. Is sufficient for effective treatment.
    b. Can be achieved by specific academic courses.
    c. Must be transformed into concrete operations and strategies.
    d. All of the above.

22. Practitioners of a universal system of counseling need all of the following qualities EXCEPT:
    a. A respect for the client.
    b. Genuineness.
    c. Empathy.
    d. The ability to work without structure.

23. The validation process by a counselor means all of the following EXCEPT:
    a. Helping a client to see that his or her view is wrong.
    b. Confirming what the client is saying.
    c. Acknowledging that the client's experiences, opinions and thoughts are legitimate.
    d. Helping the counselor to gain confidence and growth through clients' communication of "a job well-done."

24. Bartering between a therapist and client:
    a. Can enhance the professional nature of the therapeutic bond.
    b. Is specifically permitted by the state of California.
    c. Is not ethically prohibited by the ACA Code of Ethics but is not recommended as a customary practice.
    d. Is covered by most professional liability insurance polices.

25. Being "affectively charged" leads therapists to:
    a. Stick to a message that at the moment cannot be heard.
    b. Commit to a message that is more strength-based.
    c. Be objective and focus on the goals of therapy.
    d. Increase their cultural awareness of diverse populations.

26. A counselor's own culture and worldview:
    a. Have little or no effect on their counseling.
    b. May limit the success of counseling if they lead to adherence to a specific counseling theory or method.
    c. At their basic level are seldom different from their clients'.
    d. If shared, can lead clients to accept the counselor's definitions of what are appropriate treatment options.

27. Miscommunication can occur because of cultural differences in:
    a. Concepts of time.
    b. Respect and deference.
    c. Parenting practices.
    d. All of the above.

28. All of the following are common cultural competence missteps EXCEPT:
    a. Unintentional racism.
    b. A too-familiar relationship between a counselor and client.
    c. An overemphasis on cultural explanations for psychological difficulties.
    d. An inability to appropriately present questions that elicit valuable information or feedback.

29. The main components of program design for a mental health system that can facilitate culturally responsive services include all of the following EXCEPT?
    a. Organizational structures, policies and procedures.
    b. Training curricula
    c. Suitable physical space that will reflect a multicultural focus.
    d. Supervisory and staff roles and responsibilities.

30. Assimilation is defined as:
    a. Adoption of another culture's values and way of life.
    b. The belief that everyone within a culture is exactly alike, shares the same values, beliefs and attitudes.
    c. A social group within a cultural social system that is based on variable traits, including religious, linguistic, ancestral or physical characteristics.
    d. The dynamics of difference in which one group regards another group as subhuman and seeks to destroy that group or their culture.

SWCA06CCE16

Chapter 4: Elderly Mental Health: Depression and Dementia

6 CE Hours

By: Leah Kulakowski, LMFT, Wade T. Lijewski, Ph.D. and Kathryn Brohl, MA, LMFT

Learning objectives

This workshop is designed to help you:

- Describe the most common types of mental health conditions and issues related to the diagnosis of mental illness in the elderly.
- Analyze the different forms and elements related to dementia / neurocognitive disorders.
- Assess the psychosocial factors that affect the elderly, such as living arrangements and cultural influences.
- Describe the influence of mental illness in the elderly on both the afflicted person and the caregiver, such as depression, and different prevention strategies.
- Facilitate different treatments of mental illness in the elderly and prevention, both through therapy and medications.
- Analyze issues regarding the different services available to assist the elderly mentally ill.

Elder mental health – Case examples

Lillian is an 84-year-old widow who lives with her married daughter. She is often unable to sleep and often stays awake at night with racing thoughts about her future, the health of her daughter, fears of moving to a nursing home and money. She frequently jokes about these racing thoughts with her friends, and knows they are not logical. However, she finds herself unable to control them. On occasion, she is frozen by panic during the day as well. Lillian is somewhat ashamed of these self-termed “silly thoughts,” and she often relies on prayer to stop them. However, they are becoming more and more difficult for her to control. During her last panic attack, she was sure she was having a heart attack and called 911. She is reluctant to leave the house for fear of having another panic attack in public and being embarrassed.

Margaret is a 69-year-old married woman who always amazed friends with her zeal for life. She traveled extensively and was active in a number of social groups and organizations. Nine months ago, Margaret fell and broke her pelvis. While recuperating in a nursing home, she and her husband made the decision to move in with their son and his wife following her release. But Margaret feels she cannot get back into her former pace even though she feels fine physically. For the last two months, she’s lost her appetite, sleeps excessively and has refused to meet friends for lunch or to attend her social groups. Although she is not sure why, she feels like “giving up” and dying. Her daughter-in-law is very concerned and wants Margaret to see a psychiatrist as she feels her mother-in-law is depressed. Embarrassed at the prospect of receiving psychiatric intervention, Margaret refuses and her husband agrees, both saying that psychiatrists are for crazy or weak people.

William is a 73-year-old married man who is often confused about his daily activities. He is having trouble remembering how to proceed with some tasks because he loses track of the sequencing of events. A retired carpenter, he now has problems remembering how to complete simple household repairs. In addition, he cannot always remember the names of people he frequently sees. His wife is very worried and urges him to see a doctor for a physical examination, but William is terrified he will be diagnosed with Alzheimer’s disease. His wife has also noticed that his decline began three months ago and has been very rapid. She also knows that William began taking sleeping pills around that time as well, but is doubtful that a sleep aid could lead to his current daytime problems.

The above cases examples illustrate mental health issues typical to the elderly. The most commonly diagnosed forms of mental illness in the elderly include depression, bipolar disorder, anxiety and non-Alzheimer’s dementia. In the previous examples it appears that:

- Lillian is suffering with anxiety.
- Margaret is probably struggling with depression.
- William may be either developing non-Alzheimer’s dementia, or suffering from severe side effects from taking medication.

While not uncommon, these examples are not normal, and need to be addressed and treated. Yet, many elderly people grew up during an era when mental health intervention was unacceptable. Consequently, persuading an elderly person to seek and accept psychotherapy and/or medication intervention is often very difficult.

The elder population is growing in large numbers in the United States, mainly due to aging Baby Boomers. Dr. Dipal Jeste, M.D., professor of psychiatry and neuroscience at the University of California, San Diego, notes that this population, born between 1946 and 1964, will turn 65 in 2011, resulting in 69 million persons over the age of 65. He also notes that there will be an estimated 15 million mentally ill senior citizens by 2030, compared to only 4 million in 1970 (Jeste, et al, 1999).

The numbers of persons 65 and older will be unprecedented in our cultural history in the United States. Part of the reason for the growing number of elderly persons with a mental illness is that so many more people are living much longer, due to innovations in prevention and health care. Consequently, for the first time in U.S. history, persons over 65 will soon outnumber those aged 30-44. Therefore, social services communities will be largely unprepared to handle large numbers of elderly persons with mental illness. The previous lack of large numbers of elderly persons with mental illness has also left researchers with few studies that are comprehensive enough to establish “best practices” for treating mental illness in this population (Jeste, Alexopolous, Bartels, et al., 1999).

Alzheimer’s disease has received a good bit of attention in past years, and most lay people would identify Alzheimer’s disease as a prominent issue confronting the elder population. However, while it is frequently diagnosed in the elderly, other mental illnesses such as depression and bipolar disorder receive little to no attention from the popular press and relatively little interest from researchers. Yet some mental health professionals, including researchers, have now recognized the increasing numbers of elderly persons with mental illness and are calling for more research, as well as establishment of best practices.

In the September 1999 issue of the Archives of General Psychiatry, researchers warned of an impending mental health crisis among the elderly because there are virtually no geriatric mental health specialists in this country who can handle the impending need for treating mentally ill elderly persons. The authors of this paper (Jeste, Alexopoulos, Bartels, et al.) noted that ageism also plays a role in under-diagnosing mental illness in the elderly due to the fact that many doctors dismiss depression and anxiety, simply because it is expected in this population. The author also alleges that the population in general and doctors in particular, have lowered expectations for the quality of life for the elderly and see little point in trying to improve their mental states. This negative attitude toward elder mental health was also found in a more recent study of physicians who were found to be knowledgeable about depression in the elderly, but saw it as an inevitable outcome of old age, and not necessarily a condition that should and could be successfully treated (Zylestra and Steitz, 2001). However, with recent changes in our society surrounding Medicaid coverage and Health Care Reform, the ability to adequately provide mental health services to the elderly remains to be seen.

How is "elderly" defined?

When we begin a discussion about the elderly, we need to determine what we mean when we say "elderly." In general, we consider those adults over the age of 65 to be elderly. However, this age cut-off does not begin to explain differences between cohorts of elderly persons. Some elderly persons are disabled by the age of 65 while many others are active and working at their professions into the 80s or 90s. The Administration on Aging, the federal agency designated to serve the elderly, writes on its website that the elderly are defined as those who are a member of the aging populations comprised of people who are at least 60. The Administration on Aging (2009) notes several key issues related to the demographics of the elderly:

- Elderly persons comprise about 12.9 percent of the U.S. population.
- Elderly persons over the age of 85 make up 10 percent of the elderly.
- Elderly women far outnumber elderly men (20 million versus 14 million).
- About one-third of the elderly live alone.
- Poverty rises with increased age. About 16 percent of adults over 75 live in poverty.

As people grow older they naturally accumulate more losses, not only coping with losses of loved ones, but also simultaneously coping with physical and often financial problems. In addition, the elderly are somewhat devalued in society in general (Butler, Lewis and Sutherland, 1991).

The American Geriatrics Society (AGS) has developed a summary regarding the elderly and mental health and has written a position statement regarding mental health and the elderly at *www.americangeriatrics.org.*

Background

Mental illness is an important contributing factor to the disease burdens of the elderly. While the elderly do not appear to suffer a disproportionate share of most classifiable mental illnesses (depression or schizophrenia, for example), they do have a much higher prevalence of dementing illnesses such as Alzheimer's disease and are subject to high rates of interpersonal losses. Despite substantial rates of morbidity, the proportion of elderly persons recognized as impaired and who actually receive adequate treatment is markedly lower than in younger groups. This under-provision of services persists despite the fact that treatment of mental illnesses such as depression or paranoia in the elderly has been shown to be as effective as treatment in younger groups. Under-treatment of mental illness in the elderly appears to be a significant factor in the high suicide rate among elderly men, as well as in the premature or inappropriate placement of elderly persons in nursing homes.

According to Institute for Health Metrics and Evaluation (2010), over 20 percent of adults aged 60 and over suffer from a mental or neurological disorder (excluding headache disorders) and 6.6 percent of all disability (disability adjusted life years-DALYs) among over 60s is attributed to neurological and mental disorders.

The most common neuropsychiatric disorders in this age group are dementia and depression. Anxiety disorders affect 3.8 percent of the elderly population, substance use problems affect almost 1 percent and around a quarter of deaths from self-harm are among those aged 60 or above. Additionally, substance abuse problems among the elderly are often overlooked or misdiagnosed.

Research on mental illness in the elderly has been ignored and neglected until very recently. Even with the attention that has been given to the existence of large numbers of patients with Alzheimer's disease, funding for research in comparison to the frequency and devastating nature of mental illness in the elderly remains inadequate.

Assessments of elder mental health

It is important to consider how mental health symptoms may present quite differently in elderly persons. Older adults tend to acquire psychosomatic complaints in the form of sleep disorders, poor appetite and multiple physical complaints. Their primary care physicians are often the professionals most likely to come in contact with elderly persons and need to be alert to potential depression (Chew-Graham, et al., 2008).

Historically in the United States, our society has treated the elderly population differently. For example, society has viewed and treated this group as less capable and has lowered its expectations for their quality of life (Clark, 1996). These cultural attitudes are undoubtedly an influence on the well-being of the elderly and could be a contributing factor in depression, but this has not yet been researched to any great degree.

In addition, it has been noted for decades that the elderly grapple with different issues due to their life-stage development. To paraphrase the Eriksonian psychosocial life stage theory, persons in the last stages of life are in the midst of a struggle to determine whether their life had meaning, if they contributed in some way to the world, and whether their life was truly worthwhile. Erikson noted that some elderly persons are in a great state of despair in which they are not certain life meant anything, are wracked with feelings of regret, unsure that they made a difference, and are frightened that they were failures, with little time left to make changes. These persons are in a state of anxiety as they struggle to accept that their death is imminent, clinging to and trying to make sense of their lives before dying (Erikson, 1966).

COMMONLY DIAGNOSED MENTAL HEALTH DISORDERS IN THE ELDERLY

Depression has been the most widely researched mental illness in the elderly, and consequently, there is much more information available regarding depression than for other elder mental health disorders such as anxiety, bipolar disorder and dementia. Researchers have also focused on substance abuse.

Depression

The American Psychiatric Association has identified depression as the most commonly diagnosed mental disorder in the elderly, affecting about 5 percent of those individuals ages 65 and over. However, experts suspect that this number is a low estimate. Persons with the highest suicide rate in the United States are over the age of 65, and presumably, many of these suicides can be attributed to undiagnosed depression and lack of appropriate treatment. Over half of those elderly persons who could be classified as depressed receive no treatment for the condition, and only about 10 percent receive appropriate treatment (Katon, et al., 1992).

Diagnosing elder depression can be more difficult due to the existence of their physical problems. Feeling tired, loss of appetite and other physical complaints are all hallmarks of depression. However, in older persons these symptoms can have a physiological basis and may not be signs of depression. Consequently, doctors might dismiss the signs of depression as merely physiological. Depressed elderly persons do tend to have more physical than mental health complaints, and this often makes it difficult to determine whether a physical ailment or depression is the cause of their problems (Landefield, et al, 2006).

Assessment of the elderly can utilize tools specifically designed to provide insight into the particular aspects of an elderly person's mental state. The Geriatric Depression Scale asks such questions as "are you happy most of the time," and "do you feel pretty worthless the way you are now?" and offers yes and no answer options. Answers are assigned a value of "1" or "0," and an overall score of greater than "5" indicates depression (Sheikh and Yesavage, 1986).

According to the American Psychiatric Association (2013), the DSM-V outlines a few changes to the "what" and "how" depression is diagnosed:

> Major Depressive Disorder (MDD) is a medical illness that affects how you feel, think and behave causing persistent feelings of sadness and loss of interest in previously enjoyed activities. Depression can lead to a variety of emotional and physical problems. It is a chronic illness that usually requires long-term treatment.
>
> Using DSM-IV, clinicians were advised to refrain from diagnosing major depression in individuals within the first two months following the death of a loved one in what has been referred to as the "bereavement exclusion." By advising clinicians not to diagnose depression in recently bereaved individuals, the DSM-IV bereavement exclusion suggested that grief somehow protected someone from major depression.
>
> As part of the ongoing study of major depression, the bereavement exclusion has been removed from DSM. This change from DSM-IV, would be replaced by notes in the criteria and text that caution clinicians to differentiate between normal grieving associated with a significant loss and a diagnosis of a mental disorder. Removing the bereavement exclusion helps prevent major depression from being overlooked and facilitates the possibility of appropriate treatment including therapy or other interventions.
>
> While the grieving process is natural and unique to each individual and shares some of the same features of depression like intense sadness and withdrawal from customary activities, grief and depression are also different in important aspects:

- ○ In grief, painful feelings come in waves, often intermixed with positive memories of the deceased; in depression, mood and ideation are almost constantly negative.
- ○ In grief, self-esteem is usually preserved; in MDD, corrosive feelings of worthlessness and self-loathing are common.
- ○ While many believe that some form of depression is a normal consequence of bereavement, MDD should not be diagnosed in the context of bereavement since diagnosis would incorrectly label a normal process as a disorder.

Research and clinical evidence have demonstrated that, for some people, the death of a loved one can precipitate major depression, as can other stressors, like losing a job or being a victim of a physical assault or a major disaster. However, unlike those stressors, bereavement is the only life event and stressor specifically excluded from a diagnosis of major depression in DSM-IV.

While bereavement may precipitate major depression in people who are especially vulnerable (i.e. they have already suffered a significant loss or have other mental disorders), when grief and depression co-exist, the grief is more severe and prolonged than grief without major depression. Despite some overlap between grief and MDD, they are different in important ways, and therefore they should be distinguished separately to enable people to benefit from the most appropriate treatment.

Changes to the Bereavement Exclusion
The diagnostic criteria proposed for the manual's next edition includes language in the criteria for Major Depressive Disorder (MDD) to help differentiate between normal bereavement associated with Major Depressive Disorder and the "Bereavement Exclusion" a significant loss and a diagnosis of a mental disorder, which characterizes bereavement as a severe psychological stressor that can incite a major depressive episode even shortly after the loss of a loved one.

In DSM-IV, there was an exclusion criterion for a major depressive episode that was applied to depressive symptoms lasting less than 2 months following the death of a loved one (i.e., the bereavement exclusion). This exclusion is omitted in DSM-V for several reasons. The first is to remove the implication that bereavement typically lasts only 2 months when both physicians and grief counselors recognize that the duration is more commonly 1–2 years.

Second, bereavement is recognized as a severe psychosocial stressor that can precipitate a major depressive episode in a vulnerable individual, generally beginning soon after the loss. When major depressive disorder occurs in the context of bereavement, it adds an additional risk for suffering, feelings of worthlessness, suicidal ideation, poorer somatic health, worse interpersonal and work functioning, and an increased risk for persistent complex bereavement disorder, which is now described with explicit criteria in Conditions for Further Study in DSM-V Section III.

Thirdly, bereavement-related major depression is most likely to occur in individuals with past personal and family histories of major depressive episodes. It is genetically influenced and is associated with similar personality characteristics, patterns of comorbidity, and risks of chronicity and/or recurrence as non–bereavement-related major depressive episodes.

Finally, the depressive symptoms associated with bereavement-related depression respond to the same psychosocial and medication treatments as non–bereavement-related depression.

Causal factors

The causes of depression vary. The National Institute on Aging (2014) notes that depression can be preceded by a single event such as the death of a spouse or a serious illness. Strokes, heart disease, Parkinson's disease or diabetes can also lead to depression because older people might be more physically worn down or worried that an illness will force them to undergo significant lifestyle changes.

There is no one cause of depression. For some people, a single event can bring on the illness. Depression often strikes people who felt fine but who suddenly find they are dealing with a death in the family. For some people, changes in the brain can affect mood and cause depression. Sometimes, those under a lot of stress, like caregivers, can feel depressed. Others become depressed for no clear reason.

People faced with life-changing health problems, such as cancer, diabetes, heart disease, stroke, or Parkinson's disease, may become depressed. They may worry about how the illness will change their lives. They might be tired and unable to cope with things that make them sad. Treatment can help people manage their symptoms and improve their quality of life.

Genetics can also play a role. Studies show that depression may run in families. Children of depressed parents may be at a higher risk for depression. Also, depression tends to be a disorder that occurs more than once. Many older people who have been depressed in the past will be at an increased risk for becoming depressed again.

What to look for:

- An "empty" feeling, ongoing sadness, and anxiety.
- Tiredness, lack of energy.
- Loss of interest or pleasure in everyday activities, including sex.
- Sleep problems, including trouble getting to sleep, very early morning waking, and sleeping too much.
- Eating more or less than usual.
- Crying too often or too much.
- Aches and pains that don't go away when treated.
- A hard time focusing, remembering, or making decisions.
- Feeling guilty, helpless, worthless, or hopeless.
- Being irritable.
- Thoughts of death or suicide.

Newton (1992) notes that bereavement is harder on elderly persons because friends that die are not replaced as readily as when a person is younger. The resulting deterioration of a social support system takes away protective factors that help people get through these types of situations. Consequently, older adults may have few people to lean on when a spouse dies, whereas a younger person may have multiple friends to rely on. It is not uncommon for older people to note that they may be the last of a generation, which can lead to a profound sense of loss, prompting feelings of loneliness and isolation that can be difficult for younger people to comprehend.

In addition, the National Strategy for Suicide Prevention also notes on its website, http://mentalhealth.samhsa.gov/SuicidePrevention, that older persons are more likely to be socially isolated through being widowed and thus more inclined to be depressed. A lack of social support among the elderly is also cited by the National Alliance for the Mentally Ill (NAMI) as a factor that often leads to depression in the elderly.

Statistically, the elderly are more likely to go through major life changes, such as moving from their homes, losing their spouses, or having major health crises. All of these events are associated with increased risk of depression. Emory University has developed a program focused on depression and the elderly. The Fuqua Center for Late-Life Depression offers clinical mental health services specializing in the elderly through outpatient counseling, group therapy and psychiatric services.

Elder depression statistics

According to the Geriatric Mental Health Foundation (2014), an estimated 6 percent of people ages 65 and older in a given year, or approximately 2 million individuals in this age group, have a diagnosable depressive illness. Depression affects approximately 25 percent of those with chronic illness and is particularly common in patients with ischemic heart disease, stroke, cancer, chronic lung disease, arthritis, Alzheimer's disease, and Parkinson's disease. Most disturbing among depression statistics is the fact that depression affects upwards of 50 percent of nursing home residents.

In 2002, the annual suicide rate for persons over the age of 65 was over 15 per 100,000 individuals; this number increases for those aged 75 to 84, with over 17 suicide deaths per every 100,000. The number rises even higher for those over age 85. Further, elder suicide may be under-reported by 40 percent or more. Not counted are "silent suicides," like deaths from overdoses, self-starvation or dehydration, and "accidents." The elderly have a high rate of completing suicide because they use firearms, hanging, and drowning. Double suicides involving spouses or partners occur most frequently among the aged. In 2010, the highest suicide rate (18.6) was among people 45 to 64 years old. The second highest rate (17.6) occurred in those 85 years or older.

Anxiety

Anxiety is a mental health condition characterized by muscle tension, irritability and insomnia.

Previously referred to as *social phobia* in the DSM-IV, it has been renamed *social anxiety disorder* in the fifth edition of the Diagnostic and Statistical Manual of Mental Disorders (DSM-V). This change reflects a new and broader understanding of the condition in a variety of social situations.

In the past, social phobia primarily was diagnosed if an individual felt extreme discomfort or fear when performing in front of others. Research has shown that this definition is too narrow. With DSM-V, social anxiety can be diagnosed because of an individual's response in a variety of social situations.

According to the American Psychiatry Association (2013), social anxiety disorder is about more than just shyness and can be considerably disabling. A diagnosis requires that a person's fear or anxiety be out of proportion—in frequency and/or duration—to the actual situation. The symptoms must be persistent, lasting six months or longer. In DSM-IV, the timeframe was required only for children; DSM-V expands this criterion to include adults as well. The minimum symptom period reduces the possibility that an individual is experiencing only transient or temporary fear.

To be diagnosed with social anxiety disorder, the person must suffer significant distress or impairment that interferes with his or her ordinary routine in social settings, at work or school, or during other everyday activities. Unlike in DSM-IV, which requires that the individual recognize that his or her response is excessive or unreasonable, the DSM-V criteria shift that judgment to the clinician.

The clinician also will work to determine whether the person's reaction might be explained by such reasons as a more general anxiety or an adverse response to certain medications. If the person suffers from another medical condition—for instance, stuttering or obesity—the fear or anxiety experienced must be unrelated to the other condition or out of proportion to what would normally be felt.

It is noted by Salzmann (2004) that while clinical rates of anxiety in the elderly are lower overall than rates of anxiety in younger persons, many older adults experience anxiety that does not actually meet clinical diagnostic criteria, but is still troublesome to their overall well-being. He also noted that mixed presentations of anxiety and depression are the most common co-occurring mood disorder diagnoses among the elderly. Other researchers note similar findings. It has been shown that only 2 percent of the elderly fit the criteria for a diagnosis of anxiety, but 40 percent of those diagnosed with depression also presented with anxiety (Cassel, 2004). In addition, many elderly persons with dementia also have concurrent anxiety (Merck Manual, 2005).

It is, however, quite difficult to diagnose anxiety in the elderly. Beck and Stanley (1997) note that the nature of anxiety may change over the lifespan and may be quantified differently for the elderly. Whereas, in younger persons anxiety is characterized as actually facilitating performance, this has not been the case in studies of older persons. This difference in the outcomes of anxiety indicates that anxiety may have different characteristics in the elderly. In the elderly, anxiety most often takes the form of worry. Furthermore, there tend to be five areas of worry in the elderly:

- Family.
- Health.
- Money.
- Work.
- Miscellaneous.

Worries about health tended to be the most common in the elderly.

Harem et al. (2002) noted that the number of elderly persons visiting their doctors seeking treatment for anxiety disorders increased dramatically from 1985 to 1998. Furthermore, they determined that while a number of elderly persons utilized psychiatrists, a large number of elderly persons went to their primary care physicians for treatment and the primary care physicians were far less likely than psychiatrists to offer medication and/or psychotherapy. Consequently, it appears that under-recognition and under-treatment are continuing problems with anxiety disorders in the elderly. Researchers argue that anxiety is highly prevalent yet gets little attention from researchers compared to depression (Lenze, et al., 2000). Beck and Stanley (1997) also noted that anxiety disorders tended to be much more common than affective disorders and major depression.

The Penn State Worry Questionnaire has been utilized in the assessment and diagnosis of worry in younger adults and was recently assessed as a screening instrument for elderly persons. The instrument did require some modifications to fit well with the diagnosis of anxiety in the elderly. The items that were removed were primarily reverse items (i.e., the question “I never worry about anything,” required a higher level of cognitive processing than the non-reversed item, “My worry overwhelms me,” which is a basic agree or disagree question). The cognitive abilities required to answer a reversed item may be harder for an elderly person with some cognitive impairments and lead to answers that did not reflect the true feelings of the elderly person being assessed (Hopko, et al., 2003).

In addition, the Beck Anxiety Inventory (BAI) has also been found to be effective in the assessment of generalized anxiety disorder in the elderly (Wetherell and Gatz, 2005).

It is important to note that anxiety symptoms in the elderly are often the result of medical conditions as well. For example, cardiac problems can lead to shortness of breath and heart palpitations. Hyperthyroidism can also cause agitation and anxiety (Merck Manual, 2005).

Of all of the anxiety disorders studied in the elderly, generalized anxiety disorder has been the most widely researched. There has been very little systematic investigation of other forms of anxiety disorders, such as post-traumatic stress disorder (PTSD), or phobic disorders. In reviewing past studies of PTSD, researchers noted that the symptoms are similar in the elderly and younger persons that include:

- Reliving of the trauma.
- Avoidance of situations that remind a person of the trauma.
- Hyper-vigilance.

PTSD in the elderly can run a chronic course over a lifetime, with intermittent reappearances, or can start in later years as the result of such events as natural disasters, or being victimized by crime. There has been very little study of PTSD in the elderly, regardless of the course or cause of the disorder (Weintraub and Ruskin, 1999). In a similar fashion, there are very few studies of phobias in the elderly. The small amount of research in this area indicates that the elderly do sometimes present with phobias such as traveling, being alone, insects and close spaces (Lindesay, Briggs and Murphy, 1989).

Bipolar disorder

While bipolar disorders are typically thought to emerge relatively early in life, it is estimated by the University of Pittsburg Medical Center that 10 percent of elderly persons with bipolar disorder develop the disorder for the first time after the age of 50 (www.latelifedepression.org). There is a paucity of research on late-onset bipolar disorder, but the early research has indicated that those with late-onset bipolar have a history of major depression. In the manic episodes, elderly persons can present with increased activity, suspiciousness of others, irritability, trouble sleeping and grandiose thoughts. Manic episodes can then rapidly cycle into depression and pose a strong risk of suicide during these abrupt shifts.

In the elderly, bipolar disorder often presents with symptoms of mental confusion and disorientation, and is often misdiagnosed, as it is mistaken for dementia (Medscape, 1998). Oftentimes, elderly persons show less grandiosity and more depressive symptoms, which can also make the disorder more difficult to correctly diagnose (Finn, 2006).

Bipolar disorder in persons over the age of 65 is thought to be relatively rare, occurring in less than 1 percent of the population. However, it is suspected that the disorder is under-diagnosed (Sajatovic and Kales, 2006). Although it is less prevalent than depression, the overall impact of a person with a bipolar disorder is far greater on the mental health system. A study that compared the hospitalization rates and mental health utilization rates of those elderly persons with bipolar disorder as compared to those with depression demonstrated that elderly persons with a bipolar disorder were four times as likely to be hospitalized and to use mental health services (Bartel, Forester, Miles and Joyce, 2000).

To enhance the accuracy of diagnosis and facilitate earlier detection in clinical settings, the DSM-V revised Criterion A for manic and hypomanic episodes, which now includes an emphasis on changes in activity and energy as well as mood. The DSM-IV diagnosis of bipolar I disorder, mixed episode, requiring that the individual simultaneously meet full criteria for both mania and major depressive episode, has been removed. Instead, a new specifier, "with mixed features," has been added that can be applied to episodes of mania or hypomania when depressive features are present and to episodes of depression in the context of major depressive disorder or bipolar disorder when features of mania/hypomania are present. (APA, 2013)

Other Specified Bipolar and Related Disorder

DSM-V allows the specification of particular conditions for other specified bipolar and related disorder, including categorization for individuals with a past history of a major depressive disorder who meet all criteria for hypomania except the duration criterion (i.e., at least 4 consecutive days). A second condition constituting another specified bipolar and related disorder is that too few symptoms of hypomania are present to meet criteria for the full bipolar II syndrome, although the duration is sufficient at 4 or more days.

Substance abuse

Overall, the aging Baby Boomer population has historically used alcohol and drugs much more freely than previous generations, and higher numbers of them are entering their senior years with longstanding alcohol and drug abuse issues. The numbers of elderly substance abusers will only increase over the next few years. Consequently, there will be unprecedented numbers of elderly persons who need treatment for alcohol and drug abuse (NHSDA, 2000).

However, substance abuse is one of the most under-diagnosed disorders in the elderly. Elderly persons are often retired and consequently do not have accountability to an employer who might notice their overuse of chemical substances. The Hazelden Treatment Center notes on its website www.hazelden.org that about 17 percent of persons in this country who are over the age of 60 have issues with substance abuse, including the misuse of prescription drugs. The center notes that some of these persons are chronic abusers who have had lifelong problems, but others develop problems later in life, particularly with painkillers and other prescription medications.

Just as risk factors are different for elderly persons with substance abuse issues, so are the issues with diagnosis of substance abuse. Liberto and Oslin (1995) indicate in their research that late-onset substance abusers tend to respond fairly well to treatment, but are more likely to go undiagnosed, as physicians are not well trained to look for late-onset substance abuse. Substance abuse in the elderly can be hidden by physical illnesses, dementia or depression (Reid and Anderson, 1997). O'Connell, et al., (2003), notes that screening instruments for substance abuse have been designed for younger people and fail to take into account many life-stage differences between younger and older people.

The recently updated DSM-V outlines diagnosis criteria that differs slightly from the previous DSM-IV. Substance use disorder in DSM-V combines the DSM-IV categories of substance abuse and substance dependence into a single disorder measured on a continuum from mild to severe (APA, 2013). Each specific substance (other than caffeine, which cannot be diagnosed as a substance use disorder) is addressed as a separate use disorder (e.g., alcohol use disorder, stimulant use disorder, etc.), but nearly all substances are diagnosed based on the same overarching criteria. In this overarching disorder, the criteria have not only been combined, but strengthened. Whereas a diagnosis of substance abuse previously required only one symptom, mild substance use disorder in DSM-V requires two to three symptoms from a list of 11. Drug craving will be added to the list, and problems with law enforcement will be eliminated because of cultural considerations that make the criteria difficult to apply internationally.

In DSM-IV, the distinction between abuse and dependence was based on the concept of abuse as a mild or early phase and dependence as the more severe manifestation. In practice, the abuse criteria were sometimes quite severe. The revised substance use disorder, a single diagnosis, will better match the symptoms that patients experience.

Additionally, the diagnosis of dependence caused much confusion. Most people link dependence with "addiction" when in fact dependence can be a normal body response to a substance.

Prescription drugs and the elderly

The abuse and misuse of prescriptions drugs among elderly persons is a legitimate concern for mental health practitioners. Psychotropic medications are often times inappropriate for elderly persons to consume because they tend to increase confusion, sleep disorders and falls, and yet 50 percent of all psychotropic drug prescriptions are given to seniors. Elderly persons also have problems understanding instructions on taking medications properly, and it has been demonstrated that doctors do not spend adequate time explaining medication issues to their elderly patients. Even when they understand the instructions, elderly people often fail to take their medications appropriately, partly because they lack the money to buy prescriptions and they attempt to save money by cutting back on their medications (Brazeau, 2001; Carlson, 1994).

Alcohol abuse in the elderly

There are also further distinctions with types of problem drinkers in the elder population. In general, problem drinkers are divided into two types: early-onset and late-onset. Given their much shorter alcohol-problem history, late-onset alcoholics are further differentiated from their early-onset counterparts as less likely to have alcohol-related health problems or to experience physical withdrawal, with a lower frequency of intoxication and with more stable emotional, financial, and social situations (Schonfeld and Dupree 1991).

One primary distinguishing feature of late-onset alcoholism is its apparent development in response to stress, particularly stress connected with aging (Akers and La Greca 1991). Consequently, late-onset alcoholics are also known as "reactive" drinkers (Gomberg, 1990). Stressors associated with aging also have been linked to heavier drinking among early-onset alcoholics and reduced drinking by the elderly with a long-standing alcohol problem (Atkinson, 1984).

As Blazer and his colleagues (1986) point out, the primary distinguishing feature in late-onset alcoholics is their initiation of problem drinking as seniors. This particular feature identifies earlier onset elderly alcoholics from late-onset alcoholics. Mulford and Fitzgerald (1992) found that the late-onset problem drinkers included in their study of DWI offenders would not meet DSM-II or other clinical diagnostic criteria for alcoholism, a factor that may make them easier to treat but also less likely to be identified as in need of treatment. The lowered alcohol tolerance of the aging body may play a role here, making drinking a problem for persons whose consumption levels may be unchanged or relatively moderate.

Risk factors for substance abuse in the elderly

According to O'Connell, Chin, Cunningham and Lawler (2003), bereavement, (as elderly persons lose friends and family members) as well as the difficulty in adjusting to a loss of role identity upon retirement, are risk factors in substance abuse. Menninger (2002) also notes that economic difficulties from living on a fixed income and medical problems are all risk factors for substance abuse. These risk factors are quite different than for younger people who are facing different life-cycle issues. Those most likely to abuse alcohol in the elderly population are males who are under 75 years of age, from lower socioeconomic backgrounds with less education and are widowed or divorced. Interestingly, widowhood was not cited as a risk factor for women (Carlson, 1994).

Atkinson (2008) gives a comprehensive outline of risk factors for substance abuse:

- **Predisposing factors:**
  - Family history (alcohol).
  - Previous substance abuse.
  - Previous pattern of substance consumption (individual and cohort).
  - Personality traits (sedative-hypnotics, anxiolytics).
- **Factors that may increase substance exposure and consumption level:**
  - Gender (men: alcohol, illicit drugs; women: sedative-hypnotics, anxiolytics).
  - Chronic illness associated with pain (opioid analgesics), insomnia (hypnotic drugs), or anxiety (anxiolytics).
  - Long-term prescribing (sedative-hypnotics, anxiolytics).
  - Caregiver overuse of "as needed" medication (institutionalized elderly).
  - Life stress, loss, social isolation.
  - Negative effects (depression, grief, demoralization, anger, alcohol).
  - Family collusion and drinking partners (alcohol).
  - Discretionary time, money (alcohol).
- **Factors that may increase the effects and abuse potential of substances:**
  - Age-associated drug sensitivity.(pharmacokinetic, pharmacodynamic factors).
  - Chronic medical illness.
  - Other medications (alcohol-drug; drug-drug interactions).

Dementia

What is dementia?

According to the recently published DSM-V, dementia is a neurocognitive disorder. In fact, the term "dementia" has been eliminated and replaced with major or minor neurocognitive disorder. It was believed that the word dementia was stigmatizing toward older individuals and not well accepted by younger individuals with HIV dementia. The new term focuses on the decline from a previous level of functioning as opposed to a deficit. (APA, 2013)

Further, the dementia chapter in DSM-V is titled "Neurocognitive Disorders," whereas in DSM-IV it was titled "Delirium, Dementia, Amnestic, and Other Cognitive Disorders." According to DSM-V, changes for delirium include the following:

1. Disturbance in attention (i.e., reduced ability to direct, focus, sustain, and shift attention) and orientation to the environment.
2. Disturbance develops over a short period of time (usually hours to a few days) and represents an acute change from baseline that is not solely attributable to another neurocognitive disorder and tends to fluctuate in severity during the course of a day.
3. A change in an additional cognitive domain, such as memory deficit, disorientation, or language disturbance, or perceptual disturbance that is not better accounted for by a preexisting, established, or evolving other neurocognitive disorder.
4. Disturbances in No. 1 and 3 must not occur in the context of a severely reduced level of arousal, such as coma.

The old dementia terminology required the presence of memory impairment for all of the various dementias. It has been recognized that memory impairment is not the first domain to be affected in all of the other diseases that cause a neurocognitive disorder. For instance, in frontal temporal disorder, language could be affected first. This change in terminology will require that all diagnosing healthcare professionals first establish the presence of a neurocognitive disorder and then determine whether the neurocognitive disorder is minor or major.

In DSM-V, a minor neurocognitive disorder is defined by the following:

- There is evidence of modest cognitive decline from a previous level of performance in one or more of the domains outlined above based on the concerns of the individual, a knowledgeable informant, or the clinician; and a decline in neurocognitive performance, typically involving test performance in the range of one and two standard deviations below appropriate norms (i.e., between the third and 16th percentiles) on formal testing or equivalent clinical evaluation.
- The cognitive deficits are insufficient to interfere with independence (e.g., instrumental activities of daily living, like more complex tasks such as paying bills or managing medications, are preserved), but greater effort, compensatory strategies, or accommodation may be required to maintain independence.
- The cognitive deficits do not occur exclusively in the context of a delirium.
- The cognitive deficits are not primarily attributable to another mental disorder (e.g., major depressive disorder, schizophrenia).

In DSM-V, a major neurocognitive disorder is defined by the following:

- There is evidence of substantial cognitive decline from a previous level of performance in one or more of the domains outlined above based on the concerns of the individual, a knowledgeable informant, or the clinician; and a decline in neurocognitive performance, typically involving test performance in the range of two or more standard deviations below appropriate norms (i.e., below the third percentile) on formal testing or equivalent clinical evaluation.
- The cognitive deficits are sufficient to interfere with independence (i.e., requiring minimal assistance with instrumental activities of daily living).
- The cognitive deficits do not occur exclusively in the context of a delirium.
- The cognitive deficits are not primarily attributable to another mental disorder (e.g., major depressive disorder, schizophrenia).

When diagnosing a minor neurocognitive disorder, one and two standard deviations below appropriate norms are required. In diagnosing a major neurocognitive disorder, two or more standard deviations below appropriate norms are required. This need for cognitive testing will add to patient cost since neither the Mini Mental State Examination nor the Montreal Cognitive Assessment, the common screening tools utilized by many clinicians, yields results in standard deviations. In addition, the requirement that the cognitive deficits are insufficient to interfere with independence is subjective and will cause additional confusion for both clinicians and patients.

Having determined whether a patient has a major or minor neurocognitive disorder, the healthcare professional making the diagnosis must then decide on the etiological subtype of the major or minor neurocognitive disorder. The subtypes that have been listed are neurocognitive disorder due to Alzheimer's disease; vascular neurocognitive disorder; frontotemporal neurocognitive disorder; neurocognitive disorder due to traumatic brain injury, Lewy body dementia, Parkinson's disease, or HIV infection; substance-induced neurocognitive disorder; neurocognitive disorder due to Huntington's disease, Prion disease, or to another medical condition; and neurocognitive disorder not elsewhere classified.

What conditions can cause neurocognitive disorders?

Doctors have identified many other conditions that can cause dementia or dementia-like symptoms. Many of these conditions are reversible with appropriate treatment.

Reactions to medications – Medications can sometimes lead to reactions or side effects that mimic dementia. These dementia-like effects can occur in reactions to just one drug, or they can result from drug interactions. They may have a rapid onset, or they may develop slowly over time.

Metabolic problems and endocrine abnormalities – Thyroid problems can lead to apathy, depression or dementia. Hypoglycemia, a condition in which there is not enough sugar in the bloodstream, can cause confusion or personality changes. Too little or too much sodium or calcium can also trigger mental changes. Some people have an impaired ability to absorb vitamin B12, which creates a condition called pernicious anemia that can cause personality changes, irritability or depression. Tests can determine whether any of these problems are present.

Nutritional deficiencies – Deficiencies of thiamine (vitamin B1) frequently result from chronic alcoholism and can seriously impair mental abilities, in particular memories of recent events. Severe deficiency of vitamin B6 can cause a neurological illness called pellagra that may include dementia. Deficiencies of vitamin B12 also have been linked to dementia in some cases. Dehydration can also cause mental impairment that can resemble dementia.

Infections – Many infections can cause neurological symptoms, including confusion or delirium, due to fever or other side effects of the body's fight to overcome the infection. Meningitis and encephalitis, which are infections of the brain or the membrane that covers it, can cause confusion, sudden severe dementia, withdrawal from social interaction, impaired judgment or memory loss. Untreated syphilis also can damage the nervous system and cause dementia. In rare cases, Lyme disease can cause memory or thinking difficulties. People in the advanced stages of AIDS also may develop a form of dementia (see HIV-associated dementia, in this chapter). People with compromised immune systems, such as those with leukemia and AIDS, may also develop an infection called progressive multifocal leukoencephalopathy (PML). PML is caused by a common human polyomavirus, JC virus, and leads to damage or destruction of the myelin sheath that covers nerve cells. PML can lead to confusion, difficulty with thinking or speaking, and other mental problems.

Subdural hematomas – Subdural hematomas, or bleeding between the brain's surface and its outer covering (the dura), can cause dementia-like symptoms and changes in mental function.

Poisoning – Exposure to lead, other heavy metals or other poisonous substances can lead to symptoms of dementia. These symptoms may or may not resolve after treatment, depending on how badly the brain is damaged. People who have abused substances such as alcohol and recreational drugs sometimes display signs of dementia even after the substance abuse has ended. This condition is known as substance-induced persisting dementia.

Brain tumors – In rare cases, people with brain tumors may develop dementia because of damage to their brains. Symptoms may include changes in personality, psychotic episodes or problems with speech, language, thinking and memory.

Anoxia – Anoxia and a related term, hypoxia, are often used interchangeably to describe a state in which there is a diminished supply of oxygen to an organ's tissues. Anoxia may be caused by many different problems, including heart attack, heart surgery, severe asthma, smoke or carbon monoxide inhalation, high-altitude exposure, strangulation, or an overdose of anesthesia. In severe cases of anoxia, the patient may be in a stupor or a coma for periods ranging from hours to days, weeks or months. Recovery depends on the severity of the oxygen deprivation. As recovery proceeds, a variety of psychological and neurological abnormalities, such as dementia or psychosis, may occur. The person also may experience confusion, personality changes, hallucinations or memory loss.

Heart and lung problems – The brain requires a high level of oxygen in order to carry out its normal functions. Therefore, problems such as chronic lung disease or heart problems that prevent the brain from receiving adequate oxygen can starve brain cells and lead to the symptoms of dementia.

What are the risk factors for neurocognitive disorder?

Researchers have identified several risk factors that affect the likelihood of developing one or more kinds of dementia. Some of these factors are modifiable, while others are not.

- **Age** – The risk of AD, vascular dementia and several other dementias goes up significantly with advancing age.
- **Genetics/family history** – As described in the section "What causes dementia?" researchers have discovered a number of genes that increase the risk of developing AD. Although people with a family history of AD are generally considered to be at heightened risk of developing the disease themselves, many people with a family history never develop the disease and many without a family history of the disease do get it. In most cases, it is still impossible to predict a specific person's risk of the disorder based on family history alone. Some families with CJD, GSS, or fatal familial insomnia have mutations in the prion protein gene, although these disorders can also occur in people without the gene mutation. Individuals with these mutations are at significantly higher risk of developing these forms of dementia. Abnormal genes are also clearly implicated as risk factors in Huntington's disease, FTDP-17, and several other kinds of dementia. These dementias are described in the section, "What are the different kinds of dementia?"
- **Smoking and alcohol use** – Several recent studies have found that smoking significantly increases the risk of mental decline and dementia. People who smoke have a higher risk of atherosclerosis and other types of vascular disease, which may be the underlying causes for the increased dementia risk. Studies also have found that drinking large amounts of alcohol appears to increase the risk of dementia. However, other studies have suggested that people who drink moderately have a lower risk of dementia than either those who drink heavily or those who completely abstain from drinking.
- **Atherosclerosis** – Atherosclerosis is the buildup of plaque – deposits in fatty substances, cholesterol and other matter – in the inner lining of an artery. Atherosclerosis is a significant risk factor for vascular dementia because it interferes with the delivery of blood to the brain and can lead to stroke. Studies have also found a possible link between atherosclerosis and AD.
- **Cholesterol** – High levels of low-density lipoprotein (LDL), the so-called bad form of cholesterol, appear to significantly increase a

person's risk of developing vascular dementia. Some research has also linked high cholesterol to an increased risk of AD.

- **Plasma homocysteine** – Research has shown that a higher-than-average blood level of homocysteine – a type of amino acid – is a strong risk factor for the development of AD and vascular dementia.
- **Diabetes** – Diabetes is a risk factor for both AD and vascular dementia. It is also a known risk factor for atherosclerosis and stroke, both of which contribute to vascular dementia.
- **Mild cognitive impairment** – While not all people with mild cognitive impairment develop dementia, people with this condition do have a significantly increased risk of dementia compared to the rest of the population. One study found that approximately 40 percent of people over age 65 who were diagnosed with mild cognitive impairment developed dementia within three years.
- **Down syndrome** – Studies have found that most people with Down syndrome develop characteristic AD plaques and neurofibrillary tangles by the time they reach middle age. Many, but not all, of these individuals also develop symptoms of dementia.

How are neurocognitive disorders diagnosed?

Doctors employ a number of strategies to diagnose dementia. It is important that they rule out any treatable conditions, such as depression, normal pressure hydrocephalus or vitamin B12 deficiency, which can cause similar symptoms.

Early, accurate diagnosis of dementia is important for patients and their families because it allows early treatment of symptoms. For people with AD or other progressive dementias, early diagnosis may allow them to plan for the future while they can still help to make decisions. These people also may benefit from drug treatment.

The "gold standard" for diagnosing dementia, autopsy, does not help the patient or caregivers. Therefore, doctors have devised a number of techniques to help identify dementia with reasonable accuracy while the patient is still alive.

Patient history

Doctors often begin their examination of a patient suspected of having dementia by asking questions about the patient's history. For example, they may ask how and when symptoms developed and about the patient's overall medical condition. They also may try to evaluate the patient's emotional state, although patients with dementia often may be unaware of or in denial about how their disease is affecting them. Family members also may deny the existence of the disease because they do not want to accept the diagnosis and because, at least in the beginning, AD and other forms of dementia can resemble normal aging. Therefore, additional steps are necessary to confirm or rule out a diagnosis of dementia.

Physical examination

A physical examination can help rule out treatable causes of dementia and identify signs of stroke or other disorders that can contribute to dementia. It can also identify signs of other illnesses, such as heart disease or kidney failure, that can overlap with dementia. If a patient is taking medications that may be causing or contributing to his or her symptoms, the doctor may suggest stopping or replacing some medications to see if the symptoms go away.

Neurological evaluations

Doctors will perform a neurological examination, looking at balance, sensory function, reflexes, and other functions, to identify signs of conditions – for example, movement disorders or stroke – that may affect the patient's diagnosis or are treatable with drugs.

Cognitive and neuropsychological tests

Doctors use tests that measure memory, language skills, math skills and other abilities related to mental functioning to help them diagnose a patient's condition accurately. For example, people with AD often show changes in so-called executive functions (such as problem-solving), memory and the ability to perform once automatic tasks.

Doctors often use a test called the Mini-Mental State Examination (MMSE) to assess cognitive skills in people with suspected dementia. This test examines orientation, memory and attention as well as the ability to name objects, follow verbal and written commands, write a sentence spontaneously and copy a complex shape. Doctors also use a variety of other tests and rating scales to identify specific types of cognitive problems and abilities.

Brain scans

Doctors may use brain scans to identify strokes, tumors or other problems that can cause dementia. Also, cortical atrophy – degeneration of the brain's cortex (outer layer) – is common in many forms of dementia and may be visible on a brain scan. The brain's cortex normally appears very wrinkled, with ridges of tissue (called gyri) separated by "valleys" called sulci. In individuals with cortical atrophy, the progressive loss of neurons causes the ridges to become thinner and the sulci to grow wider. As brain cells die, the ventricles (or fluid-filled cavities in the middle of the brain) expand to fill the available space, becoming much larger than normal. Brain scans also can identify changes in the brain's structure and function that suggest AD.

The most common types of brain scans are computed tomographic (CT) scans and magnetic resonance imaging (MRI). Doctors frequently request a CT scan of the brain when they are examining a patient with suspected dementia. These scans, which use X-rays to detect brain structures, can show evidence of brain atrophy, strokes and transient ischemic attacks (TIAs), changes to the blood vessels and other problems such as hydrocephalus and subdural hematomas. MRI scans use magnetic fields and focused radio waves to detect hydrogen atoms in tissues within the body. They can detect the same problems as CT scans, but they are better for identifying certain conditions, such as brain atrophy and damage from small TIAs.

Doctors also may use electroencephalograms (EEGs) in people with suspected dementia. In an EEG, electrodes are placed on the scalp over several parts of the brain in order to detect and record patterns of electrical activity and check for abnormalities. This electrical activity can indicate cognitive dysfunction in part or all of the brain. Many patients with moderately severe to severe AD have abnormal EEGs. An EEG may also be used to detect seizures, which occur in about 10 percent of AD patients, as well as in many other disorders. EEGs also can help diagnose CJD.

Several other types of brain scans allow researchers to watch the brain as it functions. These scans, called functional brain imaging, are not often used as diagnostic tools but are important in research, and they may ultimately help identify people with dementia earlier than is currently possible. Functional brain scans include functional MRI (FMRI), single photon-emission computed technology (SPECT), positron emission tomography (PET), and magnetoencephalography (MEG). FMRI uses radio waves and a strong magnetic field to measure the metabolic changes that take place in active parts of the brain. SPECT shows the distribution of blood in the brain, which generally increases with brain activity. PET scans can detect changes in glucose metabolism, oxygen metabolism and blood flow, all of which can reveal abnormalities of brain function. MEG shows the electromagnetic fields produced by the brain's neuronal activity.

Laboratory tests

Doctors may use a variety of laboratory tests to help diagnose dementia and/or rule out other conditions, such as kidney failure, that can contribute to symptoms. A partial list of these tests includes a complete blood count, blood glucose test, urinalysis, drug and alcohol tests (toxicology screen), cerebrospinal fluid analysis (to rule out specific infections that can affect the brain), and analysis of thyroid and thyroid-stimulating hormone levels. A doctor will order only the tests that he or she feels are necessary or likely to improve the accuracy of a diagnosis.

Psychiatric evaluation
A psychiatric evaluation may be obtained to determine whether depression or another psychiatric disorder may be causing or contributing to a person's symptoms.

Pre-symptomatic testing
Testing people before symptoms begin to determine whether they will develop dementia is not possible in most cases. However, in disorders such as Huntington's where a known gene defect is clearly linked to the risk of the disease, a genetic test can help identify people who are likely to develop the disease. Since this type of genetic information can be devastating, people should carefully consider whether they want to undergo such testing.

Researchers are examining whether a series of simple cognitive tests, such as matching words with pictures, can predict who will develop dementia. One study suggested that a combination of a verbal learning test and an odor-identification test can help identify AD before symptoms become obvious. Other studies are looking at whether memory tests and brain scans can be useful indicators of future dementia.

Is there any treatment?

While treatments to reverse or halt disease progression are not available for most of the dementias, patients can benefit to some extent from treatment with available medications and other measures, such as cognitive training.

Drugs to specifically treat AD and some other progressive dementias are now available and are prescribed for many patients. Although these drugs do not halt the disease or reverse existing brain damage, they can improve symptoms and slow the progression of the disease. This may improve the patient's quality of life, ease the burden on caregivers or delay admission to a nursing home. Many researchers are also examining whether these drugs may be useful for treating other types of dementia.

Many people with dementia, particularly those in the early stages, may benefit from practicing tasks designed to improve performances in specific aspects of cognitive functioning. For example, people can sometimes be taught to use memory aids, such as mnemonics, computerized recall devices or note taking.

Behavior modification – rewarding appropriate or positive behavior and ignoring inappropriate behavior – also may help control unacceptable or dangerous behaviors.

Alzheimer's disease

Alzheimer's disease falls within the category of neurocognitive disorders, as it is considered a form of dementia. In the early stages, the most common symptom is difficulty in remembering recent events, known as short term memory loss. When AD is suspected, the diagnosis is usually confirmed with tests that evaluate behavior and thinking abilities, often followed by a brain scan if available; however, examination of brain tissue is required for a definitive diagnosis. As the disease advances, symptoms can include confusion, irritability, aggression, mood swings, trouble with language, and long-term memory loss.

DSM-V now recognizes a less severe level of cognitive impairment, mild NCD, which is a new disorder that permits the diagnosis of less disabling syndromes that may nonetheless be the focus of concern and treatment (APA, 2013). Diagnostic criteria are provided for both major NCD and mild NCD, followed by diagnostic criteria for the different etiological subtypes. An updated listing of neurocognitive domains is also provided in DSM-V, as these are necessary for establishing the presence of NCD, distinguishing between the major and mild levels of impairment, and differentiating among etiological subtypes.

Although the threshold between mild NCD and major NCD is inherently arbitrary, there are important reasons to consider these two levels of impairment separately. The major NCD syndrome provides consistency with the rest of medicine and with prior DSM editions and necessarily remains distinct to capture the care needs for this group. Although the mild NCD syndrome is new to DSM-V, its presence is consistent with its use in other fields of medicine, where it is a significant focus of care and research, notably in individuals with Alzheimer's disease, cerebrovascular disorders, HIV, and traumatic brain injury.

Most of the drugs currently approved by the U.S. Food and Drug Administration (FDA) for AD fall into a category called cholinesterase inhibitors. These drugs slow the breakdown of the neurotransmitter acetylcholine, which is reduced in the brains of people with AD. Acetylcholine is important for the formation of memories, and it is used in the hippocampus and the cerebral cortex, two brain regions that are affected by AD. There are currently four cholinesterase inhibitors approved for use in the United States: tacrine (Cognex), donepezil (Aricept), rivastigmine (Exelon), and galantamine (Reminyl). These drugs temporarily improve or stabilize memory and thinking skills in some individuals. Many studies have shown that cholinesterase inhibitors help to slow the decline in mental functions associated with AD, and that they can help reduce behavioral problems and improve the ability to perform everyday tasks. However, none of these drugs can stop or reverse the course of AD.

A fifth drug, memantine, (Namenda) is also approved for use in the United States, Unlike other drugs for AD, which affect acetylcholine levels, memantine works by regulating the activity of a neurotransmitter called glutamate that plays a role in learning and memory. Glutamate activity is often disrupted in AD. Because this drug works differently from cholinesterase inhibitors, combining memantine with other AD drugs may be more effective than any single therapy. One controlled clinical trial found that patients receiving donepezil plus memantine had better cognition and other functions than patients receiving donepezil alone.

Doctors may also prescribe other drugs, such as anticonvulsants, sedatives and antidepressants, to treat seizures, depression, agitation, sleep disorders and other specific problems that can be associated with dementia. In 2005, research showed that use of "atypical" antipsychotic drugs such as olanzapine and risperidone, to treat behavioral problems in elderly people with dementia was associated with an elevated risk of death in these patients. Most of the deaths were caused by heart problems or infections. The FDA has issued a public health advisory to alert patients and their caregivers to this safety issue.

Vascular dementia

There is no standard drug treatment for vascular dementia, although some of the symptoms, such as depression, can be treated. Most other treatments aim to reduce the risk factors for further brain damage. However, some studies have found that cholinesterase inhibitors, such as galantamine and other AD drugs, can improve cognitive function and behavioral symptoms in patients with early vascular dementia.

The progression of vascular dementia can often be slowed significantly or halted if the underlying vascular risk factors for the disease are treated. To prevent strokes and TIAs, doctors may prescribe medicines to control high blood pressure, high cholesterol, heart disease and diabetes. Doctors also sometimes prescribe aspirin, warfarin or other drugs to prevent clots from forming in small blood vessels. When patients have blockages in blood vessels, doctors may recommend surgical procedures, such as carotid endarterectomy, stenting or angioplasty, to restore the normal blood supply. Medications to relieve restlessness or depression or to help patients sleep better may also be prescribed.

Other dementias

Some studies have suggested that cholinesterase inhibitors, such as donepezil (Aricept), can reduce behavioral symptoms in some patients with Parkinson's dementia.

At present, no medications are approved specifically to treat or prevent FTD and most other types of progressive dementia. However, sedatives, antidepressants and other medications may be useful in treating specific symptoms and behavioral problems associated with these diseases.

Scientists continue to search for specific treatments to help people with Lewy body dementia. Current treatment is symptomatic, often involving the use of medication to control the Parkinson's and psychiatric symptoms. Although anti-Parkinsonian medication may help reduce tremor and loss of muscle movement, it may worsen symptoms such as hallucinations and delusions. Also, drugs prescribed for psychiatric symptoms may make the movement problems worse. Several studies have suggested that cholinesterase inhibitors may be able to improve cognitive function and behavioral symptoms in patients with Lewy body disease.

There is no known treatment that can cure or control CJD. Current treatment is aimed at alleviating symptoms and making the patient as comfortable as possible. Opiate drugs can help relieve pain and the drugs clonazepam and sodium valproate may help relieve myoclonus. During later stages of the disease, treatment focuses on supportive care, such as administering intravenous fluids and changing the person's position frequently to prevent bedsores.

Can dementia be prevented?

Research has revealed a number of factors that may be able to prevent or delay the onset of dementia in some people. For example, studies have shown that people who maintain tight control over their glucose levels tend to score better on tests of cognitive function than those with poorly controlled diabetes. Several studies also have suggested that people who engage in intellectually stimulating activities, such as social interactions, chess, crossword puzzles and playing a musical instrument, significantly lower their risk of developing AD and other forms of dementia. Scientists believe mental activities may stimulate the brain in a way that increases the person's "cognitive reserve" – the ability to cope with or compensate for the pathologic changes associated with dementia.

Researchers are studying other steps people can take that may help prevent AD in some cases. So far, none of these factors has been definitively proven to make a difference in the risk of developing the disease. Moreover, most of the studies addressed only AD, and the results may or may not apply to other forms of dementia. Nevertheless, scientists are encouraged by the results of these early studies and may believe it will eventually become possible to prevent forms of dementia.

Possible preventive actions include:

- **Lowering homocysteine** – In one study, elevated blood levels of the amino acid homocysteine were associated with a 2.9 times greater risk of AD and a 4.9 times greater risk of vascular dementia. A preliminary study has shown that high doses of three B vitamins that help lower homocysteine levels – folic acid, B12 and B6 – appear to slow the progression of AD. Researchers are conducting a multicenter clinical trial to test this effect in a larger group of patients.
- **Lowering cholesterol levels** – Research has suggested that people with high cholesterol levels have an increased risk of developing AD. Cholesterol is involved in formation of amyloid plaques in the brain. Mutations in a gene called CYP46 and the apoE E4 gene variant, both of which have been linked to an increased risk of AD, are also involved in cholesterol metabolism. Several studies have also found that the use of drugs called statins, which lower cholesterol levels, is associated with a lower likelihood of cognitive impairment.
- **Lowering blood pressure** – Several studies have shown that antihypertensive medicine reduces the odds of cognitive impairment in elderly people with high blood pressure. One large European study found a 55 percent lower risk of dementia in people over 60 who received drug treatment for hypertension. These people had a reduced risk of both AD and vascular dementia.
- **Exercise** – Regular exercise stimulates production of chemicals called growth factors that help neurons survive and adapt to new situations. These gains may help to delay the onset of dementia symptoms. Exercise also may reduce the risk of brain damage from atherosclerosis.
- **Education** – Researchers have found evidence that formal education may help protect people against the effects of AD. In one study, researchers found that people with more years of formal education had relatively less mental decline than people with less schooling, regardless of the number of amyloid plaques and neurofibrillary tangles each person had in his or her brain. The researchers think education may cause the brain to develop robust nerve cell networks that can help compensate for the cell damage caused by AD.
- **Controlling inflammation** – Many studies have suggested that inflammation may contribute to AD. Moreover, autopsies of people who die with AD have shown widespread inflammation in the brain that appeared to be caused by the accumulation of beta amyloid. Another study found that men with high levels of C-reactive protein, a general marker of inflammation, had a significantly increased risk of AD and other kinds of dementia.
- **Non-steroidal anti-inflammatory drugs (NSAIDs)** – Research indicated that long-term use of NSAIDs, ibuprofen, naproxen, and similar drugs, may prevent or delay the onset of AD. Researchers are not sure how these drugs may protect against the disease, but some or all of the effect may be due to reduced inflammation. A 2003 study showed that these drugs also bind to amyloid plaques and may help to dissolve them and prevent formation of new plaques.

The risk of vascular dementia is strongly correlated with risk factors for stroke, including high blood pressure, diabetes, elevated cholesterol levels and smoking. This type of dementia may be prevented in many cases by changing lifestyle factors, such as excessive weight and high blood pressure, which are associated with an increased risk of cerebrovascular disease. One European study found that treating isolated systolic hypertension (high blood pressure in which only the systolic or top number is high) in people age 60 and older reduced the risk of dementia by 50 percent. These studies strongly suggest that effective use of current treatments may prevent future cases of vascular dementia.

A study published in 2005 found that people with mild cognitive impairment who took 10mg/day of the drug donepezil had a significantly reduced risk of developing AD during the first two years of treatment, compared to people who received vitamin E or placebo. By the end of the third year, however, the rate of AD was just as high in the people treated with donepezil as it was in the other two groups.

What kind of care do people with dementia need?

People with moderate and advanced dementia typically need round the clock care and supervision to prevent them from harming themselves or others. They also may need assistance with daily activities such as eating, bathing and dressing. Meeting these needs takes patience, understanding and careful thought by the person's caregivers.

A typical home environment can present many dangers and obstacles to a person with dementia, but simple changes can overcome many of these problems. For example, sharp knives, dangerous chemicals, tools and other hazards should be removed or locked away. Other safety measures include installing bed and bathroom safety rails, removing locks from bedroom and bathroom doors and lowering the hot water temperature to 120F (48.9C) or less to reduce the risk of accidental scalding. People with dementia also should wear some form of identification at all times in case they wander away or become lost. Caregivers can help prevent unsupervised wandering by adding locks or alarms to outside doors.

People with dementia often develop behavior problems because of frustration with specific situations. Understanding and modifying or preventing the situations that trigger these behaviors may help to make life more pleasant for the person with dementia as well as his or her caregivers. For instance, the person may be confused or frustrated by the level of activity or noise in the surrounding environment. Reducing unnecessary activity and noise (such as limiting the number of visitors and turning off the television when it's not in use) may make it easier for the person to understand requests and perform simple tasks. Confusion also may be reduced by simplifying home decorations, removing clutter, keeping familiar objects nearby and following a predictable routine throughout the day. Calendars and clocks also may help patients orient themselves.

People with dementia should be encouraged to continue their normal leisure activities as long as they are safe and do not cause frustration. Activities such as crafts, games and music can provide important mental stimulation and improve mood. Some studies have suggested that participating in exercise and intellectually stimulating activities may slow the decline of cognitive function in some people.

Many studies have found that driving is unsafe for people with dementia. They often get lost and they may have problems remembering or following rules of the road. They also may have difficulty processing information quickly and dealing with unexpected circumstances. Even a second of confusion while driving can lead to an accident. Driving with impaired cognitive functions can also endanger others. Some experts have suggested that regular screening for changes in cognition might help to reduce the number of driving accidents among elderly people, and some states now require that doctors report people with AD to their state motor vehicle department. However, in many cases, it is up to the person's family and friends to ensure that the person does not drive.

The emotional and physical burden of caring for someone with dementia can be overwhelming. Support groups can often help caregivers deal with these demands, and they can also offer helpful information about the disease and its treatment. It is important that caregivers occasionally have time off from round-the-clock nursing demands. Some communities provide respite facilities or adult day care centers that will care for dementia patients for a period of time, giving the primary caregivers a break. Eventually, many patients with dementia require the services of a full-time nursing home.

What research is being done?

Current research focuses on many different aspects of neurocognitive disorders. This research promises to improve the lives of people affected by the dementia and may eventually lead to ways of preventing or curing these disorders.

Causes and prevention

Research on the causes of AD and other dementias includes studies of genetic factors, neurotransmitters, inflammation; factors that influence programmed cell death in the brain and the roles of tau, beta amyloid and the associated neurofibrillary tangles and plaques in AD. Some other researchers are trying to determine the possible roles of cholesterol metabolism, oxidative stress (chemical reactions that can damage proteins, DNA and lipids inside cells) and microglia in the development of AD. Scientists also are investigating the role of the enzyme telomerase.

Since many dementias and other neurodegenerative diseases have been linked to abnormal clumps of proteins in cells, researchers are trying to learn how these clumps develop, how they affect cells and how the clumping can be prevented.

Some studies are examining whether changes in white matter, nerve fibers lines with myelin, may play a role in the onset of AD. Myelin may erode in AD patients before other changes occur. This may be due to a problem with oligodendrocytes, the cells that produce myelin.

Researchers are searching for additional genes that may contribute to AD, and they have identified a number of gene regions that may be involved. Some researchers suggest that people will eventually be screened for a number of genes that contribute to AD and that they will be able to receive treatments that specifically address their individual genetic risks. However, such individualized screening and treatment is still years away.

Insulin resistance is common in people with AD, but it is not clear whether the insulin resistance contributes to the development of the disease or if it is merely a side effect.

Several studies have found a reduced risk of dementia in people who take cholesterol-lowering drugs called statins. However, it is not yet clear if the apparent effect is due to the drugs or to other factors.

Early studies of estrogen suggested that it might help prevent AD in older women. However, a clinical study of several thousand postmenopausal women aged 65 or older found that combination therapy with estrogen and progestin substantially increased the risk of AD. Estrogen alone also appeared to slightly increase the risk of dementia in this study.

A 2003 study found that people with HIV-associated dementia have different levels of activity for more than 30 different proteins, compared to people who have HIV but no signs of dementia. The study suggests a possible way to screen HIV patients for the first signs of cognitive impairment, and it may lead to ways of intervening to prevent this form of dementia.

Diagnosis

Improving early diagnosis of AD and other types of dementia is important not only for patients and families but also for researchers who seek to better understand the causes of dementing diseases and find ways to reverse or halt them at early stages. Improved diagnosis can also reduce the risk that people will receive inappropriate treatments.

Some researchers are investigating whether three-dimensional computer models of PET and MRI images can identify brain changes typical of early AD before any symptoms appear. This research may lead to ways of preventing the symptoms of the disease.

One study found that levels of beta amyloid and tau in spinal fluid can be used to diagnose AD with a sensitivity of 92 percent. If other studies confirm the validity of this test, it may also help doctors to identify people who are beginning to develop the disorder before they start to show symptoms. This would allow treatment at very early stages of the disorder and may help in testing new treatments to prevent or delay symptoms of the disease. Other researchers have identified factors in the skin and blood of AD patients that are different from those in healthy people. They are trying to determine whether these factors can be used to diagnose the disease.

Treatment

Researchers are continually working to develop new drugs for AD and other types of dementia. Many researchers believe a vaccine that reduces the number of amyloid plaques in the brain might ultimately prove to be the most effective treatment for AD. In 2001, researchers began one clinical trial of a vaccine called AN-1792. The study was halted after a number of people developed inflammation of the brain and spinal cord. Despite these problems, one patient appeared to have reduced numbers of amyloid plaques in the brain. Other patients showed little or no cognitive decline during the course of the study, suggesting that the vaccine may slow or halt the disease. Researchers are now trying to find safer and more effective vaccines for AD.

Researchers are also investigating possible methods of gene therapy for AD. In one case, researchers used cells genetically engineered to produce nerve growth factor and transplanted them into monkey's forebrains. The transplanted cells boosted the amount of nerve growth factors in the brain and seemed to prevent degeneration of acetylcholine-producing neurons in the animals. This suggests that gene therapy might help to reduce or delay symptoms of the disease. Researchers are now testing a similar therapy in a small number of patients. Other researchers have experimented with gene therapy that adds a gene called neprilysin in a mouse model that produces human beta amyloid. They found that increasing the level of neprilysin greatly reduced the amount of beta amyloid in the mice and halted the amyloid-related brain degeneration. They are now trying to determine whether neprilysin gene therapy can improve cognition in mice.

A clinical trial called the Vitamins to Slow Alzheimer's Disease (VITAL) study is testing whether high doses of three common B vitamins, folic acid, B12, and B6, can reduce homocysteine levels and slow the rate of cognitive decline in AD.

Since many studies have found evidence of brain inflammation in AD, some researchers have proposed that drugs that control inflammation, such as NSAIDs, might prevent the disease or slow its progression. Studies in mice have suggested that these drugs can limit production of amyloid plaques in the brain. Early studies of these drugs in humans have shown promising results. However, a large NIH funded clinical trial of two NSAIDs (naproxen and celecoxib) to prevent AD was stopped in late 2004 because of an increase in stroke and heart attack in people taking naproxen, and an unrelated study that linked celecoxib to an increased risk of heart attack.

Some studies have suggested that two drugs, pentoxifylline and propentofylline, may be useful in treating vascular dementia. Pentoxifylline improves blood flow, while propentofylline appears to interfere with some of the processes that cause cell death in the brain. (Medicine Net, 2014)

Psychosocial factors of disorders on the elderly

Factors such as where an elderly person lives and who cares for that person do have an impact on the overall well-being of the elder person. Studies have demonstrated that those elderly persons who live alone do tend to have more symptoms of depression (Dean, Kolody, Wood and Matt, 1992). Other studies have similar findings. One recent study of elderly Europeans indicated that marital partners tend to be the most important factor in preventing depression in the elderly, but frequent contact with children also predicts less depressive symptoms. Those elderly persons who lived alone experienced the highest levels of depression (Buber and Engelhardt, 2008).

Furthermore, many elderly persons are also caregivers to other elderly persons, usually their spouses, thus causing another psychosocial factor that greatly affects the mental health of many of the elderly. Not only is an elderly person affected by who they live with, he or she is also affected by the setting in which they live. The setting in which an elderly person resides can affect his or her access to care and the quality of the care received. In addition, the cultural influences in the life of an elderly person also exert a profound impact upon their view of mental illness, their coping mechanisms, and their resistance to treatment.

Nursing homes and assisted living

For many reasons, both physical and mental, it is not appropriate for some seniors to live on their own. However, that an elderly person lives in a residential facility does not ensure that mental health needs are being met. It has been estimated that two-thirds of nursing home residents have some form of emotional or behavioral disturbances, and one-half are taking psychotropic medications. However, the medical staff often failed to look at the clients holistically and focused on the behavioral issues only, ignoring the underlying medical causes, such as untreated infections and chronic pain as conditions that added to the mental health issues (Gruber-Baldini, et al., 2004).

Chapin, Reed and Dobbs (2004) also found that depression was under-diagnosed in those elderly persons living in assisted living facilities, and residents had little understanding of mental health resources or how to access those services. Other studies have similar findings, in that many of the assisted living home residents had symptoms of mental illness (Gottsman, Peskin, Kennedy and Mossey, 1991).

A survey of assisted living facility administrators indicated that while many of them were aware of mental health issues, many of their staff members who dealt directly with residents had no mental health training, and only about half of the facilities had a mental health professional to provide a mental health assessment at intake. When the facility personnel were aware of unmet mental health needs, they did make referrals, but most often the referrals were made to general practitioners rather than mental health specialists. The author noted that assisted care facilities overall needed more training for staff to assess for mental health issues and to learn about resources and referrals in the community (Cummings, 2003).

Despite the higher level of medical care provided to residents, nursing homes still overall lack effective strategies and systems of care for mentally ill residents. Carlson and Snowden (2007) noted that it has been estimated that 12 percent to 21 percent of residents in nursing homes suffer from depression. In addition, anywhere from 35 percent to 60 percent of nursing home residents take antidepressants. But about 20 percent of those getting treatment still showed significant signs of depression, which is indicative that the treatment received was inadequate and not well-monitored overall.

Some nursing homes have incorporated the use of care managers who educate the family and patient about medication and other forms of treatment, create treatment plans that incorporate the appropriate forms of treatment and monitor the patient's progress. According to Carolson and Snowden, effective programs have several common elements:

- Screening tools, such as the DSM-IV structured clinical interview, which remains in place despite revisions of DSM-V.
- Antidepressants, closely monitored by the nurse who serves as care manager and who has the authority to adjust medications as needed.
- Psychotherapy, which is most often problem-solving therapy or interpersonal therapy.
- Supervision of case managers by a psychiatrist, who may be on staff or contracted.

After extensive review of the published literature on the treatment of nursing home patients for dementia and depression, the two most common diagnoses seen in this population, there were not a sufficient number of studies to determine what the best practices were for care of the elderly with these diagnoses. The authors determined that neither medication nor therapy totally eliminated symptoms, but interventions can lessen symptoms.

Furthermore, there were not enough studies to determine whether therapy or medication was more effective. A good deal of evidence existed in the studies reviewed to support the use of antipsychotic medication, but there was less support for the use of antidepressants or benzodiazepines. The authors further recommended that there was a need for more accurate screening tools for mental illness and a need for more studies on the efficacy of medication to treat dementia and depression.

An expert interdisciplinary panel led by the American Geriatrics Society (AGS) and the American Association for Geriatric Psychiatry (AAGP) and including representatives from numerous stakeholder organizations has issued a new consensus statement calling for significant revisions to the standards of care for nursing home residents with depression and behavioral symptoms associated with dementia. The AGS and AAGP have also issued health policy recommendations that address implementation of the expert panel's clinical recommendations.

Approximately 1.5 million older adults currently reside in nursing homes across the United States, and about one-fifth of those residents have symptoms of depression. Up to 40 percent of residents with dementia have both behavioral and psychiatric symptoms that could be alleviated by proper care and treatment. According to the panel, "the current protocols for the screening and management of these problems are inadequate." Joseph G. Ouslander, MD, former AGS president and co-chair of the expert panel, states, "The current system does not provide enough specific recommendations for nursing home staff to develop optimal, individualized care plans based on their assessment of depression and behavioral symptoms."

Among its recommendations, the panel calls for routine and regular screening for depression in every nursing home resident. They also call for improved screening instruments and first-line treatment of major depression with antidepressant medications in combination with nonpharmacologic interventions. The consensus statement also outlines numerous approaches for nursing home administrators and staff to improve the environment for residents, thus enhancing their independence, sense of well-being and quality of life.

The panel states that better assessment tools for residents with dementia-related behavioral symptoms are required, as well as careful and regular evaluation to determine whether a resident's symptoms may be the result of adverse drug interactions or other medical conditions. The panel also states that barriers to using effective drug therapies such as restrictive formularies and attitudes about using psychotropic drugs as "chemical restraints" should be reassessed in order to provide the best care for residents. "Most importantly, we need to take advantage of the large body of research on effective interventions by ensuring that evidence-based mental health treatments are provided in nursing homes," says Stephen J. Bartels, MD, former AAGP president and expert panel co-chair. "Improving the quality of care for residents with mental health problems will require enhanced training and staffing in nursing home needs, complimented by greater availability of mental health consultation services."

The AGS and AAGP policy recommendations include:

- Making mental health services more available to nursing homes, particularly in rural areas and those that are publicly financed.
- Including coverage for mental health services and health medications in public and private insurance plans that cover nursing home residents.
- Rewarding facilities that provide appropriate pharmacologic and non-pharmacologic treatment for residents with mental illness.
- Encouraging staff training to identify residents with mental illness.
- Promoting research to identify the best practices in meeting the mental health care needs of nursing home residents.

The consensus statement and policy recommendations are intended to assist regulators at the Centers for Medicare and Medicaid Services (CMS) and other agencies as they make revisions to the current guidelines and quality measures for nursing homes.

In-home care

While many elderly persons enter long-term care settings, many more are cared for at home by family members. A recent interview with Dr, Stephen Golant, an expert on elderly housing at the University of Florida, notes than the elderly are moving more towards home-based care, in part due to concerns about the cost of assisted living facilities and nursing homes. In addition, seniors tend to prefer to live in their own homes (AARP, 2014). He stated that this does create burdens for caregivers that are becoming more difficult to reconcile given that many women now work outside the home. Many caregivers of older people are themselves older adults. Of those caring for someone aged 65 or older, the average age of caregivers is 63, with a third of these caregivers in fair to poor health themselves (Administration on Aging, 2004). One survey found that 58 percent of caregivers were over the age of 65, and that more than 10 percent were over the age of 80. There are two primary aspects to the roles of caregivers: relationship between caregivers and the identified patient, and caregiver's mental well-being.

The Family Caregiver Alliance (FCA), a national nonprofit organization that provides information and referral for caregivers as well as medical and social service personnel, notes that the average caregiver is a married woman between the ages of 45-55 who works full time and also devotes an average of 20 hours per week to care giving. The Family Caregiver Alliance also notes the following statistics concerning caregivers in the United States on its website: *www.caregiver.org:*

- By the year 2007, the number of care-giving households in the U.S. for persons aged 50-plus could reach 39 million.
- Over three-quarters (78 percent) of adults living in the community and in need of long-term care depend on family and friends (i.e., informal caregivers) as their only source of help; 14 percent receive a combination of informal and formal care (i.e., paid help); only 8 percent used formal care or paid help only.
- Even among the most severely disabled older persons living in the community, about two-thirds rely solely on family members and other informal help, often resulting in great strain for the family caregivers. The use of informal care as the only type of assistance by older Americans aged 65 and over increased from 57 percent in 1994 to 66 percent in 1999. The growth in reliance upon informal

care between 1994 and 1999 is accompanied by a decline in the use of a combination of informal and formal care from 36 percent in 1994 to 26 percent in 1999.

- Thirty percent of persons caring for elderly long-term care users were themselves aged 65 or over; another 15 percent were between the ages of 45-54.
- For the family caregiver forced to give up work to care for a family member or friend, the cost in lost wages and benefits is estimated to be $109 per day.

Elderly caregivers

Those elderly persons who care for others are themselves at high risk for developing a mental illness. The Family Caregiver Alliance notes that:

- **Women experience depression at a higher rate than men.** Women, primarily wives and daughters, provide the majority of care giving. In the United States, approximately 12 million women experience clinical depression each year, at approximately twice the rate of men. A National Mental Health Association survey on the public's attitude and beliefs about clinical depression found that more than one-half of women surveyed still believe it is "normal" for a woman to be depressed during menopause.
- **Men who are caregivers deal with depression differently.** Men are less likely to admit to depression and doctors are less likely to diagnose depression in men. Men will more often "self-treat" their depressive symptoms of anger, irritability or powerlessness with alcohol or overwork. Although male caregivers tend to be more willing than female caregivers to hire outside help for assistance with home care duties, they tend to have fewer friends to confide in or positive activities outside the home. The assumption that depressive symptoms are a sign of weakness can make it especially difficult for men to seek help.
- **Lack of sleep contributes to depression.** While sleep needs vary, most people need eight hours a day. Loss of sleep as a result of caring for a loved one can lead to serious depression. The important thing to remember is that even though you may not be able to get your loved one to rest throughout the night, you can arrange to get much needed sleep. Hiring a respite worker to be with your loved one while you take a nap or finding a care center or scheduling a stay-over with another family member for a few nights are ways to keep your care-giving commitment while getting the sleep you need.
- **Depression can persist after placement in a care facility.** Making the decision to move a loved one to a care center is very stressful. While many caregivers are finally able to catch up on much needed rest, loneliness, guilt and monitoring the care a loved one receives in this new location can add new stress. Many caregivers feel depressed at the time of placement, and some continue to feel depressed for a long time after.

One well-known study by Schulz, et al., (1995), looked at depression in caregivers of Alzheimer's patients over a four-year period and concluded that female caregivers overall experience more depressive symptoms, but if men stay in a long-term care-giving role, they begin to become increasingly depressed as time goes on. For men and women, the more difficult a person was to care for in terms of behavior, the higher the levels of associated stress in the caregivers. Furthermore, the authors also noted that perceived levels of high social support tended to buffer caregivers against depression. Overall, in another study, depression was found to be the most commonly reported mental health problem for caregivers (Bergman-Evans, 1994). Other studies have shown that the major risk factor for the development of depression in caregivers is loss of social contacts and support that a caregiver often experiences when devoting so much time to the person in care.

In one recent study it was determined that elderly caregivers typically report an extra 30 days per year of depression than do elderly persons who do not have care-giving responsibilities (Thompson, Fan, Unutzer, and Katon, 2007).

Caregivers of those persons with dementia are especially at a high risk of developing depression. The Family Caregiver Alliance warns caregivers of the potential consequences of providing long-term care for someone with dementia on the website www.caregiver.org:

> "Researchers have found that a person who provides care for someone with dementia is twice as likely to suffer from depression as a person providing care for someone without dementia.
> The more severe the case of dementia, such as that caused by Alzheimer's disease, the more likely the caregiver is to experience depression. It is critical for caregivers, especially in these situations, to receive consistent and dependable support."

Caring for a person with dementia can be all-consuming. It is different from other types of care giving. Not only do caregivers spend significantly more hours per week providing care, they report more employment problems, personal stress, mental and physical health problems, less time to do the things they enjoy, less time to spend with other family members and more family conflict than non-dementia caregivers. As stressful as the deterioration of a loved one's mental and physical abilities may be for the caregiver, dealing with dementia-related behavior is an even bigger contributor to developing symptoms of depression. Dementia-related symptoms such as wandering, agitation, hoarding and embarrassing conduct make every day challenging and make it harder for a caregiver to get rest or assistance in providing care.

Unfortunately, many barriers exist that keep caregivers from getting the help they need for depression. According to Grey (2003), caregivers fail to get treatment due to several factors:

- Caregivers are too focused on the needs of those they care for and do not take time to take care of themselves.
- The financial resources of the family are often being used by the person that the caregiver takes care of,
- And there is not enough left for the caregiver to pay for therapy and medication.
- Few programs exist to provide outreach to caregivers and provide them with support and linkage to resources.
- Primary care physicians tend to focus only on the patient and do not address the overall needs of the family system.
- Primary care physicians often overlook depression and do not diagnose it in caregivers.

In some areas, programs do exist to provide respite care for a few hours or even a few days, and other inventive programs are found to give support and counseling to caregivers. However, most states do not have these types of programs. The American Medical Association, as well several states including California, Wisconsin, Minnesota, Pennsylvania and Washington, have developed tools for the assessment of caregivers to identify those who are suffering from depression, anxiety, and other issues and to link these caregivers to resources.

African American elderly

Ethnic minority elderly persons have been understudied overall in mental health and psychiatry. However, their numbers are growing even more rapidly than the elder population in general. For example, the elderly African American population is expected to grow by at least 8 percent by the year 2050. However, African American elderly persons are very much underrepresented in studies of the elderly. Moreover, there are often barriers to mental health treatment for the elderly African American population that can make their treatment more difficult.

As noted by Ahmed and Kramer (2006), there is a high level of stigma attached to seeking mental health services for elderly African Americans. Frequently, these elderly persons prefer to seek help from their pastors or other religious leaders. In addition, elderly African Americans tend to be distrustful of the mental health establishment and often feel culturally disconnected to the providers who are very often Caucasian. Furthermore, a lack of cultural understanding has historically led to misunderstanding between older African Americans and the mental health profession.

For example, ethnic majority mental health professionals often overlook many of the life events that older African Americans experienced as severe trauma as a result of segregation and racial violence. Consequently, the mental health establishment often misinterprets the reactions of elderly African Americans towards society as paranoid when these behaviors are, instead, understandable when viewed with a culturally sensitive lens.

In addition, some older African Americans may also express emotional distress in ways that do not have a label in the ethnic majority culture, which are described as “culture bound syndromes.” For example, “falling out” is an emotional state that consists of dizziness and collapse and is widely recognized in the African American culture, but has no real counterpart in Caucasian culture. Some older African Americans may also believe in “rootwork,” which attributes psychological problems to someone placing a hex on an individual.

In addition, African Americans may respond differently to psychoactive medications than Caucasians do. Ahmed and Kramer (2006) cite the work of Lin, et al (1997) that indicated that African Americans might metabolize medications differently than Caucasians.

Hispanic elderly persons

Many Hispanics are reluctant to seek mental health treatment due to language and cultural barriers. This is particularly true among older Hispanics, who often know less English than younger Hispanics.

Furthermore, due to cultural differences, treating Hispanic persons can be difficult if a clinician is unaware of some cultural influences that impact the therapeutic relationship. Ahmed and Kramer cite the work of Anez, et al (2005) and Gloria and Peregoy (1996) to describe common cultural situations:

- **Falisimo** is a term that describes a cultural value among Hispanics that encourages the importance of the family over the individual and for family to be highly valued in general. Extended family tends to be very important and can serve as strength, but also a hindrance to treatment if the family disapproves of treatment for an individual.
- **Simpatia** is a cultural value that emphasizes harmony over conflict. Simpatia, however, can result in Hispanics agreeing with a mental health professional about a course of treatment to avoid creating conflict. However, the person may not follow through with recommendations, but agree to avoid conflict.
- **Personalismo** is the high regard for getting to know another person in a social setting. Hispanic persons may expect and desire to relate on a social level to the clinician and may feel offended if the clinician ignores this need and gets right to business with the client.
- **Respero** is the respect for elders and placing great value on the advice and opinions of the elders of a family. In addition, respero includes the cultural expectation that children will take care of their parents into the elderly years.
- **Fatalismo** is the belief that greater powers control life events and one’s destiny. This belief can lead to a person having a strong external locus of control.
- **Verguenza** is a cultural tradition that revolves around shame. Seeking treatment may bring shame upon a family, and Hispanics will seek to avoid bringing shame if at all possible. This can be a barrier to seeking treatment.
- **Machismo** and **marianismo** are terms that describe gender roles in Hispanic persons. Machismo refers to the traditional role of a man as a protector and provider for his family. Marianismo is the cultural expectation that a woman will be submissive to men and be a nurturing wife and mother.

In addition, many Hispanics practice various religious belief systems such as Santeria, Espiritismo, and Curanderismo. These systems have some common themes regarding the placing of spells and various healing practices to heal the afflicted. Many elderly Hispanic persons have strong beliefs regarding these practices and may wish to use these instead of traditional mental health treatment.

Asian Americans elderly

Asian Americans are the fastest growing minority group in the United States. Asian Americans are comprised of many ethnic groups from numerous countries, with the majority of Asian Americans being Chinese, who make up about 25 percent of all Asians in the United States. As a result of certain cultural and religious beliefs, many Asian Americans believe it is better to deal with mental illness within the family and avoid involving “outsiders.” In addition, the language barrier is often a reason why Asian Americans avoid seeking mental health services. It is also difficult, due to their cultural expectations, to value the needs of the individual over the needs of the family. For many Asian Americans, it can be difficult to understand Western-based therapy, which emphasis individual happiness and choices, often at the expense of the wants and desires of the family unit.

Asian Americans are typically expected to care for their elderly parents and do not consider this to be burdensome. Elderly persons expect that their children will care for them and are not as concerned as Caucasians with the notion of being a burden for their children. This high level of family support can be seen as a strength for older Asian Americans.

However, among many of the Asian cultures, there is a high respect shown for authority figures, which can include mental health professionals. This respect will sometimes result in the client agreeing to follow the recommendations of the therapist, but the client will not actually follow through with these recommendations. (Ahmed and Kramer, 2006).

Pharmacological treatment for Asian Americans
Some studies have indicated that Asian Americans do metabolize medications such as benzodiazepines and antipsychotic medications differently than Caucasians do, which can have adverse effects for treatment. Furthermore, many Asians take herbal supplements that can interact in adverse ways with medications (Ahmed and Kramer, 2006).

Cultural issues
In many Asian cultures there is a particular stigma associated with mental illness. There is a primary concern that if mental illness becomes known, other people will not want to marry into the family. Therefore, the family often conceals psychosis until it has reached the critical point, which can make it more difficult to treat.

There are also several culture-bound syndromes described by Ahmed and Kramer (2006) that occur in Asian cultures but do not have a diagnosis in our culture:

- **Amok,** which is most frequently noted in Southeast Asia, that describes a rampage often resulting in death.
- **Phii Pob:** in Thailand, this is a possession by a spirit and most frequently occurs in females.
- **Hsieh Ping,** which occurs in Thailand, is the manifestation of symptoms that include agitation, speaking in tongues and hallucinations.
- **Hwa-byung,** which is found primarily in Korea and is the presentation of symptoms such as feeling pressure in the chest, fear, headaches, fatigue and suicidal thoughts; it is believed to be the result of unexpressed anger.
- **Shenjing sheuiaro,** found in China, which results in insomnia, loss of appetite, problems with concentration, memory loss, headaches and sexual dysfunction.
- **Latah** is a disorder mostly found in Malaysian females, which results in disassociated behaviors and extreme startle responses and is believed to be caused by possession.
- **Shin-byung** is found in Koreans and results in anorexia, weakness, and insomnia and is believed to result from the possession by one's ancestors.

Native American elderly

Native Americans tend to have higher rates of substance abuse, suicide and anxiety than Caucasians or any other minority group. Native Americans have a long history of oppression and abuse from Caucasian society and have suffered many atrocities over the centuries. The resulting poverty, lack of education, grief and ongoing family conflicts have had many negative effects on Native Americans. The cultural mistrust of "outsiders" has its basis in reality and thus, makes it difficult for many Native Americans to accept services from external resources. (It is interesting to note that among some tribes, dementia is viewed as a sign of the ability to communicate with the afterlife and is actually held in high esteem by other tribal members, rather than a negative condition that requires intervention and treatment.)

Elder mental illness prevention

The key issues in preventing major mental illness in the elderly are:

- Increasing the access of seniors to services in the community.
- Eliminating the stigma that many older adults feel towards mental health therapy.

Some research relates to the importance of removing the stigma associated with receiving treatment for mental illness. Prevention efforts to change the attitudes of elderly persons towards the access of mental health services have been studied, and the research indicated that brief psycho-educational outreach could increase the participation of senior adults in outpatient mental health counseling (Alvidrez, Arean, and Stewart, 2005). Other studies have had similar findings, in that providing education to this population group can help remove that stigma and move them into treatment earlier, thus preventing some later problems. "Spiritual and community support have also been shown to help keep elderly persons more active and provide an overall greater sense of well-being. Social supports help to insulate a person against life events such as bereavement and physical illnesses," (Boyd, 2005).

Suicide prevention

Suicide prevention has received most of the attention in the area of prevention of mental illness and the elderly. There are several risk factors for suicide in the elderly that can be assessed and managed. Certain types of medications can be used in killing oneself rather easily. Therefore, in depressed persons, it is better not to prescribe amitriptyline and dosulepin (Henry et al., 1995).

The increased education and training of general medical practitioners is also critical in the prevention of suicide. A large number of elderly persons who committed suicide were found to have visited their primary care doctor in the month before they killed themselves. Training that is focused on helping doctors recognize the signs of depression would help to prevent some suicides (Vassilas and Morgan 1994; Harwood et al, 2000).

In screening the elderly for suicidal intentions, there are some indications that both the Beck Hopelessness Scale and the Geriatric Depression Scale offer insight into the intent of an elderly person. Suicidal ideations in the elderly are typically preceded by problems with physical health as well as higher scores on Beck's Hopelessness Scale (Hill, et al., 1988). Furthermore, Dennis, et al., (2005) noted that among those elderly persons who suffered from depression, the Geriatric Depression Scale showed that those who had attempted suicide were more likely to have answered yes to the question: " Do you feel your situation is hopeless?" and to have answered no to, "is it wonderful to be alive now?" Therefore, the utilization of these screening instruments can be an effective tool in identifying those elderly persons who are at higher risk of suicide and consequently alert providers to the need for increased monitoring or more intensive interventions.

Prevention of depression

There is also evidence that targeted prevention programs can help prevent the development of depression. Wilson, Mottram and Sixsmith (2007) found in their study of elderly persons between the ages of 80 to 90 that not living close to friends and family, dissatisfaction with housing and strong financial concerns were all associated with higher levels of depression. This research indicates that screening procedures that assess these types of concerns in the elderly can then lead to specific interventions to alleviate these risk factors.

It is critical for those on the "front lines" who regularly interact with elderly persons receive training to recognize depression in their clients. A recent study examined a program delivered by case managers to high-risk elderly persons. Case managers were trained to provide screening and assessment, education, referral and linkage. The authors studied levels of depression, utilization of mental health services, overall health and levels of social and physical activity. Overall, there was a modest decrease in depressive symptoms, but the participants were much more knowledgeable about services available to them and understood that engaging in increased levels of activity led to a better sense of well-being, and had overall less physical pain. (Arean, Alexopolous, and Chu, 2007).

Because many of the elderly in the United States live in nursing homes, it is essential that nursing home personnel recognize the signs of depression. A recent study of nursing home residents demonstrated that efforts to educate caregivers to recognize and respond to depressive symptoms in the residents appeared to have a positive effect. The authors studied two groups of caregivers, providing education to recognize depression symptoms to one of the groups. They assessed depressive symptoms over a period of time for residents assigned to all of the caregivers. The residents who interacted with the trained caregivers had overall lower rates of depression than those residents whose caregivers were not trained to recognize symptoms of depression (Cuijpers and Lammeren, 2000).

Substance abuse prevention

Substance abuse prevention takes on three main forms:

- The first is primary prevention, which can range from regulating certain substances in an effort to curb their usage to consultation from a pharmacist or physician when an older adult begins taking prescription drugs with a high rate of abuse, such as narcotic painkillers. Primary prevention efforts can also involve public education campaigns to educate the public about the issues of substance abuse in an attempt to prevent people from ever beginning the use of substances.
- Secondary prevention acknowledges that a person may have already begun to use a substance, and these prevention strategies are designed to intervene against further use of an illegal substance such as marijuana, or to warn people against developing issues with misuse of a substance, or to halt a progression towards addiction.
- Tertiary prevention involves efforts to halt the progression of substance abuse that is rather severe, and to stop it from becoming fatal (Carlson, 1994).

Substance abuse is typically underdiagnosed in the elderly population. Substance abuse in the elderly often involves prescription medications or alcohol, rather than street drugs such as marijuana, heroin or cocaine. In treating the elderly, it is critical to realize that prevention efforts against substance abuse often have further-reaching impacts on the elderly person's health. Substance abuse of alcohol or prescription drugs can have a profound impact on the other medications that an elderly person may truly need for other health conditions. It can also be more difficult to utilize prevention methods regarding prescription medications when many doctors do not consider that the elderly are often more sensitive to medications overall.

Many medications are simply inappropriate for elderly persons due to the tendency of some medications to lead to mental confusion and problems with physical coordination that result in falls and injuries (Carlson, 1994). It would seem incongruous that many physicians who treat the elderly are not aware of these issues, but studies have indicated about 25 percent of elderly persons were prescribed wrong medications (Wilcox, 1994).

Complicated issues accompany elderly persons and medications, in addition to the prevention of the misuse of prescription drugs. Some studies have shown that elderly persons often withhold information from their physicians because they think many of their symptoms are a normal part of aging and not important enough to mention. Other seniors have limited incomes and do not consistently stay on their medications because they cannot afford them. In addition, many doctors do not take enough time to explain side effects and the importance of medication compliance to their patients. Better training with physicians is needed to help prevent prescription medication complications within the elder population (Carlson, 1994).

Carlson goes on to note that prevention of substance abuse in the elderly should focus on general education towards preparing the elderly for life changes, financial preparation and bereavement. In addition, there needs to be more education for the elderly about the dangers of alcohol and prescription drug abuse. However, these prevention efforts need to target not just heavy drinkers, but also those who are infrequent users in order to help them understand the dangers of mixing alcohol and prescription drugs. Furthermore, moderate drinkers need to understand how the physiological differences that accompany advancing age also change the body's response to alcohol. The quantity of alcohol absorbed within the body at age 45 may be too great for a 75-year-old person. In addition, based on the extensive study of multistate prevention efforts, Carlson noted common factors that should be present for the successful implementation of substance abuse prevention efforts:

1. **Collaboration** – The plans for an elderly substance abuse and misuse prevention initiative should be developed with participation from other state-level agencies involved in services to older adults, include consultation with relevant local and regional service providers and also involve participation by representatives from the aging community.

   This recommendation recognizes the various services that might be appropriate entry or target points for prevention efforts and the importance they have had in prevention efforts elsewhere. Early involvement is critical for full utilization of these options in any program implementation. It also acknowledges the diverse interests such groups represent and the need for any initiative to reflect this diversity and draw on its strengths.
2. **Information –** Strategies for any prevention initiative should include compilation and packaging of information about the targeted problem or problems, and where and how to access additional resources and services. Such a package should make maximal use of existing materials and resources, with the primary attention directed to distribution of information rather than development of new materials.

   This recommendation addresses the existing availability of diverse informational and training materials and stresses the value of putting them together in such a way as to improve their accessibility through a carefully planned distribution strategy. The goal is to have them more readily and widely identified, reviewed and utilized.
3. **Education –** Considerations for support of education and training should include the elderly clients, their family members, senior and substance abuse services providers, other caregivers and gatekeepers, and health care providers that include physicians.

   Effective prevention requires the involvement of the individual at risk plus the complex network of associates and service providers likely to be in a position to perpetuate, identify or intervene in the substance abuse or misuse problem. The recommendation draws on indications that multiple points of action are most effective. It also acknowledges the central role often played by others in the health and well-being of older adults.
4. **Scope-prevention** initiatives for the elderly should be wide in scope and include as part of their aims not only improvement in general health behaviors other than substance abuse and misuse but also support for secondary intervention and treatment.

   This recommendation is consistent with the suggestions of experts in the field about the need to include a range of prevention strategies with this age group. It also attends to the often-overlapping causes and consequences of health behaviors among older adults and the advantages of intervening to prevent further health compromises.

5. **Pilot program –** Pilot or demonstration programs should be considered that improve linkages between information and education efforts and individualized attention or counseling.

   Standard prevention approaches often fail to lead to the desired behavioral change. One solution identified to improve these outcomes is to complete more personalized follow-up, particularly with high-risk individuals. The recommendation aims to encourage the planners of elderly prevention programs to be innovative and to draw on research knowledge of what is likely to be effective.
6. **Policy –** Finally, prevention strategies should review state and agency policies that affect this age group, seeking to identify areas for specific changes directly influencing substance abuse and misuse and their prevention or intervention, as well as more general policies affecting quality of life and social roles.

   This final recommendation addresses the power of policy to shape action. Policy directives have been identified elsewhere as ways to influence medication practice, improve access to substance abuse services and reduce ageism and stereotypes. Policy can lead to social change. Some part of the problems of substance abuse and misuse among the elderly would be substantially reduced with attention to the stigma, discrimination, social isolation and poverty affecting older adults.

TREATMENT OF MENTAL ILLNESS IN THE ELDERLY

The treatment of mental illness in the elderly has been the subject of numerous studies. It has been fairly well established that some form of treatment was better than no treatment at all (Socgin and McElreath, 1994).

Treatment of depression

One recent study of various forms of treatment for depression in the elderly concluded that there was enough evidence of the effectiveness of cognitive behavioral treatments and psychodynamic treatments for depression to be recommended for continued usage (Fiske, et al., 1999). One model, in particular, is the IMPACT model. IMPACT is an acronym for Improving Mood, Promoting Access to Collaborative Treatment for late-life depression.

IMPACT is a treatment model that studied approximately 1800 elderly persons who met DSM-IV criteria for major depression or dsythymia. A team that included a primary care physician, depression care-manager and a consulting psychiatrist implemented the model. The study compared groups of elderly persons who received only medication, only psychotherapy, or some combination of both. About 70 percent of participants received medication, 70 percent received psychotherapy and about 90 percent overall received some form of intervention. As participants began to improve, an assigned care manager facilitated creating a relapse prevention plan. The control group of elderly persons received visits with their primary care physician and referral to mental health specialists. About 50 percent of these participants received medication and another 25 percent received mental health intervention. The researchers followed the participants over a 24-month period and found that the IMPACT participants had superior outcomes overall, with less depression than those persons who did not receive the collaborative treatment (Hunkeler, et al., 2006).

However, studies that are more recent have compared the effectiveness of various treatments for depression in which the authors conducted a meta-analysis of 122 psychosocial and psychotherapeutic interventions. The studies primarily involved adults aged 55-76 diagnosed with depression. The meta-analysis looked at:

- Cognitive-behavioral therapy.
- Psychodynamic therapy.
- Reminiscence, relaxation, supportive, control-enhancing treatments.
- Psycho-educational treatments.

It was demonstrated that cognitive-behavioral therapy had above-average effects on depression and overall ratings of well-being. Overall, group therapy or group interventions were less effective than individual therapy. Better outcomes were found in the subjects who received treatment from more qualified therapists, particularly for those therapists who had specialized education in geriatrics (Pinquart and Soerensen, 2001).

Therefore, we can conclude from this study that therapists who have specialized training in working with the elderly and who provide cognitive-behavioral therapy on an individualized basis are likely to be the most effective with depressed elderly persons.

Pharmacological treatment for depression

Due to the many physiological changes that accompany advancing age, prescribing medication for the elderly can be very challenging. Swift and Triggs, (2006) noted the following physiological changes that occur in the elderly:

- Elevation of gastric pH.
- Reduction of gastric emptying rate.
- Thinning and reduction of absorptive surface.
- Decline in total body size in advanced age.
- Relative increase in total body fat until advanced age.
- Decline in metabolically active tissue.
- Decline in total body water.
- Reduction in liver mass.
- Redistribution of regional blood flow away from liver.
- Reduction in renal tubular function.

Antidepressant treatment is controversial, regardless of the age of the person. There are special considerations in prescribing medication to the elderly to treat depression. Elderly persons have different outcomes associated with the use of serotonin reuptake inhibitors than do younger persons. These medications are effective in younger people, but have a tendency to cause episodes of mania in older people for reasons that are not totally understood (Pinals, 2006).

Salzman, Wong and Wright (2002), concluded after their analysis of multiple studies involving the use of medication in treating the depressed elderly that antidepressants were, in general, effective. No one particular form of antidepressant was found to be superior to another. However, the authors also noted that the incidences of relapse among the elderly were quite high when medications were discontinued, so in conclusion, it was found to be very important for many elderly persons to be prepared to continue maintenance doses on a long-term basis. Another study found similar outcomes. As major depressive disorders do have a rather high chance of recurrence over the life course, it has been recommended that long-term maintenance pharmacological treatment is the best way to manage further recurrence (Flint and Rifat, 2000).

Marriage and family therapy

Marital therapy can be effective in helping older persons with depression. The use of marital (dyadic) therapy to assist a person in responding to a spouse's depression is often helpful for couples. The elder depressed spouse can benefit when the other partner learns to communicate more effectively, reducing counterproductive negative comments (Asen, 2006).

The use of family therapy is also considered by some authors to be an ideal intervention for an elderly person who is suicidal, as the family can give support to the elderly family member. In addition, family therapy can also be a useful intervention with the elderly who are having problems coping with their adult children, who may suffer from their own mental issues and substance abuse problems (Richman, 2004).

In addition, family therapy can assist in maintaining the well-being of an elderly person. One of the keys to determining the best family therapy framework to follow is to complete a comprehensive assessment with the elder adult. The mnemonic PRACTICE (Christie-Seeley, 1984) is a model that is designed to work with the elderly in particular, and it includes the following dimensions:

P - Presenting problem.
R - Roles and rules.
A - Affect.
C - Communication.
T - Time in family life cycle.
I - Illness.
C - Community.
E - Environmental.

- The presenting **problem** can be the actual mental illness or other systemic issues within the family. It is important for the family therapist to gather information concerning how each family member views the problems of the elderly person.
- In terms of **roles and rules,** it is critical to assess family functioning before and after the presenting problem arose. The emergence of a mental illness can result in a shift in family roles. The father who was the patriarch and is now incapacitated with depression will often abdicate this role and place the mother into a new role that may be very uncomfortable for her.
- **Affect** involves the assessment of how the family express emotion.
- **Communication** looks to assess who does the talking for the family, which family members do not speak to each other and whether the communication is clear.
- **Time in family lifecycle.** Successful transition to different stages in life requires flexibility to accept the changes that come with different life stages. For example, it is important to assess how elderly people have accepted the change in caregiving roles as children leave home and start their own families. Elderly persons who have been unable to accept this change will have more difficulty with the changes in roles that come at different life cycle stages.
- **Illness –** This dimension of assessment explores the etiology of the mental and/or physical illnesses affecting the family. In addition, it is important to explore the issues of guilt and shame associated with the emergence of the illness.
- **Community –** The interviewer needs to assess what supports exist in the community and what needs are unmet for housing, medical care, social support, etc. The family also needs to be assessed to determine which, if any, supports they are willing to accept.
- **Environment** includes the assessment of housing, finances, employment, neighborhood and cultural context.

Electroconvulsive therapy

Electroconvulsive therapy, (ECT), which is sometimes known by the slang term "shock treatment" is highly controversial. It has been shown to be effective, but is generally limited to usage in the most severe cases of depression that are unresponsive to medication and psychotherapy. The National Alliance for the Mentally Ill (NAMI) states on its website, www.nami.org, that ECT has been shown to be effective, but notes that it is very difficult to receive the treatment due to the history of the misuse of the procedure and the many myths surrounding its usage. Without specifically endorsing ECT, the organization does state that it should be considered as a treatment for only appropriately assessed individuals.

There have been other studies that indicated the effectiveness of ECT for treating depression in the elderly. It was noted that 79 percent of those people receiving the treatment showed significant improvement in their depressive symptoms. However, the authors did note a significant number of side effects, including hypertension, impaired memory and mental confusion. Consequently, it was urged that subjects for this treatment be chosen carefully (Kujala, Rosenvinge, Bekkelund, 2002).

Some researchers believe strongly in ECT. Some research indicates that even one treatment of ECT can reduce depression by 21 percent (Williams, O'Brien, and Cullum, 1997). Tew (1999) reported that one-half to three-fourths of depressed elderly persons had favorable outcomes from ECT treatment. Other studies, Zorumski et al., (1988), showed that 80 percent of elderly patients received benefits from ECT. Both Zorumski and Zal (1999), suggest that ECT should be used whenever an elderly person does not respond well to medication, as well as for those who are dangerously depressed with malnutrition or psychosis.

Another meta-analysis of studies of ECT with the elderly showed that 12 studies reported the effects of ECT and found that overall it was found to be effective. In one-third of the studies, ECT was actually found to be more effective than treatments with antidepressants. Overall, the studies did not find any outstanding incidents of negative side effects from the ECT (Salzman, Wong and Wright, 2002).

Problem-solving therapy

In addition, many of the elderly who are diagnosed with depression are chronically physically disabled or ill. The co-morbidity of physical illness and depression sets up a vicious cycle in which the physical problems aggravate the depression, but the depression in turn makes it easier for people to give up hope and not adhere to their physical recovery as well. A strong need for integrated treatment exists.

In their study of depressed elderly persons with chronic obstructive pulmonary disease (COPD), Alexopoulos, Raue, Sirey and Arean (2007) noted that the lack of energy, loss of interest in daily activities and the general apathy that accompanies depression makes it especially hard for patients with COPD to follow their physical rehabilitation. The authors identified that using a combination of therapy to help with problem-solving skills as well as techniques to help decrease the resistance to treatment appeared to be the most effective in helping to alleviate depression and to have the participants follow their treatment regime for COPD. It appears that the therapy itself had some effect on the depression, but the adherence to the medical treatment also helped participants feel better physically, which could have also alleviated some of the depression. Similar results were found in a study of depression and arthritis in the elderly. The collaborative care approach, which utilized case managers and incorporated the problem-solving therapy approach with clients, was found to result in both decreased problems with arthritis and a decrease in depression (Lin, et al., 2003).

Treatment of bipolar disorder

Many of the medications required to treat bipolar disorders are very strong with a rather high incidence of side effects. This treatment of bipolar disorder in the elderly is made more complicated by the fact that pharmacological interventions for the elderly are different due to physiological changes that occur with advancing age. For example, lithium is the drug of choice to control bipolar disorders in younger people. However, most elderly persons have somewhat diminished renal functioning, and lithium can cause complications with renal function that can be deadly in older persons (Gutman and Gutman, 2006).

Interventions which include the use of psycho-education in addition to medication have been shown to produce better outcomes than those studies in which medication alone was used (Colom, Vieta, Martinez-Aran, 2003; Colom, Vieta, Reinares, 2003).

Lithium and divalproex appear to be effective to treat mania in the elderly with bipolar disorder. However, the research in this area is still not very extensive. Other classifications of drugs, such as anti-depressants, have been examined in extremely few studies. There is almost no research on the ideal dosages or the length of administration of the medications. Age-related factors might attenuate benefit and increase vulnerability to side effects of pharmacotherapy. (Young, et al, 2004).

In examining the long-term behaviors of adults with bipolar disorder, it was also noted that persons with this diagnosis often have a hard time being compliant with medication, and this can hamper the treatment of the illness (Martire, et al., 2004).

Treatment for anxiety

There have not been a large number of studies pertaining to the treatment of anxiety in the elderly. One of the few in recent years indicated that risperidone proved useful in the treatment of anxiety disorders (Morinigo, 2004). Benzodiazepines have been used to treat anxiety for decades, but are not always the best course of treatment for the elderly as they tend to cause sedation, mental confusion and lack of physical coordination, even at fairly low doses. In addition, the tolerance for benzodiazepines builds very quickly and therefore requires the use of higher and higher doses to achieve the same results (Ettinger and Kanner, 2006).

In a meta-analysis of the treatment of anxiety in older persons, the average participant had suffered from anxiety for 19 years, had an average age of 69, and two-thirds were women. Behavioral interventions and medication were examined across all studies, and medication appeared to have some advantage over therapy for symptom improvement. Overall, control groups who received no treatment showed improvement in about 30 percent of cases. No particular form of therapy showed superiority over another. Nor were any outstanding differences found between classes of drugs used to treat anxiety (Pinquart and Duberstein, 2007).

Another study comparing different forms of cognitive behavioral therapy (CBT) did show that it was effective for generalized anxiety disorder. An enhanced form of cognitive behavioral therapy included learning and memory aids designed to make the therapy more effective with elderly patients. Homework reminders, troubleshooting calls and a weekly review of all concepts and techniques were compared with standard cognitive behavioral therapy. The enhanced version was found to be more effective.

Cognitive behavioral therapy has shown promise as an effective treatment in the elderly who suffer from anxiety. CBT with the elderly has been studied far less than the use of CBT with younger people, but it has been shown to be effective in younger people. Therefore, it has been generally assumed that it would also work well with the elderly. However, few studies have empirically tested this theory.

Services for the elderly

There is an array of services to help the elderly when they are unable to fully function, either mentally or physically. In general, case management services are not offered exclusively for mental health issues, but programs include services for the mental health needs of the elderly as part of services that are already offered. Most states do have some sort of program to serve the elderly. In Florida, for example, the Department of Elder Affairs has local offices called Area Agencies on Aging that link the elderly to a variety of programs in their county. The state level program is primarily aimed at seniors with physical impairment and offers case management, meal delivery, legal assistance, adult day care, respite services and emergency response. Fees are often charged on a sliding scale basis. In South Florida, which has a high number of senior citizens, private agencies, such as Jewish Social Services of South Florida, offer a wide and comprehensive array of services to the elderly, including in-home therapy and case management.

However, for those elderly who live in rural areas or in states with low numbers of elderly persons, services are often very limited. For the rural elderly in particular, access to services is very difficult. Many elderly persons in rural areas live in poverty and have little access to transportation. However, some efforts, such as mobile teams of psychiatrists and therapists to access rural areas, have provided more help to some communities. Though even 20 years ago, telephonic therapy was heralded as a cutting-edge idea that could provide more access to therapy and other services, there were issues related to funding of these services through Medicare, and this great technological idea never really materialized (Kirchner, 1981).

The New York State Office for the Aging lists detailed services for health care, housing, energy and transportation, and some social services that are primarily related either to persons with Alzheimer's or caregiver support groups. Yet, "mental health" receives only one link that connects to a list of county mental health departments, with no details given about the type or availability of services. In Texas, the Department of Aging and Disability focuses on a range of services, such as housing and health care and information about adult daycare. But there is no mention of mental health services in any explicit way, and only a link is provided to a general help line for an array of services. Iowa, California and Georgia are among the states that offer a typical range of services to the elderly, including comprehensive services, meal delivery, emergency response, homemaker services and respite care.

Some states, such as South Dakota, offer case management to the elderly as a way to assess needs, link families to resources in the community and hopefully avoid crisis situations before they occur. Assessment and treatment planning are utilized with the ultimate goal of preventing seniors from moving into institutional care before it is truly needed, or in some cases, prevent residential care from occurring at all. Vermont is another state that appears to have a more comprehensive approach to working with elderly persons with mental health needs, through its Elder Care program, which is a joint effort of the mental health and aging departments of the state government. This program provides a senior help line, counseling, case management and medication monitoring specifically aimed at elderly persons.

In addition to state-run programs, many private agencies offer senior care management for private-paying individuals. These agencies typically offer a variety of services, including assessment, medical in-home care, case management and guardianship. Still, many of these agencies, both public and private, do not mention mental health needs as part of their assessment or services. There are some references to dementia and Alzheimer's disease, but with a few notable exceptions, little reference to or focus on depression, substance abuse, anxiety and other mental disorders.

There has been a small amount of research conducted on the efficacy of case management in the elderly mentally ill. Arean, Alexopoulos and Chu (2007) studied the benefits of case management for a group of low-income, depressed seniors. Low-income seniors who received therapy for depression reported having too many life concerns that could not be adequately addressed in therapy alone, such as financial, transportation and housing problems. The authors conducted a study with control groups of seniors who received only CBT, only case management, and a combination of case management and CBT. The group who received both CBT and case management had better outcomes than those seniors who only received CBT, or only received case management.

Adult day care is another service that can help adults suffering from a variety of mental health problems. The National Adults Day Service Association has member agencies throughout the United States. Many of these programs focus on seniors with medical issues, and others only serve those individuals with dementia, Alzheimer's disease and related memory disorders. A few of these programs do provide services that focus on adults with mental illness, but these are not very common and are typically associated with hospitals.

In the state of Florida, the Department of Elder Affairs requires that adult day care must provide supervision, one meal per day, arts and crafts, and leisure time activities. Optional services include social services, health services, and occupational, physical and speech therapy. Many centers are not capable of handling adults with persistent mental illness. Day-care centers that provide social and mental health services provide a great service for families. However, the average cost of such a center is $64 per day, which can be very difficult for many elderly persons and their families to pay. Most states offer some sort of subsidies based on income.

Conclusion

Mental health of older adults can be improved through promoting active and healthy ageing. Mental health-specific health promotion for the older adults involves creating living conditions and environments that support wellbeing and allow people to lead healthy and integrated lifestyles. Promoting mental health depends largely on strategies which ensure the elderly have the necessary resources to meet their basic needs, such as:

- Providing security and freedom.
- Adequate housing through supportive housing policy.
- Social support for elderly populations and their caregivers.
- Health and social programs targeted at vulnerable groups such as those who live alone, rural populations or who suffer from a chronic or relapsing mental or physical illness.
- Violence or older adults maltreatment prevention programs.
- Community development programs.

There are many elderly persons in the United States who are not receiving appropriate mental health screening, diagnosis and intervention. In addition, many areas of mental illness treatment for the elderly have a paucity of research studies that use control groups and longitudinal outcomes on which to base best practices.

Much of the therapeutic and pharmacological treatments utilized for the elderly are based on studies done with much younger persons and ignore the fact that elderly persons do not have the same psychosocial needs or physiological makeup. In addition, elder clients may not respond as well to therapy interventions as would a younger person, so their medications may also affect them differently. Though many elderly persons in the United States are also from ethnic minority groups, very few social workers, therapists and psychiatrists are given the appropriate cultural diversity training to enable them to engage their elderly clients most effectively.

Many nursing homes do not have staff adequately trained to recognize mental health issues or the fact that residents may be overmedicated. Consequently, residents may be prescribed incorrect medications with the intention of regulating their behaviors. Those elderly persons who live in their homes, either alone or with family, often do not receive appropriate mental health interventions because they generally receive screening, diagnosis and treatment from their general practitioners – medical doctors who lack the expertise needed to recognize and treat mental illness.

At particularly high risk for mental health problems are elderly persons who also function as caregivers. Often, these persons are underserved by social service and mental health agencies in their communities.

A few states have comprehensive service networks for the elderly, and quite a few private agencies exist to help families coordinate services. Many services only focus on Alzheimer's and/or physical problems and ignore mental health problems. Some mental health prevention services exist, but few are currently funded even though several studies have shown that case management and a problem-solving approach can help to engage elderly persons in treatment sooner and more effectively.

A crisis looms on the horizon, as the lack of expertise in treating mental illness in the elderly and the scarce number of programs and resources collide with a rapidly increasing number of aging Baby Boomers. The call set forth years ago by the American Psychiatric Association has not been fully heeded, and as these needs arise without the necessary preparations in place, there will likely be a long struggle ahead and many lessons to be learned.

How can you help research on dementia?

People with dementia and others who wish to help research on dementing disorders may be able to do so by participating in clinical studies designed to learn more about the disorders or to test potential new therapies. Information about many such studies is available free of charge from the federal government's database of clinical trials, clinicaltrials.gov (*http://clinicaltrials.gov*).

Information about clinical trials specific to AD is available from the Alzheimer's Disease Clinical Trials Database (*http://www.nia.nih.gov/alzheimers)* a joint project of the U.S. Food and Drug Administration and the National Institute of Aging (NIA) that is maintained by the NIA's Alzheimer's Disease Education and Referral Center.

For clinical trials taking place at the National Institutes of Health, additional information is available from the following office:

Patient Recruitment and Public Liaison Office
Clinical Center
National Institutes of Health
Building 61, 10 Cloister Court
Bethesda, MD 20892-4754
800-411-1222 | 866-411-1010 (toll free) | TTY: 301-594-9774 (local)
http://clinicalcenter.nih.gov/

Voluntary health organizations may be able to provide information about additional clinical studies.

Glossary of terms

Acetylcholine – A neurotransmitter that is important for the formation of memories. Studies have shown that levels of acetylcholine are reduced in the brains of people with Alzheimer's disease.

Alzheimer's disease – The most common cause of dementia in people aged 65 and older. Nearly all brain functions, including memory, movement, language-judgment, behavior and abstract thinking, are eventually affected.

Amyloid plaques – Unusual clumps of material found in the tissue between nerve cells. Amyloid plaques, which consist of a protein called beta amyloid along with degenerating bits of neurons and other cells, are a hallmark of Alzheimer's disease.

Amyloid precursor protein – A normal brain protein that is a precursor for beta amyloid, the abnormal substance found in the characteristic amyloid plaques of Alzheimer's disease patients.

Apolipoprotein E – A gene that has been linked to an increased risk of Alzheimer's disease. People with a variant form of the gene, called apoE epsilon 4, have about 10 times the risk of developing Alzheimer's disease.

Ataxia – A loss of muscle control.

Atherosclerosis – A blood vessel disease characterized by the buildup of plaque, or deposits of fatty substances and other matter in the inner lining of an artery.

Beta amyloid – A protein found in the characteristic clumps of tissue (called plaques) that appear in the brains of Alzheimer's patients.

Binswanger's disease – A rare form of dementia characterized by damage to small blood vessels in the white matter of the brain. This damage leads to brain lesions, loss of memory, disordered cognition and mood changes.

CADASIL – A rare hereditary disorder linked to a type of vascular dementia. It stands for cerebral autosomal dominant arteriopathy with subcortical infarct and leukoencephalopathy.

Cholinesterase training – Drugs that slow the breakdown of the neurotransmitter acetylcholine.

Cognitive training – A type of training in which patients practice tasks designed to improve mental performance. Examples include memory aids, such as mnemonics, and computerized recall devices.

Computed tomographic (CT) scans – A type of brain scan that uses X-rays to detect brain structures.

Cortical atrophy – Degeneration of the brain's cortex (outer layer). Cortical atrophy is common in many forms of dementia and may be visible on a brain scan.

Cortical dementia –A type of dementia in which the damage primarily occurs in the brain's cortex, or outer layer.

Corticobasal degeneration – A progressive disorder characterized by nerve cell loss and atrophy in multiple areas of the brain.

Creutzfeldt-Jakob disease – A rare, degenerative, fatal brain disorder believed to be linked to an abnormal form of a protein called a prion.

Dementia – A term for a collection of symptoms that significantly impair thinking and normal activities and relationships.

Dementia pugilistica – A form of dementia caused by head trauma such as that experienced by boxers. It is also called chronic traumatic encephalopathy or boxer's syndrome.

Electroencephalogram (EEG) – A medical procedure that records patterns of electrical activity in the brain.

Fatal familial insomnia – An inherited disease that affects a brain region called the thalamus, which is partially responsible for controlling sleep. The disease causes dementia and a progressive insomnia that eventually leads to a complete lack of sleep.

Frontotemporal dementias – A group of dementias characterized by degeneration of nerve cells, especially those in the frontal and temporal lobes of the brain.

FTDP-17 – One of the frontotemporal dementias, linked to a mutation in the tau gene. It is much like other types of the frontotemporal dementias but often includes psychiatric symptoms such as delusions and hallucinations.

Gerstmann-Straussler-Schneiker disease – A rare, fatal hereditary disease that causes ataxia and progressive dementia.

HIV-associated dementia – A dementia that results from infection with the human immunodeficiency virus (HIV) that causes AIDS. It can cause widespread destruction of the brain's white matter.

Huntington's disease – A degenerative hereditary disorder caused by a faulty gene for a protein called Huntington. The disease causes degeneration in many regions of the brain and spinal cord, and patients eventually develop severe dementia.

Lewy body dementia – One of the most common types of progressive dementia, characterized by the presence of abnormal structures called Lewy bodies in the brain. In many ways, the symptoms of this disease overlap with those of Alzheimer's disease.

Magnetic resonance imaging (MRI) – A diagnostic imaging technique that uses magnetic fields and radio waves to produce detailed images of body structures.

Mild cognitive impairment –A condition associated with impairments in understanding and memory not severe enough to be diagnosed as dementia but more pronounced than those associated with normal aging.

Mini-Mental State Examination – A test used to assess cognitive skills in people with suspected dementia. The test examines orientation, memory and attention as well as the ability to name objects, follow verbal and written commands, write a sentence spontaneously and copy a complex shape.

Multi-infarct dementia – A type of vascular dementia caused by numerous small strokes in the brain.

Myelin – A fatty substance that coats and insulates nerve cells.

Neurofibrillary tangles – Bundles of twisted filaments found within neurons and a characteristic feature found in the brains of Alzheimer's patients. These tangles are largely made up of a protein called tau.

Neurotransmitter – A type of chemical, such as acetylcholine, that transmits signals from one neuron to another. People with Alzheimer's disease have reduced supplies of acetylcholine.

Organic brain syndrome – A term that refers to physical disorders (not psychiatric in origin) that impair mental functions.

Parkinson's dementia – A secondary dementia that sometimes occurs in people with advanced Parkinson's disease, which is primarily a movement disorder. Many Parkinson's patients have the characteristic amyloid plaques and neurofibrillary tangles found in Alzheimer's disease, but it is not yet clear whether the diseases are linked.

Pick's disease – A type of frontotemporal dementia where certain nerve cells become abnormal and swollen before they die. The brains of people with Pick's disease have abnormal structures, called Pick bodies, inside the neurons. The symptoms are very similar to those of Alzheimer's disease.

Plaques – Unusual clumps of material found between the tissues of the brain in Alzheimer's disease. See also amyloid plaques.

Post-traumatic dementia – A dementia brought on by a single traumatic brain injury. It is much like dementia pugilistica, but usually also includes long-term memory problems.

Presenilin 1 and 2 – Proteins produced by genes that influence susceptibility to early-onset Alzheimer's disease.

Primary dementia – A dementia, such as Alzheimer's disease, that is not the result of another disease.

Primary progressive aphasia – A type of frontotemporal dementia resulting in deficits in language functions. Many, but not all, people with this type of aphasia eventually develop symptoms of dementia.

Progressive dementia – A dementia that gets worse over time, gradually interfering with more and more cognitive abilities.

Secondary dementia – A dementia that occurs as a consequence of another disease or an injury.

Senile dementia – An outdated term that reflects the formerly widespread belief that dementia was a normal part of aging. The word senile is derived from a Latin term that means, roughly, "old age."

Sub-cortical dementia – Dementia that affects parts of the brain below the outer brain layer, or cortex.

Substance-induced persisting dementia – Dementia caused by abuse of substances such as alcohol and recreational drugs that persists even after the substance abuse has ended.

Tau protein – A protein that helps the functioning of microtubules, which are part of the cell's structural support and help to deliver substances throughout the cell. In Alzheimer's disease, tau is changed in a way that causes it to twist into pairs of helical filaments that collect into tangles.

Transmissible spongiform encephalopathies – Part of a family of human and animal diseases in which brains become filled with holes resembling sponges when examined under a microscope.

CJD is the most common of the known transmissible spongiform encephalopathies.

Vascular dementia – A type of dementia caused by brain damage from cerebrovascular or cardiovascular problem, usually strokes. It accounts for up to 20 percent of all dementia.

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ELDERLY MENTAL HEALTH: DEPRESSION AND DEMENTIA

Final examination questions

Select the best answer for each question and proceed to ***SocialWork.EliteCME.com*** to complete your final examination.

31. It is projected that there will be an estimated:
    a. 25 million mentally ill senior citizens by 2030.
    b. 100 million mentally ill senior citizens by 2030.
    c. 10 million mentally ill senior citizens by 2030.
    d. 15 million mentally ill senior citizens by 2030.

32. Historically in the United States, our society has viewed and treated the elderly as _________ and has lowered its expectations for their quality of life.
    a. Physically disabled.
    b. More independent.
    c. Less capable.
    d. Less independent.

33. While ____________ are typically thought to emerge relatively early in life, it is estimated by the University of Pittsburg Medical Center that 10 percent of elderly persons with bipolar disorder develop the disorder for the first time after the age of 50.
    a. Anxiety disorders.
    b. Social phobias.
    c. Neurocognitive functions.
    d. Bipolar disorders.

34. Medications can sometimes lead to reactions or side effects that mimic:
    a. Sleep apnea.
    b. Strokes.
    c. Dementia.
    d. Depression.

35. Doctors often use ___________ to identify strokes, tumors or other problems that can cause dementia.
    a. Brain scans.
    b. Blood tests.
    c. Gamma rays.
    d. EKG tests.

36. These drugs slow the breakdown of the neurotransmitter acetylcholine, which is reduced in the brains of people with Alzheimer's disease.
    a. Mood stabilizers.
    b. Stimulants.
    c. Cholinesterase inhibitors.
    d. Tricyclics.

37. Tertiary prevention involves efforts to halt the progression of substance abuse that is rather severe, and to stop it from becoming:
    a. A problem.
    b. In need of further assessment.
    c. Fatal.
    d. Habitual.

38. __________ disease is a rare, degenerative, fatal brain disorder believed to be linked to an abnormal form of a protein called a prion.
    a. Alzheimer's.
    b. Parkinson's.
    c. Creutzfeldt-Jakob.
    d. Crohn's.

39. A _________ is a type of chemical, such as acetylcholine, that transmits signals from one neuron to another.
    a. Proton.
    b. Neurotransmitter.
    c. Neurotron.
    d. Transitron.

40. Primary progressive _________ is a type of frontotemporal dementia resulting in deficits in language functions.
    a. Dementia.
    b. Aphasia.
    c. Syndrome.
    d. Disease.

SWCA06HDE16

Chapter 5: The Heroin Abuse Epidemic in America: Identification, Treatment and Prevention

4 CE Hours

By: Deborah Converse, MA, NBPTS

Learning objectives

Upon completion of this course, the student will master the following objectives:

- Discuss the composition and properties of three types of heroin and the effect of the drug on the brain.
- Identify three ways heroin is introduced into the body and compare and contrast the effects of the three types of transmission
- Describe two categories of signs and symptoms of heroin use and give four examples of each.
- Explain the differences between the psychological and physical effects of short-term and chronic heroin use, and give four examples of each.
- Discuss immediate and long-term treatment methods and including three evidence-based therapies to treat heroin use.

Introduction

The purpose of this course is to familiarize professionals with basic information concerning heroin addiction, which has reached epidemic proportions in the United States and around the globe. This includes facts about heroin and addiction, effects on the brain, progression of the disease, psychological and physical effects of short-term and chronic use, screening, treatment, and prevention. The course covers background information and statistics on the escalation of heroin addiction in the United States from 1850 to 2014 including causative factors. The review includes evidence-based treatment and prevention programs, as well as the current trends in progress to advance prevention and treatment of the disease.

Background

Addiction to opiates, in the form of opium, became a significant problem in the United States during the 1850s. Morphine was introduced as a replacement because it was thought to be weaker and non-addictive. Soon, morphine addiction became an even larger problem, and the solution was the introduction of heroin. Heroin, also thought to be non-addictive, was developed in 1898 by the Bayer pharmaceutical company in Germany as a treatment for tuberculosis and to address morphine addiction [1]. The addiction cycle continued because heroin turned out to be even more addictive than morphine. Continuing the cycle, methadone was introduced to address heroin addiction. Methadone was also developed in Germany in 1937 as an anesthesia for surgery and was exported to the United States in 1947 under the name “Dolophine”.[1] Methadone was later used to treat heroin addiction but brought with it a new set of problems if not managed properly. Heroin rapidly became a significant health problem in the United States, and over the next 150 years, the death rate due to heroin addiction has soared to 20 times higher than the drug-free population.

What is heroin and how does addiction happen?

Heroin is part of the class of drugs called opioids. The name relates to the heroin molecule that binds to the opioid receptors in the body. The term “opiates” refers to natural, or semi-natural opioids, and heroin has the chemical name diacetylmorphine. Heroin is derived from morphine which occurs naturally in the latex sap of the seed pod of opium poppy plants, which grow in Mexico, Columbia, Turkey, Asia, Afghanistan, and parts of Europe.[2]

Heroin and morphine bind to the opioid receptors in the brain and body but heroin binds more effectively, enhancing pain relief and euphoria in the addict. Heroin and morphine, along with codeine, hydrocodone, oxycodone, and oxymorphone are similar in structure because they all bind to the opioid receptor. Many substances can be used to cut heroin, including sugar, caffeine, flour, baby powder, starch, powdered milk, quinine, strychnine, other poisons and drugs which increase the likelihood of death. Strychnine, rat poisoning, is deadly and if ingested, the person will show behavioral effects similar to other drug-induced behaviors, but marked physical symptoms include muscle tightness, pain, spasms in the muscles and jaw, rigidity of the arms and legs, and arching of the neck and back.[2]

Heroin may be adulterated with compounds that are added to cheaply enhance the euphoric effects. Examples of adulterants are acetaminophen, opiate painkillers, or anesthesia-like xylocaine. Users think that their numbness and “high” is coming from high quality heroin, when in fact, it is due to the combination of an adulterant. Sometimes adulterants produce the opposite effects to heroin, such as cocaine or other stimulants, and this combination can cause lethal effects on the central nervous system. Other adulterants, such as fentanyl, can be lethal because it is 200 times more potent than heroin. In March 2014, 22 people in Pennsylvania died due to overdose, in which stamp-sized bags of heroin were mixed with prescription fentanyl.[7] Fentanyl is a synthetic opioid that binds to the opioid receptors in the brain, and when combined with heroin, produces a deadly high.[3] The danger is that users will take the same dose of heroin as usual, but the effects may be enough to stop their breathing or heart due to central nervous system depression. Other dangerous adulterants, such as levamisole accelerate the heart rate and destroy the immune system, which leads to life-threatening infections throughout the body.[3]

Not only do the addicts buying heroin on the street not know what substances are used to cut the drug, they also do not know the potency of the drug. The purity or the heroin can increase the chance of overdose and death. Street heroin is sold in different forms including black tar, brown powder, and white powder heroin. The purest form is a white powder that may be rose or gray depending on which diluting substances are used to "cut" the heroin to increase the bulk, weight, and profit. Black tar heroin is identified as a ball or chunk of hard, sticky, black or brown material, which is the cheapest and easiest form to make because it is incompletely processed from opium.[1] The next level of processing uses lactose as a diluting agent, which produces brown powder heroin. Some darker colored heroin contains dirt, ground-up brown paper, and black shoe polish as fillers. Contaminants and bacteria in black tar heroin have been known to carry allergens, botulism spores, and necrotizing bacteria causing poisoning, tissue damage, toxic shock, and death.[2] Death may also occur because these contaminants may not dissolve, thus blocking arteries and veins, which cut off blood and oxygen supply causing a deadly aneurism, stroke, or heart attack. Decreased blood flow due to contaminants may also lead to damage, infection, and ultimately failure of vital organs, as well as convulsions and death.

Street heroin can range from highly potent to forms that are mostly fillers, adulterants, and garden-variety contaminants, but all forms of heroin are dangerous, especially when injected. During the process of manufacturing heroin, a number of chemicals may be left behind, including calcium oxide, ammonia, chloroform, hydrochloric acid, and acetic anhydride, which are all lethal ingredients.[2] White powder heroin is a salt form known as diacetylmorphine hydrochloride, and even though white heroin is the purest form, it will still contain lethal contaminants. The purer the heroin, the whiter and shiner it appears, while the more heavily cut heroin will appear duller in color.[2]

When injected, heroin enters blood stream and the effects are felt within seconds, as opposed to snorting or smoking the drug, in which it may take the user ten to fifteen minutes to feel the effects. Immediately following the heroin injection, users often describe feeling a strong euphoric "rush" or a sensation of exhilaration, euphoria, extroversion, enhanced sensations, increased social and communication skills, heightened sexual performance, and a general feeling of well-being.[1] Less pleasant are the dry mouth; warm, flushed skin; heavy arms and legs; and confused mental state. After the euphoria, users experience feeling alternately drowsy and awake, often described as being "on the nod".[2] When the drug is smoked or snorted the initial powerful rush of euphoria may absent but the later effects will be the same. Users often start by smoking or snorting heroin but progress to injecting to get the enhanced rush. When heroin enters the body and crosses the blood-brain barrier, it is changed to morphine and binds to opioid receptors that are located throughout the brain and body.[3] Opioid receptors transmit nerve signals in the brain centers involved in signaling pain/pleasure perception, motivation, and reward. Heroin initially increases pleasurable feelings, decreases pain, and motivates the user to seek the "reward" of another heroin high. Opioid receptors located in the brain stem control nervous system function that signal critical processes such as blood pressure and respiration.[8] Heroin overdose often involves a suppression of breathing, due to the effects of heroin that cancel the signal for the body to breathe, often with deadly results.

Tolerance and dependence

Over time with chronic heroin use, the structure and function of the brain changes. These changes cause individuals to develop tolerance to the drug, requiring increasingly larger amounts to reach a high. The next progressive stage is physical heroin dependence and individuals need to use the drug to avoid withdrawal symptoms known as drug sickness. Psychological dependence follows in which users believe they cannot live without heroin and drug-seeking behaviors motivate their every action.

Withdrawal

Severe withdrawal symptoms occur if individuals try to taper or stop their heroin use. In a few hours after the last heroin dose, the person will begin to feel withdrawal symptoms which may include vomiting, anxiety, insomnia, diarrhea, chills, muscle spasms, panic, hyper movements, and severe drug cravings.[8] It is very difficult and medically dangerous for the individual to go through withdrawal without medical assistance, and individuals will likely relapse to avoid the sickness of withdrawal.

Definitions

The following definitions are included in the National Institute for Drug Addiction (NIDA) publication on the Science of Drug Abuse and Addiction.[3]

- **Addiction:** A chronic, relapsing disease, characterized by compulsive drug seeking and use accompanied by neurochemical and molecular changes in the brain**.** (See below.)
- **Agonist:** A chemical compound that mimics the action of a natural neurotransmitter and binds to the same receptor on nerve cells to produce a biological response.
- **Antagonist:** A drug that binds to the same nerve cell receptor as the natural neurotransmitter but does not activate the receptor, instead blocking the effects of another drug.
- **Anxiety Disorders:** Varied disorders that involve excessive or inappropriate feelings of anxiety or worry. Examples are panic disorder, post-traumatic stress disorder, social phobia, and others.
- **Attention-Deficit Hyperactivity Disorder:** (ADHD): A disorder that typically presents in early childhood, characterized by inattention, hyperactivity, and impulsivity.
- **Anxiety Disorders:** Varied disorders that involve excessive or inappropriate feelings of anxiety or worry. Examples are panic disorder, post-traumatic stress disorder (PTSD), social phobia, and others.
- **Buprenorphine:** A partial opioid agonist for the treatment of opioid addiction that relieves drug cravings without producing the "high" or dangerous side effects of other opioids.
- **Bipolar Disorder:** A mood disorder characterized by alternating episodes of depression and mania or hypomania.
- **Co-morbidity:** The occurrence of two disorders or illnesses in the same person, either at the same time (co-occurring co-morbid conditions) or with a time difference between the initial occurrence of one and the initial occurrence of the other (sequentially co-morbid conditions).
- **Conduct Disorder:** A repetitive and persistent pattern of behavior in children or adolescents in which the basic rights of others or major age-appropriate societal norms or rules are violated.
- **Craving:** A powerful, often uncontrollable desire for drugs.
- **Depression:** A disorder marked by sadness, inactivity, difficulty with thinking and concentration, significant increase or decrease in appetite and time spent sleeping, feelings of dejection and hopelessness, and, sometimes, suicidal thoughts or an attempt to commit suicide.
- **Detoxification:** A process of allowing the body to rid itself of a drug while managing the symptoms of withdrawal; often the first step in a drug treatment program.
- **Dopamine:** A brain chemical classified as a neurotransmitter, found in regions of the brain that regulate movement, emotion, motivation, and pleasure.
- **Dual Diagnosis/Mentally Ill Chemical Abuser (MICA):** Other terms used to describe the co-morbidity of a drug use disorder and another mental illness.

- **Major Depressive Disorder:** A mood disorder having a clinical course of one or more serious depression episodes that last two or more weeks. Episodes are characterized by a loss of interest or pleasure in almost all activities; disturbances in appetite, sleep, or psychomotor functioning; a decrease in energy; difficulties in thinking or making decisions; loss of self-esteem or feelings of guilt; and suicidal thoughts or attempts.
- **Mania:** A mood disorder characterized by abnormally and persistently elevated, expansive, or irritable mood; mental and physical hyperactivity; and/or disorganization of behavior.
- **Mental Disorder:** A mental condition marked primarily by sufficient disorganization of personality, mind, and emotions to seriously impair the normal psychological or behavioral functioning of the individual. Addiction is a mental disorder.
- **Methadone:** A long-acting opioid agonist medication shown to be effective in treating heroin addiction.
- **Naloxone:** An opioid receptor antagonist that rapidly binds to opioid receptors, blocking heroin from activating them. An appropriate dose of naloxone acts in less than two minutes and completely eliminates all signs of opioid intoxication to reverse an opioid overdose.
- **Naltrexone:** An opioid antagonist medication that can only be used after a patient has completed detoxification. Naltrexone is not addictive or sedating and does not result in physical dependence; however, poor patient compliance limits effectiveness. A new, long-acting form of naltrexone called Vivitrol® is now available that is injected once per month, eliminating the need for daily dosing, improving patient compliance.
- **Neonatal Abstinence Syndrome (NAS):** NAS occurs when heroin from the mother passes through the placenta into the baby's bloodstream during pregnancy, allowing the baby to become addicted along with the mother. NAS requires hospitalization and treatment with medication (often a morphine taper) to relieve symptoms until the baby adjusts to becoming opioid-free.
- **Neurotransmitter:** A chemical produced by neurons to carry messages from one nerve cell to another.
- **Opioid:** A natural or synthetic psychoactive chemical that binds to opioid receptors in the brain and body. Natural opioids include morphine and heroin (derived from the opium poppy) as well as opioids produced by the human body (e.g., endorphins); semi-synthetic or synthetic opioids include analgesics such as oxycodone, hydrocodone, and fentanyl.
- **Opioid Use Disorder:** A problematic pattern of opioid drug use, leading to clinically significant impairment or distress that includes cognitive, behavioral, and physiological symptoms as defined by the new Diagnostic and Statistical Manual of Mental Disorders, 5th edition (DSM-V) criteria. Diagnosis of an opioid use disorder can be mild, moderate, or severe depending on the number of symptoms a person experiences. Tolerance or withdrawal symptoms that occur during medically supervised treatment are specifically excluded from an opioid use disorder diagnosis.
- **Partial Agonist:** A substance that binds to and activates the same nerve cell receptor as a natural neurotransmitter but produces a diminished biological response.
- **Physical Dependence:** An adaptive physiological state that occurs with regular drug use and results in a withdrawal syndrome when drug use stops.
- **Post-Traumatic Stress Disorder (PTSD):** A disorder that develops after exposure to a highly stressful event (e.g., wartime combat, physical violence, or natural disaster). Symptoms include sleeping difficulties, hyper-vigilance, avoiding reminders of the event, and re-experiencing the trauma through flashbacks or recurrent nightmares.
- **Psychosis:** A mental disorder (e.g., schizophrenia) characterized by delusional or disordered thinking detached from reality; symptoms often include hallucinations.
- **Schizophrenia:** A psychotic disorder characterized by symptoms that fall into two categories: (1) positive symptoms, such as distortions in thoughts (delusions), perception (hallucinations), and language and thinking; and (2) negative symptoms, such as flattened emotional responses and decreased goal-directed behavior.
- **Self-Medication:** The use of a substance to lessen the negative effects of stress, anxiety, or other mental disorders (or side effects of their pharmacotherapy). Self-medication may lead to addiction and other drug- or alcohol-related problems.
- **Rush:** A surge of euphoric pleasure that rapidly follows administration of a drug.
- **Tolerance:** A condition in which higher doses of a drug are required to produce the same effect as during initial use; often leads to physical dependence.
- **Withdrawal:** A variety of symptoms that occur after use of an addictive drug is reduced or stopped.

The definition of addiction

It is well documented that heroin is a highly addictive substance and addiction can occur with only one use. In order to fully understand the process of addiction, professionals must first understand heroin addiction, treatment, and prevention. The American Society for Addiction Medicine in their Public Policy Statement included the following short definition addiction:[4]

> Addiction is a primary, chronic disease of brain reward, motivation, memory and related circuitry. Dysfunction in these circuits leads to characteristic biological, psychological, social and spiritual manifestations. This is reflected in an individual pathologically pursuing reward and/or relief by substance use and other behaviors.
>
> Addiction is characterized by:[4]
>
> - Inability to consistently abstain.
> - Impairment in behavioral control.
> - Impairment in cognitive functioning.
> - Craving.
> - Diminished recognition of significant problems with one's behaviors and interpersonal relationships.
> - Dysfunctional emotional response.
> - Cycles of relapse and remission.
> - Progression that can result in disability or premature death.

As each stage of tolerance, dependence, and addiction progresses, the user requires increasing amounts of heroin to feel pleasure and combat the pain and sickness that now occurs as the body goes through withdrawal. This class of drugs is known by the name opioids or opiates. As defined by the DEA, heroin is a Schedule 1 substance under the Controlled Substances Act, which means it has high potential for abuse, no accepted medical use for treatment in the United States, and lacks accepted safety for use even under medical supervision.[7]

Today's heroin epidemic

Heroin was formerly viewed as a drug only found in back alleys of large urban areas. Today heroin addiction is found in every corner of the country and affects people of all ages in every socio-economic group in epidemic proportions. Heroin addiction still carries the stigma that it is a behavior or character flaw, though it affects a wide cross-section of America. No one is spared, from movie stars, such as Philip Seymour Hoffman who died from a heroin overdose after 20 years, to teenagers in suburbia and the homeless on inner-city streets.

The most alarming statistics show heroin addiction among youth is increasing in children as young as nine.[6] A number of factors contribute to this epidemic by making the drug inexpensive and readily available. As the use of heroin became more widespread in contemporary culture, it became more accepted among certain segments of society. Rock stars, actors, fashion models, photographers, and other celebrities in popular culture abuse heroin, and their deaths are almost commonplace today. In fact, the "heroin look" became popular in the fashion world in the mid 90's and was characterized by a thin, pale, emaciated appearance, blank expression, dark sunken eyes, dirty hair, and disheveled clothing. Popular music and advertising campaigns included references to heroin abuse and death had the effect of making the drug seem safe, exciting, glamorous, and mainstream in the eyes of impressionable youth. Young people who would never inject a drug can now find heroin that can be smoked or inhaled. This makes heroine seem easier, safer, and more desirable, thus increasing their willingness to try the drug.[7] Many youth have become addicted, comatose, or have died after only one dose of heroin. If individuals survive the first dose and continues to use heroin, they quickly develop a tolerance to the previous amount used and must have increasing amounts of the drug to replicate the high they experienced the first time. When the high from smoking and snorting is no longer enough, as tolerance develops, users may inject the drug to enhance the rush and get the most they can from the amount they have. As the amount used and the frequency of use escalates, so does the danger of overdose. Similarly, if drug use is curtailed through incarceration or time in rehabilitation, users may overdose and die when they return to using heroin at the previous level. Sadly, another factor in the increasing number of deaths from heroin abuse is that those around them are unable or unwilling to summon help when problems occur. Death usually occurs due to the drug's suppressive effects on the automatic breathing response of the victim, which can be easily reversed through mechanical measures or medication to restore breathing.[3]

Families, schools, health agencies, local, state and federal agencies across the country are now focused on addressing the epidemic rates of addiction and death caused by heroin.

Heroin today is very different from the drug initially developed and can be found in many multiple drug combinations. With continued use, these euphoric feelings become more difficult for users to reach, and over time, the body tries to adjust to the damage caused by the drug. Individuals become addicted to heroin quickly and their immune and body systems are damaged, leaving the individual weak, sick, malnourished, thin, and if untreated, they will die. One addict reported from the time she started using heroin she never stopped, and in a week she went from snorting it to injecting and was addicted in a month.[5] To support her habit, she sold everything she had, stole all she could from her family, ran her credit cards to the limit, sold her car, lost her job and house and became homeless. While living on the street she was raped, robbed, beaten, sick, and in constant fear for her life and desperate for her next heroin hit. She realized she would die and felt that living as a junkie was worse than death, so she sought help from a local agency and continues to struggle to end her addiction.

Research into treatment and prevention programs around the world produced promising results, but it has not kept pace with the rampant addiction and death caused by heroin. The frequency of overdose among youth has increased so drastically that some states now allow family members to administer antidotal drugs in cases of near death that were previously only used by medical personnel.

Why heroin, why today?

Heroin abuse and addiction has replaced other high-priced, commonly abused opiates and became the drug of choice in the United States, increasing rapidly since 2010.[6] The general public was largely unaware of the epidemic until recent widespread media attention brought heroin addiction and death to the forefront and demands for solutions came from Vermont to California. The war against heroin must be fought on many fronts, and medical and mental health personnel must lead the charge.

Typically the drug is supplied by Mexican cartels, for just $10 a hit called a "stamp bag," and has gone up 600 percent in the last 10 years across the country.[7] As the United States cracks down on the sale of opiates such as Oxycodone by closing down pill mills throughout the country, an 80 milligram Oxycontin dose now costs $100, which makes heroine cheaper and easier to obtain.[7] Manufacturers are also making opiates and other prescription drugs in formulas that are more difficult for users to snort or dissolve to inject. Another reason heroin use is thought to have doubled in five years relates to the high rate of addiction to prescription opiate painkillers now replaced by heroin, which is a natural opiate. Approximately 34,000 12-17-year-olds experiment with heroin each year due to lower costs of the drug and its availability.[6]

Even though heroin abuse exists throughout the United States, large cities are reporting dramatic increases in the rates of heroin addiction and death. In large cities like Chicago, heroin can be found on the west side, often sold on the streets in plain sight. Addicts know where they can go to in any city, and with a phone call, they can receive the drug in a few minutes. Local police are aware of the problem but seem unable to get it under control. Addicts can be seen shooting up on the street, bleeding from their injuries as they attempt to find a vein. Special Agent Jack Riley, Regional Representative of the Drug Enforcement Agency (DEA) and Special Agent in charge of the DEA's Chicago Field Division, is familiar with the addicts on Lower Wacker Drive, a notorious drug-infested part of the community. Many addicts congregate under the overpass, injecting drugs or sleeping them off. Riley reports that the Mexican cartels supply 70 percent of the drugs used on Chicago's streets and that statistic is mirrored nationwide.[7] One of the addicts he encountered first took heroin as young as eleven years old and now lives on the street with two young children. Riley states," heroin addiction is probably at its all time high." "Heroin is the drug of choice for street gangs," says Riley, and he noted the increase started about three years ago, when Mexico's Sinaloa Cartel began importing heroin through Chicago. "We are seeing it in places like Indianapolis, Madison, and Milwaukee, places where traditionally we really did not see an uptick in heroin."[7] "The ability to smoke and snort today's pure form of heroine has made it accessible and acceptable to people who normally wouldn't come near it for fear of the needle," says Riley. "That's why it is spreading." Riley continues, "I've been doing this for 30 years in virtually every corner of this country and if anything can be likened to a weapon of mass destruction on a family, on a community, on society, it's heroin." "I just don't understand why people across the board don't see its danger. Social services are overwhelmed, our healthcare services are overwhelmed, yet Mexican organized crime and street gangs make billions from it."[7]

Many youth come from suburban areas around Chicago and other large urban areas to buy the drug, and they may spend hundreds of dollars a day to feed their habit. The streets of Chicago are filled with stories of ruined lives caused by heroin addiction, including one from a college student who went from shooting up between classes to living homeless on the street, turning to prostitution to survive and stay high. In another tragic instance, a suburban high school girl tried it once, overdosed, and died. These stories are not unique to Chicago or large urban areas, but they are echoed through the farmlands of Wisconsin and Vermont.

Illinois is not alone in its fight against the heroin epidemic that has plagued that state. Over one weekend in February 2014, a drug raid in the New York City Bronx area resulted in seizure of $8 million worth of heroin. "Heroin is pummeling the northeast, leaving addiction, overdoses, and fear in its wake," said James Hunt, acting special agent in charge of the DEA's New York office.[7] DEA heroin investigations in suburban Rockland County have doubled, and agents note that use is increasing in all age groups and across all socioeconomic levels. The Long Island Council on Alcoholism and Drug Dependence found an increase in families seeking assistance over the last five years from 100 to 850, and 80 percent of those were due to heroin addiction.[7]

Dr. Wilson Compton, deputy director of the National Institute on Drug Abuse (NIDA), described heroin addiction as consuming the user. "The most common and important outcome of using heroin is that it can cause an addiction where people organize their lives around the drug," Dr. Compton said. "They use it to the exclusion of all other aspects of their lives. It just becomes about scoring the next hit."[8]

The following NIDA statistics describe a nationwide problem:[6]

- In Maryland, state health officials believe that heroin combined with other drugs is responsible for 30 or more deaths in the six months prior to March of 2014. They also note the number of deaths attributed to heroin rose 54 percent from 2011 to 2012 totaling 378 deaths.
- The U.S. Drug Enforcement Agency (DEA) notes that Baltimore has the highest per capita heroin addiction rate in the country. In a city of 645,000, the Baltimore Department of Health estimates there are 60,000 drug addicts, with as many as 48,000 of them hooked on heroin. A federal report released last month puts the number of heroin addicts alone at 60,000.[7]
- Virginia officials note 91 heroin deaths in the first nine months of 2012, up from 90 for all of 2011 and 70 for 2010.
- Vermont Governor Peter Shumlin spent his entire 34-minute State of the State address this year discussing a "full-blown heroin crisis." Heroin-related deaths in Vermont doubled in 2013 according to the governor, and there were twice as many federal indictments against heroin dealers than in the prior two years. Per capita, the heroin use in Vermont is second in the nation.
- Heroin overdose deaths in the Minneapolis/St. Paul metro area nearly tripled from 2010 to 2011, increasing from 16 to 46 deaths, and these new heroin users were considerably younger. In Minneapolis, for example, arrestees testing positive for heroin were much younger: 19.8 percent were less than 21 years of age, which is much younder than those testing positive for cocaine and methamphetamine, according to the Arrestee Drug Abuse Monitoring Report.
- In March 2014, Maryland, Vermont, New York, and Florida each reported an unprecedented number of deaths, according to the National Institute on Drug Abuse, which is still determining the numbers. NIDA reports these numbers could be the highest ever.
- In 2012, New Jersey saw more than 800 opioid overdoses, and half involved heroin.
- The DEA reports that drug seizures in New York comprise 20 percent of the total heroin confiscated each year. The amount seized by the DEA in New York City has increased 67 percent over the past five years because heroin is now mass-produced in city apartments.[7]
- The New York City Department of Health notes fatal heroin-related overdoses increased 84 percent between 2010 and 2012, and 2012 showed a higher rate of heroin overdose deaths at 52 percent over deaths involving any other substance. The problem is particularly bad on Staten Island, where the death rate from overdoses is almost three times higher than the rest of New York City, according to the agency.[7]
- Heroin is the most commonly found illicit substance in drug intoxication deaths in Philadelphia, PA. In 2011, 251 intoxication deaths involved heroin/morphine, a significant increase from 138 in 2010. Heroin is also the most commonly found substance in mortality cases where illicit drugs are present, with 32.4 percent in 2011.
- Dr. Karen Simone from the Northern New England Poison Center said the number of heroin-related calls doubled from 2007 to 2012.
- Only 20 percent of the estimated 810,000 heroin addicts seek or receive any form of treatment for their addiction.

Street names for heroin

It is important to know the street names of the drugs to help identify the user's drug of choice. There are many street names for heroin, including the following:[7]

- Big H, H.
- White, White Lady, China White.
- Mexican Mud.
- Scag, Skag.
- Black Tar, Tar.
- Brown Crystal, Brown Sugar.
- Nod.
- Negra.
- Chiba, Chiva.
- Snowball.
- Black Pearl.
- Junk.
- Smack.
- Hell dust.
- Nose drops.
- Thunder.
- Horse.
- Dragon (smoking heroin is called "Chasing the Dragon").
- Dope.

Heroin combinations
Heroin is often used in combination with other drugs that are known by specific names as follows:

Heroin and Cocaine
- Speedball, Snowball.
- Belushi.
- Boy-Girl.
- H&C.
- Murder One, one and one.
- Smoking Gun.
- Whiz Bang.

Heroin and Methamphetamine:
- Meth Speedball.

Heroin and Marijuana
- Canade.
- Woolie.
- Woola.

Heroin, Cocaine, Methamphetamine, Rohypnol. and Alcohol:
- The Five Way.

Heroin and Fentanyl
- Theraflu.
- Bud Ice.

Heroin, Cocaine and Tobacco:
- Flamethrowers.

Heroin and Cold Medicine
- Cheese.

Cheese heroin is a combination of Mexican black tar heroin and cold medicine obtained over the counter. It is a highly addictive substance, which is very inexpensive, only a few dollars, so it is often targeted at young people. Children as young as nine years old have been identified in emergency rooms with addiction, overdose, and withdrawal to this form of heroine which suppresses the central nervous system causing breathing and heartbeat to slow or stop. Since 2004, 40 deaths in North Texas are attributed to cheese heroin.[7]

Facts and figures of increased heroin addiction, overdose and death

Statistics from the United States Government Substance Abuse and Mental Health Services Administration (SAMHSA) noted the following statistics:[9]

- Nearly a half million Americans are addicted to heroin, and this number is thought to be the highest in history.
- In 2011, 4.2 million Americans aged 12 or older (or 1.6 percent) had used heroin at least once in their lives. It is estimated that about 23 percent of individuals who use heroin become dependent.
- NSDUH reports the number of new heroin users increased from 142,000 in 2010 to 178,000 in 2011. Both numbers are a sizeable increase from the average annual estimates of 2002 to 2008 (ranging from 91,000 to 118,000).
- In 2012, there were 156,000 persons aged 12 or older who had used heroin for the first time within the past 12 months.
- A SAMHSA study from August of 2012 found that persons aged 12 to 49 who abused prescription pain killers were 19 times more likely to try heroin than those who abused pain killers in the previous year.
- In 2011, the average age at first use among heroin abusers aged 12 to 49 was 22.1 years and in 2010 it was 21.4 years, significantly lower than the 2009 estimate of 25.5 years.
- The 2012 average age at first use among recent heroin initiates aged 12 to 49 was 23.0 years, which was similar to the 2011 estimate (22.1 years).
- The annual Monitoring the Future survey of teens reported in 2012 that 20 percent of high school seniors felt that heroin was "easily available."
- From 2007 to 2012, the number of Americans using heroin nearly doubled, from 373,000 to 669,000, according to the federal government's most recent National Survey on Drug Use and Health, released fall 2013.
- One out of every four people who try heroin become addicted.
- The number of people meeting Diagnostic and Statistical Manual of Mental Disorders, 4th edition (DSM-IV) criteria for dependence or abuse of heroin doubled from 214,000 in 2002 to 467,000 in 2012.[10]
- When teens were surveyed to find out why they started using drugs in the first place, 55 percent replied that it was due to pressure from their friends. They wanted to be cool and popular.
- Heroin accounts for 18 percent of the admissions for drug and alcohol treatment in the United States.
- An estimated 9.2 million-use heroin worldwide.

The U.S. Drug Enforcement Agency (DEA) 2013 National Drug Threat Assessment Summary found that heroin smuggling is increasing across the United States border from Mexico and Mexican cartels, called Transnational Criminal Organizations (TCOs) by the DEA.[7] The summary noted, "The availability of heroin continued to increase in 2012, likely due to high levels of heroin production in Mexico and Mexican traffickers expanding into white powder heroin markets in the eastern and Midwest United States." Previous to 2012, heroin from Mexico was predominantly west of the Mississippi River with heroin from Asia coming through the major airports east of the Mississippi River. Some heroin from South America is smuggled through Mexico to the United States. The DEA report noted a steady decrease in cocaine trafficking from Mexico to the U.S. during this time period and theorizes that the increase in heroin trafficking may be a push by the Mexican TCOs to make up for the loss of cocaine profits. The DEA 2013 National Drug Threat Assessment Report includes the following:[7]

- The availability of white powder heroin continued to increase in 2012 due to an increase in Mexican heroin production and trafficking which expanded into the Eastern and Midwest markets.
- There was an increased level of smuggling of both Mexican-produced heroin and South-American-produced heroin, which was smuggled through Mexico into the United States in 2012.
- According to National Seizure System (NSS) data from January 15, 2013, the amount of heroin seized each year at the Southwest Border increased 232 percent from 2008 (558.8 kilograms) to 2012 (1,855 kilograms).
- The increase in Southwest Border seizures appears to correspond with increasing levels of production of Mexican heroin and the expansion of Mexican heroin traffickers into new US markets.
- Heroin-related overdoses and deaths are increasing in certain areas, possibly due to high-purity heroin on the streets and increasing numbers of heroin abusers at a younger age because it can be smoked or inhaled. Inexperienced abusers, such as teens, college students, and those who would normally not inject a substance start by smoking or inhaling. Law enforcement officials reported an increase of high-purity heroin available at the street level.
- People are switching from abusing prescription drugs to abusing heroin. Law enforcement and treatment officials throughout the country report that many heroin abusers began using the drug after having first abused prescription opioids. These abusers turned to heroin because it was cheaper and/or more easily obtained than prescription drugs and because heroin provides a high similar to that of prescription opioids.
- According to treatment providers, many opioid addicts will use whichever drug is cheaper and/or available to them at the time. Several treatment providers report the majority of opioid addicts will eventually end up abusing heroin and will not switch back to another drug, because heroin is highly addictive, relatively inexpensive, and more readily available. Those abusers who have recently switched to heroin are at higher risk for accidental overdose.
- Unlike prescription drugs, heroin purity and dosage amounts vary, and heroin is often cut with other substances, all of which could cause inexperienced abusers to accidentally overdose.

Etiology of heroin addiction: Physical effects on the brain

The thorough study of the effects of heroin on the brain would require a separate course, but it is important to include an outline of the effects of heroin on the brain that lead to addiction. Whether heroin is smoked, snorted, or injected, it is rapidly absorbed and crosses the blood brain barrier. Addiction occurs due to specific effects on the brain caused by the drug that interfere with normal brain function in the following ways:[4]

- Addiction affects the transmission of neurons within the parts of the brain that control motivation and reward. These parts include the basal forebrain amygdala and the anterior cingulate cortex. This part of the brain affects the individual's ability to conduct routine behaviors related to healthcare, motivation, and normal reward-seeking behavior.
- Addiction interferes with cortical and hippocampal interactions that affect reward; memory of reward; and control of physical, mental, and behavioral response to stimuli that drives individuals' drug cravings and drug-related behaviors. These behaviors may include lack of judgment and impulse control, inability to delay gratification, poor decision-making and repeated inability to react appropriately despite patterns of repeated negative consequences.
- Addictive behaviors are exacerbated when younger individuals, whose brain systems have not fully matured, use heroin.
- Addiction causes changes in brain chemistry and function, which results in physical changes to the nerve cells that transmit messages in the brain. Damage to neuron transmission in the nerve cells may disrupt signals and cues that communicate a variety of messages affecting learning, perception, memory, impulse control, motivation, pleasure/pain sensations, and more critically, central nervous system function that controls breathing responses and heart rate.

Factors influencing addiction

Psychological factors
Individuals may have psychological disorders or mental illness that interfere with their ability to function normally. They may use heroin and other substances to deal with their psychological issues, which may be the only coping mechanism they know. Their self-medication to escape their negative feelings turns to addiction, which may mask an undiagnosed mental disorder. As the heroin addiction progresses, the underlying issues will be complicated by increasing psychological and physical changes cause by the damaging effects of the drug.

Genetic factors
Though genetics factors do not cause an addiction to heroin, they can indicate addictive behavior and were found to be significant in about 50 percent of addictions.[8] One or more immediate family members with an addictive disorder may be an indicator that the individual addicted to heroin has a genetic predisposition. Social and environmental influences may determine the impact of genetic factors on addiction. The individual's sense of security, stability, personality, motivation, emotional and mental well-being are influenced by their role models, early experiences, culture, health and behavior patterns as they mature. These factors can influence whether genetic indicators of addiction come into play.

Environmental Factors
Environmental factors include a complex set of interacting variables and may be difficult to measure initially. Issues related to the individual's upbringing, family dynamics, belief systems, educational level, peer group influences, cultural or religious beliefs, stress, trauma, community values, and group affiliations may influence an individual's decision to try heroin.

Screening

The two main ways to identify the presence of heroin is in either the blood or urine of a user. The analytical methods used are gas chromatography-mass spectrometry (GC-MS) and liquid chromatography-mass spectrometry (LC-MS).[11] Both methods do the same thing, which is to separate a mixture of compounds present in the sample prepared from the urine or blood, followed by the detection of those compounds. The separation step allows for detection of any substance that has been used in combination with heroin.. The urine is screened for 6-acetylmorphine (6-AM) by immunoassay and confirming the results by GC-MS analysis, which can take four to five days to complete. Heroin can be detected for one to two days after use. Heroin metabolizes into 6-AM, and this differentiates the use of heroin from other drugs such as codeine, morphine, and other prescription opiate drugs. Since October 1, 2010, the Substance Abuse and Mental Health Services Administration (SAMHSA) established mandatory guidelines that require 6-AM screening as part of the required screening for all federally mandated drug testing in the workplace.[12] The 6-AM screening can be done in house and one version can deliver results in 11 minutes with 98 percent accuracy when compared with GC-MS. The Supreme Court has approved this test as defensible technology.[11]

In addition to the tests above, medical history, criminal records, and physical health/appearance typically identify chronic users. Chronic heroin abusers commonly have a lengthy arrest record for drug possession or theft; they may have overdosed one or more times and were brought to the hospital; and they will typically have "track marks" over the veins in their arms, which are small areas of contusions from injecting the drugs; along with other indicators of chronic use. Track marks may be found on any part of the body if larger veins are destroyed by repeated injection. A very lengthy, expensive way to identify chronic users would be hair analysis for the accumulation of small amounts of the drug. Extracting drugs from hair is extremely expensive and time consuming. The low amounts of the drugs that are present in the hair require highly sensitive instrumentation, and those techniques would typically not be done by a lab.[13]

Signs and symptoms of heroin addiction

No two individuals who are addicted to heroin will present with the same signs and symptoms, which will vary due to the method of use, level of tolerance, dependency, addiction, frequency of use, form of the drug, and secondary illness and disease. HIV/AIDS is often the consequence of injecting heroin. Common signs and symptoms of heroin use can be divided into the following categories:[8]

Psychological indicators
- Hallucinations, delusions.
- Paranoia.
- Depression.
- Disorientation.
- Sudden changes in behavior.
- Slurred, forced, or incoherent speech.
- Negative school or work performance.
- Distractibility.
- Frequent comments indicating low self-esteem, negativity.
- Insomnia or excessive sleep.
- Euphoria.
- Blaming others for their issues.
- Withdrawal from friends and family, association with new, unknown friends.
- Constant runny nose or bloody nose.
- Avoiding eye contact.
- Mood swings.
- Anxiety.
- Apathy, lack of motivation in interests and regular activities.
- Fatigue/exhaustion.
- Hostility toward others, agitation, and irritability.
- Lying about drug use.
- Stealing.
- Avoiding loved ones and others.

Physical indicators
- Cuts, contusions, bruises, and needle marks on the body, not just arms.
- Weight loss.
- Scabs or bruises as the result of picking at the skin.
- Decreased attention to personal hygiene and appearance.
- Shortness of breath.
- Frequent respiratory infections.
- Dry mouth, loss of teeth.
- Skin infections and abscesses.
- Warm, flushed skin.
- Drooping heavy extremities.
- Constricted pupils.
- Hyperactivity or hyper alertness followed by lethargy.
- Extreme itching.
- Loss of menstruation.
- Miscarriage.

Other indicators[7]
- Possession of burned spoons.
- Needles or syringes.
- Items to use as tourniquet such as a shoelaces or rubber bands.
- Evidence of drug residue in baggies or foil.
- Foil, straws or gum wrappers with burn marks.
- Glass pipes or water pipes.
- Wearing long pants and shirts, even in warm weather.
- Repeated borrowing of money, missing valuable items.
- Criminal activity.

Short term effects of heroin

Every addict will present with different side effects due to the type, amount, and frequency of heroin use, other substances used, co-existing physical and mental disorders ,and pre-existing conditions. In addition to the initial ”rush” or feeling of euphoria, short-term side effects of heroin use include:[3]

- Dry mouth.
- Flushed skin.
- Poisoning due to contaminants or adulterants.
- Vomiting.
- Itching externally and feeling itchy sensation internally, picking at skin.
- Nausea.
- Breathing that is slow, shallow, or irregular.
- Slurred speech.
- “Nodding out,” “crashing,” lethargy, sleep/alert cycles.
- Confused cognition.
- Decreased sensations of pain, physical and emotional “numbness”.
- Constipation.
- Stomach cramps.
- Overdose/death.

Long-tem effects of heroin

Chronic abuse of heroin leads to severe medical complications, many irreversible, and may lead to death:[3]

- Heart problems such as infection of heart lining, infection of the heart’s surface called endocarditis, valve prolapse, blockage, myocardial infarction and arrhythmia, congestive heart failure.
- Infectious diseases transmitted through needles (HIV/AIDS and Hepatitis B and C).
- Chronic pneumonia, pulmonary diseases.
- Collapsed veins, vascular blockages, clots, resulting tissue death due to lack of blood supply.
- Bacterial infections.
- Liver and kidney disease.
- Immune disorders.
- Pulmonary edema.
- Coma.
- Paralysis.
- Cognitive disorder.
- Seizures.
- Miscarriage.
- Birth defects.*
- Diseases and infections from sharing needles.
- Overdose/death.

In addition to miscarriage, babies born to mothers using heroin suffer problems associated with malnutrition, drug toxicity, infection. These problems include low birth weight, developmental delays, prematurity, birth defects, failure to thrive, drug dependence, or addiction known as neonatal abstinence syndrome (NAS). NAS is drug withdrawal that the baby must endure under strict medical care in the hospital. Studies have shown that pregnant mothers with heroin addiction can be treated in the hospital with the drug buprenorphine, which treats the mother and baby and reduces their withdrawal symptoms. Heroin addicted mothers will often lose custody of their baby and many are charged with child neglect or abuse. Addicted mothers often abandon their babies after birth.

Heroin withdrawal

Heroin withdrawal symptoms can occur within an hour after the last drug dose, based on the level of abuse. Withdrawal symptoms may include:[4]

- Severe heroin cravings.
- Sweating.
- Severe muscle and bone aches.
- Nausea and vomiting.
- Heavy extremities.
- Muscle cramping.
- Crying.
- Insomnia.
- Edema.
- Chills.
- Runny nose.
- Diarrhea.
- Fever.
- Death.

Addicts facing withdrawal must receive medical care in a clinic, rehabilitation facility, or hospital from providers who are specifically trained to treat patients for heroin withdrawal. They should never attempt withdrawal alone.

Signs and symptoms of multiple substance abuse

Among persons with heroin addiction, multiple substance addiction is common. Cocaine and alcohol are the substances most often abused with heroin.[14] A trained professional should assess for abuse of other substances and determine the effects of the overlapping substances. The American Psychiatric Association (APA) suggests the following four approaches for assessing heroin dependent people for other substances:

- **Screening instruments:** MAST, DAST, CAGE-AID, AUDIT.
- **Clinical assessments** using interview with the patient, family of significant others.
- **Structured interviews:** DSM-V SCID-1, Structured Clinical Interview for DSM-V Axis 1 Disorders.
- **Laboratory tests:** Urine samples done onsite for immediate results that can be addressed with the patient.

Heroin addiction and co-occurring disorders

As with other substance abuse addictions, individuals with heroin addiction often have co-occurring mental disorders. Since psychological and emotional causative factors for heroin addiction exist, it may be critical to determine the primary and secondary disorder in planning a long-term treatment plan. Of course, chronic addiction to heroin and the physical ravages of the disease must be addressed immediately, which will require medical care and monitoring. Patients must be screened for suicide ideation and self-harm tendencies, which are often part of the heroin addict’s coping or escape mechanism. The following co-occurring mental disorders are commonly seen among heroin addicts on the street and those in rehabilitation programs:[4]

- Depressive and/or anxiety disorder.
- Addiction to other drugs and/or alcohol.
- Personality disorder.
- Cutting, self-harm behaviors.
- Bipolar disorder.
- Eating disorders.
- Post traumatic stress disorder.
- Schizophrenia.
- Conduct disorder.
- Psychosis.

Treating heroin overdose

A new and controversial medication to reverse the effects of heroin overdose has been approved and released for sale by prescription by the Federal Food and Drug Administration (FDA) in April 2014.[15] Naxalone comes in the form of a hand-held device, injection, or nasal spray, and is being hailed by government and health care leaders as a ground-breaking tool to address the epidemic of heroin overdoses across the nation. The states of New York and New Jersey are already mandating its use by first responders, and after training, the drug was saving lives in the first weeks of use.

The drug, also known as Narcan, is marketed under the name of Evzio.[15] A single dose of the drug, which acts as an antidote to heroin, has been successful in bringing back overdose victims from death due to respiratory failure and lack of blood pressure. Naloxone works by reversing the suppressive effects of heroin on the opioid receptors that signal respiration to bring back consciousness and normal breathing. The drug is not new and has been used by emergency medical personnel on the street and in the hospital for over 40 years in injectable form. The release of the drug is controversial, because some, like Maine Governor Paul LePage, believe it will give addicts a false sense of confidence that they can continue to use much heroin as they want and the drug will save them from death from overdose. Many also object on the grounds that it will drive up insurance costs. Proponents of the drug do not believe addicts will purposely take enough drugs to overdose just because the drug is available and feel the FDA has addressed a life threatening public health crisis that has reached epidemic proportions.

Evzio works like an Epipen, which counteracts anaphylactic shock, and can go into the muscle or the skin. New Jersey has approved the use of naloxone for law enforcement officers. “We think greater availability of immediate treatments like naloxone are important as New Jersey confronts this crisis in heroin and opioid overdoses,” said Aline Holmes, a registered nurse and senior vice president of clinical affairs at the New Jersey Hospital Association.[16] In May 2013, New Jersey signed the Overdose Protection Act, which gives legal immunity to anyone using the drug to save a life.

The state of New York has also approved the use of the drug by all law enforcement agents, and 17 other states have followed suit, with some allowing prescriptions to family and friends of the addict. It comes in a nasal spray or injectable form and can be used by anyone without advanced training in an emergency situation. It is suggested for use after calling 911 and checking for breathing, though additional training is advisable.

One drawback of the drug is that if the heroin is adulterated with fentanyl, patients will need a larger dose over a longer period of time to combat longer-acting drug combinations, which may cause them to sink back into respiratory distress. Patients will also require emergency medical care and/or hospitalization despite receiving the drug and being revived.

The CDC reports local and state health departments fund the drug and provide it to hospitals and community-based clinics free of charge.[22] San Francisco’s Drug Overdose Prevention and Education Project and Massachusetts’ Overdose Education and Naloxone Distribution Program are examples of two community-based programs using the drug.[15]

Moving from withdrawal to treatment

The American Society for Addiction Medicine (ASAM) provides a wealth of information about the changes faced by the person who is withdrawing or has withdrawn from addiction. Addiction by definition includes periods of withdrawal and relapse, and the journey will be different for each individual. It is important to remember that unlike the feelings of early heroin use, as time goes by, the euphoria, pleasure or “reward” felt when the individual gets high does not continue to escalate with each subsequent use. As outlined previously, users need more heroin to achieve the same high and actually builds tolerance to the “high.” However, they continue to experience deeper and more painful “lows” as their addiction progresses. As explained by ASAM:[4]

> Persons with addiction compulsively use even though it may not make them feel good and in some cases long after the pursuit of “rewards” is not resulting in pleasurable feelings. Although people from any culture may choose to “get high” from one or another activity, it is important to appreciate that addiction is not solely a function of choice. Simply put, addiction is not a desired condition.

Addiction is classified as a chronic brain disorder or disease and not a behavioral one, which is important to remember when working with a person in recovery. As in any chronic disease there will be periods of relapse which will vary by frequency, duration or amount of use but ASAM points out that, “the return to drug use or pathological pursuit of reward is not inevitable.”[4] They provide the following information about the recovery process:

- Clinical interventions can help to alter the course of addiction.
- Close monitoring of the behaviors of the individual and contingency management, sometimes including behavioral consequences for relapse behaviors, can contribute to positive clinical outcomes.
- Engagement in health promotion activities that encourage personal responsibility and accountability, connection with others, and personal growth also contribute to recovery.
- The patient must be monitored and managed over time to decrease the frequency and intensity of relapses, to sustain remission and optimize functioning, and to minimize episodes of relapse and their impact.
- Medication management can improve treatment outcomes. Integration of psychosocial rehabilitation and ongoing care with evidence-based pharmacological therapy provides the best results.
- Recovery is best achieved through a combination of self-management, mutual support, and professional care provided by trained and certified professionals.

Treatment and recovery

The ultimate goal of treatment is recovery, because the person addicted to heroin has so many levels of life that have been damaged or destroyed. Some individuals have co-occurring mental disorders that may have preceded the addiction or occurred during drug use. Knowing that the individual is ready to enter treatment to move toward recovery, and developing a treatment plan to support them in reaching their goal are the first steps in the process. The recovering patients may face unresolved issues that initially led to their drug use. Therefore, patients may need to make total life changes with the assistance from their treatment team. According to the Substance Abuse and Mental

Health Services Administration (SAMHSA), "Recovery from Mental Disorders and Substance Use Disorders" is a process of change through which individuals improve their health and wellness, live a self-directed life, and strive to reach their full potential.[17] SAMHSA has delineated four major dimensions that support a life in recovery:

- **Health:** Overcoming or managing one's disease(s) as well as living in a physically and emotionally healthy way.
- **Home:** A stable and safe place to live.
- **Purpose:** Meaningful daily activities, such as a job, school, volunteerism, family caretaking, or creative endeavors, and the independence, income, and resources to participate in society.
- **Community:** Relationships and social networks that provide support, friendship, love, and hope.

Heroin addiction is a chronic disease that cannot be treated easily or quickly since it has been prevalent since the late 1880s . Scientific research and treatment trials conducted over decades have yielded the following guiding principals for treatment:[18]

- Addiction is a complex but treatable disease that affects brain function and behavior.
- No single treatment works for everyone.
- Treatment needs to be readily available.
- Effective treatment attends to multiple needs of patients, not just their drug abuse.
- Remaining in treatment for an adequate period of time is critical, sometimes continuing for years.
- Counseling, individual and/or group, along with behavioral therapies are the most commonly used forms of drug abuse treatment.
- Medications are an important element of treatment for many patients, especially when combined with counseling and other behavioral therapies.
- Patients' treatment and services plan must be assessed continually and modified as necessary to ensure that it meets their changing needs.
- Many drug-addicted individuals also have other mental disorders, which must be addressed.
- Medically assisted detoxification is only the first stage of addiction treatment and by itself does little to change long-term drug abuse.
- Treatment does not need to be voluntary to be effective.
- Drug use during treatment must be monitored continuously, as lapses during treatment do occur.
- Treatment programs should assess patients for the presence of HIV/AIDS, hepatitis B and C, tuberculosis, and other infectious diseases, as well as provide targeted risk-reduction counseling to help patients modify or change behaviors that place them at risk for contracting or spreading infectious diseases.

After the patient is stabilized and makes the decision to enter treatment, a long-term treatment plan is developed. There is no single method that works for all individuals, but practitioners need to review a variety of programs available in the vicinity of the patient and match the program to the patient's needs. This course outlines some current programs and provides resources for free training materials and program guides.

Therapeutic communities for residential treatment

For individuals with severe drug and addiction problems, therapeutic communities (TC) are the next step after hospital or medical management of their withdrawal symptoms.[18] These programs provide a highly structured, strictly monitored program to meet the medical and psychological needs of patients. Patients may live in the facility for up to a year and receive treatment for their addiction as well as other therapy and services needed for recovery. They receive support and treatment to address behavior issues, including criminal behavior, social, communication and family issues. Specialized centers can accommodate pregnant women, children, and adolescents. The goal of the therapeutic community is to provide the treatment and skills necessary for individuals to return to the community as healthy, drug-free individuals who can successfully when re-enter society and live productive lives. After care will continue through outpatient or support services in the community following successful release from residential care.

Pharmacological treatment

Heroin addiction changes the structure and function of specific parts of the brain, so for medication to be effective, it must work despite changes that occur in the short and long term. In the beginning stages of withdrawal, medication must curb the strong cravings for heroin and lessen the painful side effects of withdrawal to avoid a relapse. In later stages of recovery, individuals need medication to help them think clearly, gain control, make decisions, and focus on goals and skills for a healthy new life.

Pharmacological treatment of heroin addiction has proven to be successful by increasing time in treatment, decreasing rates of relapse, and reducing rates of infectious disease and illegal drug-seeking behaviors. Medications such as buprenorphine, methadone, and naltrexone can help people to escape the grip of heroin, because it reduces their cravings by blocking the euphoric effect. The medications used in this treatment work in the same manner as heroin by impacting the opioid receptors, but they do not cause the dangerous side effects or lead to addiction. The three types of medications interact with the opioid receptors in different ways as follows:[19]

1. Agonist medication such as Methadone, also known as Dolophine and Methadose, activates receptors by gradually reaching the brain slowly, preventing the euphoric feeling, and preventing withdrawal symptoms. These drugs are appropriate for use by certified physicians in outpatient treatment programs and are given to the patient orally each day. An estimated 200,000 people in correctional facilities each year are addicted to heroin. Therapy such as methadone maintenance treatment has been effective in prison populations and shown to increase time in treatment and diminish criminal activity if continued in the community upon release, because it eliminates the need to commit crime to buy heroin.
2. Partial agonists, such as Buprenorphine, also called Subutex, produce a small response in the brain, which relieves cravings with no euphoria or side effects when taken orally. The FDA approved buprenorphine in 2002 for prescription by certified physicians in their office, which extends the availability of this drug to a wider population of patients and makes it more accessible. Some critics theorize that the ease of obtaining this drug will encourage more individuals to enter and stay in pharmacologic treatment. In 2013, the FDA approved two generic forms of Suboxone, which is buprenorphine that contains naloxone, in 2013.[15] This drug prevents attempts to get high by causing severe withdrawal symptoms if injected but no negative effects when taken orally as directed. Buprenorphine can be used effectively with prisoners and could be implemented through collaboration with health professionals and the juvenile justice system.

   Many governmental agencies are working together to address the heroin addiction epidemic. An example of one partnership, known as the Blending Initiative,[20] combines the efforts of SAMHSA and NIDA to fund and conduct research and clinical trials on a variety of therapies that can effectively treat heroin addiction. Currently, they are developing and disseminating protocols to educate multidisciplinary treatment professionals about buprenorphine. Information can be found at (http://www.ctndisseminationlibrary.org/ display/85.htm). This information contains the following goals:

Blending teams of NIDA researchers, treatment practitioners, and trainers have completed two buprenorphine training packets:[21]

- To increase overall awareness of buprenorphine therapy.
- To instruct physicians and treatment practitioners in implementing a 13-day detoxification intervention for opiate-dependent patients.
- To change the mindset of many community treatment providers previously unwilling to consider the use of medications to treat drug addiction.
- To expand the programs now regularly use buprenorphine to assist in opiate detoxification and treatment maintenance.
- To work with SAMHSA's Addiction Technology Transfer Centers (ATTC), State Directors, and other stakeholders, to spread the word about buprenorphine to more proactively address the urgent needs of drug addiction.
- To continue clinical tests on the safety and efficacy of buprenorphine in other affected populations, including pregnant women, adolescents, and patients addicted to opiate analgesics.
- To increase the use of this and other addiction medications in different settings and locales, including in the U.S. criminal justice system and in countries where injection drug use is still a primary mode of HIV transmission.[21] Additional information on buprenorphine can be found at http://www.ctndisseminationlibrary.org/ display/85.htm.

3. Antagonists, such as Naltrexone, also known as Depade and Revia, block opioid receptors that send pleasure signals, thus blocking the "high." They doo not cause dependence, addiction, or sedation. Patients must take this drug daily, but the FDA recently approved a long-acting form called Vivitrol that can be administered once a month, which may increase compliance. Naltrexone does not suppress all drug craving, and many patients cannot remain abstinent and relapse in six months. According to Dr. George,[22] "Drug abusers are notoriously ambivalent and just because they decide to quit using heroin one week doesn't mean they'll be motivated to quit a week later." Extended-release forms like Vivitrol can provide long-lasting protection over time, which can help patients in their resolve to stay drug-free. Patients taking a daily oral dose of naltrexone must make a daily decision to remain drug-free. Patients using Vivitrol will receive a sustained dose each month, so they have more time in treatment and recovery between doses and do not face a daily decision to use heroin when the naltrexone tapers every 24 hours. Clinical trials are being conducted on patients in Russia with extended release implants that last up to two months and can be refilled without having to be removed.[22] Early trials of these implants are proving to be three times more effective in some patients than the daily dose pill in preventing relapse. Dr. Woody continues, "Methadone and buprenorphine have helped hundreds of thousands of people around the world who are drug dependent, and they have helped reduce the spread of HIV." "The new injectable and implantable naltrexone formulations are really the new kids on the block, but they're offering us more options in an area where we really need a lot of help."

Urine testing for compliance

Treatment programs that include medication are only effective if they include strict monitoring to make sure patients comply with the program and have not relapsed. This is done through urine testing, patient interview, observation, and input from family and other significant parties in the patient's life. Drug treatment programs that are administered through outpatient or doctor's office settings may have limited contact with the patient and must rely on tightly controlled drug monitoring protocols. These testing protocols must contain the following components:[12]

- **Location**
  A decision must be made about whether testing will be on site or off site.

  There are advantages to each setting, depending on the person's needs. On- site testing will give immediate, affirming results if positive. The sample will require less handling, and the patient may feel this testing is more confidential because it is kept on site. If the results are negative, the therapist can immediately address the issue with the person. In both cases, the samples may have to be confirmed off site depending on the lab, and additional tests may be required if the result is negative. Off-site testing allows for more comprehensive testing; a higher level of expertise among personnel, which may yield higher rates of accuracy; and admissibility in court.
- **Type of test**
  Different types of tests provide different levels of information. Immunoassay can test for heroin and other natural opioids, and it provides almost immediate results. Methadone is a synthetic opioid but specific immunoassay tests have been developed for this drug. Immunoassay tests will not detect the presence of other synthetic opioids, like fentanyl and buprenorphine, so it is not as comprehensive as other tests. Laboratory tests such, as GS-MS, will detect all types of opioids but take four to five days.[11]

Current research in pharmacology new medications

NIDA is committed to new treatments for heroin addiction, which include improved medication and other forms of therapy. When combined, they have proven to raise recovery rates. The NIDA is working to improve treatment for heroin addiction that they can implement to large numbers of patients across the country. A new drug called Probuphine is producing positive results in clinical trials. It is a long-acting form of buprenorphine that is administered as an implant under the skin to provide medication over a six-month period.[23] This drug is more convenient for the patient and eliminates daily dosing which increases adherence to treatment goals.

The heroin vaccine

Another exciting NIDA clinical trial currently underway is vaccine research that can effectively block addiction to heroin and other drugs. Dr. Ronald Crystal and Dr. George Koob and Dr. Kim Janda are among the many researchers around the world conducting research and clinical trials to develop a vaccine to address heroin addiction.[24] The vaccine acts to combat the effects of heroin as it enters the bloodstream before it reaches the brain and the opioid receptors so the euphoric or reward sensation is not released. The medication would be part of a treatment plan that would increase the chance of recovery by lowering the risk of relapse. The vaccine works by interfering with the immune system's ability to conduct the action of heroin on the brain. The antibodies in the vaccine identify and attach to molecules of heroin and the together they are too big to cross the blood brain barrier to enter the brain. When the drug does not enter the brain, it cannot reach the opioid receptor and signal the pleasurable sensation that drivers the need for the drug.

Two parts must be present in the vaccine to accomplish this action.[24] The first is a protein that causes the immune system to produce sufficient antibodies to overtake the total molecules in the amount of heroin taken so they do not reach the brain. The second part of the drug, hapten, has molecules that are similar to heroin in structure. Hapten serves as the schematic for the development of the antibodies that identify and combine with the heroin molecules. Each person's immune system responds differently, and the system is often compromised from heroin addiction. The drug trials focus on identifying the effective combinations of the parts of the vaccine to illicit the immune response necessary to block the action of the heroin in the bloodstream.

Several concurrent trials are underway for the vaccine, which are in the early stages of development and have not yet been tested on humans. Researchers agree that vaccine treatment should be part of a comprehensive therapy plan.[24] Dr. Janda and Dr. Crystal note, "People have the misconception that a single vaccine can protect patients from substance abuse, that's not true." Dr. Crystal states, "A patient who has attained abstinence could be vaccinated to block the effects of the drug, thereby preventing relapse. Dr. Janda notes, "Our vaccine will not alleviate craving, but it could help patients maintain abstinence in weak moments." "The vaccine approach provides an alternative strategy for treating drug addiction," says Dr. Nora Chiang of NIDA's Division of Pharmacotherapies and Medical Consequences of Drug Abuse. "There is much more work to be done on these vaccines, but the results so far are promising."[25]

Treatment for adolescents

Many biological factors, such as immature brain development in the frontal cortex, social and environmental factors, influence drug abuse and addiction in adolescents. Government health agencies, through their initiatives to blend the fields of study that research addiction, have combined neurobiology and social sciences to develop prevention and treatment programs that address the multiple and overlapping factors that influence heroin addiction in adolescents. NIDA explains this process as follows:

> The resulting social neuroscience initiative will help us better understand how neurobiological mechanisms and responses, genetic, hormonal, and physiological, underlie, motivate, and guide social behaviors related to abuse and addiction. This perspective may help us understand adolescents' heightened sensitivity to social influences and decreased sensitivity to negative consequences, for example, that make them particularly vulnerable to drug abuse.[20]

Pharmacology

None of the medications used with adults to treat addiction have been approved by the FDA for use with children and adolescents. At this time, clinical trials for additional medications are in development.

Behavioral treatment

Behavioral therapies are effective with children and adolescents and follow the same procedures noted in the section on therapy for adults. Contingencies and incentives help to motivate youth, and cognitive behavioral strategies work effectively when they are structured to meet the child's needs, age, developmental and maturity level. Any healthcare provider trained and certified to provide services to young clients can deliver behavioral treatment.

Family therapy

Children and adolescents can benefit from treatment using family therapy approaches, which include all significant people in their lives, including parents, guardians, mentors, siblings, and peers. Family therapy can address all areas of children's lives and increase communication and address problems in family dynamics, which may add to the stress of recovery. Therapy can build a wide circle of support for adolescents and help them gain confidence and self-esteem as they fight their addiction. Involving the family is a critical part of adolescent substance abuse treatment.

The following evidence-based family treatments programs work effectively to treat adolescent substance abuse.[26]

Brief strategic family therapy (BSFT)

BSFT focuses on unhealthy family interactions that contribute to the young person's drug problem. The therapist works to establish rapport with each family member, while observing how each member interacts, to identify problem areas and strategies. During the course of 12–16 sessions, the therapist will work to address problems and guide the family members to work together to resolve them. This approach can target any family issue and can be conducted in any setting.

Family behavior therapy (FBT)

FBT includes strategies from behavioral therapy, including behavior contracts that include contingencies to motivate the young person, and build impulse control and appropriate behaviors. The therapist works with the adolescent and parent to develop behavior goals, treatment plans, behavior strategies, and treatment interventions. The therapist writes a contact based on the goals and treatment plan, with contingencies based on measurable behaviors. The adolescent and parent work together to practice new behaviors and skills in the home, school, and community. Therapists and adolescents review the contract on a schedule that is appropriate for the child's age and maturity level to motivate and reinforce behavior. Professionals should reinforce appropriate behavior and goal mastery frequently in order for the program to work effectively.

Functional family therapy (FFT)

FFT is based on the premise that problem behaviors stem from dysfunctional family interactions. Therapy uses behavioral strategies to resolve conflict by improving skills for parenting, communication, and problem solving within the family involving all family members. Program goals include engaging and motivating all family members to work together to change their patterns of interaction through techniques of behavior therapy.

Multidimensional family therapy (MDFT)

The MDFT approach combines treatment components from all programs addicted youths encounters as a result of their addiction or conduct. At-risk or addicted youths can benefit from techniques of family therapy combined with treatment at school, juvenile justice, child protective services, clinics, family court, or other community agencies involved in their treatment plans. Often adolescents abusing drugs exhibited at-risk behavior, conduct disorder, family problems, or illegal behavior in the past that brought them in contact with special services in a number of organizations. MDFT goals work toward pooling resources and developing consistency and collaboration among all agencies involved in the child's care. Representatives from these agencies meet together with the adolescent and family to plan and implement goals and strategies consistently and hold the young person accountable on all fronts. According to NIDA, the MDFT program has been effective with severe substance-use disorders and can facilitate the reintegration of juvenile detainees into the community.

Multisystemic therapy (MST)

Similar to MDFT, this therapy uses a multidimensional approach that combines family therapy approaches with treatment strategies from a variety of treatment programs in the community. This approach is a natural out-growth of treatment for adolescents involved in severe drug addictions, violent behavior, and illegal activity. MST focuses on adolescents' personality, attitude, behavior, emotions, and peer influences related to their addiction and behavior. The second component includes a review of family interactions such as discipline, parenting skills, communication, and history of substance abuse among family members, and attitudes and values that influence them. The last variable looks to adolescents' performance and attitudes in the community at school, on the street, and membership in gangs or other groups in the community. The therapist works with the youth individually, with the family and youth together, and they coordinate and lead meetings with community agencies to coordinate services and build program consistency.

Recovery support for adolescents

If addiction treatment and recovery programs work effectively, there must be support services for aftercare to avoid relapse and support adolescents as they develop and apply skills to maintain a healthy, drug-free lifestyle. NIDA notes the following programs in clinical trials show promise in supporting recovery and lowering relapse among adolescent addicts.[26]

Assertive continuing care (ACC). ACC is a home-based continuing-care approach delivered by trained clinicians to prevent relapse, and is typically used after an adolescent completes therapy utilizing the Adolescent Community Reinforcement Approach (A-CRA). ACC combines A-CRA, behavior therapy, and assertive case management services using a multidisciplinary team of professionals, round-the-clock coverage, and assertive outreach to help adolescents and their caregivers acquire the skills needed to engage in positive social activities.

Peer recovery support services. Peer recovery support services connect youth with groups and individuals who have experienced addiction and recovery and act as peer mentors. They help individuals, based on their specific needs, support and coach the individual through treatment, and help them connect with community support groups and resources. More importantly, these services can provide new social connections so the adolescent can build positive social interactions with sober peers.

Recovery high schools. Recovery high schools can take different forms, but they are designed to meet the specific needs of students recovering from drug abuse. Students may attend a separate school or be part of a community school, but initially, they attend classes in a separate area with students who share their specific experiences and needs. The high school program may run concurrently with other treatment programs. Students benefit from specially trained teachers and counselors who support their treatment plan, which may address mental disorders as well as substance abuse. Students participate with peers who have experienced similar issues in a structured setting that promotes recovery.

Behavioral therapies

Outpatient behavioral treatment provides therapy through individual and group settings based on the program that best meets the needs of the person. It can be designed to meet the needs of youth and adults and is often combines with pharmacological treatment to increase efficacy. The NIDA outlines the following types of outpatient behavioral treatment programs:[27]

- Cognitive–behavioral therapy aims to help patients recognize, avoid, and cope with the situations in which they are most likely to abuse drugs.
- Motivational interviewing capitalizes on the readiness of individuals to change their behavior and enter treatment.
- Motivational incentives and contingency management uses positive reinforcement to encourage abstinence from drugs.

Contingency programs and cognitive-behavioral therapy are commonly used forms of therapy to help patients take control and responsibility for their behavior and build coping and life skills to move toward long-term recovery and health. Behavior therapy uses strategies to address unwanted behaviors using learning theory, conditioning, and reinforcement with the focus on the present and addicts' ownership and responsibility for their behavior. Therapy focuses on targeted behaviors to change and strategies to identify the triggers, or antecedents, and consequences of the behavior. The addict identifies behavior patterns to change and works toward healthy replacement behaviors. The therapist and client work to identify goals and barriers to those goals that may include habits, obsessions, compulsions, denial, procrastination, fear, depression, anxiety, dysfunctional inter-personal relationships, communication issues, and any other negative thought and behavior patterns. They work through these barriers together to build the client's awareness of the former thoughts, feelings, and behaviors that have a negative impact on recovery and must be changed. Behavior therapy has been around for decades, and many forms have proven effective with addiction. In the case of heroin addiction, this therapy works best when combined with pharmacological therapy.

Motivational incentives for enhanced drug abuse recovery: Promoting awareness of motivational incentives

The National Institute on Drug Abuse (NIDA) a division of the Substance Abuse and Mental Health Services Administration (SAMHSA) noted the challenge of helping patients avoid relapse while in a treatment program. They conducted research and clinical trials to develop an evidence-based approach called Promoting Awareness of Motivational Incentives (PAMI) to train other organizations to use incentive techniques, sometimes called contingencies, in programs to maintain abstinence from drug and alcohol use.[30] After testing the program, they developed a package of tools and training resources to replicate the program and share evidence-based research data behind the clinical use of motivational incentives. The strategies of the approach used low-cost incentives with patients that were successful in maintaining abstinence and program compliance to avoid relapse during treatment. PAMI is based on positive research outcomes from the NIDA Clinical Trials Network (CTN) study, Motivational Incentives for Enhanced Drug Abuse Recovery (MIEDAR), and uses strategies from Dr. Nancy Petry's Fishbowl Method of incentives.[31] "We use rewards as a clinical tool not as by bribery but for recognition; the really profound will come later."

The researchers used motivational incentives because they lead to higher rates of retention in treatment and abstinence from drug abuse. They found incentives that were motivating, low cost, and supported the patient's treatment plan included prices, vouchers, and clinic privileges. The patients earned reinforcers on the results of their on-site urine screening and completion of treatment goals. The study noted that patients who participated in incentive programs were more likely to submit urine samples that were negative than patients not receiving incentives. The average cost of incentives was $120 per patient.[32] PAMI is designed to build awareness of motivational incentives as a research-based therapeutic strategy for addiction treatment. The package, which is free of charge, reviews the research, provides support materials and resources along with suggestions for implementation, data collection, training and replication of the program and includes a video, *Successful Treatment Outcomes Using Motivational Incentives.*

The NIDA[31] reported data showing that approximately 25 percent of samples from both study groups tested negative for stimulants and alcohol at the first study visit. Overall, participants in the incentive group (54.4 percent) were significantly more likely to submit target drug-negative samples than were participants in the usual care group (38.7 percent).

The motivational incentives and interviewing techniques address patients' feelings and barriers about stopping drug use. Motivational interviewing is a therapeutic approach to help patients in recovery, and the incentives help patients modify and change specific behaviors. The incentives acted as a supplement to therapy were effective in the treatment of substance-use disorders. The study noted that the incentives improved therapeutic climate because they were based on positive, affirming, and celebratory strategies. Positive reinforcement incentives will be effective if they are valuable to the person and motivate them to work to change target behaviors. Patients received a menu of incentives to choose from, and therapists were consistent in the distribution of the incentives earned. Intermittent schedules of reinforcement were the most powerful, and the Fishbowl Method used this schedule to deliver low or no-cost incentives, such as coupons, vouchers, and privileges. Patients had a chance to earn and win prizes when they drew from the fishbowl. Target behaviors must be observable and measurable, and they should include abstinence and the successful completion of goals from the patient's treatment plan. The PAMI program outlines seven core principles of motivational incentive programs.[30]

Seven Core Principles of Motivational Incentive Programs:

1. Identification of target behavior.
2. Choice of target population.
3. Choice of reinforcer.
4. Incentive magnitude.
5. Frequency of incentive distribution.
6. Timing of the incentive.
7. Duration of the incentive.

The PAMI program materials include all the information needed to replicate the program and include supplemental software to track information about patients' participation and progress in the program. Information on these programs, and others to address the heroin addiction epidemic, can be obtained from the Motivational Incentives Web-Portal: www.bettertxoutcomes.org; National Institute on Drug Abuse: http://www.drugabuse.gov/blending-initiative; and SAMHSA ATTC: http://www.attcnetwork.org/blendinginitiative

Prevention

Prevention programs to address heroin addiction have been researched for over 20 years, which is not very long, considering the heroin addiction goes back to the late 1800s.

To find a solution to the complex, epidemic disease of heroin addiction, the process must include the following components:

- Identification and definition of heroin addiction.
- Determine the scope of the problem, sequence of events and factors that lead to addiction.
- Review evidence-based programs proven to effectively break the cycle of addiction including prevention and treatment.
- Matching prevention and treatment programs to the individual needs of the individual and community.

There is a rush to implement these steps because of the public's awareness of the problem of heroin addiction and the number of overdose deaths in every community, large or small. For those in the field of medical and mental health, the work to eradicate this complex problem has been in progress for decades. It is clear to all who work in this field that there is no easy and quick solution because the predictors or heroin addiction are varied and there is no definitive "test" to determine who will become addicted. Instead, many factors overlap to increase the chance that a person will become addicted. Biology, genetics, age at onset of use, environment, personality, and social influences are a few of the factors that contribute to addiction but are impossible to unravel or measure. Researchers, therapists, medical personnel, school staff, and families know that addiction to the substance may take hold quickly, but addiction is a developmental disease that begins long before the person becomes addicted to heroin. NIDA research shows that in some cases, the signs were there in childhood and adolescence while the brain is rapidly developing and changing. Brain research shows that the prefrontal cortex develops last, and that is the part of the brain that controls decisions and judgments, which explains why adolescents often engage in at risk behaviors. These factors correlate with statistics that show heroin addiction is rising among young people because they are open to experimentation with drugs, and therefore, vulnerable to heroin addiction.

These facts, established from evidence-based research, conclude that for prevention programs to work, they must begin early in order to address all the factors that lead to addiction, which often begin in childhood. NIDA identifies the following factors that can be addresses to prevent addiction at an early age:[33]

- Mental illness.
- Neurobiology.
- Physical or sexual abuse.
- Aggressive behavior.
- Academic problems.
- Poor social skills.
- Lack of motivation.
- Peer influences.
- Poor parent-child relations.

Effective prevention programs must have a multidimensional approach involving family, school staff, community health agencies, media, and other social and cultural modes of communicating prevention education, information, and early intervention. Because heroin addiction crosses all boundaries and excludes no one, community prevention outreach programs must speak directly to the intended audience in a way they can understand; therefore, the programs must encompass all languages, cultures, and educational levels. Community education for prevention must also address the relationship between at-risk behavior, addiction and the spread of HIV/AIDS, which is part of the heroin addiction epidemic.

The NIDA and other federal research organizations have included prevention as a primary goal. The principles outlined in this section focus on numerous, long-term, evidence-based studies of addiction behavior and combined concepts from many successful prevention programs. The prevention principles target children through young adults across the country with the goal of implementation at the community level. Prevention programs are geared to specific settings and specific needs of the participants and address the needs of all youth, whether they are drug-free, at-risk, or already experimenting with drugs. These principles can be implemented at home, school, community or all three.

The entire list and specific details on each principle, including research information, can be obtained on the NIDA website Prevention section at http://www.drugabuse.gov/publications/preventing-drug-use-among-children-adolescents. The following information and principles can guide the development of prevention programs for children and youth:[35]

> NIDA's prevention research program focuses on risks for drug abuse and other problem behaviors that occur throughout a child's development, from pregnancy through young adulthood. Research funded by NIDA and other federal research organizations—such as the National Institute of Mental Health and the Centers for Disease Control and Prevention—shows that early intervention can prevent many adolescent risk behaviors.

Principle 1 - Prevention programs should enhance protective factors and reverse or reduce risk factors. The risk of becoming a drug abuser involves the relationship among the number and type of risk factors, deviant attitudes and behaviors, and protective factors. Specific risk and protective factors change with age and stage of development. For example, risk factors within the family have greater impact on a younger child, while association with drug-abusing peers may be a more significant risk factor for an adolescent. Early intervention with risk factors, such as aggressive behavior and poor self-control, often has a greater impact than later intervention by changing a child's life path away from problems and toward positive behaviors. These factors can have a different effect depending on a person's age, gender, ethnicity, culture, and environment.

Principle 2 - Prevention programs should address all forms of drug abuse, alone or in combination, including the underage use of legal drugs and substances and the use of illegal drugs.

Principle 3 - Prevention programs should address the type of drug abuse problem in the local community, target modifiable risk factors, and strengthen identified protective factors.

Principle 4 - Prevention programs should address risks specific to population or audience characteristics, such as age, gender, and ethnicity, to improve program effectiveness.

Principle 5 - Family-based prevention programs should enhance family bonding and relationships including parenting skills and training in drug education and information. Family bonding is the bedrock of the relationship between parents and children. Family bonding can strengthen through skills training on parent supportiveness of children, parent-child communication, and parental involvement. Parental monitoring and supervision are critical for drug abuse prevention. Training on rule-setting; techniques for monitoring activities; praise for appropriate behavior; and moderate, consistent discipline that enforces defined family rules should be included. Drug education and information for parents or caregivers reinforces what children learn about the effects of drugs and opens opportunities for family discussions about the abuse of legal and illegal substances. Brief, family-focused interventions for the general population can positively change specific parenting behavior and reduce children's later risks of drug abuse.

Principle 6 - Prevention programs can be designed to intervene as early as infancy to address risk factors for drug abuse, such as aggressive behavior, poor social skills, and academic difficulties.

Principle 7 - Prevention programs for elementary school children should target academic and social-emotional skills to address risk factors for drug abuse. Education should focus on the following skills:

- Self-control.
- Emotional awareness.
- Communication.
- Social problem solving.
- Academic support, especially in reading.

Principle 8 - Prevention programs for middle or junior high and high school students should increase academic and social competence with the following skills:

- Study habits and academic support.
- Communication.
- Peer relationships.
- Self-efficacy and assertiveness.
- Drug resistance skills.
- Reinforcement of anti-drug attitudes.
- Strengthening of personal commitments against drug abuse.

Principle 9 - Prevention programs aimed at general populations at key transition points, such as the transition to middle school, can produce beneficial effects even among high-risk families and children.

Principle 10 - Community prevention programs that combine two or more effective programs, such as family-based and school-based programs, can be more effective than a single program.

Principle 11 - Community prevention programs reaching populations in multiple settings such as schools, clubs, faith-based organizations, and the media, are most effective when they present consistent, community-wide messages in each setting.

Principle 12 - When communities adapt intervention programs to match their needs, community norms, or differing cultural requirements, they should retain core elements, which include the structure, content, and delivery of the program.

Principle 13 - Prevention programs should be long-term with repeated interventions to reinforce the original prevention goals. Benefits from middle school prevention programs diminish without follow-up programs in high school.

Principle 14 - Prevention programs should include teacher training on good classroom management practices, such as rewarding appropriate student behavior to foster students' positive behavior, achievement, academic motivation, and school bonding.

Principle 15 - Prevention programs work most effectively when they use interactive techniques, such as peer discussion groups and parent role-playing.

Principle 16 - Research-based prevention programs can be cost-effective. Research shows that for each dollar invested in prevention, a savings of up to $10 in treatment for alcohol or other substance abuse.[28]

The community youth development study

This NIDA program offers assessment tools and technical trainings to communities so they can more accurately identify risk and protective factors for youth drug use and related behavior problems. This system allows communities to select appropriate evidence-based prevention programs based on their particular needs.[29]

Future trends

In addition to the pharmacological and therapeutic models in clinical trials previously reviewed, additional research studies may prove effective in the identification, prevention, and treatment of heroin addiction.

High-resolution mapping of targeted brain areas.
Research is currently underway that will increase knowledge of the brain systems and pathways taken by drugs and their effects on centers of the brain that influence drug-related behaviors involved in motivation, impulse control, pleasure, reward, compulsions, addiction, and relapse.[34] With this information, advances can be made to identify medications that interfere and block these drug behaviors to prevent drug addiction in persons at risk or assist in recovery and relapse prevention.

Blending initiative
Research and clinical trials are of no use if the results languish in a government publication and remain unused. The goal of the Blending Initiative of 2001[20] was to address this problem of disseminating research-based addiction treatment information so that it could be implemented in clinical practice. NIDA explains the process as follow:

> NIDA and the Substance Abuse and Mental Health Services Administration (SAMHSA) joined together to create the Blending Initiative in 2001 to reduce the gap that exists between the publication of research results and impact on treatment delivery. This initiative incorporates collaboration between clinicians, scientists, and experienced trainers to catalyze the creation of user-friendly treatment tools and products and facilitate the adoption of research-based interventions into front-line clinical settings. Through this initiative, NIDA and SAMHSA's Addiction Technology Transfer Centers (ATTC) disseminate treatment and training products based on results from studies conducted by the National Drug Abuse Clinical Trials Network (CTN) as well as other NIDA-supported research.

Conclusion

It is the responsibility of all health care professional to advocate for their clients and promote access to health care for everyone. The disease of heroin addiction impacts all ages in all communities, so health professionals today must work to bring heroin addiction out of the shadows. They must educate others to remove the stigma and address heroin addiction as a brain disease that can affect anyone. As with many diseases, such as HIV/AIDS, heroin addiction causes fear and is widely misunderstood in the community. Scientists and researchers are collaborating on better screening, treatment, and prevention techniques, health professionals and the general public should be educated about what they can do in their daily lives to prevent heroin addiction from spreading. This course points to the need for a multiple disciplinary approach that must start early in life to address the complex factors that lead to at-risk behaviors that may lead to drug experimentation. Environmental, social, genetic, physical, and mental health factors that contribute to addiction have been identified and are critical in developing effective treatment and prevention programs. Addressing these factors among youth at an early age may be the only way to control the epidemic, while law enforcement tries to eradicate the source of the drug from Mexico, South America, and Asia.

Prevention begins by educating parents, teachers, and healthcare staff about early identification of risk factors in childhood as well as the early the signs and symptoms of drug use. Health care professionals, school staff, and community resource agencies can identify and refer at-risk individuals and struggling families to social services for prevention and treatment programs. Once identified, these families can benefit from early intervention programs, including, health care, counseling, assistance with parenting, and discipline to support healthy family interaction. Health care professionals must participate in prevention and treatment programs in the community through fundraising activities, lobbying local officials and state legislators, conducting community outreach activities to identify and offer services to young people and adults at risk, educating the public about the disease, and working with the media to develop effective campaigns to combat negative cultural influences.

By moving forward through a multi-disciplinary approach, health care professionals can close the heroin treatment gap and increase prevention efforts. As advocates, health professionals, government agencies, and politicians must collaborate to write policies and increase funding for heroin addiction prevention and treatment to stop the escalating cycle of addiction and relapse. NIDA research has demonstrated that prevention is cost effective in lowering expenditure in areas such as residential treatment, hospital and health care, incarceration, crime, and the justice system. Funds are necessary to increase the accessibility and ease of treatment to encourage families and individuals to seek help to stop the cycle of addiction and prevent it in the future. There is no way to put a price on the mounting death toll from this epidemic, and health care professionals are the front line of defense. The epidemic of heroin addiction is a massive problem that requires effort on the part of every health care professional to identify what they can do today to break the cycle of addiction in their community.

Resources

- Addiction Severity Index. Provides a structured clinical interview designed to collect information about substance use and functioning in life areas from adult clients seeking drug abuse treatment. triweb.tresearch.org/index.php/tools/download-asiinstruments-manuals.
- Blending Teams Web site at nida.nih.gov/blending. drugabuse.gov/blending-initiative.
- Center for Substance Abuse Treatment (CSAT), Substance Abuse and Mental Health Services (SAMHSA)
- Center for Substance Abuse Treatment; Substance Abuse and Mental Health Services Administration(SAMHSA). www.samhsa.gov/about/csat.aspx. http://www.samhsa.gov/data/NSDUH/2012SummNatFindDetTables/NationalFindings/NSDUHresults2012.htm. Treatment Locator: 1-800-662-HELP or search www.findtreatment.samhsa.gov. SAMHSA's Store has a wide range of products Web site: store.samhsa.gov
- Clinical Trials. For more information on federally and privately supported clinical trials, please visit clinicaltrials.gov.
- Drugs, Brains, and Behavior: The Science of Addiction (Reprinted 2010). This publication provides an overview of the science behind the disease of addiction. Publication #NIH 10-5605. Available online at drugabuse.gov/publications/science-addiction.
- Complete NSDUH findings are available at National Institute for Drug Addiction drugabuse.gov.
- National Institute of Drug Addiction. Web site: www.drugabuse.gov NIDA Public Information Office: 301-443-1124.
- The National Institute of Justice. The research agency of the Department of Justice. For information contact the National Criminal Justice Reference Service at 800-851-3420 or 301-519-5500; or visit www.nij.gov.
- National Institute of Mental Health nimh.nih.gov.
- The National Registry of Evidence-Based Programs and Practices. This database of interventions for the prevention and treatment of mental and substance use disorders is maintained by SAMHSA and can be accessed at nrepp.samhsa.gov.
- NIDA DrugFacts: Treatment Approaches for Drug Addiction (Revised 2009). This is a fact sheet covering research findings on effective treatment approaches for drug abuse and addiction. Available online at drugabuse.gov/publications/drugfacts/treatment-approaches-drugaddiction.
- NIDA DrugPubs Research Dissemination Center. NIDA publications and treatment materials are available from this information source. Staff provide assistance in English and Spanish, and have TTY/TDD capability. Phone: 877-NIDA-NIH (877-643-2644); TTY/TDD: 240-645-0228; fax: 240-645-0227; e-mail: drugpubs@nida.nih.gov; Web site: drugpubs.drugabuse.gov.
- Preventing Drug Use among Children and Adolescents: A Research-Based Guide for Parents, Educators, and Community Leaders– Second Edition. This booklet lists over 20 examples of effective research-based drug abuse prevention programs and is available free on NIDA's website.
- Principles of Drug Abuse Treatment for Criminal Justice Populations: A Research-Based Guide. NIH Publication No.: 11-5316. Available online at nida.nih.gov/PODAT_CJ.
- Research Report Series: Therapeutic Community This report provides information on the role of residential drug-free settings and their role in the treatment process. NIH Publication #02-4877. Available online at NIDA's National Drug Abuse Treatment Clinical Trials Network (CTN) drugabuse.gov/CTN/Index.htm.
- Seeking Drug Abuse Treatment: Know What To Ask NIDA Publication #12-7764. Available online at drugabuse.gov/publications/seeking-drug-abuse-treatment.
- The "Find A Physician" feature on the American Society of Addiction Medicine (ASAM) Web site: http://community.asam.org/search/default.asp?m=basic Patient Referral Program on the American Academy of Addiction Psychiatry Web site: http://www.aaap.org/patient-referral-program.
- The Child and Adolescent Psychiatrist Finder on the American Academy of Child and Adolescent Psychiatry Web site: http://www.aacap.org/cs/root/child_and_adolescent_psychiatrist_finder/child_and_adolescent_psychiatrist_finder

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THE HEROIN EPIDEMIC IN AMERICA: IDENTIFICATION, TREATMENT AND PREVENTION

Final Examination Questions

Select the best answer for each question and proceed to ***SocialWork.EliteCME.com*** to complete your final examination.

41. Heroin and morphine, along with codeine, hydrocodone, oxycodone, and oxymorphone are similar in structure because of the following:
    a. They all bind to the opioid receptor.
    b. They are all benzodiazipines.
    c. They are inexpensive.
    d. They are easily accessible.

42. A chronic, relapsing disease, characterized by compulsive drug seeking and use accompanied by neurochemical and molecular changes in the brain is the definition of which term below?
    a. Dependence.
    b. Tolerance.
    c. Addiction.
    d. Drug abuse.

43. Young people who would never inject a drug can now find heroin that can be smoked or inhaled. As a result which of the following occurs?
    a. Heroin seems easier, safer, and more desirable, thus increasing their willingness to try the drug.
    b. Young people will not try the drug because of anti smoking campaigns.
    c. There is no difference in the use of the drug.
    d. Youth will only inject the drug as a last resort.

44. Agonist medication such as Methadone, also known as Dolophine and Methadose work in what way?
    a. They activate receptors quickly and stop cravings.
    b. They over enhance euphoria which causes sickness.
    c. They activate receptors by gradually reaching the brain slowly, preventing the euphoric feeling.
    d. They de-activate receptors to stop the euphoria.

45. This NIDA program offers assessment tools and technical trainings to communities so they can more accurately identify risk and protective factors for youth drug use and related behavior problems.
    a. The Teacher Training for Youth Safety Program.
    b. The Youth at Risk Program.
    c. The Community Youth Development Study.
    d. Stop Addiction Now!

SWCA04HEE16

Chapter 6: Identifying and Addressing Cyber Bullying

4 hours

By: Kathryn Brohl, MA, LMFT

Learning objectives

After completing this course, learners should be able to:

- Define cyber bullying.
- Understand the impact of cyber bullying on targets.
- Understand how to address cyber bullying with clients and their families.
- Understand the different ways technology is being used to bully individuals.
- Advocate against cyber bullying.
- Describe cyber bullies.
- Understand the difference between cyber bullying and other types of bullying.
- Understand what schools and parents can do to help address cyber bullying.
- Assist clients with identifying resources.
- Understand what schools and communities do to help prevent cyber bullying.

Throughout this course the word "youth" refers to "teens" and adolescents."

Introduction

Cyber bullying can be very damaging to children, youth, young adults, and even adults. It can lead to anxiety, depression, and even suicide. Once things are circulated on the Internet, they may never disappear, resurfacing later to renew the pain of cyber bullying. Cyber bullying is a persuasive problem.

The following story has, sadly, become more common:

> Brandon did not have friends in 6th grade, and often ate alone at lunch, following his move to a new school. He knew no one at the school. While browsing MySpace one day, he saw that someone from school had posted a bulletin -- a message visible to multiple people -- declaring that he was a "fag." Students he had never even spoken with wrote on it, too, saying they agreed. Feeling confused and upset, Brandon wrote in his comments asking his classmates why they would make those comments. The response on MySpace stated that a group of 12 kids wanted to beat him up, and that he should stop going to school and die. On his walk from his locker to the school office to report what was happening, students yelled things like "fag" and "fatty." "It was just crazy, and such a shock to my self-esteem that people didn't like me without even knowing me," said Brandon, now 18 and a senior in high school in Oregon. "I didn't understand how that could be."

The American Academy of Pediatrics calls cyber bullying "the most common online risk for all teens. [youth]"

Brandon was aware. Instead of lying "low" and hoping the cyber bullying would simply go away, he took action. He demonstrated courage as a 6th grader by reporting the cyber assault immediately, and was able to talk about it years later.

Brandon was one of the survivors of cyber bullying. While still affected, he was able to come out of the other side and discuss his experience and move forward with his life. Other targets of cyber bullying are not so fortunate. The next story touches every counseling professional, and parent who loses a client or child as a result of this terrible cyber assault terrorizing, not only children, youth, and young adults, but adults as well.

> Jessica Logan 1990–2008 – Jessica (Jessie) was a petite, blond-haired, blue-eyed Ohio high school senior who committed suicide after sexting a nude photo of herself to her boyfriend. When they broke up, he sent the photo to everyone at her school. Jessie was cruelly bullied for months by the other girls at her school, who called her a slut and a whore. When Jessie's grades dropped, she started skipping school and when she did go to school, she would hide in the bathroom to avoid being assaulted.
>
> Jessie Logan decided to tell her story on a Cincinnati television station. Her purpose was simple: "I just want to make sure no one else will have to go through this again." The interview was in May 2008. Two months later, on July 3, 2008, Jessie attended the funeral of a boy who committed suicide, then came home and killed herself.
>
> Her mother found her hanging in the closet with Jessie's cell phone on the floor nearby.

Child and youth statistics

The research results for past years below reflect whom and how many children and youth are cyber bullied. Research on cyber bullying is growing. However, because technology use changes rapidly with children and youth, it is difficult to design surveys that accurately capture trends with regard to those populations.

- According to the 2011 National Youth Risk Behavior Survey, 1 in 6 U.S. high school students were bullied through e-mail, chat rooms, instant messaging, websites, or texting in the previous year. Another recent survey found that 26 percent of teens were bullied or harassed via text messages or phone calls.
- Cyber bullying incidents more than quadrupled in five years between 2000 and 2005. A 2000 survey by the Crimes Against Children Research Center at the University of New Hampshire reported 6 percent of young people had experienced some form of cyber bullying. In 2005, studies of 1500 Internet-using adolescents found that over one third had been cyber bullied and half of those admitted to cyber bullying others. (Hinduja and Patchin, In Review) A 2005

study by National Children's Home Charity revealed that 20 percent had been cyber-bullying victims. A 2004 survey conducted by i-Safe America of 1556 adolescents found that 42 percent had been bullied online. As many as 25 percent of teenagers have experienced cyber bullying at some point, said Justin W. Patchin, who studies the phenomenon at the University of Wisconsin-Eau Claire. He and colleagues have conducted formal surveys of 15,000 middle and high school students throughout the United States, and found that about 10 percent of teens have been victims of cyber bullying in the last 30 days. "In our research, about 85 percent of the time, the target knows who the bully is, and it's usually somebody from their social circle," Patchin said. Patchin's research has also found that, while cyber bullying is, in some sense, easier to perpetrate, the kids who bully online also tend to bully at school. "Technology is not necessarily creating a whole new class of bullies," he said. 55 percent did not know who had cyber bullied them.

- About one in every three children between the ages of 12 and 17 years and one in every six kids ages 6 to 11 years are victims of cyber bullying, according to a national poll. And officials say the mean, threatening, or embarrassing Internet missives are not only anonymous, but they are becoming more prevalent in today's digital age. (McCarthy, 2006)
- Reuters reported that a growing number of American children say they have been picked on via text messaging, including having rumors spread about them or being threatened, a study says. Of more than 1,000 middle school and high school students surveyed in 2008, 24 percent said they had been "harassed" by texting — up from 14 percent in a survey of the same students the year before.
- The 2008–2009 School Crime Supplement (National Center for Education Statistics and Bureau of Justice Statistics) indicates that 6 percent of students in grades 6 through 12 experienced cyber bullying.
- The 2011 Youth Risk Behavior Surveillance Survey finds that 16 percent of high school students (grades 9 through 12) were electronically bullied in the past year.

The Cyberbullying Research Center also completed a series of surveys that resulted in these cyber bullying statistics:

- More than 80 percent of youth use a cell phone regularly, making it the most popular form of technology and a common medium for cyber bullying.
- About half of young people have experienced some form of cyber bullying, and 10 to 20 percent experience it regularly.
- Mean, hurtful comments and spreading rumors are the most common type of cyber bullying.
- Girls are at least as likely as boys to be cyber bullies or their victims.
- Boys are more likely to be threatened by cyber bullies than girls.
- Cyber bullying affects all races.
- Cyber bullying victims are more likely to have low self-esteem and to consider suicide. (Hinduja & Patchin, 2013.) During childhood and adolescence, many behavioral choices are influenced and conditioned by the role of major socializing agents, including friends, family, and adults at school. The purpose of this study was to determine the extent to which peers, parents, and educators influence the cyber bullying behaviors of adolescents. To explore this question, data were analyzed from a random sample of approximately 4400 6th through 12th grade students (49 percent female; 63 percent nonwhite) from 33 schools in one large school district in the southern United States. Results indicate that cyber bullying offending is associated with perceptions of peers behaving similarly and the likelihood of sanction by adults. Specifically, youth who believed that many of their friends were involved in bullying and cyber bullying were themselves more likely to report cyber-bullying behaviors. At the same time, respondents who believed that the adults in their life would punish them for cyber bullying were less likely to participate. Implications for schools and families are discussed with the goal of mitigating this behavior and its negative outcomes among adolescent populations. (Hinduja & Patchin, 2013.)

Despite the potential damage of cyber bullying, it is alarmingly common among children and youth. It is rare that an online bully will be a total stranger. According to cyber bullying statistics from the i-SAFE foundation:

- More than half of adolescents and teens have been bullied online, and about the same number have engaged in cyber bullying.
- More than 1 in 3 young people have experienced cyber threats online.
- More than 25 percent of adolescents and teens have been bullied repeatedly through their cell phones or the Internet.
- More than half of young people do not tell their parents when cyber bullying occurs.

The Harford County Examiner reported similar cyber bullying statistics:

- Around half of youth have been the victims of cyber bullying.
- Only 1 in 10 youth tells a parent if they have been a cyber-bully victim.
- Fewer than 1 in 5 cyber bullying incidents are reported to law enforcement.
- 1 in 10 youth have had embarrassing or damaging pictures taken of themselves without their permission, often using cell phone cameras.
- About 1 in 5 youth have posted or sent sexually suggestive or nude pictures of themselves to others.
- Girls are somewhat more likely than boys to be involved in cyber bullying.

Cell phones and computers themselves are not to blame for cyber bullying. Social media sites can be used for positive activities, like connecting with friends and family, with school and work, and for entertainment. But these tools can also be used to hurt other people. Whether done in person or through technology, the effects of bullying are similar. Cyber bullying can be the spreading of hurtful rumors or directing harmful words or images toward another person using electronic devices. While adults have separated cyber bullying from face-to-face bullying, children and youth increasingly view their offline and online worlds as one. For today's young people, it is all the same bullying. Either way, bullying is never okay and unfortunately, bullying can spread more quickly with today's online technologies. As the number of households with Internet access approaches saturation and cell phone ownership expands to the 100 million mark, so do the ways people bully each other.

This course will look at cyber bullying through the lens of varying age groups, from elementary age children, youth, young adults and adults. But as various targeted populations they are not all effected in the same way. Most of the focus of this course will highlight youth, and yet, all ages can be targets of cyber bullying and all can experience psychological pain as a result.

Defining cyber bullying

A cyber bullying discussion should first begin with defining "bullying" in its general terms. Bullying is "unwanted, aggressive behavior individuals that involves a real or perceived power imbalance. The behavior is repeated, or has the potential to be repeated, over time." (Brohl, 2013) Both cyber and other bullying targets and bullies, themselves, may have serious, lasting problems.

In order to be considered bullying, it must be aggressive and include:

- **An imbalance of power:** Children and youth who bully use their power—including physical strength, access to embarrassing information, or popularity—to control or harm others. Power imbalances can change over time and in different situations, even if

they involve the same people. With adults, bullies use an imbalance of power through status, exclusion, and psychological control.
- **Repetition:** Bullying behaviors happen more than once or have the potential to happen more than once.

Bullying includes making threats, spreading rumors, attacking someone physically or verbally, and excluding someone from a group on purpose. With kids, more bullying happens at school than online. According to Margaret Ross, of the Kamaron Institute, approximately half of U.S. students are impacted by traditional bullying each school day. The most frequent form bullying takes is words (teasing, taunting, ridiculing, name-calling, and gossip - not blows). This type of bullying happens in the "physical" world and that world has time and space limits. Cyber bullying makes school days even more painful for many children and some school staff. Bullying in cyberspace is not bound by school hours, school days, or facing the intended bully victim. Unfortunately, the perceived anonymous nature of the internet often insulates the bully from the consequences of their damaging behavior.

There are many warning signs that may indicate that someone is affected by bullying—either being bullied or bullying others. Recognizing the warning signs is an important first step in taking action against bullying. Not all children who are bullied or are bullying others ask for help.

It is important to talk with children who show signs of being bullied or bullying others. These warning signs can also point to other issues or problems, such as depression or substance abuse. Talking to the child can help identify the root of the problem.

Types of Bullying: There are three general types of bullying:

1. Verbal bullying is saying or writing mean comments. Verbal bullying includes:
    - Teasing.
    - Name-calling.
    - Inappropriate sexual comments.
    - Taunting.
    - Threatening to cause harm.
2. Social bullying, sometimes referred to as relational bullying, involves hurting someone's reputation or relationships. Social bullying includes:
    - Excluding someone on purpose.
    - Telling other children not to be friends with someone.
    - Spreading rumors about someone.
    - Embarrassing someone in public.
3. Physical bullying involves hurting a person's body or possessions. Physical bullying includes:
    - Hitting/kicking/pinching.
    - Spitting.
    - Tripping/pushing.
    - Taking or breaking someone's things.
    - Making mean or rude hand gestures.

Some signs that may point to a bullying problem are:
- Unexplainable injuries.
- Lost or destroyed clothing, books, electronics, or jewelry.
- Frequent headaches or stomachaches, feeling sick or faking illness.
- Changes in eating habits, like suddenly skipping meals or binge eating. Kids may come home from school hungry because they did not eat lunch.
- Difficulty sleeping or frequent nightmares.
- Declining grades, loss of interest in schoolwork, or not wanting to go to school.

Bullying in children and youth can occur after school. While most reported bullying happens in the school building, a significant percentage also happens in places like on the playground or the bus. It can also happen travelling to or from school, in the youth's neighborhood, as well as the internet.

And while bullying in the physical world harms greater numbers of targets, cyber bullying is a serious issue. In extreme cases, it may have legal and/or psychological consequences for the victim and bully.

Cyber bullying is bullying that takes place using electronic technology

Electronic technology includes electronic devices. Sometimes cyber bullying can be easy to spot. For example, if a child displays a text message, tweet, or response to a status update on Facebook that is harsh, mean, or cruel. Other acts are less obvious, like impersonating a victim online or posting personal information, photos, or videos designed to hurt or embarrass another person. Some people report that a fake account, web page, or online persona has been created with the sole intention to harass and bully.

Cyber bullying messages are communicated through:
- Text or digital imaging messages sent on cell phones.
- e-mails.
- Instant messaging.
- Web pages.
- Web logs (blogs).
- Chat rooms or discussion groups.
- Other information communication technologies.

Cyber bullying messages are communicated by:
- Sending mean messages or threats to a person's e-mail account or cell phone.
- Spreading rumors online or through texts.
- Posting hurtful or threatening messages on social networking sites or web pages.
- Stealing a person's account information to break into their account and send damaging messages.
- Pretending to be someone else online to hurt another person.
- Taking unflattering pictures of a person and spreading them through cell phones or the Internet.
- Sexting, or circulating sexually suggestive pictures or messages about a person.

On a cellphone, smartphone, or tablet, cyber bullying may include phone calls, text messages, social network posts, videos, and photos. Cyber bullying, in the form of text messages, e-mails, photos, website postings, can go school- or community-wide in minutes and global in days. Slanderous information sent into cyberspace is difficult, if not impossible, to remove. Cyber bullying often takes the form of gossip, where damaging content is posted online based on whim; not facts, and is posted on social networking sites, including Twitter, MySpace, and Facebook.

Cyber bullying also can occur accidentally. The impersonal nature of text messages, IMs, and e-mails make it very hard to detect the sender's tone — one person's joke could be another's hurtful insult. Nevertheless, a repeated pattern of e-mails, text messages, and online posts is rarely accidental.

Cyber bullying has a lot in common with bullying in school: Both behaviors include harassment, humiliation, teasing, and aggression. Cyber bullying presents unique challenges in the sense that the perpetrator can attempt to be anonymous, and attacks can happen at any time of day or night.

Nancy Willard with the Center for Safe and Responsible Internet Use (CSRIU) states that cyber bullying has unique characteristics that are different from traditional bullying:

- **Anonymity:** As bad as the bully on the playground may be, he or she can be readily identified and potentially avoided. On the other hand, a child who cyber bullies is often anonymous. The victim is left wondering who the cyber bully is, which can cause a great deal of stress.
- **Accessibility:** With children and youth, most who use traditional ways of bullying terrorize their victim at school, on the bus, or walking to or from school. Although bullying can happen elsewhere in the community, there is usually a standard period of time during which these children have access to their victims. Children who cyber bully can wreak havoc any time of the day or night. Cyber bullying can happen 24 hours a day, 7 days a week, and reach a kid even when he or she is alone. Kids who are being cyber bullied are often bullied in person as well. Additionally, kids who are cyber bullied have a harder time getting away from the behavior.
- **Punitive Fears:** Child and youth targets of cyber bullying often do not report it because of: (1) fear of retribution from their tormentors, and (2) fear that their computer or phone privileges will be taken away. Often, adults' responses to cyber bullying are to remove the technology from a victim - which in their eyes can be seen as punishment.
- **Bystanders:** Most traditional bullying episodes occur in the presence of other people who assume the role of bystanders or witnesses. The phenomenon of being a bystander in the cyber world is different in that they may receive and forward e-mails, view web pages, forward images sent to cell phones, etc. The number of bystanders in the cyber world can reach into the millions.
- **Disinhibition:** The anonymity afforded by the Internet can lead children to engage in behaviors that they might not do face-to-face. Ironically, it is the anonymity that allows some individuals to bully at all.

Additional reasons why cyber bullying is different:

- Cyber bullying messages and images can be posted anonymously and distributed quickly to a very wide audience. It can be difficult and sometimes impossible to trace the source.
- Deleting inappropriate or harassing messages, texts, and pictures is extremely difficult after they have been posted or sent.

Common forms of cyber bullying: Cyber bullying can take many forms. However, there are six forms that are the most common:

- **Harassment:** Repeatedly sending offensive, rude, and insulting messages.
- **Denigration:** Distributing information about another that is derogatory and untrue through posting it on a Web page, sending it to others through e-mail or instant messaging, or posting or sending digitally altered photos of someone.
- **Flaming:** Online fighting using electronic messages with angry, vulgar language.
- **Impersonation:** Breaking into an -e-mail or social networking account and using that person's online identity to send or post vicious or embarrassing material to/about others.
- **Outing and Trickery:** Sharing someone's secrets or embarrassing information, or tricking someone into revealing secrets or embarrassing information and forwarding it to others
- **Cyber Stalking:** Repeatedly sending messages that include threats of harm or are highly intimidating, or engaging in other online activities that make a person afraid for his or her safety (depending on the content of the message, it may be illegal).

They are discussed more fully below:

- **Flaming** is a type of online fight. It is an act of sending or posting electronic messages that are deliberately hostile, insulting, mean, angry, vulgar, or insulting, to one person or several, either privately or publicly to an online group.
- **Denigration,** also known as **dissing**, occurs when a person sends or publishes cruel rumors, gossip, or untrue statements about a person to intentionally damage the victim's reputation or friendships.
- **Bash boards** are online bulletin boards where people can post anything they choose. Generally, the postings are mean, hateful, and malicious.
- **Impersonation** can be particularly harmful and occurs when someone pretends to be or poses as another person. This is usually accomplished by breaking into someone's account, by stealing a password and perhaps changing it, or by maliciously using that information provided by a friend (one reason to never give a password to anyone but a trusted adult). Once the impersonator has access to the victim's information, considerable damage can occur. By sending out e-mails supposedly from the victim or by posting material online, the victim's reputation or friendships can be irreparably harmed.
- **Outing** occurs when someone sends or publishes confidential, private, or embarrassing information, online. Private e-mail messages or images meant for private viewing, is then forwarded to others.
- **Trickery** is when a person purposely tricks another person into divulging secrets, private information or embarrassing information, and publishes that information online.
- **Exclusion** is an indirect method of online bullying, intentionally excluding someone from an online group or community.
- **Harassment** is when the electronic bully repeatedly sends insulting, hurtful, rude, insulting messages.
- **Happy slapping** is a relatively new type of bullying. This occurs when an unsuspecting victim is physically attacked, in person, as an accomplice films or take pictures of the incident. The image or video is then posted online or distributed electronically. Often the attackers will say it was only a prank or joke, hence the term happy slapping. Happy slapping is becoming more common, especially since many cell phones now include cameras.
- **Text wars or attacks** are when several people gang up on the victim, sending the target hundreds of e-mails or text messages. Besides the emotional toll it can take on the victim, the victims' cell phone charges can be costly.
- **Online polls** ask readers to vote on specific questions, often very hurtful and demeaning, such as "Who is the ugliest person in 8th grade" or "Who do you love to hate?"
- **Sending malicious code** intentionally, to damage or harm the victim's system or to spy on the victim.
- **Images and videos** are a rapidly growing concern. Due to the prevalence and accessibility of camera cell phones, photographs and videos of unsuspecting victims, taken in bathrooms, locker rooms or other compromising situations, are being distributed electronically. Some images are e-mailed to other people, while others are published on video sites, including *YouTube*.
- **Griefing** involves chronically causing grief to other members of an online community, or rather, intentionally disrupting the immersion of another player in their game play. (Shoemaker-Galloway, 2007)

Many cyber bullies think that bullying others online is funny. Cyber bullies may not realize the consequences for themselves of cyber bullying. The things youth post online now may reflect badly on them later when they apply for college or a job. Cyber bullies can lose their cell phone or online accounts for cyber bullying. Also, cyber bullies and their parents may face legal charges for cyber bullying, and if the cyber bullying was sexual in nature or involved sexting, the results can include being registered as a sex offender. Teens may think that if they use a fake name they will not be caught, but there are many ways to track someone who is cyber bullying.

Cyber bullying also occurs among adults. For adults, cyber bullying can be very subtle; especially at work, and is associated with leaving someone out of the communication loop. “Didn’t you get my e-mail? I sent it 2 weeks ago,” is an excuse used by bullies. . Individuals who bully via the computer are more or less doing it to cut someone out of the communication. Bullies will also text one another during meetings, again leaving targets out of their world by bypassing communication. Bullies will be disrespectful of their targets by continuing phone conversations or texting during a conversation. The intentions are to use technology as a wall between the bully and the target. Adults can experience cyber bullying outside of work as well.

What are the warning signs of cyber bullying in children and youth?

The warning signs of cyber bullying are similar to those for traditional bullying in terms of emotional effects; however, there are some differences. For example, a bruise or torn clothing is not expected as a sign that a child, youth or adult is being cyber bullied, but it is also important to keep in mind that some children, youth, or adults who are cyber bullied may also be experiencing traditional bullying at school.

A child, youth or adult may be experiencing cyber bullying if he or she:

- Appears sad, moody, or anxious.
- Avoids school or work.
- Withdraws from or shows a lack of interest in social activities.
- Experiences a drop in grades or decline in academic or work performance.
- Appears upset after using the computer or being online.
- Appears upset after viewing a text message on a cell phone.
- Children and youth who are cyber bullied are more likely to:
- Use alcohol and drugs.
- Skip school.
- Experience in-person bullying.
- Be unwilling to attend school.
- Receive poor grades.
- Have lower self-esteem.

The full scope of cyber bullying is difficult to measure. However, peer approval is very important to children and youth. This means that cyber bullying can have a negative or even destructive emotional effect on victims, ranging from hurt feelings to intense anger. Cyber bullying can also result in significant depression and in the most severe cases has even resulted in suicide. Unfortunately, children rarely report occurrences to an adult.

If a child or youth shows any of these warning signs, it is important to talk with them and investigate their online presence to determine whether cyber bullying is occurring and to offer help when needed.

Cyber bullies: What makes them tick?

Mentioned earlier in this course, bullying is unwanted, aggressive behavior that involves a real or perceived power imbalance. The behavior is repeated, or has the potential to be repeated, over time. Mobbing is similar to bullying. However, mobbing is broadened as ganging up by the individuals who systemically collude to behave in mob-like behavior. (Davenport, Distler Schwartz, & Pursell-Elliott, 2005) While bullying can result from a one-on-one exchange, mobbing generally includes two or more individuals. Bullying and mobbing are characterized by detrimental outcomes as a result of physical and/or psychological behavior on the part of the bully toward the target.

Bullying could also be defined as actualized arrogance that affirms the power needs of the abuser, and takes advantage of the vulnerability of the victim, particularly when there is a lack of support that leaves the target feeling isolated and exposed, often with lasting consequences that include damaged self-esteem.

Bullies feel contempt for their targets, often considering them to be worthless, inferior, or undeserving of respect. Signs of contempt for another range from disregard to scorn, or hate. Bullies exclude, isolate, segregate, or bar targets from participating fully at school, other social environments, or in the workplace.

They view themselves privileged to control, dominate, and subjugate others. Also, depending on their worldview, they have acquired intolerance for individuals and situations that do not share their particular beliefs. Consequently, targets who do not subscribe to their way of thinking are not worthy of their respect.

Bullies have:

- The power to exclude the target victim who is viewed as unworthy.
- The feeling of entitlement and privilege to control and dominate another person.
- Intolerance for differences (in other words, difference means inferior and not worthy of respect).

Given certain circumstances, anyone can morph into a bully. But some people are more predisposed to it than others. Aggression is a basic biological state in humans, and certain factors can increase levels of aggression beyond acceptable norms. High levels of testosterone in men, for example, can encourage aggressive behavior that inflicts harm and leads to antisocial behaviors. Higher levels of testosterone have been found even in preschool bullies. (Beane, 2008) In addition, when humans perceive threat, their arousal systems go into action and prepare them to defend themselves through aggression, withdrawal, submission, or freezing behaviors.

Fear drives many people to behave poorly. When bullies feel threatened, their arousal response normally operates at the aggressive or withdrawal level. Threats aren’t perceived as physical. Much of their perception depends on how transference, a psychological process that triggers an unconscious response when prompted by sensory stimulation.

Transference prompts an unconscious reaction to someone because of what a person (in this case, the bully) needs to see in order to feel less threat, fear, and insecurity. Bullies project characteristics onto another person, even when they know very little about their target.

Transference is psychological projection usually caused by unmet emotional needs, neglect, seductions, and other abuses that occurred in earlier life. Transference causes bullies to misread someone, and then react negatively.

Projection is placing feelings, emotions, and/or motivations onto another without recognizing that the self-made projections are truly about the individual projecting. Real or perceived threats cause stress, prompting heightened arousal within human beings. Heightened arousal can trigger survival reactions.

Stress can be positive or not; depending on how it compels us toward, or away from, something. When bullies perceive someone as a threat, their arousal systems become heightened and their survival reactions are either to become aggressive or to avoid the person altogether, and they may use underhanded methods to target their victims.

Most bullies are not socially isolated. They normally have at least a small group of friends who support and/or encourage them. Many bullies have strong family ties, are active in their communities, and do not necessarily have low self-esteem.

People who are both victims and bullies are at higher risk for young adult depression, panic disorder, agoraphobia (among females), and suicide (among males). Individuals who are only bullies show a risk of antisocial personality disorder.

A bad temper is a characteristic of childhood bullies, and unless harnessed, child bullies can grow up to be impulsive and explosive adults as well. When bullying behaviors are practiced and reinforced over years, it is very difficult to change those behaviors.

Conformity plays a large role in the current bullying culture. In other words, if someone is not capable or willing to adapt to the majority's view (meaning the controlling view), that someone can be perceived by a bully to be a threat. For this reason, many child, youth, and adult targets are people who happen to be more nonconforming types.

Jealousy drives much bully behavior. Bullies are often motivated by besting someone who threatens them and are easily threatened by competition or someone they perceive to have skills or physical attraction. Other factors that drive jealousy include comparing another's school or athletic performance, luck, family life, and likeability with one's own circumstances. Revenge can also urge on bullying and mobbing behavior.

Other bullies are just plain biased against certain cultures, personality types, genders, religions, and so on. Bullies emerge through social influences; particularly during adolescence through:

- Gossiping or spreading rumors about the target.
- Manipulation.
- Failing to communicate.
- Other forms of intimidation.
- Intent to cause pain or personal distress.

Children and youth may be bullying others if they:

- Get into physical or verbal fights.
- Have friends who bully others.
- Are increasingly aggressive.
- Get sent to the principal's office or to detention frequently.
- Have unexplained extra money or new belongings.
- Blame others for their problems.
- Do not accept responsibility for their actions.
- Are competitive and worry about their reputation or popularity.

Targets young and old

Risk factors
No single factor puts a child or youth at risk of being bullied or bullying others. Bullying can happen anywhere—cities, suburbs, or rural towns. Depending on the environment, some groups, including lesbian, gay, bisexual, or transgendered (LGBT) youth, youth with disabilities, and socially isolated youth—may be at an increased risk of being bullied. Generally, children and youth who are bullied have one or more of the following risk factors are:

- Perceived as different from their peers, including being overweight or underweight, wearing glasses or different clothing.
- Being new to a school.
- Being unable to afford what kids consider cool.

A physiologic body response can occur when a target is cyber bullied
For all ages, the physical and emotional fallout of bullying and cyber bullying can be dramatic. For example, the brain is physiologically affected by insults and put-downs. Verbal and emotional abuse, in fact, literally harms the brain.

Magnetic Resonance Imaging scans (MRIs) are used to image the brain's response when people experience psychological trauma. A Purdue University study using real-time experiences found that insults actually trigger neuronal pain pathways in the brain. In addition, when individuals are provided with information that excludes them from enjoyable activity with others, their brains respond similarly to trauma and pain. (Namie & Namie, 2011)

Continuous activation of aroused stress states can also cause compromised immune systems and metabolic regulatory functions. Toxic stress contributes to creating or exacerbating health conditions, including hypertension, heart disease, diabetes, weight gain or loss, addictions, compromised immune systems, mental illness (e.g., depression and anxiety), and an abundance of other physical and mental health conditions. Bullying victims showed greater likelihood of agoraphobia, where people do not feel safe in public places, along with generalized anxiety and panic disorder.

In a study by Elizabeth Blackburn published in 2004, toxic stress was discovered to interfere with cellular replication by destroying telomeres, or structures that protect DNA chromosomes. Destruction of telomeres can result in shortened life spans. (Blackburn, 2004)

Prolonged bullying (toxic stress) also contributes to acute stress and post-traumatic stress disorder (PTSD). The German-born Swedish researcher Heinz Leymann demonstrated that prolonged exposure to ongoing bullying creates high arousal states and anxiety, which lead to PTSD. (Leymann & Gustafsson, 1990) The effects of bullying, through chronic health conditions and hyperreactive physiological and psychological responses, last much longer than the actual experience.

Acute Stress
Acute stress occurs when individuals become terrified by an out-of-the-ordinary experience and perceive themselves, or persons close to them, to be in life-threatening danger. It is possible to be threatened by others through using technical devices. These threats can surface the same psychological and psychological effect as someone who is physically exposed to bullying. At the time, survival systems, responding to the real or perceived threat, become overly activated, causing intense and/or prolonged arousal responses in their brains and bodies. As a result, sensory stimulation related to the memory of the experience can trigger these survival responses for about a month following the life-threatening event.

Symptoms of acute stress include intrusive or ruminating thoughts, sleep disturbances, emotionality, excessive fear and anxiety, and markedly changed behavior, in addition to being easily triggered into repeatedly re-experiencing one's surprised and threatening bullying experience. One example is being anonymously sent a message about being identified as the next rape to occur within a community.

Post-traumatic Stress Disorder (PTSD)
Post-traumatic stress disorder lasts beyond 1 month and is defined by clustered physical and emotional acute stress symptoms (described above) that emerge as a result of a real or perceived life-threatening event. Formerly traumatized targets can be triggered into panic attacks and severe anxiety as past trauma memories are triggered by their bullies. PTSD is a condition that takes time to repair, and often includes embedding compensating life practices.

Individuals traumatized by their cyber bullying are often prescribed antidepressants, sleep aids, and anti-anxiety medication. Their psychic wounds can leave lasting scars that prevent them from trusting new friends or situations causing a loss of spontaneous quality of life. Included here is a list of what targets may experience as a result of cyber bullying:

- Anxiety.
- Diminished quality of life.
- Depression and anger.
- Low morale.
- Isolation, shame.
- Feelings of worthlessness.
- Humiliation and guilt.
- Irrational thinking and paranoia.
- Impaired relationships.
- Sleep disorders.
- Loss of purpose.
- Poor school or work performance.
- Hypertension.
- Hyper-vigilance.
- Panic attacks.

- Loss of status or money.
- Medication management.
- Addiction.
- Toxic stress.
- Suicidal ideation or suicide.
- Loss of confidence.
- Heart disease.
- Digestive problems.
- Feeling unsafe.
- Prolonged or higher incidences of chronic health conditions.
- Self-mutilation.
- Avoidance of social situations.
- Feelings of helplessness or decreased self-esteem.
- Self-destructive behaviors, including running away from home, harming themselves, or talking about suicide.

There are different degrees of suffering as a result of cyber bullying that can be classified similar to physical burns: (Davenport et al., 2005)

- **First degree:** Targets identify their abuse, suffer moderate impairment, and are supported through the experience to move forward.
- **Second degree:** Targets are unable to identify and receive support for their bullying immediately, and as a result, experience temporary or prolonged mental and/or physical impairment, with difficulty moving beyond their experience.
- **Third degree:** Targets are unable to cope and experience mental and/or physical impairment. Rehabilitation is not possible without a prolonged recovery and assisted specialized support through medication management and/or psychotherapy.

What are some of the qualities cyber bullied targets possess?

With regard to bullied adult targets, they are usually:

- Loyal.
- Open and honest.
- Committed to their beliefs.
- Transparent.
- Optimistic.

Consequently, they are can become more unsettled and confused as to why they would be cyber bullied.

For example, a 50-year-old man, Jeff, reported an incident involving his former wife. He states, “My wife and I separated because of our vast difference in personalities. I am a lawyer, and I tend to think things through before acting. My former wife was impulsive and angry much of the time. After we decided to divorce, she began texting friends terrible and untrue things about me. She stated I was an adulterer, that I had left her penniless, and that I had an issue with women. To the best of my knowledge, I am not and did none of those things. At one point, she went so far as to text a mutual friend that I had had said some nasty things about our former mutual friend. Again, not true, but I was very upset for a long time, and unsure of how to go about repairing my relationships.”

Cyber targets are loyal whereas bullies identify individuals they consider worthy of their loyalty. Their targets are probably too transparent about their feelings for their own good. In addition, children and youth targets are viewed from the perspective of vulnerability. For example, if a new, attractive girl arrives at school, she is assessed as to her threat to the larger female population as a whole, and becomes a potential target if one of the more popular males seeks her out. Another example could include the brainy 6th grader that tends to raise his or her hand too quickly and does not perform at the same level in gym class. At various times children and youth become targets because of their religion, socio-economic status, race, clothes, sexual orientation, or if their verbal, mental or physical attributes may be impaired in anyway. Other times, children with self-regulation problems issues or lacking in social skills are targeted. Children and youth have an especially difficult time if they stand out from the accepted group norm.

Cyber bullying generally occurs in stages gradually escalating. These stages are not written in stone often due to the fact that the cyber bully may not even know his or her target, but scaffolding upon other cyber comments.

Initial targeting phase
During the initial targeting phase, bullies meet or already know their targets and begin to identify them as different and a perceived problem. Described earlier, their assumptions have more to do with a bully’s transference and projection issues, as well as their cultural orientation, and parental messages.

Engagement and conflict
The bully makes the first move. If targets know their bullies, they may make attempts to work with their bullies. Though they’ve already been identified and targeted, most of the time targets have no clue why. A minor conflict can prompt their abuse, and may range from the target’s perceived threatening skill sets or lack thereof to simply being at the wrong place at the wrong time.

The target is often stunned, and especially with children and youth, who normally believe some of what the bullies are saying. Whereas adults generally rationalize that the bully was having a bad day. Adult targets may shrug off the bully’s aggressive behavior. Within a few hours or days weeks, the bully amps it up by additional cyber comments that can include other people. The bully’s comments are meant to humiliate the target. If challenged, the bully(ies), depending on his or her age, can ignore or minimize the target’s concerns, but may continue to escalate the behavior.

Targets of all ages usually respond to their treatment by first blaming themselves. Their further attempts to contact and to coordinate effective communication are sidelined or blocked, unless they get outside help in the case of children and youth. But very often, bullied children and youth do not disclose their cyber bullying. As a result, targets begin to experience isolation and disconnect at school. Adults can experience these feeling or psychological alienation/estrangement at work; especially if they have been subtly cyber bullied there. Targets often struggle alone to grasp their situation, and question themselves.

Fall-out
Targets begin to suffer emotionally and physically. They often lose sleep trying to figure something out that doesn’t make sense. As their frustration and exhaustion grow, often along with a health problem, they can react impulsively to their abuse. Given the right triggers, targets risk behaving impulsively and angrily cyber texting responses to their bullies that can often be used against them.

Having gotten their targets to this place of frustration, anxiety and anger, bullies relish the opportunity to point out the targets’ flaws. They delight in spreading rumors that have to do with the targets’ “apparent” inability to control themselves or reinforce what they have cyber shared with targets and others already.

Mentally figuring out how to fix the problem becomes an ongoing obsession and can become rumination for children, youth and adults. Obsessed with righting their situations, this distraction can become intrusive in everyday life. Frustration and low morale play a part in a target’s emotions, and often, the fallout from these feelings occurs in the target’s own home. Family members have been vicarious victims of bullying, when the rudeness of bullies has a ripple effect cyber bullying.

The tension can disrupt normal routines, as targets may turn to sleep as an escape or even worse, to addictions. Targets often experience situational depression because they are unable to control their bullying.

Consequently, depression turns into self-doubt, which takes on a life of its own. Distorted thinking becomes part of the mix by becoming patterned.

The conversations that need to be happening around cyber bullying extend beyond schools, said Thomas J. Holt, associate professor of criminal justice at Michigan State University. "How do we extend or find a way to develop policies that have a true impact on the way that kids are communicating with one another, given that you could be bullied at home, from 4 p.m. until the next morning, what kind of impact is that going to have on the child in terms of their development and mental health?," he said. He suggests that both victims and perpetrators of bullying can feel long-lasting psychological effects.

Reporting cyber bullying

Everything online has a digital footprint, and it is possible to trace anonymous sources of bullying on the Internet. Patchin noted that tangible evidence of cyber bullying may be more clear-cut than the traditional bullying situation of "your word against mine."

Patchin advises that children, youth, and even adults who are being cyber bullied keep the evidence, whether it's an e-mail or Facebook post, so that they can show it to adults they trust. Historically, there have been some issues with schools not disciplining if bullying did not strictly happen at school, but today, most educators realize that they have the responsibility and authority to intervene. (Patchin)

Adults should keep this in mind as well.

Adults can experience cyber bullying also, although there is less of a structure in place to stop it. However, adults do have the ability to address their bullying, more so than children and youth who need strong advocacy from adults. If the following suggestions do not work, the recourse adults have is to hire a lawyer and proceed through the courts, Patchin said. Brohl (2013) makes the following suggestions for adults when they begin to addressing their bullying, remembering that almost every resource on workplace bullying mentions that bullies are not above lying or plotting revenge on folks who challenge their bullying:

- At the first sign of bullying, call him or her out. You do not have to hit them over the head with a hammer. Just let them know you will not tolerate the behavior. One way to begin is to have a heart-to-heart with a bully. (With children and youth, their caregivers may be the best people to do this.) Bullies have any number of responses when they are challenged for their actions. Responses can range from anger or confusion to recognition and apology. Because bullies don't see themselves (1) as bullies and (2) as flawed, their first response could be anger. Another likely response could be bewilderment: "What are you saying? I have no idea what you're talking about."
- Identify helpful influencers and ask them to advocate on your behalf. You may know someone in a position to report your circumstances to the right people well enough.

Even in school, though, solutions are not always clear. Brandon's mother (see introduction) called the school on his behalf, but the students involved only got a "talking-to" as punishment. Cyber bullying was not considered school-related behavior, at least at that time, he said. "I was just so afraid of people," says Brandon, explaining why he went to different middle schools each year in 6th, 7th, and 8th grade. He stayed quiet through most of it, barely speaking to other students.

Brandon started slowly merging back into socialness in eighth grade when he started putting video diaries on YouTube. Soon, other students were asking him to help them film school project videos, track meets, and other video projects. In high school, he discovered an organization called WeStopHate.org, a nonprofit organization devoted to helping people who have been bullied and allow them a safe space to share their stories. Emily-Anne Rigal, the founder of the organization, experienced bullying in elementary school, getting picked on for her weight. Although she and Brandon lived on opposite sides of the country, they became friends online, united by their passion for stopping bullying.

WeStopHate.org has achieved a wide reach. Ms. Rigal has received all sorts of honors for her efforts, from the Presidential Volunteer Service Award to a TeenNick HALO Award presented by Lady Gaga.

Brandon designed the WeStopHate.org website and most of its graphics, and is actively involved in the organization. In additional to Rigal, he has many other friends in different states whom he has met online. "I got cyber bullied, and I feel like, with that, it made me think, like, well, there has to be somebody on the Internet who doesn't hate me," he said. "That kind of just made me search more."

Brandon and Ms. Rigal are currently promoting the idea of having a "bully button" on Facebook so that people can report cyber bullying to the social network and have bullies suspended for a given period of time. They haven't gotten a response yet, but they're hopeful that it will take off. In the meantime, Brandon is feeling a lot safer in school than he used to. "Times have changed definitely, where people are becoming slowly more aware," he said. "At my school, at least, I'm seeing a lot less bullying and a more acceptance overall. People just stick to their own."

Parents' Agony – The worse than can happen.

John and Kelly lost their 13-year-old son, Ryan, to suicide on October 7, 2003. At the time of his death, Ryan was a student at a middle school in Essex Junction, Vermont. After Ryan's death, it was revealed that he was ridiculed and humiliated by peers at school and online. Ryan father writes, "A few days after his funeral I logged on to his AOL IM account because that was the one place he spent most of his time during the last few months. I logged on to see if there were any clues to his final action. It was in that safe world of being somewhat anonymous that several of his classmates told me of the bullying and cyber bullying that took place during the months that led up to his suicide. The boy that had bullied him since 5th grade and briefly befriended Ryan after the brawl was the main culprit. My son the comedian told his new friend something embarrassing and funny that happened once and the friend (bully) ran with the new information that Ryan had something done to him and therefore Ryan must be gay. The rumor and taunting continued beyond that school day … well into the night and during the summer of 2003."

Ryan's father, John, devotes his time to touring the United States and Canada, meeting with young people and promoting the need for more education and prevention of bullying, cyber bullying and youth suicide. He has also established a website in his son's memory. (See more at: http://www.puresight.com/Real-Life-Stories/ryan-halligan-1989-2003.html#sthash.DRLsWzee.dpuf)

Fighting back by speaking out: parental controls

Licensed mental health professionals are being increasingly asked by parents these days how to identify and address cyber bullying with their children. It is not always easy to know how and when to step in as a parent. Children and youth tend to use technology differently than adults. They begin playing games online and sending texts on their cell phones at an early age, and most youth have smart phones that keep them constantly connected to the Internet. Many are logged on to Facebook and chatting or sending text messages all day. Even sending e-mail or leaving a voice mail seems old- fashioned to them. Their knowledge of the digital world can be intimidating, but if parents stay involved in their children's online world, just as they do in their real world, they can help protect them from online dangers.

Why don't kids ask for help?

Statistics from the 2008–2009 School Crime Supplement show that an adult was notified in only about a third of bullying cases. Only 20 percent of cyber bullying victims tell their parents about the incident. Victims are most likely to tell a friend (42 percent), (2007-2009, Kamaron Institute, School Surveys). Many children and youth who are cyber bullied are reluctant to tell a teacher or parent, often because they feel ashamed of the social stigma, or because they fear their computer privileges will be taken away at home.

Kids do not tell adults for many reasons:

- Bullying can make a child feel helpless. Kids may want to handle it on their own to feel in control again.
- They may fear being seen as weak or a tattletale.
- Kids may fear backlash from the kid who bullied them.
- Bullying can be a humiliating experience. Kids may not want adults to know what is being said about them, whether true or false. They may also fear that adults will judge them or punish them for being weak.
- Kids who are bullied may already feel socially isolated. They may feel like no one cares or could understand.
- Kids may fear being rejected by their peers. Friends can help protect kids from bullying, and kids can fear losing this support.
- Kids are unable to defend themselves.
- Kids are depressed, anxious, or have low self-esteem.
- Kids are less popular than others and have few friends.
- Kids do not get along well with others, seen as annoying or provoking, or antagonize others for attention.

However, even if a children and youth have these risk factors, it does not mean that they will be bullied.

Here is one example that illustrates one parent's advocacy for her daughter:

> Ashley Berry, 13, of Littleton, Colorado, experienced unpleasantness with peers online. When she was 11, a classmate took photos of Ashley and created an entire Facebook page about her, but denied doing it when Ashley confronted the student whom she suspected. "It had things like where I went to school, and where my family was from and my birthday, and there were no security settings at all, so it was pretty scary," she said.
>
> The page itself did not do any harm or say mean things, Ashley said. But her mother, Anna Berry, was concerned about the breach of privacy, and viewed it in the context of what else was happening to her daughter in school: Friends were uninviting her to birthday parties and leaving her at the lunch table. "You would see a girl who should be on top of the world coming home and just closing herself into her bedroom," Berry said.
>
> Berry had to get police involved to have the Facebook page taken down. For 7th grade, her current year, Ashley entered a different middle school than the one her previous school naturally fed into. She says she's a lot happier now, and does media interviews speaking out against bullying. These days, Berry has strict rules for her daughter's online behavior. She knows Ashley's passwords, and she's connected with her daughter on every social network that the youth has joined (except Instagram, but Ashley has an aunt there). Ashley will not accept friend requests from anyone she does not know.

Parents, extended relatives, Internet service providers, and technology providers can all be incorporated in thinking about how children use technology. Apps that control how much time children spend online, and other easy-to-use parental control devices, may help. There could also be apps to enable parents to better protect their children from certain content and help them report bullying.

Parents should begin by knowing the signs of bullying and cyber bullying, and licensed mental health professionals can begin a checklist handout that parents can refer to as they observe their children.

Another Tragedy

Kenneth, a gay high school freshman from Paullina, Iowa, took his own life after being bullied by classmates at school and online, and with death threats by phone. The bullying began with an anti-gay Facebook group, created by Kenneth's classmates. His mother, Jeannie Chambers, said she knew her son was being harassed, and said that her son told her, "Mom, you don't know how it feels to be hated." According to his sister Kayla, the abuse that started after he came out was from people he had trusted: "People that were originally his friends, they kind of turned on him. A lot of people, they either joined in or were too scared to say anything." (2012)

All parents need to discuss Internet safety and the problem of cyber bullying with their children. This is especially important for children and youth, as they spend much of their time online. Just as kids must learn and practice good manners in public, they also need to mind their manners online. If a child would not say something to another young person's face, then the same words should not be e-mailed or texted. It is really as simple as that.

This is what is called the "front door rule." Tell your child that if he/she writes an e-mail or text, or posts something derogatory about another person on Facebook, Twitter, Instagram (or other sites), to think before they push "send." If they would not want to post the information on their front door for family members and all the neighbors to see, they should stop, think, and change – or forget about – the message. It could hurt someone more than they realize and could also be forwarded on to hundreds, thousands, even millions of others.

There was something to be said for conversations that were limited to face-to-face encounters and telephones made for nothing more than talking! (Hubard, 2013)

Parents can work to prevent cyber bullying problems in their children by discussing the problem before it begins. Here are some suggestions:

- Talk to your children about cyber bullying, explaining that it is wrong and can have serious consequences. Make a rule that they may not send mean or damaging messages, even if someone else started it, or suggestive pictures or messages or they will lose their cell phone and computer privileges for a time.
- Encourage children to tell an adult if cyber bullying is occurring. Tell them if they are the victims they will not be punished, and reassure them that being bullied is not their fault.
- Children and youth should keep cyber bullying messages as proof that the cyber bullying is occurring. Parents may want to talk to the parents of the cyber bully, to the bully's Internet or cell phone provider, and/or to the police about the messages, especially if they are threatening or sexual in nature.
- Try blocking the person sending the messages. It may be necessary to get a new phone number or e-mail address and to be more cautious about giving out the new number or address.
- Children and youth should never tell their password to anyone except a parent, and should not write it down in a place where it could be found by others.
- Children and youth should not share anything through text or instant messaging on their cell phone or the Internet that they would not want to be made public – remind teens that the person they are talking to in messages or online may not be who they think they are, and that things posted electronically may not be secure.
- Encourage your children never to share personal information online or to meet someone they only know online.
- Keep the computer in a shared space like the family room, and do not allow your children to have Internet access in their own rooms.

- Encourage children to have times when they turn off the technology, for example, at family meals or after a certain time at night.
- Parents may want to wait until high school to allow their children to have their own e-mail and cell phone accounts, and even then, parents should still have access to the accounts. Hinduja & Patchin, (2013).
- Listen and talk with children regularly about why cyber bullying is wrong and hurtful and let them know that engaging in cyber bullying is unacceptable and possibly illegal.
- Communicate online rules and responsibilities to children and enforce rules with tangible consequences.
- Support the school policies and rules that help create a safe place for students to learn.

In addition, parents can further support their children to disclose their cyber bullying or prevent them from becoming cyber bullies by:

- Being a good example – kids often learn bullying behavior from their parents.
- Teaching your child what it means to be a good friend.
- Making your home a safe haven for kids after school.
- Using teachable moments on TV to show the power of bystanders.
- Listening. Don't be in denial about incidents that are brought to your attention.

Additional help for targeted children and youth

It is extremely helpful for parents know the signs of cyber bullying if they suspect their child or youth is being targeted. Look for changes in them. However, be aware that not all children and youth who are bullied exhibit warning signs. The signs that a child or youth is being cyber bullied vary, but a few things to look for in addition to what has previously been reviewed are:

- Signs of emotional distress during or after using the Internet or the phone.
- Being very protective or secretive of their digital life.
- Withdrawal from friends and activities.
- Avoidance of school or group gatherings.
- Slipping grades and acting out in anger at home.
- Changes in mood, behavior, sleep, or appetite.
- Health problems.

It is important that parents speak to their children and youth to help them handle bullying. For example, licensed mental health professionals can advise parents to listen to their child's worries and convey that it is perfectly understandable and okay for him or her to feel that way. They should offer assurance without trying to dismiss their child's feelings.

As children begin to disclose their abuse and feelings, parents should be sure to repeat back the same thoughts and feelings using phrases like, "I know you are feeling worried." When a child feels understood by his or her parents, he or she more is receptive to their parents' help and any advice on coping that is offered.

Encourage parents to let their children know that everyone worries, even adults, at one time or another. But also make sure that their child knows that there are ways to feel better and less fearful. Parents should go over some strategies that children can used if someone teases them. Ignoring the bully and simply walking away, or using humor to combat aggressiveness, might get the bully to stop. Bullies often give up when they do not get a response from their target. Ask parents to ask their children to talk about what has been going on at school as well. Just listening can be helpful.

Although children and youth may resolve many incidents of bullying on their own, parents should keep an eye on the situation. If it persists, they need to get involved by talking to their child's teacher or school counselor, if it is occurring there, (Reviewed by: D'Arcy Lyness, PhD, Date reviewed: September 2010). It is also highly recommended that children and youth speak with a licensed mental health professional to be assessed and perhaps treated for any trauma they have experienced.

The Kamaron Institute Resource Center provides tips for parents to pre-empt any potential cyber bullying: (Kamaron Institute Resource Center, 2013)

- Consider installing filtering and blocking software, but understand clearly that proactive parents are the only real deterrent and the best resource for bullying preemption.
- Keep your home computer(s) in easily viewable places, such as a family room or kitchen.
- Model the behavior you want to see in your child.
- Talk regularly with your child about on-line activities he or she is involved in.
- Set firm guidelines for cell phone use and monitor that behavior.
- Talk specifically about cyber bullying. Explain that it is harmful and unacceptable behavior.
- Outline your expectations for responsible online behavior and clearly explain the consequences for inappropriate behavior.
- Encourage your child to tell you immediately if he or she is a victim of cyber bullying. Tell your child does not respond to the bully.
- Stay calm. Plan in advance how you will calmly receive the news that your child is being bullied and the solution steps you will take. You will want the evidence. Tell your child to save the bullying messages or photo.

If your child has been bullied or cyber bullied at school, call your child's school; ask the principal what measurable, bullying preemption, activity-based programs they have in place today. Offer to serve on the group that expands the school's behavior policy to include cyber bullying behavior that disrupts the schools teaching and learning environment. Ask about results.

> "Some girl in my class e-mailed me, calling me a freak and a loser. It made me feel really depressed because I had other thing going on too at that time. I told my dad and he called her up and spoke to her. He told her that I didn't read it yet, that it would crush me and that she should think before she does anything like that again. Well, she never did it again, so I guess it worked."
>
> - 15-year-old girl from NY

When someone close is being bullied, there are many steps to take to help resolve the situation. Make sure advocates understand what bullying is and what it is not, the warning signs of bullying, and steps to take for preventing and responding to bullying, including how to talk to children about bullying, prevention in schools and communities, and how to support children involved. The below can help clients address the problem.

School intervention must work in partnership with parents and become aware and proactive

> My son hates going to school because there's a boy who teases and picks on him every day. What can I do to help him?
>
> —Jesse

Having to deal with a bully is hard for kids — especially at school. Henry's story below describes his cyber bullying:

> Henry was a shy 6th-grader who was new to the school, having recently arrived from out of state. One day as he was browsing a social media site, he came across a page about the school with pictures of students, including one of him labeled "The Fat Nerd." Upset, he posted a reply expressing his dismay. The postings became nastier, and soon some students were making loud comments in the lunchroom and on the playground. A teacher overhead some of the catcalls, and asked Henry what was going on. He described the social media page and the cyber bullying he was enduring.

The school, which had trained its teachers and had a zero-tolerance policy on bullying in any form, responded quickly. They identified the ringleaders, and with the help of their parents, had the creator of the unauthorized school page take it down from the social media site. School officials hosted sessions for parents and students about cyber bullying and how to prevent it.

However, Henry had to endure many weeks of feeling humiliated and hurt before anyone realized what was going on. Even his parents did not know, as Henry was too embarrassed to tell them. It will take the still-shy teen a long time to regain his confidence.

Preventing cyber or physical bullying in schools

Bullying can threaten students' physical and emotional safety at school and can negatively impact their ability to learn. The best way to address bullying is to stop it before it starts. There are a number of things school staff can do to make schools safer and prevent bullying.

Who should get involved? … Everyone. Educators, school administrators, victim service providers, law enforcement, community partners, parents, and even students should all be involved. Develop and sustain a network of health care, mental health, counseling, and social services in your community. The more stakeholders that are involved, the better prepared you are to tackle the issue.

School administrators start the ball-rolling
In getting started first assess school prevention and intervention efforts around student behavior, including substance use and violence. You may be able to build upon them or integrate bullying prevention strategies. Many programs help address the same protective risk factors that bullying programs do.

- **Assess bullying in your school** - Conduct assessments in your school to determine how often bullying occurs, where it happens, how students and adults intervene, and whether your prevention efforts are working.
- **Engage parents and youth** - It is important for everyone in the community to work together to send a unified message against bullying. Launch an awareness campaign to make the objectives known to the school, parents, and community members. Establish a school safety committee or task force to plan, implement, and evaluate your school›s bullying prevention program.
- **Create policies and rules** -Create a mission statement, code of conduct, school-wide rules, and a bullying reporting system. These establish a climate in which bullying is not acceptable. Disseminate and communicate widely.
- **Build a safe environment** - Establish a school culture of acceptance, tolerance and respect. Use staff meetings, assemblies, class and parent meetings, newsletters to families, the school website, and the student handbook to establish a positive climate at school. Reinforce positive social interactions and inclusiveness.
- **Educate students and school staff** - Build bullying prevention material into the curriculum and school activities. Train teachers and staff on the school's rules and policies. Give them the skills to intervene consistently and appropriately.

Cyber specific steps to address the problems in schools should:

- Implement and enforce an anti-bullying school code of conduct that includes both bullying and cyber bullying. Spell out what behaviors and actions will not be tolerated and the consequences that will follow.
- Have students sign an anti-bullying and cyber bullying pledge where students pledge not to bully others and to speak up if they know someone is being bullied.
- Create a safe place for students to voice concerns or problems and encourage students to come forward and speak to someone.
- Learn how to tell the warning signs that a child might be being cyber bullied and how to get the child appropriate help. Educate teachers and staff on the warning signs and what they should do to help a student.
- Talk with students about cyber bullying: what it is, the impact it has, and its consequences. Let them know cyber bullying is a serious issue that will not be tolerated.
- Educate parents on cyber bullying. Let them know what signs to look for at home and how to talk with their children about the issue. Invite parents to talk with you about cyber bullying and send home resources.
- Learn and teach conflict resolution and anger management skills. Help students practice applying them in everyday life.
- Develop and sustain a network with health care, mental health, counseling, victim services, and social work resources in your community. Make sure all staff knows how to connect students with available resources.
- Encourage and sponsor a student-led, anti-bullying program. Work with students to help raise cyber bullying awareness within the school through student-led clubs, assemblies, or posters.
- Stay informed! Stay up to date with the latest internet and technology trends.

For more information on how you can prevent cyber bullying in your school, visit www.ncpc.org.

School staff
School districts much provide training to school staff and the community on victimization, victim services, and resources. Schools should also develop an anti-bullying code of conduct that clearly spells out what behaviors will not be tolerated. Teachers should talk and educate students on the issue of cyber bullying. Let students know where they can report an incident or seek help.

Training staff to address cyber bullying is necessary when creating policies and directly impacting children and youth by supporting all involved. All kids involved in bullying—whether they are bullied, bully others, or see bullying can be affected. It is important to support all everyone involved to make sure the bullying doesn't continue and effects can be minimized.

It helps to know and understand to:

- Make sure the child or youth bully knows what the problem behavior is. Young people who bully must learn their behavior is wrong and harms others.
- Show kids that bullying is taken seriously. Calmly tell the child or youth that bullying will not be tolerated. Model respectful behavior when addressing the problem.
- Work with the child or youth to understand some of the reasons he or she bullied.
- Sometimes children and youth bully to fit in. These kids can benefit from participating in positive activities. Involvement in sports and clubs can enable them to take leadership roles and make friends without feeling the need to bully.
- Other times kids act out because something else—issues at home, abuse, stress—is going on in their lives. They also may have been bullied. These kids may be in need of additional support, including mental health services.
- Use consequences to teach. Consequences that involve learning or building empathy can help prevent future bullying. School staff should remember to follow the guidelines in their student code of conduct and other policies in developing consequences and assigning discipline. For example, the child or youth who bullied can:
    1. Lead a class discussion about how to be a good friend.
    2. Write a story about the effects of bullying or benefits of teamwork.

    3. Role-play a scenario or make a presentation about the importance of respecting others, the negative effects of gossip, or how to cooperate.
    4. Do a project about civil rights and bullying.
    5. Read a book about bullying.
    6. Support a student-led, anti-bullying program.
    7. Provide information to parents, educators, and law enforcement about how youth use the Internet, what websites they frequent, and how to talk to youth about appropriate Internet use.
- Provide appropriate services to victims.
    1. Make posters for the school about cyber bullying and being smart online.
    2. Involve the kid who bullied in making amends or repairing the situation. The goal is to help them see how their actions affect others. For example, the child can:
        - Write a letter apologizing to the student who was bullied.
        - Do a good deed for the person who was bullied or for others in your community.
        - Clean up, repair, or pay for any property they damaged.
- Avoid strategies that do not work or have negative consequences.
    1. Zero tolerance or "three strikes, you're out" strategies do not work. Suspending or expelling students who bully does not reduce bullying behavior. Students and teachers may be less likely to report and address bullying if suspension or expulsion is the consequence.
    2. Conflict resolution and peer mediation do not work for bullying. Bullying is not a conflict between people of equal power who share equal blame. Facing those who have bullied may further upset kids who have been bullied.
    3. Group treatment for students who bully does not work. Group members tend to reinforce bullying behavior in each other.

Supporting bullying children and youth whether or not it has been physical or through electronic devices:

- Listen and focus on the child. Learn what's been going on and show you want to help.
- Assure the child that bullying is not his or her fault.
- Know that kids who are bullied may struggle with talking about it. Consider referring them to a school counselor, psychologist, or other mental health service.
- Give advice about what to do. This may involve role-playing and thinking through how the child might react if the bullying occurs again.
- Work together to resolve the situation and protect the bullied child. The child, parents, and school or organization may all have valuable input. It may help to:
    1. Ask the child being bullied what can be done to make him or her feel safe.
    2. Remember that changes to routine should be minimized. He or she is not at fault and should not be singled out. For example, consider rearranging classroom or bus seating plans for everyone. If bigger moves are necessary, such as switching classrooms or bus routes, the child who is bullied should not be forced to change.
- Develop a game plan. Maintain open communication between schools, organizations, and parents. Discuss the steps that are taken and the limitations around what can be done based on policies and laws. Remember, the law does not allow school personnel to discuss discipline, consequences, or services given to other children.
- Be persistent. Bullying may not end overnight. Commit to making it stop and consistently support the bullied child.
- Avoid these mistakes:
    1. Never tell the child to ignore the bullying.
    2. Do not blame the child for being bullied. Even if he or she provoked the bullying, no one deserves to be bullied.
    3. Do not tell the child to physically fight back against the kid who is bullying. It could get the child hurt, suspended, or expelled.
    4. Parents should resist the urge to contact the other parents involved. It may make matters worse. School or other officials can act as mediators between parents.
- Follow-up. Show a commitment to making bullying stop. Because bullying is behavior that repeats or has the potential to be repeated, it takes consistent effort to ensure that it stops. After the bullying issue is resolved, continue finding ways to help the child or youth who bullied to understand how what they do affects other people. For example, praise acts of kindness or talk about what it.

Stop Bullying on the Spot

In schools and even outside of schools, when adults respond quickly and consistently address bullying behavior, they send the message that it is not acceptable. Research shows this can stop bullying behavior over time. There are simple steps adults can take to stop bullying on the spot and keep kids safe. Licensed mental health professionals again, may wish to develop handouts or can even ask to address the problem of cyber bullying and bullying in schools as well as community environments such as the YMCA or local child safety council.

Do:

- Intervene immediately. It is ok to get another adult to help.
- Separate the kids involved.
- Make sure everyone is safe.
- Meet any immediate medical or mental health needs.
- Stay calm. Reassure the kids involved, including bystanders.
- Model respectful behavior when you intervene.

Avoid these common mistakes:

- Do not ignore it. Do not think kids can work it out without adult help.
- Do not immediately try to sort out the facts.
- Do not force other kids to say publicly what they saw.
- Do not question the children involved in front of other kids.
- Do not talk to the kids involved together, only separately.
- Do not make the kids involved apologize or patch up relations on the spot.

Get police help or medical attention immediately if:

- A weapon is involved.
- There are threats of serious physical injury.
- There are threats of hate-motivated violence, such as racism or homophobia.
- There is serious bodily harm.
- There is sexual abuse.
- Anyone is accused of an illegal act, including robbery or extortion—using force to get money, property, or services.

At the first sign find out what happened. Whether you have just stopped bullying on the spot or a child has reached out to you for help, follow the steps below to determine the best way to proceed.

- Get the facts.
- Determine if it is bullying.
- Keep all the involved children separate.
- Get the story from several sources, both adults and kids.
- Listen without blaming.
- Do not call the act "bullying" while you are trying to understand what happened.
- It may be difficult to get the whole story, especially if multiple students are involved or the bullying involves social bullying or cyber bullying. Collect all available information.

Determine if it's bullying. There are many behaviors that look like bullying, but require different approaches. It is important to determine whether the situation is bullying or something else. Review the definition of bullying. State law and school policy may have additional guidelines for defining bullying behavior.

To determine if this is cyber or other bullying, consider the following questions:

- What is the history between the kids involved? Have there been past conflicts?
- Is there a power imbalance? Remember that a power imbalance is not limited to physical strength. It is sometimes not easily recognized. If the targeted child feels like there is a power imbalance, there probably is.
- Has this happened before? Is the child worried it will happen again?
- Have the kids dated? There are special responses for teen dating violence.
- Are any of the kids involved with a gang? Gang violence has different interventions.
- Remember that it may not matter who started it. Some kids who are bullied may be seen as annoying or provoking, but this does not excuse the bullying behavior.
- Once you have determined if the situation is bullying, support the kids involved.

Other bullying discussion

Parents, school staff, and other caring adults have a role to play in preventing bullying. They can:

- Help kids understand bullying. Talk about what bullying is and how to stand up to it safely. Tell kids bullying is unacceptable. Make sure kids know how to get help.
- Keep the lines of communication open. Check in with kids often. Listen to them. Know their friends, ask about school, and understand their concerns.
- Encourage kids to do what they love. Special activities, interests, and hobbies can boost confidence, help kids make friends, and protect them from bullying behavior.
- Model how to treat others with kindness and respect.
- Kids who know what bullying is can better identify it. They can talk about bullying if it happens to them or others. Kids need to know ways to safely stand up to bullying and how to get help.
- The adult can give comfort, support, and advice, even if they can't solve the problem directly.
- Encourage the child to report bullying if it happens.
- Talk about how to stand up to kids who bully. Give tips, like using humor and saying "stop" directly and confidently. Talk about what to do if those actions do not work, like walking away
- Talk about strategies for staying safe, such as staying near adults or groups of other kids.
- Urge them to help kids who are bullied by showing kindness or getting help.
- Watch the short "webisodes" and discuss them with kids.

The punishment for cyber bullies can include being suspended from school or kicked off sports teams. Certain types of cyber bullying also may violate school codes or even anti-discrimination or sexual harassment laws. Law enforcement also serves as a resource on current cyber bullying issues, laws, and policies. And they can discuss ways to create an enforceable anti- cyber bullying policy for on and off school grounds.

Several school districts now have policies in place. For example, Chicago Public Schools officials say cyber bullying is covered by a district-wide student code of conduct. Any student who uses "any computer or information technology device to stalk, harass, or otherwise intimidate others" risks a 10-day suspension or expulsion, according to the policy.

Young adults and cyber bullying

Although media reports often call unwanted, aggressive behavior among young adults bullying, this is not exactly accurate. Many state and federal laws address bullying-like behaviors in this age group under very serious terms, including hazing, harassment, and stalking. Additionally, most young adults are uncomfortable with the term bullying; they associate it with school-aged children.

Advise for young adults:

- Encourage young adults to talk to someone they trust.
- Determine if the behavior violates campus policies or laws. Review student codes of conduct, state criminal laws, and civil rights laws.
- Report criminal acts to campus or community law enforcement.
- Consult the college's Title IX coordinator to help determine if the behavior is sexual harassment.
- Many college campuses also have an ombudsperson or similar person who handles a variety of concerns and complaints. He or she can help direct the young adult to appropriate campus resources.
- Young adults may be reluctant to seek help for cyber bullying, although they do recognize it as a serious issue for their age group. Encourage young adults to report cyber bullying.

Take concerns directly to the community

Bullying can be prevented, especially when the power of a community is brought together. Community-wide strategies can help identify and support children who are bullied, redirect the behavior of children who bully, and change the attitudes of adults and youth who tolerate bullying behaviors in peer groups, schools, and communities.

Community partners provide counseling, extended learning programs, and other youth programs or services. They can also sponsor Internet safety awareness days for youth to learn about safe Internet use. And community partners can help recruit additional volunteer

Bullying does not happen only at school. Community members can use their unique strengths and skills to prevent bullying wherever it occurs. For example, youth sports groups may train coaches to prevent bullying. Local businesses may make t-shirts with bullying prevention slogans for an event. School after-care staff may read books about bullying to kids and discuss them. Hearing anti-bullying messages from the different adults in their lives can reinforce the message for kids that bullying is unacceptable.

Potential Partners

- Involve anyone who wants to learn about bullying and reduce its impact in the community. Consider involving businesses, local associations, adults who work directly with kids, parents, and youth.
- Identify partners, including mental health specialists, law enforcement officers, neighborhood associations, service groups, faith-based organizations, and businesses.
- Learn what types of bullying community members see and discuss developing targeted solutions.
- Involve youth. Teens can take leadership roles in bullying prevention among younger kids.

Strategies – Study community strengths and needs:

- Ask: Who is most affected? Where? What kinds of bullying happen most? How do kids and adults react? What is already being done in our local area to help? Think about using opinion surveys, interviews, and focus groups to answer these questions. Learn how schools assess bullying.
- Consider open forums like group discussions with community leaders, businesses, parent groups, and churches.

Develop a comprehensive community strategy:

- Review what you learned from your community study to develop a common understanding of the problem.
- Establish a shared vision about bullying in the community, its impact, and how to stop it.
- Identify audiences to target and tailor messages as appropriate.
- Describe what each partner will do to help prevent and respond to bullying.
- Advocate for bullying prevention policies in schools and throughout the community.
- Raise awareness about your message. Develop and distribute print materials. Encourage local radio, TV, newspapers, and websites to give public service announcements prime space. Introduce bullying prevention to groups that work with kids.
- Track your progress over time. Evaluate to ensure you are refining your approach based on solid data, not anecdotes.

Parents, school staff, and community organizations all have a role to play.

Technology research

Scientists at Massachusetts Institute of Technology are working on an even more automated solution. They want to set up a system that would give bullying victims coping strategies, encourage potential bullies to stop and think before posting something offensive, and allow onlookers to defend victims, said Henry Lieberman. Lieberman's students Birago Jones and Karthik Dinakar are working on an algorithm that would automatically detect bullying language. The research group has broken down the sorts of offensive statements that commonly get made, grouping them into categories such as racial/ethnic slurs, intelligence insults, sexuality accusations, and social acceptance/rejection.

While it's not all of the potential bullying statements that could be made online, MIT Media Lab scientists have a knowledge base of about 1 million statements. They have thought about how some sentences, such as "you look great in lipstick and a dress," can become offensive if delivered to males specifically.

The idea is that if someone tries to post an offensive statement, the potential bully would receive a message such as "Are you sure you want to send this?" and some educational material about bullying may pop up. Lieberman does not want to automatically ban people, however. "If they reflect on their behavior, and they read about the experience of others, many kids will talk themselves out of it," he said.

Lieberman and colleagues are using their machine learning techniques on the MTV-partnered website "A Thin Line," where anyone can write in their stories of cyber bullying, read about different forms of online disrespect, and find resources for getting help. The researchers' algorithm tries to detect the theme or topic of each story, and match it to other similar stories. They're finding that the top theme is sexting, Lieberman said.

"We're trying to find social network sites that want to partner with us, so we can get more of this stuff out into the real world," Lieberman said.

Cyber bullying laws

It is imperative that everyone who works with youth, especially law enforcement officers, stay up-to-date on the ever-evolving state and local laws concerning online behaviors, and equip themselves with the skills and knowledge to intervene as necessary. Recent attention to bullying has focused not only on the passing of new state laws on bullying and cyber bullying, but also on what's happening within the courts. Although it is difficult to track bullying-related litigation, a number of recent high-profile cases against school systems have resulted in significant awards to parents or guardians for harm caused to children who are bullied. (Kowalski, Limber, and Agatston 2008)

Although published case laws relevant to cyber bullying are very limited and somewhat unclear (Kowalski, Limber, and Agatston 2008; Willard 2006), these three legal questions are particularly relevant to public school staff members in the United States:

1. Under what circumstances might school staff members be liable for failing to address cyber bullying?
2. When can school staff members intervene to address cyber bullying without violating students' First Amendment rights regarding freedom of expression?
3. Under what circumstances can school staff members monitor or search Internet records of students without violating students' Fourth Amendment restrictions on illegal searches and seizures?

Under what circumstances might school staff members be liable for failing to address cyber bullying?

School staff members may, under certain circumstances, be held liable under state or federal laws if they do not address cyber bullying or harassment. Under state laws, students (or parents or guardians on behalf of their children and youth) may search students' computers or Internet records at school. (This begs the question. Are these actions permissible, or do they violate students' Fourth Amendment protections against illegal searches and seizures?) Following the legal precedent set in cases that have involved searches of students' desks and lockers, students should expect limited privacy of the contents of computers at school. On a regular basis, school staff members may make general inspections of school computers and Internet accounts. They may make more specific searches of computers or accounts in cases when they have reason to suspect content that either (a) is illegal or (b) may provide evidence of activities that are illegal or violate school rules (Kowalski, Limber, and Agatston, 2008).

Summary

Cyber bullying is defined as: bullying that takes place using electronic technology.

Cyber bullying can be very damaging to adolescents and teens, and even adults. Cyber bullying can lead to anxiety, depression, and even suicide. Also, once things are circulated on the Internet, they may never disappear, resurfacing at later times to renew the pain of cyber bullying. Cyber bullying is a persuasive problem. It is rare that an online bully will be a total stranger.

There are several statistics regarding cyber bullying. A few include:

- More than half of adolescents and teens have been bullied online, and about the same number have engaged in cyber bullying.
- More than 1 in 3 young people have experienced cyber threats online.
- More than 25 percent of children and youth have been bullied repeatedly through their cell phones or the Internet.
- More than half of young people do not tell their parents when cyber bullying occurs.

Cell phones and computers themselves are not to blame. Social media sites can be used for positive activities, like connecting with friends and family, with school and work, and for entertainment. But these tools can also be used to hurt other people. Whether done in person or through technology, the effects of bullying are similar. Cyber bullying can be the spreading of hurtful rumors or directing harmful words or images toward another person using electronic devices. While adults have separated "cyber" bullying from face-to-face bullying, children and youth increasingly view their offline and online worlds as one. For today's young people, it is not "cyber" bullying, but bullying. Either way, bullying is never okay and unfortunately, bullying can spread more quickly with today's online technologies.

Electronic technology includes devices. Sometimes cyber bullying can be easy to spot. For example, if a child displays a text message, tweet, or response to a status update on Facebook that is harsh, mean, or cruel. Other acts are less obvious, like impersonating a victim online or posting personal information, photos, or videos designed to hurt or embarrass another person. Some people report that a fake account, web page, or online persona has been created with the sole intention to harass and bully.

Cyber bullying messages are communicated through:
- Text or digital imaging messages sent on cell phones.
- e-mails.
- Instant messaging.
- Web pages.
- Web logs (blogs).
- Chat rooms or discussion groups.
- Other information communication technologies.

Cyber bullying messages are communicated by:
- Sending mean messages or threats to a person's e-mail account or cell phone.
- Spreading rumors online or through texts.
- Posting hurtful or threatening messages on social networking sites or web pages.
- Stealing a person's account information to break into their account and send damaging messages.
- Pretending to be someone else online to hurt another person.
- Taking unflattering pictures of a person and spreading them through cell phones or the Internet.
- Sexting, or circulating sexually suggestive pictures or messages about a person.

On a cellphone, smartphone, or tablet, cyber bullying may include phone calls, text messages, social network posts, videos, and photos. Cyber bullying in the form of text messages, e-mails, photos, website postings can go school or community-wide in minutes and global in days. Slanderous information sent into cyberspace is difficult, if not impossible, to expunge. Cyber bullying often takes the form of cyber gossip, where damaging content is based on whim; not facts, and is posted on social networking sites such as MySpace Facebook, and Twitter.

Cyber bullying also can occur accidentally. The impersonal nature of text messages, instant messages, and e-mails make it very hard to detect the sender's tone — one person's joke could be another's hurtful insult. Nevertheless, a repeated pattern of e-mails, text messages, and online posts is rarely accidental.

Online bullying has a lot in common with bullying in school: Both behaviors include harassment, humiliation, teasing, and aggression. Cyber bullying presents unique challenges in the sense that the perpetrator can attempt to be anonymous, and attacks can happen at any time of day or night.

Only 20 percent cyber bullying victims tell their parents about the incident. Victims are most likely to tell a friend (42 percent), (2007-2009, Kamaron Institute, School Surveys). Many children and youth who are cyber bullied are reluctant to tell a teacher or parent, often because they feel ashamed of the social stigma, or because they fear their computer privileges will be taken away at home.

All parents need to discuss Internet safety and the problem of cyber bullying with their children. This is especially important for children and youth, as they spend much of their time online. Just as kids must learn and practice good manners in public, they also need to mind their manners online. If a child would not say something to another young person's face, then the same thing should not be e-mailed or texted. It is as simple as that.

Scientists at Massachusetts Institute of Technology are working on an even more automated solution. They want to set up a system that would give bullying victims coping strategies, encourage potential bullies to stop and think before posting something offensive, and allow onlookers to defend victims. Students are working on an algorithm that would automatically detect bullying language. The research group has broken down the sorts of offensive statements that commonly get made, grouping them into categories such as racial/ethnic slurs, intelligence insults, sexuality accusations and social acceptance/rejection.

Cyber bullying resources for professionals and clients

There are two sources of federally collected data on youth bullying:
- The 2011 Youth Risk Behavior Surveillance System (Centers for Disease Control and Prevention) indicates that, nationwide, 20 percent of students in grades 9 through 12 experienced bullying.
- The 2008–2009 School Crime Supplement (National Center for Education Statistics and Bureau of Justice Statistics) indicates that, nationwide, 28 percent of students in grades 6 through 12 experienced bullying.

Get Wise About Wireless
The National Crime Prevention Council (NCPC) knows that cell phones can be valuable tools in preventing and reporting crime, but sometimes people use cell phones to bully or cause other problems. The Wireless Foundation's GET WISE ABOUT WIRELESS program helps educate students about the responsible behaviors associated with using cell phones. GET WISE ABOUT WIRELESS is designed to encourage educators and families to help students practice proper cell phone etiquette and safe behavior. The program also seeks to serve as a catalyst for discussions at home among family members about using wireless technology in their day-to-day lives.

Cyber Bullying Tip Sheets
Handouts for teens, educators, etc. on cyber bullying
- Cyber bullying Tips for Teens
  A reproducible handout for teens on cyber bullying safety.
- Cyber bullying: What is it?
  A reproducible handout on the basics of cyber bullying.
- Cyber bullying Prevention: Working Together
  A reproducible handout on how everyone can get involved in cyber bullying prevention.
- Cyber bullying: Spotting the Signs
  A reproducible handout on the signs that someone is being cyber bullied.
- Educators Preventing Cyber Bullying
  A reproducible handout for educators on how to prevent cyber bullying in school.
- Staying Informed: Cyber Bullying Laws and Legislation
  A reproducible handout on how to stay up-to-date on cyber bullying laws and legislation.

Social Media

Three Bold Steps for School Community Change: A Toolkit for Community Leaders (Safe Schools/Healthy Students). This kit shows how partnerships with people from different parts of a community can create positive, lasting change for students.

Striving to Reduce Youth Violence Everywhere (STRYVE) is a national youth violence prevention effort. STRYVE Online helps communities with access to information and tools, effective strategies, training and technical assistance, and online community workspaces.

Contact the National Suicide Prevention Lifeline online or at 1-800-273-TALK (8255). The toll-free call goes to the nearest crisis center in our national network. These centers provide 24-hour crisis counseling and mental health referrals.

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IDENTIFYING AND ADDRESSING CYBER BULLYING

Final Examination Questions

Select the best answer for each question and proceed to ***SocialWork.EliteCME.com*** to complete your final examination.

46. The 2011 Youth Risk Behavior Surveillance Survey finds that 16 percent of high school students (grades 9-12) were electronically bullied in the past:
    a. 1 year.
    b. 6 months.
    c. 1 month.
    d. 2 years.

47. Flaming is online:
    a. Fighting using electronic messages with angry, vulgar language.
    b. Fighting using electronic messages with physical threats.
    c. Copying messages and sending them to other people.
    d. Destroying messages.

48. No single factor puts a child or youth at risk of:
    a. Being affected by targeting.
    b. Being bullied or bullying others.
    c. Being targeted.
    d. Being bullied by a stranger.

49. Many children and youth who are cyber bullied are:
    a. Usually eager to tell an adult.
    b. Reluctant to tell a teacher or parent.
    c. Want to tell parents instead of friends.
    d. Reluctant to go back online.

50. Most young adults are uncomfortable with the term bullying;
    a. Because they do not believe they are actually having any effect.
    b. They associate it with school-aged children.
    c. They believe they are adults already.
    d. They do not want to bother anyone.

SWCA04CBE16

Chapter 7: Understanding Enabling Behavior and How to Address It

4 CE Hours

By Wade Lijewski, Ph.D.

Learning objectives

- Understand the elements of enabling behavior.
- Explore the definition and research on codependency.
- Review and understand the various family dynamics related to enabling behavior.
- Understand the different techniques to address and stop enabling behavior (from the perspective of a counselor dealing with addiction and enabling and the perspective of the person who is enabling a loved one).
- Consider the existing myths about enabling behavior and myths about therapy.
- Discover the various elements of confrontation and how to use them.

Overview

In the world of psychology, the term "enable" is used in both a positive and a negative sense. It is used by psychologists in a positive light to describe the empowerment of others as well as the implementation of positive resources to address a problem. However, enabling is also used as a term to describe approaches by individuals that are intended to help but in fact may perpetuate a problem.

A common theme of enabling in the latter sense is that third parties take responsibility, blame, or make accommodations for a person's harmful conduct. They often have the best of intentions, but become an element that needs to be addressed when counseling individuals and families on addiction.

Enabling is a term that is frequently used in 12-step recovery programs to describe the behavior of family members or other loved ones who rescue an alcoholic or drug addict from the consequences of his or her own self-destructive behavior. It also includes rescuing anyone who is caught up in any of the compulsive or addictive self-destructive behaviors that are symptoms of codependency, such as:

- Gambling.
- Spending.
- Eating disorders.
- Sexual or relationship addictions.
- Inability to hold a job.

Enabling comes in many forms, such as giving addicts whatever they want. This deprives them of learning how to build self-esteem, which you build by doing esteemable acts, such as going to work every day, going to school, being productive, and building a life and healthy relationships. Another example of enabling is setting boundaries but failing to uphold them when the time comes. An addict/alcoholic must understand the consequences of his or her actions or will most likely continue with the same behavior; this responsibility lies with the family.

Another common example of enabling can be seen in the relationship between alcoholics/addicts and their codependent spouses. The spouses often believe incorrectly that they are helping alcoholics by calling into work for them, making excuses that prevent others from holding them accountable, and generally cleaning up the mess that occurs in the wake of the alcoholic's impaired judgment. In reality, what those spouses are doing is hurting, not helping. Enabling prevents psychological growth in the person being enabled and can contribute to negative symptoms in the enabler.

Many people who are drug abusers and addicts recognize that they can't stop using on their own. Likewise, a large number of these same people literally wouldn't be able to continue to use on their own if they weren't being helped by an enabler. From covering up lies and criminal activity to making excuses to other family members, enablers often make a person's substance abuse and addiction possible. However, the reality of the matter is that enablers are doing the addict great harm, and in some ways are just as responsible for their behavior as the addicts themselves. Understanding the enabler's role and how it can be reversed is critical for anyone who wants to permanently break the cycle of drug abuse, alcoholism and addiction.

To enable the individual with the addiction, the mutually dependent person makes excuses and lies for the addict, which enables the addiction to continue. Codependency is reinforced by a person's need to be needed. The enabler thinks unreasonably by believing he can maintain healthy relationships through manipulation and control. He believes he can do this by avoiding conflict and nurturing dependency.

Is it normal for people to think that they can maintain a healthy relationship when they do not address problems and lie to protect others from their responsibilities? The way a codependent person can continue to foster this dependency from others is by controlling situations and the people around them. The ongoing manner of a codependent home is to avoid conflicts and problems and to make excuses for destructive or hurtful behavior. (Albury, 2011)

Why does enabling cause so much hurt in a relationship? The power afforded to the mutually dependent person in a relationship supports his need for control, even if he uses inappropriate means to fulfill that need. A second and overlooked reason, centers on the contradictory messages and unclear expectations presented by someone who is codependent. These characteristics lead to a relationship filled with irrational thoughts and behavior. This kind of relationship has no clear rules to right and wrong behavior. The unhealthy patterns a person enables may be one or more of these behaviors:

- Drinking too much.
- Spending too much.
- Overdrawing bank accounts and bouncing checks.
- Gambling too much.
- Getting into trouble with loan sharks and check cashing agencies.
- Working too much or not enough.
- Maxing out credit cards.
- Abusing drugs (prescription or street drugs).

- Getting arrested (the enabler must bail him or her out).
- Any of a number of other unhealthy behaviors and patterns of addiction.

Any time people help or allow another person to continue their unproductive, unhealthy, addictive behavior, whether actively or passively, they are enabling. Even when they say nothing, they are enabling the behavior to continue. Sometimes people say nothing out of fear – fear of reprisal; fear of the other person hurting, hating or not liking them; or fear of butting in where they don't think they belong. Perhaps they even fear being hit or worse.

Enablers often participate in such behavior because of their own low self-esteem. They haven't gained the ability to say no without fear of losing the love or caring of that other person. People who learn tough love have to learn that their former behaviors have been enabling and that to continue in them would represent allowing the other person's pattern of behavior to continue and to worsen.

Because enabling behavior is most often discussed in substance abuse issues, it is interesting to note the prevalence of this issue and its impact on society.

A major source of information on substance use, abuse, and dependence among Americans age 12 and older is the annual National Survey on Drug Use and Health (NSDUH) conducted by the Substance Abuse and Mental Health Services Administration. Following are facts and statistics on substance use in America from 2010, the most recent year for which NSDUH survey data have been analyzed.

- Illicit drug use in America has been increasing. In 2010, an estimated 22.6 million Americans age 12 or older – or 8.9 percent of the population – had used an illicit drug or abused a psychotherapeutic medication (such as a pain reliever, stimulant or tranquilizer) in the past month. This is up from 8.3 percent in 2002. The increase mostly reflects a recent rise in the use of marijuana, the most commonly used illicit drug.
- In 2010, 7.0 million Americans age 12 or older (or 2.7 percent) had used psychotherapeutic prescription drugs non-medically (without a prescription or in a manner or for a purpose not prescribed) in the past month – similar to previous years. And 1.2 million Americans (0.5 percent) had used hallucinogens (a category that includes ecstasy and LSD) in the past month – unchanged from previous years.
- Cocaine use has gone down in the last few years; from 2006 to 2010, the number of current users age 12 or older dropped from 2.4 million to 1.5 million. Methamphetamine use has also dropped, from 731,000 current users in 2006 to 353,000 in 2010.
- Most people use drugs for the first time when they are teenagers. There were 3.0 million new users (initiates) of illicit drugs in 2010, or about 8,100 new users per day. Over one-half (57 percent) were under 18.
- Binge and heavy drinking are more prevalent among men than among women. In 2010, 30.9 percent of men 12 and older and 15.7 percent of women reported binge drinking (five or more drinks on the same occasion) in the past month; and 10.1 percent of men and 3.4 percent of women reported heavy alcohol use (binge drinking on at least five separate days in the past month).
- In 2010, 17.9 million Americans (7.0 percent of the population) were dependent on alcohol or had problems related to their use of alcohol (abuse). This number is basically unchanged since 2002.
- There continues to be a large treatment gap in this country. In 2010, an estimated 23.1 million Americans (9.1 percent) needed treatment for a problem related to drugs or alcohol, but only about 2.6 million people (1 percent) received treatment.

UNDERSTANDING ENABLING BEHAVIOR

Many people think they are helping a loved one with an addiction, when in reality they are giving an addict permission to sink further into it. As the addiction has more room to grow, the addict gets sicker, and loved ones become more discouraged that the addict will ever recover.

In most cases, an addict needs to hit rock bottom to make a paradigm shift and get into recovery. Consistent rescuing of the addict will only extend the time it takes for someone to hit rock bottom.

What is the difference between helping and enabling?

- Helping includes doing things that will positively benefit another.
- Enabling allows the addict to continue destructive behavior, often by supplying money, shelter, legal, or any other form of help.
- Enabling is done with good intentions but is not truly healthy.
- Enabling prevents addicts from experiencing the consequences of their actions; it may keep them from seeing they have a problem.

Some common examples of enabling

- **Giving or lending money:** Giving addicts money might open more doors for addicts to invest in their addiction. Having easy access to money can keep them from realizing how much their addiction is actually costing because they don't experience the pain of struggling to get money.
- **Providing a place to live:** A roof over our heads is a necessity. If an addict has pushed the boundaries so far that keeping him or her in your home will feed the person's addiction more, then you might need to consider kicking the individual out. This can be a painful and scary situation for both individuals involved, but might be what creates a rock-bottom moment for the addict.
- **Cleaning up after messes:** When an addict doesn't have the chance to see what messes he or she has created, the person will not know how bad it has gotten. As hard as it might be, you need to let things sit until the person is able to clean things up on his or her own.
- **Supplying a car:** Having a car gives addicts an easier ability to participate in an addiction. The freedom a car provides can enable people to be blinded to their addiction. This could also be a safety issue in that they may use a car after engaging in an addiction and could hurt themselves and someone else. (Claassen, 2011)

Here are some additional examples of behavior that enable those struggling with addiction:

- Repeatedly bailing them out of jail, financial problems or other "tight spots" they get themselves into.
- Giving them "one more chance," ... then another ... and another.
- Ignoring the problem because they get defensive when you bring it up or because you hope that it will magically go away.
- Joining them in the behavior when you know they have a problem with it, such as drinking, gambling and so on.
- Joining them in blaming others for their own feelings, problems and misfortunes.
- Accepting their justifications, excuses and rationalizations, such as, "I'm destroying myself with alcohol because I'm depressed."
- Avoiding problems to keep the peace, or because of a belief that a lack of conflict will help.
- Doing for them what they should be able to do for themselves.
- Softening or removing the natural consequences of the problem behavior.
- Trying to "fix" them or their problems.
- Repeatedly coming to the rescue.
- Trying to control them or their problems.

Effects of enabling

Over time, enabling becomes routine, but the frustration grows in the enabler. The combination of continued drug use of the addict and the cycle of frustrated enabling affects the entire family. Mental health issues can develop in the enabler or other members of the family, such as:

- Depression.
- Bursts of verbal and physical anger.
- Anxiety.
- Uncontrollable emotions.

Stages of enabling

Much like addiction itself, it is believed that enablers actually experience their own stages in their behavior and see how it impacts them as a result.

Early stage

- Relief through enabling, such as eating for comfort, spending, working or helping someone with his or her problem to avoid an internal focus and experience the payoff.
- Increase in tolerance for the behaviors of the problem person.
- Preoccupation with the problem person or persons.
- Loss of control over emotions or behavior, such as excessive eating, yelling at the kids.
- Continued use of enabling behavior despite serious negative consequences to the enabler as well as the person with the problem.

Middle or "crucial" stage

- **Family problems** – The drama triangle or the variation below (punishment/forgiveness cycle).
- **Social problems** – Embarrassment, avoiding parties where there may be "too much temptation" for a partner.
- **Emotional problems** – Depression, anxiety, chronic stress.
- **Financial problems.**
- **Legal problems** – Domestic disturbances.
- **Occupational or academic problems** – Loss of concentration due to preoccupation with the problem person or persons.

Late or chronic stage

- **Physical deterioration** – Headaches, stomach problems, stress disorders and so forth.
- **Serious physical withdrawal syndrome** – Cannot stay away after a break-up or separation.
- **Obsession** – Preoccupation increases until it takes the majority of the person's thoughts.
- **Loss of social supports** – Stops seeing friends and begins to isolate; other people give up trying to get the person to see what he or she is doing.
- **Collapse of the alibi system** – Can no longer make excuses for themselves OR the problem person.
- **Drinking, using prescription meds, eating, working, etc. to keep functioning or "feel normal."**
- **Hopelessness and despair.**
- **Untimely death** – Accident, suicide, illnesses secondary to the codependency.

Enabling and eating disorders

While the majority of research on enabling behavior focuses on addiction and substance abuse, the problem of enabling exists in another prevalent issue: eating disorders.

- It is estimated that 8 million Americans have an eating disorder – 7 million women and 1 million men.
- One in 200 American women suffers from anorexia.
- Two to three in 100 American women suffers from bulimia.
- Nearly half of all Americans personally know someone with an eating disorder. (Note: One in five Americans suffers from mental illnesses.)
- An estimated 10-15 percent of people with anorexia or bulimia are males.
- Mortality rates:
  - Eating disorders have the highest mortality rate of any mental illness.
  - A study by the National Association of Anorexia Nervosa and Associated Disorders reported that 5-10 percent of anorexics die within 10 years after contracting the disease; 18-20 percent of anorexics will be dead after 20 years; and only 30-40 percent ever fully recover.
  - The mortality rate associated with anorexia nervosa is 12 times higher than the death rate of ALL causes of death for females 15-24 years old.
  - 20 percent of people suffering from anorexia will prematurely die from complications related to their eating disorder, including suicide and heart problems.
- Access to treatment:
  - Only 1 in 10 people with eating disorders receives treatment.
  - About 80 percent of girls and women who have accessed care for their eating disorders do not get the intensity of treatment they need to stay in recovery; they are often sent home weeks earlier than the recommended stay.
  - Treatment of an eating disorder in the U.S. ranges from $500 per day to $2,000 per day. The average cost for a month of inpatient treatment is $30,000. It is estimated that individuals with eating disorders need anywhere from three to six months of inpatient care. Health insurance companies for several reasons do not typically cover the cost of treating eating disorders.
  - The cost of outpatient treatment, including therapy and medical monitoring, can extend to $100,000 or more.
- Adolescents:
  - Anorexia is the third most common chronic illness among adolescents.
  - 95 percent of those who have eating disorders are between the ages of 12 and 25.
  - 50 percent of girls between the ages of 11 and 13 see themselves as overweight.
  - 80 percent of 13-year-olds have attempted to lose weight.
- Racial and ethnic minorities:
  - Rates of minorities with eating disorders are similar to those of white women.
  - 74 percent of American Indian girls reported dieting and purging with diet pills.
  - Essence magazine in 1994 reported that 53.5 percent of their respondents, African-American females, were at risk of an eating disorder.
  - Eating disorders are one of the most common psychological problems facing young women in Japan.

The National Institute for Clinical Excellence (NICE) guidelines for eating disorders recommend that most people with anorexia nervosa (AN) and bulimia nervosa (BN) should be managed on an outpatient basis (NICE, 2004). This places family members in the forefront of care. Family members report that they have insufficient information and skills for this role, which involves managing very challenging behaviors.

Living with someone with an eating disorder is associated with mental and physical ill health and a poor quality of life (de la Rie, van Furth, De Koning, Noordenbos, & Donker, 2005; Santonastaso, Saccon, and Favaro, 1997; Treasure, Murphy, Szmukler, Tood, Gavan, & Joyce, 2001). Emotional reactions to the symptoms may inadvertently play a role in maintaining the problem. Families then become stuck in unhelpful interactions and lose sight of their own strengths and resources. The resulting transformation of family life can be perceived as a direct demonstration of dysfunctional relationships within the family, and one that is considered to be a causal factor rather than a consequence of the illness.

The purpose of an assessment of family function is to allow family members to stand back and reflect on whether and in what way the eating disorder has become the central organizing principle of home life.

The organization of the family around the eating disorder can be conceptualized using an AMC framework.

- "A" represents the antecedents, which include the shared vulnerabilities of anxiety and compulsivity. The three types of traits that run within families of people with eating disorders include anxiety, compulsivity and eating disorders.
- "M" is for the meaning that is made of the symptoms and the repercussions that this has on the role of other family members. The lack of a clear, coherent, conceptualization of eating disorders produces a lack of understanding with idiosyncratic meanings ascribed to the illness.
- The response to the illness behavior varies according to the meaning constructed by individual family members. For example, the belief that an eating disorder is attributable to the sufferers' personality is associated with less warmth (Whitney et al., 2007; Whitney, Murray, Gavan, Todd, Whitaker, & Treasure, 2005).
- If the illness is seen as life-threatening, a form of self-destruction or suicide, parents become anxious, and then an overprotective parenting style that accommodates and even accepts some of the behaviors develops (Kyriacou et al., 2008). If the illness is thought to be a "hunger strike," families may feel guilt and bend over backwards to make reparation. Others may see it as a form of revenge that results in criticism and hostility in retaliation.
- The shame of having a family member with an overt form of mental illness leads to family isolation, and so family reactions to the illness are not buffered by normative forces.
- "C" is for the consequences, which include the emotional reaction to the illness and how families accommodate and allow eating symptoms to dominate their lives that may, in turn, enable some of the behaviors to continue. The reactions and behaviors of family members can inadvertently reinforce eating disorder symptoms.
- Family members may give attention or acceptance to the eating disorder "voice," or they may remove negative consequences that arise from the eating disorder behavior. They may accept that eating disorders symptoms dominate the household:
  a. By becoming subservient to eating disorder food rules (where, why, how, when and with whom, and so on).
  b. By accepting safety behaviors (exercise, vomiting, body checking, fasting or cutting back) and
  c. By adhering to obsessive-compulsive behaviors (reassurance seeking, counting, checking and control).
- Individuals with an eating disorder control those around them by explicit or implicit emotional blackmail and by the unbending rigidity and narrow focus of their opinions. For example, if eating disorder rules are disobeyed, then the person threatens to not eat at all or to harm her- or himself or act destructively in other ways. Those with eating disorders may control, compete, compare or calibrate themselves with other family members (often siblings) on what and how much to eat or exercise.
- This behavior is tolerated in an effort to keep the peace and because there is fear over the consequences of resistance. Family members may be drawn into removing negative consequences, covering up or removing or buffering the natural negative consequences that would accrue from the behavior, for example, replacing missing food, cleaning kitchens and bathrooms, making excuses to others and so on.

CODEPENDENCY

Codependency (or codependence, interdependency) is defined as a psychological condition or a relationship in which a person is controlled or manipulated by another who is affected with a pathological condition (as in an addiction to alcohol or heroin).

In broader terms, it refers to the dependence on the needs of or control of another. It also often involves placing a lower priority on one's own needs, while being excessively preoccupied with the needs of others.

Codependency can occur in any type of relationship, including family, work, friendship, and also romantic, peer or community relationships. Codependency may also be characterized by denial, low self-esteem, excessive compliance, or control patterns.

The benefits of enabling are two-fold. Let's look at substance abuse specifically:

- Individuals who use substances can continue the behavior they want, and enablers do not have to acknowledge that anything is wrong. This action, however, is a short-term solution to a long-term problem. Over the long term, enabling drug abuse behavior leads to unhappiness for the enabler and the further deterioration of the individual using drugs.
- Another reason enabling occurs is because of codependency, which occurs when people are overly involved in another person's life. Codependents have a constant preoccupation with another person's behavior and feel unnecessarily guilty when not taking care of that person's needs. This often stems from not having adequate self-esteem.

Some common themes in the codependency cycle for the dependent person are:

- My feelings are not important.
- I am not good enough.
- I am responsible for my friend or significant other's behavior.
- I am not lovable.
- Having my own problems is not acceptable.
- It's not OK for me to have fun.
- I don't deserve love.

Historically, the concept of codependence comes directly out of Alcoholics Anonymous as part of the realization that the problem was not solely the addict, but also the family and friends who constitute a network for the alcoholic. It was later broadened to cover the way that the codependent person is fixated on another person for approval, sustenance, and other things.

Codependency describes behaviors, thoughts and feelings that go beyond normal kinds of self-sacrifice or caretaking. For example, parenting is a role that requires a certain amount of self-sacrifice and giving a child's needs a high priority. However, parents can nevertheless still be codependent towards their own children if the caretaking or parental sacrifice reach unhealthy or destructive levels.

Typically, parent who take care of their own needs (emotional and physical) in a healthy way will be better caretakers, but codependent parents may be less effective or may even do harm to a child. Another way to look at it is that the needs of an infant are necessary but temporary, but the needs of the codependent are constant.

People who are codependent often take on the role as a martyr. They consistently put others' needs before their own, and in doing so, forget to take care of themselves. This creates a sense that they are needed. They simply cannot stand the thought of being alone and no one needing them. Codependent people are constantly in search of acceptance. When it comes to arguments, codependent people also tend to set themselves up as the victim. Further, when they do stand up for themselves, they feel guilty.

In marriage, codependency occurs when one partner puts the needs of the addict spouse before his or her own. It fosters the tendency to behave in overly passive and caretaking ways that harm the relationship. When a codependent partner has had enough, it can nudge the addict toward change.

Codependency is a vicious cycle in which both the person being enabled and the enabler need to disentangle themselves. It is recommended by experts in the field that codependent family members or loved ones remind themselves on a regular basis that they did not cause the problem and cannot control or fix the problem. They need to understand that the only thing they can do is offer assistance, which may or may not be heeded. The codependent person needs to understand that the only person who can help a substance abuser is the substance abuser him- or herself, and that the person needs to obtain the help that is available.

In a codependent situation, both the abuser and dependent person need assistance. The substance abuser needs to fix both the chemical and psychological bonds he or she has to alcohol or substances, and the codependent individual has to understand why he or she feels the need for this dependency. Experts in the field recommend that help in the form of substance abuse counseling be obtained for the substance abuser as well as therapy for the dependent person.

ADDRESSING FAMILY AS PART OF TREATMENT

As a counselor or therapist, it is important to understand the elements of enabling behavior and how to address it with the client as well as those involved in the client's life.

The important thing is to educate the family about what is really going on. Their issues have never been looked at because everything was hiding behind the addiction. As a counselor, if you only provide services to an alcoholic/addict and send the person back to a dysfunctional family, he or she will relapse into the self-destructive behavior within months.

Families need education about drugs and alcohol and help with healthy parenting. Quite often, by the time an individual comes in for treatment, the whole family is dysfunctional. Some people don't even realize a loved one is on drugs. They don't keep the connection with those close to them on a daily basis, so they can't gauge what is right or what is wrong.

One of the roles of a counselor is to help families reevaluate what they're doing and to be humble enough to change. Drug addiction and alcoholism provide an opportunity to help families change for the better. Families get very frustrated, which is why they need as much help as the addict/alcoholic. The family also needs to change and learn not to enable or shame the person.

Addictions are a painful reality for all involved. Whether it is alcohol, drugs, food, sex, gambling or the list of many others, it is imperative for counselors and family members to not enable addicts to continue down their self-destructive path. (Jay & Jay, 2011)

Some things to consider

One is that family members may be so angry that they don't want to be a part of treatment. They simply avoid the situation, treating it as if it's not their problem. They may believe that it's the wife's problem or the child's problem or the husband's problem. The other is that the family is afraid of being blamed. In reality, they already have been blamed. Addicts and alcoholics are always pointing their finger at the people closest to them. In their minds, they are the victims; everyone else has caused their problems.

Enabling is linked to denial, which is when family and friends refuse to recognize or refuse to admit to a problem. This happens not only with substance abuse, but also is a defense mechanism that is used when people find the truth of a situation too difficult to deal with. In this case, denial of substance abuse behavior can mean that family and friends do not recognize how the behavior is affecting work, school, relationships, or causing financial problems.

Most striking in the denial phenomenon is the enabler's refusal to acknowledge the deterioration of the relationship he or she has with the substance abuser. In fact, quite often, the denial mechanism will continue until it no longer can – meaning, until something horrific occurs.

Helping others recognize early signs

There are times in relationships when we cross that sometimes invisible line between truly being helpful and supportive and acting as enablers, or becoming codependent with another person. Sharon Wegscheider-Cruse in her work with families suggests that 96 percent of the general population, and persons in helping professions especially, exhibit some forms of codependent behavior at one time or in fairly consistent patterns. (Burress, 2008)

Counselors should equip themselves with a list of relevant questions to engage family members in the issue at hand. Here are some examples of questions counselors may use to help family members identify what it is that they are dealing with and recognize their own responses to early warning signs of enabling:

- Do you find yourself worrying about a person in ways that consume your time, or do you find yourself trying to come up with solutions to his or her problems instead of letting that person do the solving?
- Do you find yourself afraid for this person, or convinced that he or she cannot handle a situation or relationship without falling apart?
- Do you ever do something for a person that he or she could and even should be doing for him- or herself?
- Do you ever excuse this person's behavior as being a result of stress, misunderstanding, or difficulty coping, even when the behavior hurts or inconveniences you?
- Have you ever considered giving or given this person money, your car, or talked to someone for this person as a way of reducing this person's pain?
- Do you feel angry if this person does not follow through with something you have suggested – or do you worry that you may not be doing enough for this person?
- Do you ever feel you have a unique and special relationship with this person, unlike anyone else they may know?
- Do you feel protective of this person – even though he or she is an adult and is capable of taking care of his or her life?
- Do you ever wish others in this person's life would change their behavior or attitudes to make things easier for this person?
- Do you feel responsible for getting this person help?
- Do you feel reluctant to refer an individual to a source of help or assistance, uncertain that another person can understand or appreciate this person's situation the way you do?
- Do you ever feel manipulated by this person but ignore your feelings?
- Do you ever feel that no one understands this person as you do?

- Do you ever feel that you know best what another person needs to do or that you recognize his or her needs better than he or she does?
- Do you sometimes feel alone in your attempts to help a person, or do you feel you may be the only person to help this individual?
- Do you ever want to make yourself more available to another person at the expense of your own energy, time or commitments?
- Do you find yourself realizing that an individual may have more problems than you initially sensed and that you will need to give him or her your support or help for a long time?
- Do you ever feel that as a result of getting to know this person, you feel energized and can see yourself helping people like him or her to solve their problems?
- Have you ever begun to see yourself in this person and his or her problems?
- Has anyone ever suggested to you that you are too close to this person or this situation?

If family members answer "yes" to two or more of these questions, it is likely that they have crossed the line from being supportive to being an enabler or codependent. Having heard themselves answer such questions often helps them understand how they may have contributed to the issue, and further discussion with that family member on changes they may need to make can ensue.

When working with families, you don't know what issues will crop up. Eventually, everyone falls back into the old pattern, which is why you can't just change the addict/alcoholic. You have to change the family system. It's about the family as a whole.

Each case is different, but it is often recommended that addicts/alcoholics distance themselves from the family unit for their own well-being. When working with young adults with addiction, it is suggested that they become more independent. They hate the dependency, but they're too scared of being on their own. Once sober, they can enter the homes of family members who live sober lives. Programs such as AA or NA help them to stand on their own two feet and build self-esteem.

With married couples, if there is a spouse who is highly dysfunctional or unwilling to give positive support, it may be suggested through therapeutic means that the spouse move out. Treatment is an attempt to get the family unit to be open to change, just as the addict/alcoholic must be.

What do families most misunderstand about the role of the family?

In many circumstances, family members are too controlling. However, there's no intimacy in control. Counselors must focus on helping family to let go a little and develop some trust. Family members have to allow addicts to grow and build self-esteem on their own or to fall on their face and hit rock bottom and learn from their mistakes.

Conversely, addicts often misunderstand their family members and their role within the family. Addicts can be very self-centered; most mistakenly think that everything is all about them. They feel like victims to the world and take no responsibility for how their behavior has hurt so many people.

How do counselors begin to change such ways of thinking?

Case study on family dynamics (as presented by Burress, 2008)

"A mother of a 16-year-old teenage boy wrote to me saying that her son has become increasingly disrespectful towards her over the last couple of years, going so far as to cuss and swear at his parents over what she refers to as 'trivial matters.' This mother, I'll call her 'Jane,' says that she has always prided herself on doing everything she possibly could to make things as easy on her son as possible, including preparing her son's school lunches, doing his laundry, cleaning his room, making his bed, giving him spending money, etc., but says, 'Nothing I do for my son is appreciated, and he's always asking for more money and telling his father and I to leave him alone,' followed by the slamming of his bedroom door. (Burress, 2008)

"Jane has discussed the problems with other family members and close friends, and they have all told her that she needs to 'learn to let go' of her son and stop controlling his life. Her husband also told her that she's enabling their son, and that she needs to allow their son to deal with the responsibilities that go with growing up and becoming a responsible adult. Those responses, along with being told that she is too close to her son, caused her to begin looking for information about what it means to be an enabler, in order to improve her relationship with her son.

"I was very surprised that Jane continues to do these various chores for her teenage son, including making his lunches, cleaning his room and doing his laundry, even though her son is fully capable of doing these things for himself. Jane was shocked to learn that my now-grown children were taught from a young age how to do their own laundry, and that they began doing it themselves since they were about 10 years old, because I taught them how. I also allowed them the freedom to do these things on their own, so they could feel proud of themselves and their own accomplishments. (Burress, 2008)

"I explained to Jane that from the time my children learned how to walk, I began teaching my children everything they needed to know in order to become responsible, independent adults. Each of my children learned how to prepare basic meals, including cooking on the stove, from a very young age. I still remember the excitement in their young voices when they each learned how to make macaroni and cheese, or grilled cheese sandwiches, and the sheer glee of knowing they did it all by themselves (while I carefully observed, of course). My sons were not going to grow up with the idea that cooking and cleaning was 'women's work,' and my daughters were not going to grow up thinking they 'need a man to take care of them.' (Burress, 2008)

"I am a firm believer in the old saying, 'Give a man a fish and you'll feed him for a day. Teach a man to fish, and you've fed him for a lifetime.' Does that put me in line for the next 'mother of the year award'? No. It only means I take parenting very seriously. It is the responsibility of each and every parent, mothers and fathers alike, to teach and train their children how to become responsible, independent, self-sufficient adults." (Burress, 2008)

"Very young children can and need to be taught how to pick up after themselves and put their clothes and toys in their proper place; how to make their bed; how to wash dishes; how to dust and vacuum; how to properly clean a bathroom; how to cook or prepare basic meals, and so on. But most important, parents must allow their children the needed age-appropriate independence, to have pride in their own achievements. When children have learned how to do these basics of living, parents must learn to let go of any controlling tendencies, such as not criticizing their children when chores aren't completed perfectly.

"Final advice: The advice given to Jane was that she immediately stop the enabling behaviors and allow her teenage son to do for himself what he is capable of doing, as well as lovingly teach her son the life-skills that he may be lacking. Looking at the situation from a teenager's point of view, one can see how Jane's son might feel oppressed and angry by his mother's efforts to make things as easy on him as possible, and I believe his angry outbursts and door slamming is his way of acting out his frustrations of being controlled. He's growing up to become a man, and he needs to know that his mother and father have faith and trust in his ability to handle the many responsibilities of being an adult."

HOW TO STOP ENABLING

The following information can be useful in your approach as a counselor or provided to family members to address enabling behaviors by using rational emotive behavioral therapy (REBT):

Building high frustration tolerance

In the world of addictions, the path of least resistance is often the path to inevitable defeat. Let's look at how to get on the path of high frustration tolerance. When you feel blocked from reaching an important goal, your perception activates brain centers that are associated with pain. When you feel frustrated and uncomfortable, those feelings can stimulate you to solve a problem and get past the barrier. It can also signal taking the easier, more comfortable path. (Knaus, 2012).

Some individuals tend to tolerate frustration well. They work through it and continue to press on to achieve their shorter or longer-term goals. However, let's consider the idea of what if you don't tolerate frustration well, and you have an addicted friend or relative who takes advantage of your tendency to take the easy way out?

To practice high frustration tolerance, you put reason between an impulse to escape discomfort and discomfort-dodging actions. (Knaus, 2012) That step can make a big difference. Once you delay reacting, you are in a position to start choosing. Part of this imposing reasoning process involves accepting that it is important to live through the discomfort if you expect to overcome barriers. This acceptance is like building emotional muscle. The more you work at it, the stronger you get.

By working at building high frustration tolerance, you are likely to solve more of your immediate problems and reach more of your longer-term goals.

Seven steps to end enabling using rational emotive behavioral therapy (REBT)

Family members and friends of those who abuse substances can often benefit from building their frustration tolerance. Rational emotive behavior therapy (REBT), previously called rational therapy and rational emotive therapy, is a comprehensive, active-directive, philosophically and empirically based psychotherapy that focuses on resolving emotional and behavioral problems and disturbances and enabling people to lead happier and more fulfilling lives (Ellis, 1994).

For example, your family member, Bob, tells you that he needs to get past a tense time and then he will quit using. Could you spare some money for these tough times? If you cave in, you are enabling him by rewarding his dependency on you. You are probably rewarding yourself by caving in to avoid a conflict. Whatever the dynamic may be, by giving Bob money to fund his substance abuse habit, you are signaling that you may also have low frustration tolerance in this situation.

You can use REBT principles and practices to boost your tolerance for frustration. By modeling high frustration tolerance for conflict and for resisting Bob's demands, you avoid procrastinating on building high frustration tolerance. You help him see that you are no longer a pushover. Bob may still have an addictive problem, but you are no longer helping him sustain it. You may also be in a stronger position to influence a change. (Knaus, 2012).

This is obviously easy to say and harder to do. However, if you see the merit in building high frustration tolerance, here are seven steps to help yourself build high frustration tolerance by combating low frustration tolerance:

1. Remind yourself that frustration tolerance is like a muscle. The more you build it, the stronger you get. Recognize that you won't build it overnight. Then remind yourself that in the process of learning to avoid knee-jerk, low frustration tolerance reactions, you are building high frustration tolerance. So, seriously consider frequently practicing high frustration tolerance.
2. Focus on the longer-term goal that you want to achieve. Consider whether you would like to see your family member get healthier. Would you prefer a relationship based upon a healthy bond (rather than one of dependency)? If so, then make decisions that will support your family member's independence and health. Remind yourself that the real rewards normally come from high frustration tolerance actions. Low frustration tolerance gives you a specious reward of quick relief from enabling.
3. Make two lists: (1) the short- and long-term advantages and disadvantages of you engaging in enabling behavior and (2) the short- and long-term advantages and disadvantages of enabling your loved one. The enabling trap is a joint venture. Your loved one also has responsibility to think and do better. That includes stopping baiting this trap.
4. Reward yourself when you practice high frustration tolerance. Allow yourself to do something you enjoy, such as watching a movie, taking a bubble bath, listening to favorite music, calling a friend, or reading a favorite book.
5. When you practice low frustration tolerance, enabling behavior with your loved one, give yourself a response-cost. For example, force yourself to do something you dislike, like cleaning for an extra hour. Deny yourself the reward you identified in No. 4.
6. Accept yourself regardless of whether you practice low or high frustration tolerance, but know that it is to the advantage of all concerned if you practice high frustration tolerance.
7. Get help and support when you find it necessary to strengthen your resolve. Connect with resources that could support you in your journey.

What if I'm the enabler?

- Do you sometimes feel as if you were put on earth to serve others?
- Are you overly accommodating and find it difficult to say no?
- Are you drained from overdoing for others?
- When you complain, are you told that you sound like a martyr?

If your answers are yes, you might wish to consider the possibly that you are an enabler.

Enablers are motivated by love and the need to be valued, qualities especially encouraged in females. An enabler is a person who through his or her action allows someone else to attain something. Most often, the term enabling has been associated with alcoholism, but it is not always the case. Enabling can have broader implications and include other forms of codependent behavior. Enabling is considered codependent because the act will often satisfy the need to help someone, but simultaneously foster dependency. Are you an enabler? Are you in any codependent relationships? Have you ever wondered why? (Ceccarelli-Egan, 2009)

If you are like most enablers, you were born with a generous heart and enjoy helping others. You might have been an older sibling or had non-available parents. It was necessary for you to step into the void and help out in your family. Your behavior became identified, and you received positive reinforcement for your actions. The recognition helped you feel good about yourself and internalize the belief that your role in life was to help others. Eventually, your role became cemented into the system, and people stopped appreciating your kind acts and came to expect them.

This response would have caused you to develop a low self-esteem because you experienced love as conditional, and feel selfish when you were not doing enough for others. I once had a client who was such an enabler that when someone bought her a thank-you gift for helping them out, she actually bought them a "small thank-you gift" to thank them for their thank-you gift!

Enablers unconsciously believe that relationships can only be maintained by doing nice deeds and placating others. If you are an enabler, as a child you probably became motivated by a desire to be loved, learned to avoid conflict and give in to unrealistic demands. You learned that to challenge a loved one might result in anger and possible rejection. To survive in this type of system, you began to ignore and overlook problems, because to address them or your feelings would be too risky. (Ceccarelli-Egan, 2009)

Unfortunately, this behavior exacerbates the loss of self because with each capitulation, you further disconnect from your true feelings and minimize your sense of entitlement. Your behavior not only makes you appear more accommodating, it also allows you to become prey to more selfish people. Suddenly you find your life filled with takers, and there is no reciprocity in your relationships. You become increasingly upset because others do not tune into your needs, but then criticize yourself for being selfish or not acting in a loving manner.

If this sounds familiar, what can you do about it?
The first step is to recognize that you are an enabler or have tendencies toward enabling. If so, admit it and make the decision to practice some new ways of relating to people. Begin to engage in solitary activities that bring you pleasure and satisfaction. This will help you keep the focus on your needs and get in touch with exactly how, when and where you want to do something. Give yourself some of the pampering that you usually give to others; spend time and money on yourself instead of a loved one or friend. State the affirmation that "I am as important as everyone else" and "I do not have to give in order to be loved." (Ceccarelli-Egan, 2009)

Commit to looking for new, healthier relationships as you pledge to change your old relationship patterns. Decide to become your own person, not the person others want you to be. Begin associating with people who have the ability to have a mutual relationship and are responsible for their own behavior. Go slowly in a new relationship, and practice new behavior: abstain from rescuing people, stop overfunctioning and graciously accept assistance when offered to you.

Are you tired of being the person who seems to have been put on Earth to help others? Do you sometimes feel unappreciated, exploited and used? If so, I invite you to explore the following dynamics and solutions:

> Ask yourself if the person is asking for your support and if your help is appropriate. Sometimes an individual is merely looking for a listening ear. If you are an enabler, when a problem is presented, you tend to feel duty-bound to fix the situation. When someone comes to you with a problem, take a deep breath, listen, then ask, "What do you need?" and "How would you like me to help you?" For years, I jumped in and offered my daughter lots of solutions when she came to me with a problem. This resulted in both of us feeling frustrated! I thought that she was not listening to my sage advice. It turns out, she just wanted to vent, knew she could solve her own problem and took my advice as a vote of no confidence.

Sometimes a person does approach you with a specific request for assistance. In this case, you want to ask yourself whether this is a reasonable request and consider whether you have the time, energy or desire to assist them. While helping others can be seductive and feed your enabler's "need to be needed," you do not want to prevent another from learning life's lessons. An example would be the parent who always brings her forgetful children's homework to school or drives them to school when they miss the bus.

- Does this merely perpetuate irresponsibility?
- Would it better for the child to have the consequences in school rather than as an adult?
- Is this well-meaning parent preventing the child from learning to take responsibility?

It might be more helpful for the parent to support the child by compassionately asking, "What do you need to do about it?" or "What can you do to avoid it happening next time?" This offers support and compassion, but puts the onus on the person and encourages personal responsibility.

Do you feel good about your participation? Enablers tend to feel used because they go too far with their help. While it stems from a generous heart, they will often overfunction and end up feeling exhausted, unappreciated and resentful. This is a case where you want to measure the "return on your investment" and estimate what benefit the person might receive from your assistance versus what it is costing you. If you are unsure about whether you want to be of assistance, tell the supplicant that you will need to get back to them, then step away and get some distance.

You will also want to consider your current level of emotional energy. When your energy is low and you assist another, you may end up giving out of your reserve and become further depleted. In this case, everyone would be better served if it is possible for you to postpone your assistance until a time when your energy is higher and the service does not drain you. When you give from a place of greater emotional energy, you are able to be more attentive and generous with your assistance and feel good about the service.

- Is the individual doing 50 percent or more of the work?
- Do you feel as if you are dragging the person up the hill?
- Are you doing the majority of the person's work?

If you are working harder than the person that you are trying to help, you are overfunctioning.

If you have a "need to be needed," allow yourself to recognize this fact and explore the reasons that motivate you as well as the price that you pay. Is it habit? Is it the way you define yourself? Do you wish to continue overfunctioning? As you begin to look at the benefit you get out of helping another, notice your reaction, the cost to you and whether you feel used and resentful.

The next time you are tempted to help another, examine your intentions for doing so as you refrain from automatically offering help and giving advice. When you feel you are being treated unfairly or being taken advantage, speak up right away. Set limits, and say, "No, this is not a good time to talk," or "No, I will not be able to help you at this time," when you feel that another's request or appeal would be too demanding for you. Trust yourself to know what you want and need and make your feelings known because they are important. If someone has to be unhappy or do all the giving, it doesn't always have to be you!

What if it's my child? – How to stop being an enabler to your adult child

Once you become a parent, your life changes forever. You always will be concerned with your children's well-being, no matter their age. When your concern become enabling, you need to take control back. No one ever said being a parent was without conflict.

When your children were just toddlers and learning how to walk, you held their hand to keep them safe. As they became steadier on their feet, you didn't need to hold their hand as much. As they grew and entered school, you did your best to teach them values and help them find their way in the world. As any parent knows, no parent is perfect and no child is perfect. No child is the same. Parents who have more than one child know this. You can raise two children the same way, and the effect might not always be the same. (Albury, 2011)

We have all heard the term "late bloomer." Some children grow up having a strong desire to "be" something when they grow up. Nothing keeps them from their goal. Then there are the kids who march to a beat of a different drummer – not that is a bad thing; it can be good. Then there is the child who, for whatever reason, seems to struggle. Sometimes, as a parent, we unwillingly find ourselves caught in an unhealthy pattern of enabling.

Here are a few tips on how to break the pattern:

Step one: **Resist the urge to fix your adult children's problems.** It is not up to you to fix everything. Sometimes you have to fall in order to learn how to get back up. If you keep fixing things, how are they ever going to make it on their own?

Step two: **Allow the situation to get worse.** As hard as it might seem to do, you must. You can push someone out of the way of a speeding train, but you can't stop the train.

Step three: **Your adult child might regress to acting like a spoiled 2-year-old.** Demanding and abusive behavior should not be tolerated. It is all right to hang the phone up if your child is being abusive. You gave her a time-out when she was 2 because she didn't obey the rules. You don't have to be subjected to her behavior now.

Step four: **Try not to feel guilty about being firm.** Whatever you do, don't apologize. Don't scream back, just calmly inform your child you deserve to be spoken to respectfully, and you will not accept any other kind of behavior. Fighting the guilt that you feel is why some people have a lot of trouble with tough love. It is called "tough" for a reason.

Step five: **Keep a journal.** Writing how you feel is so good to do. It helps get out some of the pain and frustration that you can be feeling. It is also a great way of tracking your progress with the situation.

Step six: **Call on your friends for support.** Once you get to talking about it, you might find they went through a similar situation. That's what friends are for!

Step seven: **Don't give up, and don't give in.** Your child might act angry at you, but trust me, they will get over it. Remember why you are doing this. It is to better them as a person, and in return, it will better your relationship with them.

This might take time. Remember to praise yourself for standing firm. Take it one day at a time, and try not to get overwhelmed by the situation. You love your child, remember that sometimes love is tough love.

MYTHS ABOUT THERAPY AND ENABLING BEHAVIOR

Because many family members of addicts have gone to clergy, counselors, and general mental-health practitioners, and have become even more confused and despairing after doing so, this is meant to clarify why the sessions may have been ineffective and why an individual's problems may have gotten worse instead of better during the course of the therapy. (Drews, 2011)

Myths can prevent the healing process for both clients and their families when counseling addiction. Understanding myths about therapy and enabling behavior can be very helpful to the ever-growing number of therapists who are recognizing how pervasive all forms of addiction are in their caseloads, and are looking for addiction education and understanding to add to their expertise and enhance their effectiveness.

Myth No. 1: Patients always tell therapists the truth about their drinking.
Many parents take their children to see a therapist in an effort to bring some sanity back into their households. After the therapist poses a question or two to the child about his or her drinking, the matter is often dropped. Why? Let's look at a typical encounter:

Therapist: Do you drink?

Child: Yeah, some.

Therapist: How much?

Child: A couple of beers at parties, with other kids. That's all. All the kids do it. My mother's paranoid.

Therapist: Why do you say that?

Child: I don't know. Ever since we moved, after my father got transferred on his job, my mom is really unhappy. She takes it out on all of us. My dad's always telling her she nags.

Therapist: Does she?

Child: Yeah! Ask my sister if you don't believe me. She's going to leave home as soon as she's 18 next year. She told me she can't stand it there anymore.

Therapist: Do you feel the same way?

Child: Yeah.

Therapist: Let's talk about that next session. Maybe we can find some ways for you to talk more directly to your mother about how you feel about the way she treats you.

This therapist has made her first mistake by believing the alcoholic's minimizing of the drinking problem. The child's disease helped him divert the issue completely.

Those struggling with addiction (even child alcoholics) will lie to protect their habit. In counseling, alcoholics are incapable of telling the truth because of a disease process that is extremely cunning in its efforts to protect its supply of alcohol. This is not a moral judgment. It is merely a fact of the disease.

Myth No. 2: These "underlying mental-health issues" can be resolved by teaching good communications skills to members of that alcoholic family.
This concept is impossible. Those dealing with addiction can be very sincere and really want to cooperate by trying to communicate better. But even after a terrific family therapy session, all their insight can go flying out the window with the next intake of alcohol.

Furthermore, every day a person continues to drink, the disease is progressing. That means that in addition to experiencing secondary physical problems, his or her ability to cope with life at all is progressively diminished. If someone is going through withdrawal, the severe agitation will cause anger, anxiety, and overall, an inability to have any "good communications." (Drews, 2011)

Myth No. 3: Alcoholism is a result of unresolved conflicts, anxieties, and anger. As soon as a therapist can get at the root of the problem, the need to drink will wither away by itself.
Putting it simply, problems do not cause alcoholism. Almost all of the time, after alcoholics stop drinking and attend AA regularly, their serious emotional problems disappear or at least diminish greatly with help. On the other hand, it is impossible for the still-drinking alcoholic to get well emotionally.

Myth No. 4: Even if the addiction is not dealt with as the primary issue, good therapy is being practiced if families are straight about feelings.
Even during therapy sessions where the addict is acknowledged to be an addict, many therapists have been trained to focus on asking family members how they feel about all this. On the surface, this may seem sensitive and caring. Unfortunately, such an approach often leads to 15, 30, or even 50 sessions on how each family member feels about everybody else, and not much else is accomplished.

In this erroneous process, the next step for the therapist is to help everybody improve their communications skills about how they feel! By that time, the drinking is no longer brought up on any regular basis. The drinking is merely discussed in terms of how everyone else feels about it. More damaging, perhaps, is the probability that a therapist can get sucked into believing the addiction might be overexaggerated and lose focus on the intent of therapy.

Myth No. 5: The addict does not know how the family feels.
Counselors often wish that if parents stated their feelings and needs in a straightforward manner (that is, learned good communications skills to "express feelings appropriately"), then the child would be given the incentive needed to want to stop the drinking or drug use. Not only is this magical thinking, resulting from lack of knowledge about the dynamics of the disease process of alcoholism, but it also again subtly places the responsibility for the cause of the drinking on the parents instead of on the alcoholism. (Parents often quit the counseling at this point, feeling even more depressed and despairing than when they entered counseling.)

There may be at least a partial explanation for this lack of understanding and knowledge about the disease concept of alcoholism. We all once believed alcoholism's lie that "the alcoholic wouldn't drink if all was right with his or her world." Unfortunately, no one's world can be just right.

Another partial explanation for this professional lack of knowledge about the disease concept of alcoholism is more hidden: Many helping professionals are themselves adult children of alcoholics, spouses or former spouses of alcoholics, and parents of addicts. Because denial is the main symptom of alcoholism and addiction – and because professionals are no more immune to the symptom than anyone else – when counselors are themselves untreated for their family disease symptoms, they bring this denial symptom to their work. Thus, we have a client whose main problem is a disease that may remain undiagnosed because the therapist's own family disease remains undiagnosed, and the therapist's main symptom, too, is denial about even seeing the disease. (Drews, 2011)

Myth No. 6: When parents are told they are "enablers," it leads them to stop the rescuing.
Enabling is meant to describe the rescue operations that the spouse or parent of an alcoholic carries out when he can't stand watching the alcoholic suffer the consequences of the disease. When that happens, he cleans up the alcoholic's messes (such as, lies to the school that his son has the flu when the child was actually picked up for drunken driving). That way, the alcoholic doesn't suffer the real consequences of his behavior.

Parent must learn eventually to get some detachment watching these crises happen so they can stop cleaning up after the child. They need to accept that they must allow the disease to hurt the child so much that he or she wants to get sober. Of course, it takes parents a lot of time in a healing group such as Al-Anon to be able to do this. And this detachment can't be forced or rushed by counselors. It is a slow process, and very frightening. (Albury, 2011).

When a mother rescues her alcoholic child and I label her an enabler, she obviously is still doing the rescuing behaviors and is not yet unafraid enough to give them up. She knows I am being judgmental when I use this term. Even when I say it lovingly, I seem to be admonishing her to go faster than she is capable of doing at that time. And she feels despairing, because she is doing her best. She may get so discouraged and frustrated and overwhelmed that she stops treatment.

More specifically, the term enabler implies that while the parents did not cause the drinking, their rescue operations contributed to the perpetuation of the drinking. Such thinking is dangerous; it leads alcoholics, who are already looking for a way to blame others for the drinking, into again placing responsibility for the drinking on the family.

Alcoholics do not need any encouragement to blame others. Alcoholism counselors spend most of their time trying to crack through the blame systems of alcoholics. It is considered to be a major breakthrough in the wellness process of alcoholics when they begin to acknowledge that nothing got them drunk. In contrast, alcoholics who have had relapses and are re-entering treatment are now often heard saying, "I wouldn't have gone out that time if I hadn't been enabled!" (Drews, 2011)

The alternative to being labeled enablers is to teach you to end the rescue operations through the simple but effective process of detachment. It is your fears that originally caused you to rescue, and detachment will help end those fears. And even though in this book, we are primarily talking about parents and kids, the detachment process is especially important if you also are married to an alcoholic. It is important for you to lose your fears of that adult alcoholic so you can get on with your life and become more able to deal with your children-alcoholics.

Detachment

How does detachment work? How does it help you to lose your fears of your alcoholic child or spouse? The general process goes something like this:

1. When you begin to learn ways to stop watching the alcoholic and to begin the healing process of seeing to your own needs, the alcoholic has radar and senses this switch in focus.
2. Much of the games stop then, because the alcoholic child knows that less attention will be paid to him or her.
3. By continuing to focus on yourself instead of the alcoholic, you get an even greater distance (detachment) from the threats, and begin to lose your fears of them. You begin to see how you gave the alcoholic so much of his or her power. You can take it back!
4. Again, the alcoholic senses this. He or she begins to threaten even less.
5. You see that detachment works! You gain more confidence. Many of the illusions in your household are beginning to end.
6. You lose much of your preoccupation with the alcoholic. Your preoccupation was based on your need to stop him or her from hurting you. You now see they are much less capable of hurting you than you thought. They've already done most of the damage they can do. But the game has been to keep up more of the same junk, to keep up the illusion that the alcoholic is powerful. This no longer works. You have learned not to look at him or her, to walk out of the room and out of the house and to not beg.
7. The alcoholic now stands alone with his or her disease. The person has lost his or her audience, and therefore drops much of the bullying. You are not watching it.
8. The alcoholic can no longer get you to believe you are responsible for his or her drinking and for the craziness in that house.
9. The alcoholic has a chance to grow up and make a decision to get help.
10. You are free.

When parents start to understand the dynamic of what was just described, they begin to naturally let go of the disease, to detach, and therefore stop enabling because they are losing their fears of addiction. All of us stop manipulating and controlling people when we lose our fears of them.

As a counselor

- Try to let parents know that you will gently help them along the not-straight road toward freedom from their fears.
- Let them know that they do not have to meet a timetable. In fact, let them know that you are aware that you do not walk in their shoes, that they must be comfortable to make even a small step; that what you will do is love and accept them, even when they vacillate in their ability to detach from the disease.
- Let the parents know that you know they will be ready some day. Try to give them the same hope that Al-Anon holds out – that your acceptance of them will be part of the healing process and will help move them along toward health and the choices that they now can only dream of.
- And then, gently, naturally, interventions do happen, because with one hand you can provide the healing embrace and comfort of total acceptance and without pressure; while with the other hand, hold up the mirror of reality and nudge them along ever so gently toward reality.

Many counselors do not call people "enablers," but instead refer to them as "rescuers." This is a much more kind word; the connotation allows them to gently look into their behavior and begin to make some changes. It draws them into healing and does not shame them or drive them away from getting help. (Albury, 2011)

ELEMENTS OF CONFRONTATION

Confronting addicted persons and their families

In this context, confronting means your compassionate perception that the person is addicted, and urging him or her and relevant family members (enablers) to commit to a meaningful recovery program. Such confrontations are becoming known as "interventions."

An intervention is an orchestrated attempt by one or many people (usually family and friends) to get someone to seek professional help with an addiction or some kind of traumatic event or crisis or other serious problem. The term intervention is most often used when the traumatic event involves addiction to drugs or other items. Intervention can also refer to the act of using a similar technique within a therapy session.

Three areas that counselors need to consider for the confrontation of addicts are why, who, and how.

Why confront?
A quick response might be "To help the addict." A more thoughtful reason is "To honor my integrity and earn my self-respect by doing what I can to help the addict's family break their denials." Another reason is "To reduce the stress I and others feel because of the addict's behavior." This is especially true if the addict is parenting young children.

Confront who?
Your most likely choices are: the addict, one or more family members (enablers), or both (separately or together). The most powerful as well as difficult confrontation is with an addict's whole family.

If you focus only on "fixing" an addict's way of thinking and toxic actions without confronting the underlying personal and family causes of their addiction, you greatly reduce your odds for long-term success. Notice the difference between saying...

> *"I want to help Pat break her denials, hit bottom, and want to manage her gambling addiction,"* and ...
>
> *"I want to do what I can to respectfully help Pat's family adults recognize how their beliefs, wounds, and habits are enabling Pat's compulsive gambling and its harmful effects."*

An initial confrontation goal is getting all affected people (including helpers) to see changing the addict's family as the target. Doing this will often evoke family adults' denial of their enabling, psychological wounds, and ignorance.

Like any addiction, enabling is a symptom of the core problems: psychological wounds and unawareness.

Typical enablers...
- Have many false self-behaviors, and will deny, rationalize, or discount them ("I know I should confront Frieda about her compulsive shopping, but ..."), and then deny or justify it.
- May choose a helpless rationale, saying "I can't help (enabling)."
- Have codependent (relationship-addiction) traits and deny, minimize or defend them.
- Refuse to learn about or discuss addictions, enabling, and recovery, or to attend an addiction support group like Al-Anon or equivalent.
- Get significantly angry, hostile, defensive, or combative if someone brings up the addiction and the enabler's behaviors and choices.

Reality check!

Think of the person you feel is addicted and his or her key family members, friends, and co-workers. Then one at a time, decide whether any of them has any of the enabling symptoms above. Not identifying or confronting enablers raises the odds of an addict's relapsing.

Confront how?

There are many approaches and variations of approach in choosing how to confront individuals. You may choose to confront:
- The addict and some or all of the family adults.
- Over time or one-time.
- Alone.
- With informed help.

Many factors affect which of these options you and any supporters choose, such as ages; responsibilities; priorities; family composition and member locations, family roles and history; family-relationship quality; grieving progress; communication styles; and family ethnicity, customs, and nurturance level. Regardless of the factors involved, there are some general confrontation guidelines to consider.

General confrontation guidelines

- Keep a long-term perspective (i.e., the rest of the addicted person's life or the life span of the family's youngest child).
- Remember that you and any partner are not responsible for the addicted family adults' decisions; they are.
- Keep your priorities clear and firm. **Suggestion:** put your integrity (self-respect) first, any primary relationship second, and everything else third, except in emergencies.

- Stay clear on the specific results you want to achieve by confronting. The alternative is "riding off in all directions" or major disappointments, anxieties and family conflicts.
- Work steadily to improve your communication over time. Awareness, digging down, empathic listening, and assertion are especially powerful in any addiction confrontation (intervention). Experiment with these examples.

If you choose lay or professional people to help make the confrontation, ask them to prepare with steps like these:

- Be clear that in this context, confrontation and addiction/wound recovery are lengthy processes, not events. It is also important to remember that addictions can be managed, not cured.
- Help each other to stay aware of the difference between true and pseudo (trial) recovery and the relationship between preliminary (addiction) recovery and full (false self-wound) recovery.
- Aim to help the addicted person hit true bottom versus stopping or controlling their addiction.
- Correct the misperceptions that addiction is a shameful conscious choice and a disease rather than a compulsive, unconscious self-medication reflex and a sign of family dysfunction.
- Stay aware that a vital part of family confrontation is to inform minor kids in the family of key concepts, such as inner pain, compulsions, personality subselves, addiction, enabling, and recovery, and how to and express their feelings without anxiety, guilt or shame.
- Consider that trying to help someone who isn't asking for help is inherently disrespectful no matter how well-intentioned. It implies "I know what you need better than you do." This may be true, but it still feels insulting and promotes resentment and resistance.
- View personal and family resistance to breaking addiction and enabling denials as a frantic attempt to avoid pain and loss of security, not stubbornness, rigidity, ignorance, stupidity, defiance, arrogance, weakness, and self-centeredness.

Of course, you should always consider adding any personal confrontation guidelines that you feel are important in your unique situation.

Types of confrontation

Once you're well prepared, you've decided whom to confront, and your self is usually guiding you, you have a few options with each client or each person you care about:

- An indirect confrontation over time ("plant seeds").
- A direct confrontation alone or with one or more helpers.
- Plan and make a group intervention.

Let's look at each of these choices:

Indirect confrontation – "Seeding"

Trying to confront some people directly about their addiction will only evoke conflict, hurt, anger, anxiety, guilt, hostility, and frustration. This will increase family dysfunction and the addict's inner pain.

The practical alternative is to make indirect comments about addiction and recovery over time, i.e., to plant seeds that may help break denials later. An effective way to plant seeds is a series of sincere statements spoken calmly, with good eye contact and an attitude of mutual respect.

Another way is to ask relevant questions. Some examples include:

- "Maria, did you know that when you don't keep your promise to stop losing our money at the casino, I get really frustrated, and I'm learning to distrust you?"
- "What do you think about the idea that addictions are a family problem, not an individual one, Phil?"
- "I think Harry has a food addiction, but he can't admit that. Some people say that addictions are attempts to self-medicate major inner pain. What do you think?"
- "Our son just asked me if you were a rageaholic. Did you know he was wondering about that?"
- "I found another collection of pornography hidden in the basement, and I worry that you're addicted to it, Larry. Your denying that increases my fear."
- "Janice just told me about a book she read which said that parental drug addiction causes major psychological problems for all kids in the family."
- "Do you agree that Joan hasn't helped with her obsessive workouts and dieting?"
- "I just read that mental health pros define 'workaholism' as a true addiction. Some say it's being unable to work less than 65 hours a week, despite major health and family problems. Alex, I'm really concerned that that's true of you and us recently."
- "Would you say that your grandfather is addicted to poker and gambling? Has he ever tried to cut back because of his losses and marital strife?"
- "I hear that chronic overeating is linked to addiction to compulsive craving for sugar and fats, just like addiction to heroine and marijuana. Our doctor told me yesterday that he feels you're at least 70 pounds overweight, despite his warnings about related health risks. That really scared me, Roberto."
- "Helping other people avoid taking self-responsibility is called 'enabling.' I think Janice is enabling her mother by chauffeuring her all over the place, and not insisting that she learn to drive herself. Janice may be codependent, too – what do you think?"
- "Norma just told me her sister just got caught shoplifting again, despite her arrest last February. That really shows the power of true addictions, doesn't it?"
- "Sal, you say you can quit marijuana anytime, but you smoke it every day. I'm scared that's going to result in major health problem for you, and that it teaches the kids that using toxic drugs is OK."
- "I just finished reading 'Bradshaw on: The Family' – a book about children of alcoholics. It made me think of you and your mother, and I felt sad."

Please note that these statements and questions are not judgmental, sarcastic, scornful or critical, and they don't request or demand any change in the listener. Imagine the accumulated emotional impact of an addict or enabler hearing a focused series of statements (the "seeds") like these over weeks or months.

Recall that the primary goals of confronting an addict are:

- To preserve your self-respect (integrity).
- To increase the odds the individual will hit true bottom and break protective denials.

Can you imagine saying things like these to the person you're concerned about? If so, how would he or she react over time? If not, what is it that you are scared of? Does it make sense that patiently planting seeds like this would prepare all affected people for a direct confrontation about an addiction?

If you can tolerate the effects of the addicted person's behaviors and you estimate the person is not ready to hit true bottom, you can patiently plant seeds without expecting change – i.e., make respectful, informational statements and observations about wounds, unawareness, inner pain, self-medication, addiction, denials, enabling, and recovery.

Confront directly with qualified assistance

The emotional impact of any confrontation rises significantly if you ask one or two other concerned adults or older children to join you in asserting your needs and any boundaries. If you choose this option, you need to carefully pick and prepare qualified helpers.

Ideally, each adult you ask to help you confront will:

- Be clearly guided by his or her true self.
- Have studied and discussed this article or equivalent.
- Be willing to discuss and follow the foundation preparations fully.

Additionally, qualified helpers should:

- Be able to clearly describe their own reasons (primary needs) for confronting.
- Want to join you in preparing specifically for each confrontation you want to make, whether indirect or direct.

There are a couple of downsides to this type of confrontation:

- First, each additional person you involve raises the odds you'll have to resolve conflicts over whether, who, how and when to confront.
- Second, your target person is more apt to resist (feel embarrassed, guilty, anxious, resentful, hurt, angry and defensive) if several people confront him or her. The local confrontation preparations can help you handle this calmly.

It's important to reflect on how you want to interview prospective helpers to decide if you want to ask their help. There are many choices. Four criteria to consider are:

1. Who would have the most impact on the addicted person?
2. Who is most likely to agree to help you?
3. Who is least likely to cause major polarization and uproar in the target person's family if she or he confronts with you?
4. Who best meets the criteria above?

Plan and make a group intervention

Probably the most effective choice you can make toward helping an adult hit bottom and want to recover is to do a well-planned group intervention To intervene means "to come between." In this context, an intervention is a planned group meeting to come between a person dealing with addiction and their denials and compulsive toxic behaviors (i.e., to respectfully force them to confront the effects of their behavior.)

The two goals of an effective intervention are to:

- Motivate the addict to participate in a qualified in-patient recovery program.
- Satisfy the deep need of people who care about the addict and her or his family to do their best to offer meaningful help without feeling responsible.

If the first goal isn't met, the second one may be.

Typical intervention steps

A typical intervention starts with a concerned person who decides there is enough of a problem to act. *That person then* locates and consults with a trained addictions counselor. Some people attempt interventions without professional help, which lowers the odds of successful outcomes. If the counselor agrees that an intervention is warranted after hearing the situation, he or she will outline a version of the steps below. (Howard, 2012)

If you are the concerned person requesting help from the counselor, the counselor would then ask if you'll commit to these steps. If you commit, then the counselor asks you to identify every relative, friend, co-worker, neighbor, professional (like clergy or doctor), and church mate who is concerned about the addict, and has been significantly affected by the addict's (or enablers') behaviors. This list includes older children and people who live far away.

The counselor is responsible for identifying and providing basic educational material about addictions, recovery, and the intervention process.

Those materials can be used to guide the process of contacting each adult and child on the list in person or by phone without telling the addict. You explain the intervention goals and process, and ask them if they would be willing to help. If they are, ask the helpers to review the educational materials and thoughtfully write down several instances where the addict's actions inconvenienced, hurt, frustrated or concerned them.

The general format of each instance is:

> *"(Name), I really care about you. On (date) at (place), you (did something) which affected me (in these specific ways), and I felt _____."*

An instance might sound like:

> *"Jeff, last August 15th, you told Marcy and me that you and your partner would meet us at Granville's at 7 p.m. for dinner the following Saturday. We waited at the restaurant for 50 minutes, and the maitre d' said we had a phone call. It was your partner, who apologized and said you hadn't come home from work yet. Marcy and I were hurt, puzzled, frustrated and concerned, and were out the price of an expensive baby sitter. You never offered us an explanation."*

The intent is not to shame, guilt-trip, attack, blame, or preach to the addict, but to inform him or her factually of the impacts of their behavior. Other goals are for helpers to affirm their deep concern for the addict and to respectfully describe new boundaries if the target person chooses to make no change. The general format is:

> *"(Name), if you choose not to get help now, the next time you (do specific addictive behavior), I'm going to (take some specific nonpunitive action)."*

The addict may complain that this is a threat, power play or a controlling ultimatum. His or her defensive subselves may choose to see it that way, rather than seeing each helper's statement as a respectful assertion with clear consequences. Each helper's statement says: "Because I care for you and myself, I will no longer enable you. You have free choice on how to respond."

With the counselor's help, concerned individuals can research local addiction-recovery treatment facilities and pick one that provides the best mix of reputation, service, accessibility and cost. Then they should negotiate a planning date that helpers and the counselor can attend, and make reservations for the addict at the treatment facility without her or his knowledge (Albury, 2011).

The next step is for all of the helpers (including the older children) to meet with the counselor. You introduce each other and the counselor facilitates planning the intervention and answers any questions. Everyone then reaffirms their common goals (to help the addict hit bottom and protect their integrities); review key realities about addiction and recovery; rehearse and edit each helper's anecdotes for objectivity, clarity and impact; and discuss effective ways of responding to the addict's likely reactions to hearing these anecdotes and new consequences.

The role of the counselor is to educate and coach everyone, offering questions, examples, suggestions, confrontations and encouragement.

When everyone feels ready enough, you then pick a date, time and location for the planned intervention. Someone approaches the addict with a fictitious request on that date, and gets his or her agreement to come. The addict walks into a room where you all are gathered, and someone explains that you're all there to help.

Conclusion

An enabler is someone who (usually unintentionally) helps to make a person's drug use problems and addictions possible by engaging in behaviors they mistakenly think will help the person. In reality, the enabler only hurts the user. When defining family roles in addiction, Colorado State University describes the enabler:

> "The enabler is the person who allows substance abuse to continue by 'saving' the abuser from the consequences of his or her actions. For example, if an alcohol-dependent teen doesn't come home on time, an enabler would likely make excuses to other family members for that absence."

While this description is accurate, the example is somewhat benign. Enablers have been known to directly procure drugs for the user because they assume they'll simply acquire them elsewhere if they don't. They'll lie about the user's criminal activity because they fear losing them to incarceration. And perhaps worst of all, some enablers simply pretend like there isn't a problem at all and allow chronic addiction to continue unabated for years or even decades.

Drug Addiction Treatment.Com makes some other important observations about damaging enabler behavior:

- Enablers aren't always family members. They can be neighbors, friends, co-workers, or even teachers.
- Enablers generally believe that they are actually helping those they care about by preventing worst-case scenarios.
- Enablers may also fear rejection from their loved ones if they do not yield support. It could be something as simple as providing the addict with housing or transportation because he is spending all his money on drugs.

The definition of enabling in Random House dictionary is as follows: "To make able; give power, means, competence or ability to authorize. To make possible or easy." Now, what does that have to do with drug abuse? After all, no one wants a loved one to do something that would hurt themselves or others. So how could an individual possibly enable someone else's behavior? Furthermore, why would one want to enable someone to use drugs?

The reality is, this behavior does occur and contributes to substance abuse. There are three factors related to perpetuating substance abuse: denial, enabling and codependency.

As enabling makes a behavior possible or easy, behaviors by family members allow individuals with addiction problems to avoid the negative consequences that may accompany their actions. There are many ways in which this behavior can manifest. In addition, enabling behavior can be instigated by various individuals, including:

- Parents.
- Siblings.
- Co-workers.
- Supervisors.
- Neighbors.
- Friends.
- Teachers.
- Doctors.
- Even therapists.

Though initially, enabling occurs as a way to protect individuals from their behavior, it can go on to perpetuate actions that cause repetitively bad behavior. Some ways in which enabling takes place are:

- Doing something for people that they should do themselves.
- Making excuses for the individual's behavior.
- A spouse calling his or her significant other's employer to say that the person is sick and can't work, when in reality, the person is just hung over.
- Bailing out a child who has been arrested for possession, use or abuse of drugs, or breaking other societal rules.
- Defending the substance abuser, thereby allowing the behavior to continue, instead of recognizing a problem.
- Generally covering the tracks of the individual in question, whether it be by giving or loaning money, finishing up work, or just generally ignoring behaviors that should have repercussions. Usually, the enabler stays silent when faced with repeated inappropriate or destructive behavior.

As a counselor, it is important to understand the impact of enabling behavior and what can be done about it. While we've discussed several methods of approach, each client is different and each family has a different dynamic. Over time, counselors may be able to determine what type of intervention and level of support that needs to occur to diminish enabling behavior and help addicts overcome their addiction.

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UNDERSTANDING ENABLING BEHAVIOR AND HOW TO ADDRESS IT

Final examination Questions

Select the best answer for each question and proceed to ***SocialWork.EliteCME.com*** to complete your final examination.

51. Enablers often participate in such behavior because of their own:
    a. Needs.
    b. Low self-esteem.
    c. Fear.
    d. Motives.

52. What is used to allow family members to stand back and reflect on whether and in what way an eating disorder has become the central organizing principle of home life?
    a. Home study.
    b. Phone consultation.
    c. Orientation.
    d. Family assessment.

53. Which of following can help family members identify what it is that they are dealing with and recognize their own responses to early warning signs of enabling?
    a. An external provider.
    b. Financial incentives.
    c. Play therapy.
    d. A list of relevant questions.

54. Which of the following is a comprehensive, active-directive, philosophically and empirically based psychotherapy that focuses on resolving emotional and behavioral problems and disturbances and enabling people to lead happier and more fulfilling lives.
    a. Group therapy.
    b. Rational emotive behavior therapy.
    c. Principle assessment.
    d. Fulfillment therapy.

55. What is an orchestrated attempt by one or many people (usually family and friends) to get someone to seek professional help with an addiction or some kind of traumatic event or crisis or other serious problem called?
    a. Intervention.
    b. Group therapy.
    c. Acknowledgement.
    d. Clinical supervision.

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