CHAPTER 1
CLINICAL ASPECTS OF ORGAN DONATION AND RECOVERY

(I CONTACT HOUR)

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Learning objectives
 Identify members of the transplant team.
 Discuss the factors involved in the waiting times for a transplant.
 Discuss transplant options.
 Identify select provisions of the National Organ Transplant Act.
 Explain the process of nursing self-assessment as it pertains to transplant issues.
 Identify key elements of the role of procurement organizations and hospitals in organ recovery.

Introduction
According to the United Network for Organ Sharing (UNOS) on January 3, 2013 there were 117,000 waiting list candidates for organ transplantation. Between January and September, 2012 21,132 transplants were performed.\(^5\)

Transplant data show that more people receive transplants every year and that many persons who have received transplants are living longer after receiving organs than ever before.\(^4\)

The issue of organ donation and recovery is fraught with ethical and legal questions such as the definition of death, conflict of issues among family members of the potential donor, the wishes of the donors themselves, grief over the death of a loved one, and the needs and hopes of those who are waiting for transplants (as well as their families).

The purpose of this education program is to discuss the clinical aspects of organ donation and recovery and the nurse’s role in the organ donation and recovery process.

Members of the transplant team
Successful organ transplant depends on many people. Each person who serves on a transplant team functions as an expert in various areas of transplantation. The transplant team members include, but are not limited to, the following professionals.\(^3,4\)

 Clinical transplant coordinators: These individuals are responsible for evaluating the patient, his/her treatment, and the care following transplant.

 Financial coordinators: Financial coordinators must have in-depth knowledge of financial matters, the costs associated with organ donation and transplantation, and hospital billing. These financial experts must work with a variety of persons including other members of the transplant team and insurers to coordinate financial features of the patient’s care before, during, and following transplantation. This often includes helping patients and families to navigate the complexities of insurance billing as well.\(^3,4\)

 Nurses: Transplant nurses are involved in the care of living donors and organ recipients. Transplant nurses are also involved in preparing the patient for transplantation, offering emotional support for the recipient and his/her loved ones, and providing postoperative transplant care and patient/family education.

 Social workers and case managers: These individuals help to coordinate care and services associated with transplantation. They may also take on responsibilities for some aspects of financial coordination as well.

 Transplant physicians: These physicians manage the patient’s medical care, diagnostic and other tests, and medications. They do not perform surgery. Transplant physicians work in conjunction with other members of the transplant team to coordinate care until the patient is transplanted, and usually provide follow-up care for the organ recipient.

 Transplant surgeons: These physicians perform the actual transplant surgery and may also provide the recipient’s follow-up care. Special expertise, education, and training, in transplantation are part of the transplant physician/surgeon’s qualifications.

Other persons who may be members of the transplant team are psychologists, clergy, and therapists depending on the needs of the individual patient. Follow-up care with physicians who have expertise in transplantation and other relevant specialists is also necessary.

Waiting times for a transplant
One of the most frustrating, and frightening, aspects of transplantation can be waiting for a donor organ. Patients are sick and are generally becoming sicker the longer they wait for a suitable organ. The physical and emotional effects of any long-term illness are intense. Waiting for an organ adds to the discomfort, fear, and frustration of illness. Patients and families are fearful that patients may die before transplantation is possible. They may also worry that, after receiving a transplant, the recipient’s body may reject the organ. In the event of a successful transplant, they must anticipate dealing with life-long follow-up care and immunosuppression medication to avoid organ rejection and a relapse back into illness. Thus, significant stressors exist in conjunction even with a successful transplant.

Waiting times differ significantly among patients who are on the transplant waiting list. Reasons for such differences include, but are not limited to:\(^3,4\)

 The severity of illness of the patient (medical urgency).

 The response of patients to their current treatment regimens.

 The medical conditions that make a transplant necessary.

 The patient’s blood type.

 The patient’s tissue type.

 Height and weight of the patient.

 The size of the donor organ.

 The length of time the patient has been on the waiting list.

 The availability of donors.

 The transplant center’s criteria for accepting donor organ offers.

It is important that all healthcare professionals involved in the transplant process work to enhance communication between transplant centers and their patients. If patients and families understand the waiting list and transplant process, it is possible to reduce some of the stress and anxiety they experience.

Review of transplant options
Patients must be notified of their waiting list status. They must be notified in writing within 10 business days of registration that they have been placed on the national transplant waiting list. Likewise, the transplant program must notify patients in writing within 10 days after evaluation is completed if they are not going to be placed on the patient waiting list.\(^4\)

Patients must also be notified if they are removed from the list for any reason other than death or transplantation. The transplant program must notify patients, in writing, within 10 business days if they are removed from the list.\(^4\)

Patients waiting for organs have a variety of options such as listing at hospitals in different geographic regions in the country and transferring waiting time to a different center.

Here is a summary of some of the options.\(^4\)

 Multiple listing: Patients may elect to register for a transplant at more than one hospital. Patients who list at a transplant hospital are usually considered for organs in that local area first. If patients are listed at multiple hospitals, they will be considered for donor organs in more than one local region.

Transplant alert! Although national transplant policy allows the registration for transplants at more than one transplant hospital, each hospital may have its own policies for allowing patients to be on multiple lists. Multiple listings do not guarantee that patients will receive donor organs more quickly.\(^4\)

 Transferring waiting time: Patients are allowed to switch to a different transplant hospital and transfer their waiting time to that new hospital. The amount of waiting time from the original hospital is added to the time collected at the new hospital.\(^3\)

Transplant alert! The transplant teams at the original and new hospital are responsible for coordinating the information exchange and notifying the United Network for Organ Sharing (UNOS).\(^6\)

 Living donation: Patients may also receive organs from living donors, who offer (another option for persons waiting for organs). In 2007, there were more than 6,300 living donor transplantations. The first successful living donor transplant was performed between identical twins in 1954, and the
stage was set for both related and unrelated donors to be tested as matches for persons needing organs.4

**Transplant alert!** A critical issue regarding transplantation is the length of time an organ is viable once procured until transplantation:

- Heart: Approximately 4-6 hours.
- Lungs: Approximately 4-6 hours.
- Liver: Approximately 12 hours.
- Pancreas: Approximately 12-16 hours.
- Kidneys: Approximately 48 hours.

### The National Organ Transplant Act

In 1984, The National Organ Transplant Act (NOTA) called for an Organ Procurement and Transplantation Network (OPTN) to be created and run by a private, non-profit organization under federal contract. The act mandates that the OPTN should:

- “Increase and ensure the effectiveness, efficiency and equity of organ sharing in the national system of organ allocation.”
- “Increase the supply of donated organs available for transplantation.”

The United Network for Organ Sharing (UNOS) was awarded the national OPTN contract in 1986 by the U.S. Department of Health and Human Services. UNOS is the only organization to ever operate the OPTN. As part of the OPTN contract, UNOS has established:

- An organ sharing system to maximize the efficient use of deceased organs.
- A process to collect, store, analyze, and publish data concerning the patient waiting list, organ matching, and transplants.
- A process of informing, consulting, and guiding persons and organizations concerned with human organ transplantation to help increase the number of organs available for transplantation.

### Nursing ethical self-assessment pertaining to transplantation issues

Nurses are expected to provide compassionate care without bias or judgment. They face situations that may deal with ethical and/or legal issues frequently. Transplantation involves issues that relate to the definition of death, the effect of refusing to donate organs, and the cultural and religious beliefs pertaining to donating parts of the body after death.

Nurses may have their own deep-rooted, cultural and religious beliefs pertaining to the issue of transplantation. However, they must not project their values and beliefs on their patients and their patients’ loved ones. Nurses routinely care for patients nearing the end of life, but only specially trained nurses from an Organ Procurement Organization should approach and counsel patient family members about organ donation. Nurses trained in transplantation are best suited to care for patients after they have received donor organs. In order to provide safe, compassionate and appropriate care, nurses should perform a self-analysis of their feelings and beliefs regarding transplantation.

Ethical discussions show that nurses have a variety of beliefs about transplantation. Some of these (sometimes conflicting) beliefs include:

- Organ donation is a moral obligation.
- The needs of the transplant recipients take priority over the terminally ill or injured potential donor.
- Removal of vital organs is the cause of death not the existing illness or injury.
- Removal of vital organs is a violation of certain religious beliefs.

Self-analysis begins with a review of the definition of death. What is the legal definition of death? What is the nurse’s personal definition of death? How does the potential donor’s family define death?

### The role of procurement organizations and hospitals in organ recovery

The Association of Organ Procurement Organizations (AOPO) is “the non-profit organizations recognized as the national representatives of the 58 federally-designated organ procurement organizations (OPOs) serving more than 300 million Americans.”1 The purpose of AOPO is to provide education, share information, conduct research, and offer technical assistance and collaboration with healthcare organizations and federal agencies.1

The organ recovery process is a multifaceted process that is coordinated by healthcare professionals in OPOs and hospitals. When a patient dies or is expected to die in a hospital a call is placed to the OPO. This call initiates the organ recovery and donation process.2

The following summary of steps is a general review of the organ recovery process as described by the Association of Procurement Organizations (AOPO).1,2

- Death is declared by a physician according to brain death criteria or by cardio-pulmonary arrest in compliance with state law and hospital policy and procedure.1,2
- After the declaration of death, the patient must remain on ventilation before organ procurement can occur.

**Transplant alert!** This is an especially difficult time for family and loved ones. They see the patient’s chest rise and fall with mechanical ventilation. They see that his/her heart continues to beat. It can be very difficult for them to accept that the patient has been declared dead, and even more difficult to agree to the donation of organs.

- Medicare Conditions of Participation mandates that all hospitals must notify their local OPO when death occurs or is about to be declared. An OPO clinical recovery coordinator is given information about the patient. The coordinator then evaluates the patient’s suitability as a donor and checks the donor Registry of the potential donor’s state of residence.
- If the patient is registered to be an organ and tissue donor his/her next of kin or healthcare proxy is approached. The next of kin or proxy is informed, in detail, of the donor process. However, the patient’s wishes about donation may not be known. In this case, the coordinator discusses, with the next of kin or proxy possible donor options. Such options may include transplantation, research, education, and/or therapy.1,2

**Transplant alert!** This is a challenging time for family friends, even if the patient is registered as a potential donor. They need the support and understanding of the entire healthcare team.

- If donation is agreed upon, the OPO coordinator carries out a medical evaluation as well as a social history of the patient. If there is potential for an organ donation, the UNOS is requested to complete a waiting recipient list for every organ that can be placed for transplantation. Criteria are entered into the computer program to identify potential recipients. Information accessed includes donor blood type, body, size, and possibly genetic tissue type.
- Possible recipients are identified, and their transplant surgeons are notified. If the offered organ is accepted the recipients go to their transplant centers for transplant preparation. If the surgeon declines the offered organ, the surgeon of the next patient on the list is notified.
- The notification process can take 8-12 hours. During this time period the donor’s organs must be medically maintained by the OPO coordinator and the medical staff of the donor’s hospital.
- While the donor is being mechanically ventilated it is imperative that adequate heart rate, blood pressure, and urinary output be maintained. Federal law mandates that physicians who were responsible for the patient’s medical care prior to determination of brain death cannot be part of the recovery of organs process.
- The OPO recovery coordinator schedules use of the operating room and the arrival and departure of the surgical transplant teams. Recovery is conducted in an operating room. For removal of donor hearts, livers, and pancreas, complete operating room staffs and special surgical teams are required. Kidneys are generally removed by a local surgeon. Organs are placed in protective solutions and packaged and sent to the recipient’s hospital.1,2
- Recovery of tissues takes place after organs are removed. A recovery team removes the tissues, packs them under sterile conditions, and transports them to a tissue bank. They are prepared for transplantation, research, or therapy at the tissue bank.
- Following removal of organs and/or tissues the donor’s body is reconstructed and removed to the funeral home per the family’s wishes and hospital policy.1,2
Transplant alert! The family needs to be supported during this difficult time. They may wish to view the donor’s body to say goodbye to their loved one.

Recovery follow-up is provided by the OPO. The organization sends letters to the donor family, physicians, nurses, and other hospital staff as appropriate concerning the outcome of the recovery. The recipient’s transplant hospital reimburses the OPO for costs of obtaining the organ(s) and/or tissues. That hospital is reimbursed by the recipient’s insurance company or by Medicare.

An advocate from the OPO follows up with the family of the donor by sending bereavement letters, literature, advice, support, and information about the progress of the recipient.

OPOs must provide service and education to hospitals and help them to develop best practices regarding identification of potential donors and how to provide safe, appropriate, and compassionate care to patients and families. Nurses should take every opportunity to avail themselves of such education as they work with donors and their families and recipients and their families.

References

CLINICAL ASPECTS OF ORGAN DONATION AND RECOVERY

Self Evaluation Exercises

Choose True or False for questions 1 through 10 and check your answers at the bottom of the page.

You do not need to submit this self-evaluation exercise with your participant sheet.

1. Transplant physicians perform surgical removal of donated organs.
   
   True  False

2. The height and weight of the patient can affect the waiting time for an organ.
   
   True  False

3. Multiple listings generally guarantee that patients will receive donor organs more quickly.
   
   True  False

4. Patients must be notified in writing within 15 business days that they have been placed on the national transplant waiting list.
   
   True  False

5. In 1984, The National Organ Transplant Act (NOTA) called for an Organ Procurement and Transplantation Network (OPTN) to be created and run by a private, non-profit organization under federal contract.
   
   True  False

6. UNOS has established an organ sharing system to maximize the efficient use of deceased organs.
   
   True  False

7. The purpose of AOPO is to provide education, share information, conduct research, and offer technical assistance and collaboration with healthcare organizations and federal agencies.
   
   True  False

8. The organ recovery process is a multifaceted process that is coordinated by healthcare professionals in OPOs and hospitals.
   
   True  False

9. Medicare Conditions of Participation mandates that all hospitals notify their local OPO when death occurs or is about to be declared.
   
   True  False

10. Federal law mandates that physicians who were responsible for the patient’s medical care prior to determination of brain death must be part of the recovery of organs process.
    
    True  False

CHAPTER 2
CHRONIC FATIGUE AND FIBROMYALGIA SYNDROME
(7 CONTACT HOURS)

Learning objectives
- Identify and define chronic fatigue and fibromyalgia syndrome.
- Identify and discuss the symptomatology of chronic fatigue and fibromyalgia syndrome.
- Identify and define chronic fatigue and fibromyalgia syndrome.
- Describe the differential diagnosis of chronic fatigue and fibromyalgia syndrome.
- Identify and discuss the treatment modalities for chronic fatigue and fibromyalgia syndrome.
- Describe the complexity of chronic fatigue and fibromyalgia syndrome.

Introduction
Any individual who has experienced debilitating fatigue, malaise, chronic pain and other somatic complaints has probably endured years of frustration from the health care system prior to being diagnosed with chronic fatigue syndrome (CFS), fibromyalgia (FMS) or myalgic encephalomyelitis (ME). CFS, FMS and ME are typically used interchangeably in most literature and textbooks; however there are minuscule differences that will be explored. For the sake of this continuing education course, the terms fibromyalgia and chronic fatigue syndrome will be used.

Fibromyalgia and chronic fatigue syndrome are among the most complex and misdiagnosed syndromes seen in clinical practice. The majority of the literature implies that the conditions remain poorly understood, despite an abundance of scientific research. However, according to the U.S. Department of Health and Human Services and the National Institute of Health (NIH) (2009), chronic fatigue and fibromyalgia when compared to other major disorders has had the least amount of money spent on researching the syndromes. Since 2005, an average of $4 million per year has been spent on chronic fatigue syndrome, whereas from $9 million to 12 million is spent on fibromyalgia per year [47]. To put it into perspective, $246 million to $289 million has been spent on asthma, $443 million to $512 million on alcoholism, $700 million to $729 million on breast cancer and billions on heart disease, diabetes and cancer per year [47]. It has been estimated that the average patient with fibromyalgia has been seen by approximately 15 physicians and has had the syndrome for five years before properly being diagnosed [22]. Typically, most patients are misdiagnosed, enduring costly treatments with little benefit or being informed that there is nothing medically wrong with them and that it is “all in their head.” Therefore, many patients and families become frustrated and skeptical with their provider. To this day, some health care professionals do not believe fibromyalgia truly exists [4]. Although most patients are relieved when a correct diagnosis is finally made, the patient may need to be convinced that the provider actually knows what is wrong, and that a treatment plan has been formulated to alleviate his/her symptoms [22].

Defining chronic fatigue syndrome and fibromyalgia

Based upon the known criteria of each condition, pain is the major feature of fibromyalgia, whereas post-exertional malaise and fatigue are the major symptoms of chronic fatigue syndrome. Pain and fatigue are the most prevalent complaints seen in primary care. However, both chronic fatigue and fibromyalgia syndromes remain poorly understood because both complaints may occur synonymously and can be a sign of a plethora of other medical conditions. To add to the complexity, there is a significant amount of overlap in the complex symptomology between chronic fatigue and fibromyalgia. At this time, the majority of patients with chronic fatigue meet the criteria for fibromyalgia and at least 70 percent of patients with fibromyalgia meet the criteria for chronic fatigue syndrome [5, 18]. Due to the significant complexity and overlapping presentation of chronic fatigue syndrome and fibromyalgia, it is important to define each of the syndromes.

Chronic fatigue syndrome

Chronic fatigue syndrome is a debilitating syndrome that involves multiple body systems. It is characterized by profound fatigue that is not improved by bed rest and may be exacerbated or rekindled by physical or mental activity. Patients with chronic fatigue syndrome function at substantially lower level of activity than they were capable of doing prior to the onset of their illness. Over the years, a great deal of debate has surrounded the issue of how best to define the syndrome, so the Department of Human Health and Services and the NIH have outlined the history to hopefully alleviate the confusion in the definition, uncertainties and overlapping symptoms with fibromyalgia [15]:

- Persistent or relapsing, debilitating fatigue, lasting at least six months, in a person who has no previous history of similar symptoms.
- Exclusion of other clinical conditions that may produce similar symptoms (such as, malignancy, autoimmune disease, chronic psychiatric disease, and chronic inflammatory disease, among others).

The definition also included the occurrence of at least eight symptoms including mild fever, sore throat, painful lymph nodes, prolonged fatigue after exercise, joint or muscle pain, unexplained muscle weakness, headaches and sleep disturbance.

Concurrently, while the CDC in the United States (U.S.) was defining the syndrome, researchers in Australia developed their own definition. The Australian definition captured the CDC’s major criteria, and added the symptom of “neuropsychiatric dysfunction,” which included impairment of concentration and short-term memory.

In 1990, a consensus meeting of researchers in Great Britain found neither of these definitions satisfactory in clinical practice. Therefore, the resulting guidelines included a glossary describing in detail the principal symptoms of fatigue, disability, mood disturbance, malaise (muscle pain) and sleep disturbance. The “Oxford criteria,” as they came to be known, also defined it as post-infectious fatigue syndrome (PIFS), a subtype of chronic fatigue syndrome that either followed an infection or is associated with a current infection.

In 1990, although there was no consensus about the etiology of chronic fatigue syndrome, which is needed to accurately classify a condition in the International Classification of Diseases (ICD-9), it needed a definitive billing code. ICD codes are required to properly bill insurance companies for payment reimbursements for the services rendered by physicians, nurse practitioners and clinics. Initially, the only entry in the alphabetic index of the ICD-9 was “Syndrome, fatigue,” code 300. The ICD-9 then changed it to include code 323.09 “benign myalgic encephalomyelitis.” However the 323.9 code did not reference the condition to include it as a postviral syndrome. Later, on October 1, 1991, the term “postviral syndrome” was classified to code 780.7, Malaise and fatigue [12].

In 1992, the World Health Organization (WHO) published ICD-10 codes that included many modifications. The WHO created a new category G93 that involved “other disorders of the brain” and created a new code G93.3 to include postviral fatigue syndrome, a condition which was previously mentioned in the ICD-9 code. The WHO also moved “benign myalgic encephalomyelitis” to the new code G93.3.

In keeping with the placement in the ICD-10, chronic fatigue syndromes (and its synonymous terms) were to remain at G93.3 in ICD-10. However, the WHO was not content with the ICD-9 and ICD-10 coding because [12]:
It appeared that while chronic fatigue syndrome was classified as heterogeneous group of disorders, not all were neurological in nature.

Likewise, not all patients with chronic fatigue experienced a viral infection prior to being diagnosed with the syndrome.

Also of potential concern is the similarity between the type of neurological findings in chronic fatigue syndrome and in depression, which is a psychiatric disorder.

In 2007, to avoid any confusion, the WHO updated its codes and recommended that all practitioners treating chronic fatigue syndrome code it as G93.3 (post-viral fatigue syndrome) and R 53 (malaise and fatigue). R is a newer chapter that includes symptoms, signs, abnormal results of clinical or other investigative procedures, and ill-defined conditions that no diagnosis is able to classify elsewhere [52].

Because of confusion and criticism that chronic fatigue syndrome diagnosis was too ambiguous and over-exclusive, and to facilitate a more systematic collection of data internationally, the International Chronic Fatigue Syndrome Study Group was created in 1994. The group, headed by the CDC and including representatives from Australia and Great Britain, proposed a revised definition of chronic fatigue syndrome. The revised definition was known as the Fukuda or research definition and was based on the presence of the following [12]:

- Clinically evaluated, unexplained, persistent or relapsing chronic fatigue that is of new or definite onset (has not been lifelong); is not the result of ongoing exertion; is not substantially alleviated by rest; and results in substantial reduction in previous levels of occupational, educational, social, or personal activities.
- The concurrent occurrence of four or more of the following symptoms, all of which must have persisted or recurred during six or more consecutive months of illness and must not have predated the fatigue:
  - Self-reported impairment in short-term memory or concentration severe enough to cause substantial reduction in previous levels of occupational, educational, social or personal activities.
  - Tender cervical or axillary lymph nodes.
  - Muscle pain, multijoint pain without joint swelling or redness.
  - Headaches of a new type, pattern or severity.
  - Unrefreshing sleep.

In 2001, an expert consensus panel convened in Canada to develop a case definition of myalgic encephalomyelitis designed for clinical diagnoses, rather than for research purposes as was the 1994 definition of chronic fatigue syndrome. The panel outlined criteria for the symptom categories including:

- Fatigue; post-exertional malaise or fatigue.
- Sleep dysfunction.
- Pain.
- Body system manifestations including neurological/cognitive (i.e., difficulties with memory or concentration), autonomic (i.e., vertigo), neuroendocrine (i.e., heat or cold intolerance) and immunity (i.e., sore throat).

In 2003, the international group formed in 1994 revisited its research. The original definition offered examples of conditions that would preclude a diagnosis of chronic fatigue syndrome. The study group elaborated on these exclusionary criteria and recommended the use of several specific standardized instruments in assessing fatigue and accompanying symptoms.

Patients and patient advocates often prefer to call chronic fatigue syndrome “chronic fatigue and immune dysfunction syndrome” (CFIDS) to convey the complexity of the illness and its profound impact on people’s lives. The 2003 study group addressed the name “chronic fatigue syndrome,” expressing sympathy with those concerned that the name might trivialize the illness. “However,” the report stated, “we believe that changing the name without adequate scientific justification will lead to confusion and will substantially undermine the progress that has been made in focusing public, clinical and research attention on this illness.” [15].

After all of the debating to define chronic fatigue syndrome, physicians and practitioners may safely diagnose the condition if the patient satisfies the following criteria [8]:

- Has severe chronic fatigue of six months or longer duration with other known medical conditions excluded by clinical diagnosis.
- Concurrently has four or more of the following symptoms: substantial impairment in short-term memory or concentration; sore throat; tender lymph nodes; muscle pain; multijoint pain without swelling or redness; headaches of a new type, pattern or severity; unrefreshing sleep; and post-exertional malaise lasting more than 24 hours.

In the review of literature, there is limited data available in regards to chronic fatigue and fibromyalgia syndrome in children and adolescents. Children are diagnosed with chronic fatigue syndrome if any of the following symptoms last more than three months, as opposed to a minimum of four symptoms persistent for at least six months in adults [5, 33]:

- Incapacitating fatigue.
- Impaired short-term memory and concentration problems.
- Exercise intolerance.
- Sleep intolerance.
- Severe, generalized pain.
- Dyslexic.
- Tearful and/or profound mood changes.
- Sore throat, muscle and joint pain, headaches, allergies.
- Nausea, irritable bowel syndrome, cyclic vomiting.
- Lightheadedness, low blood pressure, racing heart, shakiness, sweating, blurred vision, nausea, worsened fatigue and pain, difficulty speaking and possibly fainting when sitting or standing still.

It is apparent that it has been a struggle over the years to definitively define chronic fatigue in a consensual, professional manner. Unfortunately, that has not alleviated the difficult task for practitioners to recognize and diagnose the syndrome promptly and accurately, leading to a delay in appropriate treatment.

**Fibromyalgia**

Fibromyalgia derived its name from “fibro-” which is tissueulike ligaments and tendons, “my-” meaning muscle and “algia” indicating pain. Previously, fibromyalgia was called fibrositis, which was defined as diffuse noninflammatory nature muscular rheumatism. However, the name was later changed because fibromyalgia is no longer seen as an inflammatory disorder but as a chronic pain syndrome [27].

Fibromyalgia is a disorder of unknown etiology characterized by widespread pain, abnormal pain processing, sleep disturbance, fatigue and often psychological distress. Adults with fibromyalgia may also have other symptoms; such as [6]:

- Morning stiffness.
- Tingling or numbness in hands and feet.
- Headaches, including migraines.
- Irritable bowel syndrome.
- Problems with thinking and memory (sometimes called “fibro fog”).
- Painful menstrual periods and other pain syndromes.

Children and adolescents with fibromyalgia, which is known as juvenile fibromyalgia, typically have the same symptoms as adults, except they have experienced sleep disturbances, morning fatigue, swelling of the extremities and less ability to tolerate exercise [33].

In 1990, the American College of Rheumatology (ACR) developed specific criteria used for clinical diagnosis and classification of fibromyalgia. Diagnosis is based on the presence of widespread pain (at least three months duration) and tenderness on 11 of 18 pressure points in adults, and five of 18 pressure points in children [6, 33, 35]. The ACR’s criteria are as follows [6, 35]:

- The patient has at least a three-month complaint of widespread pain in any of the following body regions:
  - Pain in both sides of the body.
  - Pain above and below the waist level.
- In addition, axial skeletal pain (cervical spine, anterior chest, thoracic spine or low back pain) must be present. Low back pain is considered lower segment pain.
Table 1-Fibromyalgia tender points and symptoms [2]

<table>
<thead>
<tr>
<th>Condition</th>
<th>Percentage of FMS symptoms</th>
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</thead>
<tbody>
<tr>
<td>Muscular pain</td>
<td>100</td>
</tr>
<tr>
<td>Fatigue</td>
<td>96</td>
</tr>
<tr>
<td>Insomnia</td>
<td>86</td>
</tr>
<tr>
<td>Joint pains</td>
<td>72</td>
</tr>
<tr>
<td>Headaches</td>
<td>60</td>
</tr>
<tr>
<td>Restless legs</td>
<td>56</td>
</tr>
<tr>
<td>Numbness and tingling</td>
<td>52</td>
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<tr>
<td>Impaired memory</td>
<td>46</td>
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<tr>
<td>Leg cramps</td>
<td>42</td>
</tr>
<tr>
<td>Impaired concentration</td>
<td>41</td>
</tr>
<tr>
<td>Nervousness</td>
<td>32</td>
</tr>
<tr>
<td>Depression (major depression)</td>
<td>20</td>
</tr>
</tbody>
</table>

In addition to widespread pain, there must be tender points in 11 of 18 specific areas, including at least 11 of the following areas [35](See Table 1):
- Occiput (2) – at the suboccipital muscle insertions.
- Low cervical (2) – at the anterior aspects of the intertransverse spaces at cervical (C); C5-C7.
- Trapezius (2) – at the midpoint of the upper border.
- Supraspinatus (2) – at origins, above the scapula spine near the medial border.
- Second rib (2) – at the costochondral junction.
- Lateral epicondyle (2) – 2 centimeters (cm) distal to the epicondyles.
- Gluteal (2) – in upper outer quadrants of buttocks in anterior fold of muscle.
- Greater trochanter (2) – posterior to the trochanteric prominence.
- Knee (2) – at the medial fat pad proximal to the joint line.

According to coding rules provided by the CDC (2008), fibromyalgia is coded to 729.1, which is labeled “myositis and myalgia, unspecified” and can include other conditions. In addition, the WHO (2007) recommends practitioners code fibromyalgia under M 79.0 (rheumatism, unspecified) and M 79.7 (fibromyalgia). M is a coding system for diseases of the musculoskeletal system and connective tissue [12, 53]. Ironically, although chronic fatigue and fibromyalgia are very similar in their presentation and typically overlap, both are coded differently, which intensifies the complexity of the disorders and the possibility of misdiagnosing the syndromes.

Epidemiology of chronic fatigue and fibromyalgia syndrome

According to the CDC (2009), chronic fatigue and fibromyalgia are debilitating syndromes. At least a quarter of all patients with chronic fatigue and fibromyalgia are unemployed or on disability due to the extreme fatigue and/or pain [7]. At this time, 16 percent are receiving Social Security benefits compared to 2.2 percent of the general population [18]. In June 2008, the CDC reported the prevalence of fibromyalgia was approximately 2 percent, affecting an estimated 5 million adults in 2005 [1]. The CDC estimated that between 1 million and 4 million Americans suffer from chronic fatigue syndrome [7]. Additional statistical information on chronic fatigue syndrome is limited because fatigue is such a common complaint and the data is not differentiated.

According to the American College of Rheumatology (ACR) and the CDC, men have a 0.5 percent prevalence of being affected with fibromyalgia while women have a 3.4 percent risk. Therefore, most people with fibromyalgia are women (female to male ratio is 7:1) [1, 18, 50]. Women are also more likely to be affected with chronic fatigue syndrome. According to the Department of Health and Human Services and the NIH, chronic fatigue syndrome occurs three to four times more frequently among women than men and 10 times more often in white Americans than in Americans of other racial/ethnic groups. A more recent study disputes these numbers and would narrow the gap between the sexes, as well as among racial/ethnic population subgroups [15].

Fibromyalgia and chronic fatigue syndromes are typically diagnosed in individuals between the ages of 20 to 50 years; however, it may occur in children and older adults, especially among women. In 2008, it was estimated that most children diagnosed with juvenile fibromyalgia are prepubertal or adolescent girls aged 13-15 years with a mean onset at age 12 [21]. Juvenile fibromyalgia is more common in white, adolescent girls, although 35 percent boys of the same age or younger have also been diagnosed [21]. As women age, especially over the age of 70, there is a 7.4 percent risk of being affected by fibromyalgia [18, 50].

Fibromyalgia is the second-most common musculoskeletal disorder and causes over 20 percent of all visits to a rheumatologist [18]. Numerous research studies have demonstrated that over 50 percent of fibromyalgia patients have a history of eating disorders or physical or sexual abuse. Up to 30 percent of patients fall into a psychiatric diagnosis category of depression, somatization and hypochondriasis, with anxiety being the most common. Many disagree as to whether psychiatric problems develop in patients before chronic fatigue and fibromyalgia or if it occurs as a result of the syndrome [18].

As of January 2009, epidemiologists recognized that the social, emotional, economic and functional effects of fibromyalgia on an individual’s life have been compared with those of rheumatoid arthritis (RA). Research indicates that the socioeconomic impact of fibromyalgia includes the following estimates [6,22]:
- Overall, fibromyalgia costs the American economy more than $9 billion annually.
- Average yearly service utilization cost per person is $2,274.
- Total annual cost (direct and indirect) per person is $5,945.

According to the CDC (2008), in 1997, 7,440 hospitalizations listed ICD-9-CM code 729.1 as the principal diagnosis. People with fibromyalgia have approximately one hospitalization every three years [6]. They also have:
- 2.2 million ambulatory care visits.
- 1.8 million physician office visits.
- 187,000 outpatient department visits.
- 266,000 emergency department visits.

Pathophysiology of chronic fatigue and fibromyalgia syndrome

The pathophysiology of fibromyalgia and chronic fatigue syndrome is complex because there are so many aspects to consider and other overlapping conditions. The unique features of fibromyalgia are manifested primarily with chronic pain, dysregulation of neuroendocrine function and alterations in the sleep pattern [39]. At this time, the pathophysiology of fibromyalgia and chronic fatigue syndrome remains unclear, but it has been hypothesized that fibromyalgia is a disorder that may arise from a muscle energy metabolism, generalized disorder of pain perception, neuroendocrine disturbance, sleep disturbance, stress and trauma from accidents or surgery, infections, inflammatory or immunopathologic disease of the muscle, dysregulated serotonin secretion, genetics or as a result of a sexual abuse or domestic violence [18, 22,49]. However, there is limited data available relating chronic fatigue syndrome to most of the proposed etiologies and a stronger suggestion that it may arise due to a viral illness or be psychological in nature. It has also been speculated that fibromyalgia may be a rare complication of hypothyroidism, rheumatoid arthritis or, in men, sleep apnea [32].

Fibromyalgia syndrome causes

Muscle energy metabolism. For a long time it was believed that fibromyalgia was a disorder of muscle metabolism, possibly due to the result of chronic hypoxia of muscular tissue. Research studies have demonstrated an alteration in muscle metabolism, such as lower adenosine 5’-triphosphate (ATP) adenosine diphosphate (ADP), higher concentrations...
of adenine monophosphate (AMP) and more alterations of capillaries and fiber areas [1, 26]. Studies involving post-exertional pain, muscle force and lactate levels have shown a similarity among sedentary controls and fibromyalgia patients. [18] Over the years, there has been a change documented in the muscle strength of fibromyalgia patients, but it is speculated that it may result from deconditioning. A few researchers believe deconditioning results from the repetitive microtrauma of daily living. The daily fatigue along with physical inactivity may lead to unif muscles, making them even more susceptible to microtrauma.

Studies involving postexercise pain, muscle force and lactate levels have shown a similarity among sedentary controls and fibromyalgia patients. The inflammatory component of myalgia in fibromyalgia has never been exposed, which explains the reason nonsteroidal anti-inflammatory drug (NSAID) and steroid therapies efficacy are lacking as a treatment modality [18].

**Generalized disorder of pain perception.** Since 1979, the International Association for the Study of Pain (IASP) has defined pain as an unpleasant sensory and emotional experience associated with actual or potential tissue damage, or described in terms of such damage [28]. Normally, pain is the result of activation of nociceptors in the peripheral tissues [39]. The problem researchers face when trying to definitively provide a distinct cause of the chronic pain manifested in fibromyalgia is that pain is a subjective symptom. Therefore, the pathophysiological concept is speculated based upon biological, behavioral and self-report parameters associated with pain that indicate it is due to an abnormal central nervous system (CNS) exacerbated due to central sensitization, abnormalities of descending inhibitory pain pathways and abnormal levels of neurotransmitters [1].

**Central sensitization, an abnormal processing of pain due to sensory or nociceptive stimuli.** Sensory impulse amplification begins at the level of the spinal cord and it is gated by changes occurring in the sensitivity of the dorsal horn neurons. In the dorsal horn of the spinal cord at the postsynaptic membrane there is a receptor N-methyl-D-aspartic acid (NMDA). These receptors are normally inactive and do not respond to initial acute stimuli. However, after repeated neuronal depolarization, the receptors undergo activation and are responsible for windup and central sensitization [1].

In patients with fibromyalgia, the NMDA receptor antagonist ketamine attenuates windup to “a painful stimulus” causing muscular hyperalgesia, referred pain and muscle pain at rest. Research has demonstrated that NMDA-receptor antagonist dextromethorphan (a common ingredient in cough medicine) has reduced the windup in patients with fibromyalgia and control participants [1].

It can occur directly or indirectly from the brainstem via descending pathways. During a central sensitization, the nociceptors or peripheral pain nerves (such as those found in skeletal muscles) are stimulated by pressure or repetitive stretching. Once this process occurs, the nerves become sensitized, due an excess in the following excitatory neurotransmitters and a lower level of inhibitory neurotransmitters [39, 50]:

- Excitatory neurotransmitters include glutamate, aspartate, substance P and calcitonin gene-related peptide. According to the FDA (2009), the ACR also speculates that patients with fibromyalgia have an abnormal level of substance P in their spinal fluid. Substance P helps transmit and amplify pain signals to and from the brain. Researchers are looking at the role of substance P and other neurotransmitters and studying why people with fibromyalgia have an increased sensitivity to pain and whether there is a gene or genes that make a person more likely to have it [48].
- Inhibitory neurotransmitters include serotonin, dopamine and norepinephrine [50].
- Decreased serotonin in the central nervous system may lead to aberrant pain signaling.
- Decreased dopamine transmission in the brain may lead to chronic pain through unclear mechanisms [1].

The process allows the nerve impulses being carried to the central nervous system to reduce the pain threshold by central sensitization. Fibromyalgia patients have a generalized decrease in the pain perception threshold, reflecting discrimination in the quality and threshold of pain tolerance, such as allodynia (pain due to a stimulus that does not normally provoke pain) and hyperalgesia (an increased response to a stimulus that is normally painful) [28, 50].

It should be noted, deficient serotonin levels affect other aspects correlated with fibromyalgia, such as sleep, headaches and mood disorders [22].

Another form of pain sometimes associated with fibromyalgia is another poorly understood syndrome, myofascial pain, which is a disorder of trigger points. Similar to tender points (seen in fibromyalgia), trigger points are discreet areas in muscle tissue or its associated fascia that are exquisitely tender to compression; however, pain occurs at the site of the applied pressure and also at a distant site (zone of pain referral) [22]. Trigger points are involuntary, transient contractions found in taut bands (firm, elongated bands) located in muscle fibers, elicited by snapping or pinching the band [22].

**Chronic fatigue and fibromyalgia causes Neuroendocrine disturbance.** Multiple laboratory studies have suggested that the central nervous system may have an important role in the patient developing chronic fatigue and fibromyalgia syndrome [32]. There is some evidence to suggest that fibromyalgia and chronic fatigue patients may have a reduction in the secretion of adrenocorticotropic hormone (ACTH) and cortisol due to a dysfunction of the hypothalamic-pituitary-adrenal (HPA) axis [18, 22]. The HPA axis is a critical component of the stress-adaptation response. In a normally functioning system, corticospin-releasing hormone (CRH) stimulates the anterior pituitary to release ACTH. ACTH then stimulates the adrenal cortex to produce glucocorticoids, which are powerful mediators of the stress-adaptation response. However, in chronic fatigue and fibromyalgia, there are two proposed notions that may be precipitating a dysfunction in the HPA axis and thus lowering cortisol, CRH and ACTH, as follows:

- Physical or emotional stress, which is commonly reported as a pre-onset condition in chronic fatigue and fibromyalgia syndrome patients, activates the HPA axis, leading to increased release of cortisol and other hormones [9].
- Decreased amounts of circulating serotonin affect the circadian regulation and the stress-induced stimulation of the HPA axis [1, 22].

**Possible events precipitating chronic fatigue and fibromyalgia.** Since the exact cause of chronic fatigue and fibromyalgia syndromes continues to remain unknown, it is speculated that certain events may precipitate a deficiency in the immune system or the central nervous system in some patients, thus triggering the syndrome. Prior to developing the syndromes, patients led healthy, full, active lifestyles. However, after an acute prodromal infection, varying from upper respiratory infections, bronchitis, sinusitis, gastroenteritis or an acute flu-like illness, the clinical symptoms supporting chronic fatigue or fibromyalgia developed in some of the patients [30]. The CDC (2007) has identified the following possible triggers [9]:

- **Genetics.** There is increasing evidence that suggests genetics has been associated with fibromyalgia, especially a deficiency of serotonin. Some researchers speculate that the genetic predisposition manifests into symptoms after the individual is at a certain age because of environmental triggers or when the person sustains an external insult, such as trauma or illness [22].
- **Immunology.** It has been proposed that chronic fatigue syndrome may be caused by an immunologic dysfunction, for example, inappropriate production of cytokines, such as interleukin-1, or altered capacity of certain immune functions. One thing is certain at this juncture: There are no immune disorders in chronic fatigue syndrome patients on the scale traditionally associated with disease. Some investigators have observed anti-self antibodies and immune complexes in many chronic fatigue patients, both of which are hallmarks of autoimmune disease. However, no associated tissue damage typical of autoimmune disease has been described in patients with chronic fatigue syndrome.

T-cell activation markers have also been reported to have differential expression in groups of chronic
fatigue syndrome patients compared with controls, but again, not all investigators have consistently observed these differences. One intriguing hypothesis is that various triggering events, such as stress or a viral infection, may lead to the chronic expression of cytokines and then to chronic fatigue syndrome. Administration of some cytokines in therapeutic doses is known to cause fatigue, but no characteristic pattern of chronic cytokine secretion has ever been identified in chronic fatigue syndrome patients. In addition, some investigators have noted clinical improvement in patients with continued high levels of circulating cytokines; if a causal relationship exists between cytokines and chronic fatigue syndrome, it is likely to be complex. Finally, several studies have shown that chronic fatigue patients are more likely to have a history of allergies than are healthy controls. Allergy could be one predisposing factor for chronic fatigue syndrome, but it cannot be the only one, because not all patients have it.

**Infections**

**Chronic fatigue.** In the majority of literature that discusses chronic fatigue syndrome, many hypothesize that it is caused by an infection. However, after the CDC completed a four-city surveillance study, the results demonstrated that there is no association between chronic fatigue syndrome and infection by a wide variety of human pathogens, including EBV, human retroviruses, human herpesvirus 6, enteroviruses, rubella, Candida albicans and more recentlybornaviruses and mycoplasma. Taken together, these studies suggested that among identified human pathogens, there appears to be no causal relationship for chronic fatigue syndrome as a whole. However, the possibility remains that chronic fatigue syndrome may have multiple causes leading to a common endpoint, in which case some viruses or other infectious agents might have a contributory role for a subset of chronic fatigue cases. Recently published research suggests that infection with EBV, Ross River virus and Coxiella burnetii will lead to a post-infective condition that meets the criteria for chronic fatigue syndrome in approximately 12 percent of cases. The severity of the acute illness was the only factor found to predict which individuals would have persistent symptoms characteristic of chronic fatigue syndrome at the six-month and one-year period following infection.

**Fibromyalgia.** There are studies that indicate that the development of fibromyalgia may be linked to the Borrelia burgdorferi, which causes Lyme disease, brucella and the parvovirus [18]. Research has also demonstrated that patients with hepatitis C and human immunodeficiency virus (HIV) have higher rates of fibromyalgia than the general population [1]. At this time, the exact mechanism is unknown, but it is speculated that cytokine is activated in the central nervous system via viral neuropathism and subsequent glial activation [1]. Although there is a link to previous infections, anti-viral agents have not demonstrated an improvement in the symptoms for patients with chronic fatigue and fibromyalgia syndrome [32].

**Neurally mediated hypotension (NMH).** In 1995, Dr. Rowe and his coworkers at Johns Hopkins University conducted studies, The Relationship Between Neurally Mediated Hypotension and Chronic Fatigue Syndrome, published in the September 1995 issue of Journal of American Medical Association (JAMA) to determine whether disturbances in the autonomic regulation of blood pressure and pulse (neurally mediated hypotension, or NMH) were common in chronic fatigue syndrome patients. The investigators were alerted to this possibility when they noticed an overlap between their patients with chronic fatigue syndrome and those who had neurally mediated hypotension (NMH). NMH can be induced by using tilt table testing, which involves laying the patient horizontally on a table and then tilting the table upright to 70 degrees for 45 minutes while monitoring the blood pressure and heart rate. Persons with NMH will develop lowered blood pressure under these conditions as well as other characteristic symptoms, such as lightheadedness, visual dimming or a slow response to verbal stimuli. Many chronic fatigue syndrome patients experience lightheadedness or worsened fatigue when they stand for prolonged periods or when in warm places, such as in a hot shower. These conditions are also known to trigger NMH. One study observed that 96 percent of adults with a clinical diagnosis of chronic fatigue syndrome developed hypotension during tilt table testing, compared with 29 percent of healthy controls. Dr. Rowe later replicated the study in fibromyalgia patients with the same results [9].

**Physical trauma.** Fibromyalgia patients typically endure more excruciating pain in the cervical neck region. Research has demonstrated that 22 percent of patients who have endured whiplash from motor vehicle accidents have developed fibromyalgia [1].

**Pre-existing conditions.** Fibromyalgia has increased prevalence among patients with autoimmune disorders and rheumatic diseases (20 to 65 percent), such as rheumatoid arthritis (RA), systemic lupus erythematosus (SLE), ankylosing spondylitis (AS), Sjogren’s syndrome, osteoarthritis and Behcet’s disease. In addition, the prevalence of the disease is increased in chronic diseases, such as diabetes mellitus [6, 34]. Although fibromyalgia patients have an increased risk of being affected if they have a pre-existing autoimmune disorder, there is no increased risk of developing an autoimmune disorder if the patient has fibromyalgia and no prior history of an autoimmune disorder.

**Psychiatric aspects.** Over the years, researchers have been debating whether psychiatric disorders are a premonition to the development of chronic fatigue and fibromyalgia syndrome or coincidental. In primary care practices, more than one half of all patients with depression present with pain, one of the most common complaints associated with fibromyalgia. In addition, patients with chronic fatigue and fibromyalgia have increased rates of depression, anxiety and mood disorders [1, 18, 40]. At this time, further research is required to assess whether depression is independent of chronic fatigue and fibromyalgia or secondary to the consequences of the chronic illness [5]. Unfortunately, patients with chronic fatigue and fibromyalgia live in depressing situations with severe social and activity restrictions beyond their control due to the compounding plethora of symptoms that are overwhelming and debilitating.

Further research is required. At this time, it is difficult to realize whether the syndromes are precipitated by life events or have organic causes. In the meantime, health care professionals should realize the complexity while caring for a patient living with chronic fatigue or fibromyalgia syndrome.

**Nurses collecting the health history and assessing the patient**

Imagine you are caring for a patient complaining of extreme fatigue, pain, sleep deprivation and other complaints as listed above. Would you immediately think “Oh, this may be chronic fatigue or fibromyalgia?” Probably not, as chronic fatigue syndrome and fibromyalgia may present with overlapping symptoms or other diagnoses seen in clinical practice. In primary care, fatigue is the seventh-most common complaint and may be the presenting symptom for a plethora of different diseases in addition to chronic fatigue and/or fibromyalgia [43]. However, by obtaining a thorough history and completing a physical examination, appropriate diagnoses are obtained in 85 percent of the cases [43].

Most patients who present to their primary care provider or hospital complaining of generalized pain, fatigue or change in sleep patterns will typically not be diagnosed during that visit, because the first inclination may be the patient has depression, hypothyroidism, viral illness or is affected by a recent life event. In addition, chronic fatigue and fibromyalgia are diagnosis of exclusion because there are no confirmatory diagnostic tests. Therefore, one of the key things a nurse can do to help a practitioner properly diagnose the patient is to take a thorough history.

Nurses collect histories on their patients all of the time. But it can be difficult when the patient presents with vague complaints that overlap numerous other medical conditions. Without collecting a thorough history, it is impossible to completely assess the history of the present illness and past medical history in order to arrive at the proper diagnosis and appropriate, therapeutic plan of care. Ultimately, the inevitable result will be an incomplete, inappropriate treatment plan for the patient because he/she will be misdiagnosed.

Patients with fibromyalgia do significantly better when they receive a comprehensive, individualized treatment regimen [22]. It is possible that you may have cared for a patient presenting with symptoms supporting a potential
Nurses working in a doctor’s office, clinic or hospital will care for patients with chronic fatigue and/or fibromyalgia syndromes before their official diagnosis or during their care. Some questions about common ailments of chronic fatigue and fibromyalgia can be asked of any patient. Nurses should consider doing this when attempting to collect the patient history [22, 36].

Start the discussion by identifying the “subjective” chief complaint verbatim as the patient states it, which usually is pain if it is fibromyalgia and fatigue if it is chronic fatigue syndrome. Some of them may initially complain of changes in their neurological system such as confusion, inability to concentrate or inability to remember details. The nurse should always document the subjective symptoms as the patient states them, enclosed in quotation marks to reflect the patient’s exact words. However, the nurse should not leave the conversation just at the subjective statement, but elaborate upon the subjective complaint by asking specific questions about the patient’s complaint. Below are some examples of primary subjective complaints that may be conveyed by a patient with chronic fatigue or fibromyalgia and potential questions that may be asked by the nurse:

If the patient’s primary subjective complaint is pain, such as “I am in pain all the time,” “My body constantly aches” or any statement related to pain, the nurse can expand by asking:

- What is your pain level on a scale of zero to 10? The nurse should always assess and reassess the patient’s pain level with each reassessment or subsequent encounter with the patient. Fibromyalgia is classified as mild, moderate or severe based upon the subjective report of pain by the patient [38]:
  - Mild fibromyalgia is characterized by mild muscle pain with a pain level of one to three on a 10-point pain scale.
  - Moderate fibromyalgia is characterized by moderate muscle pain with a pain level of four to six, and it typically affects everyday functioning.
  - Severe fibromyalgia is characterized by severe muscle pain, with a report of seven or higher. The excruciating pain is so intense that patients are typically unable to work.

What is the location of the pain? Is the pain localized, radiating, superficial and/or deep? Encourage the patient to point to the location of the pain to ensure the nurse notes the precise location. Is it consolidated to one area? One side of the body?

- Any recent headaches? Where are the headaches located? What time of the day do the headaches occur? Do you have any nausea, vomiting or blurred vision with the headache?
  - Temporomandibular jaw pain?
  - Noncardiac chest pain?
  - Any muscle aches or joint pains? Any problems in the muscles, such as any pain or cramping? Are your muscle aches associated with fever, chills? Any stiffness in the joints? Any swelling, heat, erythema (redness)? Any limitations in your movements?
  - Chronic pelvic pain?
  - Restless leg syndrome? Restless leg syndrome occurs in 20 percent of patients [22].
  - What is the character/quality of the pain? The nurse wants to gain specific descriptive terms, such as burning, sharp, dull, aching, gnawing, throbbing and shooting.
  - What is the timing of the pain (onset, duration and frequency)? When did the symptoms first appear? How long did it last? Is the pain steady or intermittent? Does it resolve? Has it resolved completely? The majority of fibromyalgia patients remember a sudden onset of pain since it was probably when their life changed. However, if the pain began gradually, determining the exact time of onset may be difficult.
  - How do you behave when you are in pain? Patients with chronic pain (greater than six months), may not be forthcoming about their pain, since they may be just “dealing with it” [29]. Therefore, if the nurse can assess the patient’s behavior/response to pain, it may provide new clues about the pain.
  - What is the setting of the pain? Where was the patient when the symptoms first appeared and/or continuously appear? Is something bringing the pain on for you?
  - What are the aggravating and alleviating factors? Is the pain aggravated by movement, rest, position, weather? Is the pain relieved by rest, medications, application of heat or ice?
  - What are the associated factors of the pain? The nurse wants to find out if there are any other body systems related to the pain.
  - What is the patient’s perception of their pain? How does the pain affect the patient? Ask the patient, “What do you think it means?” The nurse should keep in mind that a patient with chronic fatigue and fibromyalgia will have a lower threshold of pain called allodynia.
  - What is your ultimate goal in pain relief? Many patients have experienced “chronic” pain for so long that they may have begun compensating for the pain and/or they provide little indication that they are in pain. However, the nurse can objectively assess for signs of chronic pain as well as prompting questions related to bracing, rubbing, diminished activity, sighing and change in the patient’s appetite [29].

The most defining characteristics of fibromyalgia is chronic, widespread muscle aches and pains. However the pain can also occur in the joints (arthralgia without synovitis) and may be described as “exhausting, burning, miserable or unbearable” [50]. Most fibromyalgia patients complain of a generalized, widespread pain that may “travel” or is referred to the deep tissues associated with muscle contraction and movements [18, 38, 39]. Other patients may complain of a specific pain on one side of the body as well as above and/or below the waist [18]. In the majority of the cases, axial skeletal pain in the cervical spine, anterior chest, thoracic spine, hips and/or lower back will be reported [18, 32]. Some patients report the pain and tenderness as sporadic, such as it “comes and goes,” but typically the pain will be worse in response to stress, increased activity or changes in the weather [27]. The National Guiding Clearinghouse (2009) recommends that the nurse should focus the pain assessment on the type and quality of pain, source, location, duration, time course, pain affect and effects on quality of life. Use self-report as the primary source of pain assessment, and use the same pain measurement tool at subsequent visits [28]. Research has also demonstrated that the subjective complaint of pain may be higher in women suffering with fibromyalgia than men, because of the following mechanisms [50]:

- Differences in primary afferent input to the CNS, with developmental and menstrual cycle-dependent enhancement.
- Developmental and phasic gonadal-hormonal modulation of pain regulatory systems, stress-induced analgesia and opioid receptors.
- Higher levels of trait and state anxiety.
- Increased prevalence of depression.
- Use of maladaptive coping strategies.
- Increased behavioral activity in response to pain.

In the patient with chronic fatigue syndrome, pain is often generalized and not confined to any structure or nerve root. Typically the patient will complain of sporadic pain in unexpected areas with various qualities: sharp, shooting, burning and aching [5]. The pain is generalized and is not limited to the classical fibromyalgia “tender points,” but 75 percent of the patients will exhibit positive tender points during the exam.

In order to objectively assess for “tender points,” the practitioner will elicit a subjective complaint of pain or “tender points” from the patient while palpating the muscles at multiple sites. Tender points are defined as “pain” during a digital palpation of an approximate force of 4 kilograms (kg) [18, 50]. The nurse should avoid confusing “tender points” with “trigger points.” The American Family Physician (2002) defines “trigger points” as the presence of discrete focal tenderness located in a palpable taut band of skeletal muscle. “Trigger points” produce referred regional pain and a local twitch, as opposed to “tender points,” which refer to pain at the site only [2]. Trigger points help define myofascial pain syndromes [2].
and systemic lupus erythematosus (SLE). The device is a useful tool for assessing the nature of altered central nociceptive processing, allodynia (painful response during a nonpainful stimulus) and hyperalgesia (increased sensitivity to pain) [50]. To properly use one of the mentioned device tools over the tender points, the nurse or practitioner should adhere to the following steps [22]:

- First, visually locate the evaluation sites.
- Then, with the thumb pad, press perpendicularly into the evaluation site for four seconds one time to avoid sensitization.
- Apply four kilograms of pressure to the site, enough force to blanch the examiner’s nail bed.
- Always examine the 18 diagnostic sites and three control sites in the following order: forehead, distal middle third of the right forearm, and nail of the left thumb. The three control points should be palpated and recorded to provide baseline documentation of the patient’s pain perception.
- Examine the right site and then the corresponding left site.

The patient should sit on the examination table for the evaluation of the upper body. The individual should lie on his/her side contralateral to the site for the testing of sites the greater trochanter, and should lie on his/her back for the evaluation of the medial knee. In fibromyalgia, 11 of the 18 pressure areas should have “tender points” at a minimum to support the diagnoses. The nurse needs to be sensitive and thoroughly assess the patient prior to performing the exam because if the patient is anxious or has a history of psychological trauma, such as sexual abuse or childhood trauma, he or she is more than likely to have significant “tender points,” therefore skewing the data [1, 40]. In addition, the patient with RA and SLE will not have a complaint of “tender points” in a minimum of 11 areas.

If the primary subjective complaint is fatigue, such as “I am so exhausted all the time,” “I am constantly yawning,” or “I have no energy or motivation to do anything,” the nurse can expand by asking:

- “Tell me how you spend a typical day.” This will help the nurse understand how the patient is able to perform ADLs and function on a daily basis. Asking this question and the following questions allow the nurse to assess the patient’s functional ability. The functional ability refers to one’s ability to perform activities necessary to live in modern society and can include driving, using the phone or performing functional tasks, such as bathing and use of the toilet [29].
- Ask: “Are you independent or do you require assistance with feeding, bathing, hygiene, dressing, using the toilet, walking, standing or climbing stairs?”
- “Do you require the use of a wheelchair, prosthesis or mobility aide?”
- “What is your energy level after completing your daily activities and/or exercises?” This is a key factor in potentially differentiating chronic fatigue and fibromyalgia syndrome. Many patients with fibromyalgia may be able to tolerate exercise, whereas it often aggravates the symptoms in chronic fatigue syndrome [5]. Many patients with chronic fatigue syndrome experience a significant amount of post-exertional malaise lasting more than 24 hours after exercise and/or completing their ADLs.

Ask the patient to discuss his/her previous energy level to help in comparison and to possibly pinpoint when the symptoms began.

- “What is the duration and onset of fatigue?” Typically, most patients with chronic fatigue complain about a sudden onset of pain that is continuous, regardless of the amount of sleep and/or lack of activity.
- “When during the day is the fatigue worse: morning, as the day goes on, relieved by rest, after exercise, or overall progressive rather than fluctuating?” [43]. Eighty percent of patients with fibromyalgia report fatigue that is worse in the morning and early evening [22].
- “What are your sleep patterns? How long do you typically sleep? What is your bedtime ritual? Do you use sleep aids prior to going to sleep? What is your activity during the day? Do you exercise?” If possible, ask the patient’s sleeping partner if the patient snores or kicks while asleep. “How long does it take for you to fall asleep at night? How many times do you wake up during the night? How do you feel when you awake in the morning?”

Sleep disturbances are present in most cases of fibromyalgia and chronic fatigue syndrome, approximately 65 percent [22]. However, it is usually not the presenting complaint. Typically, patients will complain about sleeping all night, but waking up and still feeling tired [18]. Treatment modalities provide only moderate benefit for the patient, suggesting it is an effect rather than the cause of the fatigue [32].

The most defining characteristic of chronic fatigue syndrome is a significant degree of unexplained, persistent or recurrent fatigue that is unrelieved regardless of the amount of sleep or rest. Patients with chronic fatigue syndrome and fibromyalgia report their fatigue as so debilitating, their activity level is reduced by at least 50 percent [5]. The nurse should inquire about the patient’s previous level of activity. In addition, ask the patient about his or her overall demeanor after exercising: most patients with chronic fatigue lose the natural effect of exercise and feel worse instead of better [5].

Children with chronic fatigue or fibromyalgia typically do worse in mathematics and analytical subjects such as science. When assessing fatigue in a child, the nurse needs to ask the parents or child the following questions:

- “Are you able to attend school? Do you participate in sports? How often do you see your friends? What type of activities do you do with your friends? What do you do after your activities?” Encourage the patient and family to keep a diary of activities and symptoms [33].
- If the primary subjective complaint is “I just cannot think straight,” “I feel like I am in a fog,” “I feel like I am losing it,” or “I just cannot remember anything,” the nurse can expand by assessing the following [29]:
  - **Assess the patient’s orientation status** by asking:
    - “What time of the day is it?” The nurse can ask any question about time, such as the date, day of the week, year or season.
    - “What is your name? How old are you? What type of work do you do?” All of the questions relate to the person.
  - **Assess the attention span.** Is the patient able to concentrate during the conversation or does it appear as if he or she is wandering? The nurse can assess this ability by giving the patient a series of directions to follow, then noting whether the patient completes them in the same order.
  - **Assess recent memory.** “Tell me what you ate in the last 24 hours,” or “What time did you arrive here today?” It is important to ask questions that the nurse can corroborate.
  - **Assess remote memory.** Inquire about past events that the nurse can verify, such as past health, birthday, anniversary dates or historical events that are relevant for the patient.
  - **Assess the patient’s ability to learn new words** that are unrelated. The nurse can say to the patient, “I am going to say four words. I want you to remember them. In a few minutes, I will ask you to recall them.” Then state four random words to the patient, repeat them, and then five minutes later, ask the patient to recall the four words.
  - **During the exam, assess the behavior** of the patient and facial expressions:
    - Are they appropriate to the conversation?
    - Does the patient make eye contact?
    - How is the patient’s speech, such as the quality, pace, articulation and choice of words?
  - **Assess the mood and affect of the patient** by their body language, facial expression and by asking “How do you feel today?” or “How do you usually feel?”

Patients with chronic fatigue and fibromyalgia typically complain of confusion, forgetfulness, an inability to concentrate and to recall simple words and numbers, and the transposition of words and numbers, a condition known as “fibro fog.” The cognitive
imperfections typically prevent patients from performing activities of daily living (ADL), getting lost in familiar places or losing the ability to communicate effectively. Patients who work may fear losing their job, and many pediatric patients drop out of school because of their inability to complete their schoolwork [22].

- “Fibro fog” may be the primary symptom in patients with fibromyalgia, reflecting impairments in working, episodic and semantic memory that are roughly equivalent to 20 years of aging [50]. Cognitive symptoms associated with chronic fatigue and fibromyalgia are exacerbated by pain, mood and anxiety disorders, and poor sleep [50].

- **Question the patient about other coinciding symptoms and/or co-morbidities.** The nurse should keep in mind that the patient may not always disclose each symptom, because pain or fatigue is typically so overpowering that patients may not always disclose each symptom, because pain or fatigue is typically so overpowering and may be debilitating for the patient. Other questions that may be appropriate due to the possibility of other conditions include the following [6, 18, 29, 50]:

  - **Overall:** “Do you have any other symptoms?”
  - **What was the state of your health when you noticed the initial symptoms?** Were you feeling sick?” Many patients with chronic fatigue syndrome began their chronic symptoms after recovering from an acute viral illness. Therefore, the nurse should prompt additional questions about the patient’s state of health when symptoms began and any preceding symptoms because the person’s memory may have been “clouded.”
  - **Cardiac.** “Do you have any chest pain? Where is the precise location? Does the pain radiate? Do you have any lightheadedness, dizziness, visual changes, sometimes syncope and a slow response to verbal stimuli? Do you ever have the urge to lie down immediately?” Each of the questions assess for NMH, which may coincide with the syndromes [5].
  - **Immunology:** “Do you currently have a sore throat? Tenderness lymph nodes? Is it associated with a cough, fever, postnasal drip or hoarseness?” Each of the questions helps determine a current infection or potential coinciding symptoms that may occur with chronic fatigue or fibromyalgia. “Nasal congestion and hypersensitivity to environmental stimuli, such as odors, bright lights and loud noises?”
  - **Gastrointestinal.** “Have you had any change in your bowel movements? When was your last bowel movement? Do you have frequent bouts of diarrhea? Constipation? Do you have any abdominal pain and/or cramping?” Irritable bowel syndrome is a common complaint, and symptoms related to the condition should be explored.
  - **Neurology:** “Any tingling or numbness in the hands and feet?” Many patients with chronic fatigue and fibromyalgia experience numbness and tingling.
  - **Motor issues:** “Any changes in motor problems, weakness and/or loss of balance?” Chronic fatigue patients also endure motor problems, such as ataxia muscle weakness and fasciculation (loss of balance and clumsiness commonly occur.) [5].
  - **The Romberg test should be completed to assess for a loss of balance.** The nurse can objectively assess for it by asking the patient to stand up with the feet together and arms at their sides. Once the patient is in a stable, standing position, instruct the patient to close his/her eyes and to hold the position. After 20 seconds, the patient should be able to hold the position. If not, it is a positive Romberg sign that occurs with cerebella ataxia, loss of perception and loss of vestibular function.
  - **Sensory:** “Do you experience any intolerance to heat and/or cold?” Raynaud’s phenomena may coincide with chronic fatigue and fibromyalgia syndrome. Raynaud’s phenomenon is abrupt episodes of progressive tricolor changes in the fingers in response to cold, vibration or stress. Initially the fingers will appear pallor (white) from arteriospasm and resulting deficit in supply; then cyanotic (blue) from slight relaxation of the spasm that allows a slow trickle of blood through the capillaries and increased oxygen extraction of hemoglobin; finally rubor (red) due to return of blood into the dilated capillary bed or reactive hyperemia. The symptoms include bilateral cold, numbness or pain with pallor or cyanosis, and then burning, throbbing, pain and swelling with rubor color [29].
  - **Psychiatric.** In general, most nurses do not feel comfortable asking a patient or his/her family about a psychiatric history, but it is imperative. The nurse can initiate the subject by asking the patient:

    - “If you had to complete this sentence, “today I feel … ” It is important to ask the patient to complete the sentence to provide a subjective response about his or her current mood instead of a closed-end question such as “Do you feel happy,” which could induce only a simple “yes” or “no.”
    - “Do you feel depressed?”
    - “Who is your support system?”
  - **Reproductive.** If the patient is female, ask about her menstrual cycles (onset, last period, increase pain, bleeding in between cycles).
  - **Skin.** “Any skin rashes? Skin breakdown?”
  - **Lifetime psychiatric co-morbidities** is common in patients with fibromyalgia, including mood disorders (bipolar disorder, major depressive disorder), anxiety disorders (generalized anxiety disorder, obsessive-compulsive disorder, panic disorder, post-traumatic stress disorder (PTSD), social phobia, eating disorders and substance use disorders. Any patient with a history of psychologic disorders and/or a potential new onset should be referred to a psychiatrist as needed [28]. In addition, if a patient responds that he or she is sad, the nurse should also ask questions to assess whether the patient is a potential threat to him- or herself or others. Ask:

    - “Do you have any intentions of hurting yourself? Others? Do you have a plan?” Always document it precisely and adhere to the protocols within the organization if the patient is ever a potential threat to him- or herself or others.

Throughout the communication with the patient, it is important to develop a professional rapport to enhance a trusting relationship. While collecting the history, nurses often must ask closed-ended questions, but they also should ask more specific, open-ended questions to ensure the patient is responding truthfully and not just providing answers he/she thinks the nurse wants to hear. In any conversation, certain answers may be elicited or perceived because of the manner in which the question was asked. Therefore nurses should be conscious and wary of that.

**Differential diagnosis of chronic fatigue syndrome and fibromyalgia**

At this time, there is no diagnostic laboratory value or radiological exam that confirms the diagnosis of chronic fatigue or fibromyalgia syndrome. However, there is a laboratory test, anti-polymer antibody assay (APA assay) that detects anti-polymer antibodies in the blood of most patients with fibromyalgia and fibromyalgia-like symptoms [3, 22]. An article published in the Journal of Rheumatology entitled “Anti-Polymer Antibody Reactivity in a Subset of Patients with Fibromyalgia Correlates with Severity” demonstrated that 47 percent of patients with fibromyalgia and 61 percent of patients with severe symptoms of fibromyalgia reacted positively to the APA assay [3]. Since the APA assay is not exclusive to fibromyalgia and reactive to all patients, a diagnosis is made by exclusion of other diagnosis with similar manifestations.

Depending upon the history of present illnesses, symptoms exhibited by the patient and physical examination, the physician or practitioner will contemplate a diagnosis by ruling out other conditions that present with overlapping similar clinical manifestations. Some of the more common differential medical conditions that may mimic or present in the same manner include acquired immunodeficiency disease (AIDS) anemia, autoimmune disease, cancer, depression, hypothyroidism, Lyme disease, multiple chemical sensitivities, myofascial pain, polymyalgia rheumatica (PMR) and sleep apne [5, 22, 27]. The conditions and symptoms manifested similar to chronic fatigue and fibromyalgia syndrome are as follows:
Anemia is the reduction of red blood cells, hemoglobin or hematocrit, manifested by a variety of abnormal conditions. The patient with anemia may present with increased fatigue (chronic fatigue and fibromyalgia), and the nurse may also notice pallor, intolerance to cool temperatures (also seen in Raynaud’s, a common phenomena, a condition prevalent in chronic fatigue and fibromyalgia), tachycardia, murmurs or dyspnea on exertion (DOE). A complete blood count (CBC) will be completed to assess for anemia because it measures the hemoglobin (Hgb), hematocrit (HCT), mean cell hemoglobin (MCH), mean cell hemoglobin concentrate (MCHC), mean cell volume (MCV) and relative or red cell distributive width (RDW). The levels vary dependent upon the type of anemia. If the laboratory values suggest anemia, the clinician will order additional tests to assess the specific type of anemia, such as megaloblastic (Folate or Vitamin B12), macrocytic or microcytic (iron deficiency) [16, 24].

Autoimmune diseases are the third-most common category of disease in the United States after cancer and heart disease, affecting approximately 5 to 8 percent of the population or 14 million to 22 million persons [14]. There are over 80 autoimmune diseases affecting virtually every site in the body, including the endocrine system, connective tissue, gastrointestinal tract, heart, skin and kidneys. Autoimmune diseases occur as a result of the body’s attack on itself by mistake. Autoimmune diseases typically affect women and have very similar symptoms overlapping chronic fatigue and fibromyalgia. The most common autoimmune diseases that present similarly to chronic fatigue and fibromyalgia include [14,46]:

- **Arthritis:** Regardles of the type of cancer, most patients will present with fatigue (chronic fatigue and fibromyalgia). Other symptoms of cancer that may present in chronic fatigue and fibromyalgia include weakness and fever (chronic fatigue). There is no specific diagnostic test for cancer, but additional screenings and laboratory values may be analyzed based upon the symptoms and history of the patient presented to the clinician.

- **Depression** is the most common mental health/behavioral disorder that may occur due to multiple life stresses, single situation, primary disorder or a problem associated with dementia [27]. Researchers have speculated that depression is the result of a lack of neurotransmitters, such as serotonin and epinephrine (both decreased in chronic fatigue and fibromyalgia) [27]. Depressed patients without fibromyalgia will not have the characteristic “tender points.” [49]. Symptoms that may occur include depressed mood and lack of energy, both occurring in chronic fatigue and fibromyalgia [27].

- **Hypothyroidism** is the result of decreased metabolism from low levels of thyroid hormones [27]. The patient may present with muscle aches and pain (fibromyalgia); delayed contraction and relaxation of muscles (fibromyalgia); slowing of intellectual functions, such as slow, slurred speech, impaired memory (chronic fatigue and fibromyalgia); depression (chronic fatigue and fibromyalgia); and weakness and fatigue (chronic fatigue and fibromyalgia). Hypothyroidism shares many clinical features with fibromyalgia and may produce a secondary fibromyalgia syndrome [32]. Other symptoms found in hypothyroidism that are not seen in chronic fatigue and fibromyalgia include lid lag and dry skin [49]. Hypothyroidism is confirmed by decreased levels of triiodothyronine (T3) and thyroxine (T4) and increased levels of thyroid stimulating hormone (TSH) (greater than 5.3).

- **Lyme disease** is a reportable systemic infection caused by the spirochete Borrelia burgdorferi that results from a tick bite [27]. Initially, the patient will present with a large “bull’s eye” circular rash, although some patients may not notice it. Other symptoms include malaise, fatigue (chronic fatigue and fibromyalgia), headache (chronic fatigue and fibromyalgia) or muscle/joint aches...

- **The first step uses an ELISA.** These tests are designed to be very “sensitive,” meaning that almost everyone with Lyme disease – and some who do not have it – will test positive. If the ELISA is negative, it is highly unlikely that the person has Lyme disease, and no further testing is recommended. If the ELISA is positive or indeterminate (sometimes called “equivocal”), a second step should be performed to confirm the results.

- **The second step uses a Western blot test.** Used appropriately, this test is designed to be “specific,” meaning that it will usually be positive only if a person has been truly infected. If the Western blot is negative, it suggests that the first test was a false positive, which can occur for several reasons. The CDC does not recommend testing blood by Western blot without first testing it by ELISA due to the potential risk for false positive results.

**Multiple chemical sensitivity (MCS)** is a controversial syndrome in which multiple symptoms reportedly occur with low-level chemical exposure. It is so controversial that the American Academy of Allergy and Immunology, the American Medical Association (AMA), the California Medical Association, the American College of Physicians and the International Society of Regulatory Toxicology and Pharmacology have rejected it as an organic disease. The most common symptoms associated with MCS includes fatigue (chronic fatigue and fibromyalgia), difficulty concentrating (chronic fatigue and fibromyalgia), depressed mood (chronic fatigue and fibromyalgia), memory loss (chronic fatigue and fibromyalgia), weakness (fibromyalgia), dizziness (fibromyalgia), headaches (fibromyalgia), heat intolerance (fibromyalgia) and arthralgias (aching around the joints, also seen in fibromyalgia) that typically interfere with daily life and work (chronic fatigue and fibromyalgia). Typically, all symptoms have been attributed to exposure to low-level chemical exposures [31]. Although there is no specific diagnostic test for MCS, patients should be encouraged to see a physician who specializes in environmental health.

**Myofascial pain** is a common, painful disorder that affects the skeletal muscles. Myofascial pain is more prevalent in men than in women seen with chronic fatigue and fibromyalgia [49]. The patient will present with a localized, unilateral muscular pain, stiffness (fibromyalgia), limited movements and muscle weakness (fibromyalgia). Upon examination, “trigger points” will be noted from referred pain [19]. Trigger points are typically more “nodular” type areas with radiating pain and muscle twitching [49]. Patients with fibromyalgia pain typically have more localized pain rather than radiating.

**Polymyalgia rheumatica (PMR)** is a disorder characterized by stiffness worse in the morning (fibromyalgia), weakness (chronic fatigue and fibromyalgia), fatigue (chronic fatigue and fibromyalgia) and pain (fibromyalgia) symptoms that are proximal, not distally within the neck, shoulders, back and upper thigh. Other symptoms include low grade fever (chronic fatigue) and arthralgias (fibromyalgia). There is no a diagnostic test, and it is diagnosed based upon symptoms, history (typically women over 50 who respond to steroid therapy) and an increased ESR and a normochromic, normocytic anemia [18, 27]. Erythrocyte sedimentation rate (ESR) is a nonspecific inflammatory test that is useful to monitor the course of a disease (such as PMR) or malignancy. A normochromic, normocytic anemia is noted, demonstrated with a low Hgb and HCT but normal MCV.

**Sleep apnea** is a disruption of breathing while sleeping that lasts less than 10 seconds and occurs a minimum of five times in an hour [27]. Many times, patients will not be aware of their sleep apnea, it will be reported by a significant other or parent, and the patient may complain of “waking up tired” and irritability. Other signs include loud snoring and thrashing in bed [49]. Sleep apnea is confirmed by a polysomnography (PSG) device and observation during an overnight exam while the patient is sleeping [27].

Other potential laboratory and diagnostic tests that may be analyzed include, but are not limited to the following:

- **Basic metabolic panel (BMP) also known as chem-7** and a SMA-7 tests the calcium, carbon dioxide (CO2), chloride, Creatinine (cr), glucose, potassium, sodium and blood urea nitrogen (BUN) levels. A BMP is an important laboratory test to rule out dehydration (CO2), diabetes (glucose) and kidney failure (BUN/cre).

- **Complete blood count (CBC) with a differential count.** A normal CBC includes a white blood count (WBC), red blood cell (RBC), hemoglobin (Hgb), hematocrit (HCT), mean cellular hemoglobin (MCH), mean cellular hemoglobin concentration (MCHC), mean cell volume (MCV), red cell distribution width (RDW) and platelets. The nurse can expect the white blood cell to be increased with a bacterial infection and the red blood cells to demonstrate anemia. Since anemia was previously discussed, the nurse needs to be aware of the differential count to provide the clinician additional clues on the type of infection (viral, bacterial or allergic in nature). It includes lymphocytes (increased or decreased with viral infection, AIDS, influenza), neutrophils (increased bacterial infections and decreased with infectious mononucleosis), and eosinophils (decreased with stress and ACTH imbalance), basophils (increased with infection and hypothyroidism) and monocytes increased bacterial infection.

- **Creatine phosphokinase (CPK) to exclude myocardial infarctions (MI) and inflammatory myopathies (heart, skeletal muscle and bone) demonstrated by an elevated CPK level [24]. A CPK test may be completed if the patient complains of noncardiac chest pain.

- **Serum cortisol.** Cortisol and corticotrophin-releasing hormone (CRH), which are also produced during the activation of the HPA axis, influence the immune system and many other body systems. Recent studies revealed that chronic fatigue and fibromyalgia patients often produce lower levels of cortisol than do healthy individuals. However, at this time it is not a conclusive diagnostic marker because some patients do not produce an abnormality [9]. Overall, neuroendocrine disturbances are associated with dysfunction of the HPA axis in the following manner [22]:

  - Low free cortisol levels in 24-hour urine samples.
  - Loss of the normal circadian rhythm, with elevated evening cortisol level (when it should be at its lowest level). Many patients with chronic fatigue and fibromyalgia experience sleep deprivation. Research has demonstrated that fibromyalgia patients have an intrusion of alpha waves (during the first few hours of sleep) into slow delta wave stage III/IV (deep) sleep, and was the first objective abnormality noted [22, 50].
  - Insulin-induced hypoglycemia associated with an overproduction of pituitary ACTH.
  - Low levels of growth hormone.
  - Stimulated ACTH secretion leading to insufficient adrenal release of glucocorticoids.

Tilt test is indicated if there is a fall in blood pressure and/or excessive rapidity of heart beat upon standing, which improves when sitting or lying down. Patients often report that they experience dizziness or are light-headed upon standing. The tilt test involves the patient lying horizontally on a table and then tilting the table upright to a 60-70 degree angle for approximately 45 minutes, during which time blood pressure and heart rate are continuously monitored [9]. A positive tilt test may occur due to a cardiac origin or coincide with chronic fatigue syndrome and fibromyalgia.

**Treatment of fibromyalgia and chronic fatigue syndrome**

Managing chronic fatigue and fibromyalgia can be as complex as the illness itself. Unfortunately, at this time there is no cure nor any prescription drugs developed specifically for the syndromes.
Cognitive behavioral therapies (CBT) and the elderly: treatment modalities are used in children, adults developed and revised as needed. The following family to ensure an individualized treatment is multidisciplinary approach with the patient and worse [10]. One key to successfully manage the patient, but it is important to begin symptom care for the patient and family. It may take some time to find a combination of traditional and alternative therapies that works for the patient, but it is important to begin symptom management without delay. For instance, untreated sleep problems can actually make other symptoms, such as pain and memory problems, worse [10]. One key to successfully manage the syndromes is to develop a collaborative, multidisciplinary approach with the patient and family to ensure an individualized treatment is developed and revised as needed. The following treatment modalities are used in children, adults and the elderly:

◊ **Cognitive behavioral therapies (CBT)** is a nonpharmaceutical measure often prescribed to help chronically ill patients cope with illness and develop behaviors and strategies to help alleviate problematic symptoms, such as pain and fatigue [10, 18]. It has been successful in helping patients with cardiovascular disease, diabetes and cancer, and recent studies indicate that CBT can be useful in treating some chronic fatigue and fibromyalgia patients [10]. The goal of CBT is to reduce pain, enhance self-efficacy and to improve the overall function of patients by helping them learn to manage their activity levels, stress and symptoms. Optimally, CBT can help the patient change his or her perceptions and behaviors that may be perpetuating symptoms and disability [5, 18, 32, 36].

◊ **Counseling** is recommended for many patients living with chronic fatigue and/or fibromyalgia, because living with the syndromes can be difficult. Similar to other debilitating chronic illnesses, chronic fatigue and fibromyalgia can have a profound impact on daily life, requiring patients to make significant lifestyle changes and adapt to a series of new limitations [18]. Consulting a trained professional will help most patients build effective coping skills and problem-solving techniques. A supportive counselor may help the patient cope with the prospects of long-term illness as well as the anxiety, depression, grief, anger and guilt that often accompany chronic illness. A competent therapist using problem-solving techniques and standard psychotherapy and counseling methods can help the patient work through these issues. In some cases, a therapist may recommend a combination of medication and psychotherapy. The CDC (2006) has outlined some common difficulties faced by patients coping with chronic fatigue and fibromyalgia syndrome [18]:

- The severe, changing and unpredictable symptoms of varying severity.
- A decrease in stamina that interferes with ADLs.
- Memory and concentration problems that seriously impact work or school performance.
- An uncertain prognosis that makes it hard to plan for the future.
- Loss of independence, livelihood and economic security.
- Alterations in relationships with family and friends.
- Worries about raising children.
- Concerns about the potential impact of decreased sexual activity on intimate relationships.
- Skepticism and misconceptions about the illness.
- Many patients may feel anger, guilt, anxiety, isolation and abandonment that can intensify other symptoms, such as depression, sleep deprivations or anxiety. It is important for patients to acknowledge the life-altering changes imposed by their illness and to develop effective coping strategies to deal with these changes [18].

◊ **Exercise** is a great component to enhance strength, reconditioning of the muscles and release endorphins to alleviate stress. However, some patients may never be able to achieve the ideal level of exercising or continue it. As many as 40 percent of all fibromyalgia patients discontinue exercise because of the pain and fatigue [18]. The percentage may be higher in patients with chronic fatigue and the extensive malaise after exercising. Therefore, the nurse should encourage patients to exercise at the highest level possible without exacerbating or worsening their symptoms. Always assess patients’ progress or decline in function to ensure the treatment plan is adjusted to meet their needs.

- Researchers recommend daily aerobic and flexibility exercises, such as aquatic therapy (swimming and water exercises), walking, rowing and biking as essential components of the rehabilitation program [22, 27]. The goal is to encourage the patient to perform 60 to 75 percent of age-adjusted maximum heart rate (210 minus the person’s age) two to three times a week [18]. Encourage the patient to begin with gentle warm-up, flexibility exercises, slowly progressing to stretching all of the major muscle groups [22]. The goal of warming up should stretch to only the point of slight resistance, not to the point of pain [5].
- Nurses should reiterate to patients that they need to exercise safely without increased pain. If increased pain is noted, patients should alter their exercise regimen, speak with their primary care provider and possibly be referred to rehabilitation therapy. Physical therapists (PT) ensure proper exercise techniques and promote strengthening of the muscles, ligaments and joints. The patient should also be informed that continuous, ongoing exercise is imperative to maintain exercise-induced gains. Ideally the patient should avoid exercising late in the evening because endorphins are released, which can cause difficulty sleeping. A number of randomized, controlled trials of multidisciplinary treatment and exercise combined with education or cognitive behavioral therapy demonstrated that patients with fibromyalgia had improvements on a six-minute walk with significant decreases in pain and efficacy in their overall symptoms [22].
- If the patient is unable to complete an exercise regimen privately or with a therapist, the patient may suffer with a condition seen in fibromyalgia, the inability of the muscles to relax. Patients can have a surface electromyogram (sEMG), a biofeedback therapy that teaches them to learn to relax their muscles [38].

◊ **The nurse needs to reiterate to the patient with chronic fatigue syndrome to avoid post-exertional malaise, a common symptom defined as an exacerbation of symptoms following physical or mental exertion, with symptoms typically worsening 12 to 48 hours after activity and lasting for days or even weeks. It is important, however, not to avoid activity and exercise altogether. Such avoidance leads to serious deconditioning and can actually worsen other symptoms. It is also important not to engage in an endless “push-crash” cycle in which patients do too much, crash, rest, start to feel a little better, do too much again, and so on. Instead, encourage patients to learn to pace activities and work with their health care professionals to create individualized exercise programs that focus on interval activity or graded exercise. The goal is to balance rest and activity to avoid both deconditioning from lack of activity and flare-ups of illness due to overexertion. Effective activity management may help improve mood, sleep, pain and other symptoms so patients can function better and engage in activities of daily living [18].

◊ **Lifestyle changes**, including prevention of overexertion, stress reduction, dietary restrictions and nutritional supplementation, are frequently recommended in addition to drug therapies to treat sleep, pain and other specific symptoms [27].

◊ **Diet.** There is no specifically recommended diet, but many patients report intolerances for
certain substances that may be found in foods or over-the-counter medications, such as alcohol or the artificial sweetener aspartame. While evidence is currently lacking for nutritional defects in chronic fatigue and fibromyalgia syndrome patients, it should also be added that a balanced diet may be conducive to better health in general and would be expected to have beneficial effects in any chronic illness [33]. In addition, encourage the patient to limit caffeine, alcohol and chocolate as they may interfere with adequate sleep [27].

- In 2001, a research study conducted by Donaldson et al., demonstrated that 19 of 30 participants responded very favorably to a raw vegetable diet, seeing marked improvement in all fibromyalgia symptoms. The authors implied that a diet composed of fresh fruit and salads results in high intakes of fiber, vitamin C, folate, potassium and magnesium. Animal product consumption was very low, especially intakes of meat, poultry and fish. Intakes were mainly from once weekly to none, resulting in low intakes of fat, cholesterol, vitamins B12 and D, and zinc. This dietary intervention shows that many fibromyalgia subjects can be helped even without understanding the full cause of their symptoms. Further controlled studies are needed to reproduce and extend the results obtained here to see whether this dietary intervention is a viable adjunctive therapy for managing fibromyalgia in a clinical setting [17].

- Manage stress. Encourage patients to identify and recognize stressors in their lives. The nurse should ask the patient how he or she responds to stress and potential stressors? Once the stressors are identified and the patients recognize their own responses, they may be able to make changes or learn to adapt adequately.

- Sleep apnea. Continuous positive airway pressure (CPAP) is a nonsurgical approach to provide air during sleep for a patient with sleep apnea. CPAP delivers air nasally via a continuous set positive pressure device. The nurse needs to ensure the mask fits properly over the nose and mouth [27].

- Sleep education. The CDC (2008) recommends educating patients with sleep deprivation to practice the following techniques [10):
  - Establish a regular bedtime routine.
  - Avoid napping during the day.
  - Incorporate an extended wind-down period.
  - Use the bed only for sleep and sex.
  - Schedule regular sleep and wake times.
  - Control noise, light and temperature.
  - Light exercise and stretching earlier in the day, at least four hours before bedtime, may also improve sleep.

Support systems are imperative and beneficial for the patient. Because of the enormous amount of stress and symptoms, patients need a supportive system surrounding them. In addition to support from families and friends, there are local support groups available, which may be located through the Arthritis Foundation (AF), chronic fatigue and fibromyalgia websites [49].

Medications are used to alleviate many of the “problematic” symptoms, such as anxiety, depression, pain and sleep deprivation. Health care professionals should assess the baseline medications, prescribed medications and use of any herbs and/or over the counter (OTC) drugs to avoid contraindications. In addition, at this time, many prescribed medications are initiated based on the patient’s complaints and the primary care provider’s knowledge and experience of other patients in their practice who use the drugs. Therefore, what may work now or for somebody else may need to be tailored to meet the needs of another patient. No two patients should be treated identically, but the care should be individualized. At this time, there are only three medications approved by the United States Food and Drug Administration (FDA) for the medical treatment of fibromyalgia [48]:

- In June 2007, Lyrica (pregabalin) became the first FDA-approved drug for specifically treating fibromyalgia. Lyrica (Pregabalin), marketed by Pfizer Inc., was previously approved to treat seizures, as well as pain from damaged nerves that can happen in people with diabetes (diabetic peripheral neuropathy) and in those who develop pain following the rash of shingles. Lyrica is not considered an antidepressant but it is related to gabapentin (neurontin) classified as an analgesic/anticonvulsant. The major side effects of Lyrica include sleepiness, dizziness, blurry vision, weight gain, trouble concentrating, swelling of the hands and feet, and dry mouth. Allergic reactions, although rare, can occur. In June 2008, Cymbalta (duloxetine hydrochloride) became the second FDA-approved drug for specifically treating fibromyalgia. Cymbalta (duloxetine hydrochloride) marketed by Eli Lilly and Co., a serotonin-norepinephrine (SNRI), was previously approved to treat depression, anxiety and diabetic peripheral neuropathy. The major side effects of Cymbalta include nausea, dry mouth, sleepiness, constipation, decreased appetite and increased sweating. Similar to other antidepressants, Cymbalta may increase the risk of suicidal thinking and behavior in people who take the drug for depression. Therefore, the nurse should assess the patient’s mood and suicidal ideations with each encounter and educate the patient and family about the risk.
  - Both Lyrica and Cymbalta reduce pain and improve the overall function in people with fibromyalgia. While those with fibromyalgia have been shown to experience pain differently from other people, the mechanism by which these drugs produce their effects is unknown. Eli Lilly announced, although it is not understood how Cymbalta works in people, medical experts believe it increases the activity of two naturally occurring substances called serotonin and norepinephrine [30]. There is some data suggesting that these drugs affect the release of neurotransmitters in the brain. The FDA (2009) has stated that studies of both drugs demonstrated that a substantial number of people with fibromyalgia received good pain relief, but there were others who did not benefit. Therefore, it reiterates the importance of assessing each patient’s response to therapy.
  - Lyrica and Cymbalta are approved for use in adults 18 years and older. As of June 2009, there is no data available for the safe efficacy in children and breastfeeding women, and both drug manufacturers have agreed to implement studies.

- In January 2009, Forest Laboratories Inc. and Cypress Bioscience Inc. announced that Savella (Milnacipran HCI), an SNRI, was approved by the FDA for the management of fibromyalgia. The safety and efficacy of Savella was established in two U.S. pivotal phase III clinical trials involving over 2,000 patients with fibromyalgia. The two studies demonstrated that Savella doses of 100 mg/day and 200 mg/day demonstrated statistically significant and clinically meaningful concurrent improvements in pain, patient global assessment and physical function. As of March 2009, Savella is available in pharmacies. The most common side effects noted during the clinical trials were nausea, constipation, hot flush, hyperhidrosis (abnormal perspiration), vomiting, palpitations, heart rate increased, dry mouth and hypertension [20]. Although there are no FDA-approved medications for chronic fatigue, the other most common medications prescribed for chronic fatigue and fibromyalgia are [18, 36]:
  - Antidepressants are recommended as the initial treatment of fibromyalgia to alleviate depression and promote sleep. Sleep-maintenance disorders are more difficult to manage than are sleep onset problems. In general, antidepressants are most commonly used because of their effect on serotonin. Nurses should educate patients taking an antidepressant to take the dose as prescribed and avoid double dosing; relief and change in problematic symptoms may take two to four weeks; avoid abrupt discontinuation and notify the primary care provider if they feel suicidal [25].
  - Tricyclic antidepressant agents (TCAs) have the strongest evidence for efficacy, such as amitriptyline (Elavil, apo-amitriptyline) 10 milligrams (mg) orally at bedtime, gradually increasing to 40 to 50 mg depending upon
the efficacy [32, 36]. Research studies have indicated that amitriptyline (Elavil) has been effective in improving sleep and increased the non-REM stage four sleep by increasing serotonin levels in the patient [10]. Nortriptyline (Pamelor) also has a unique component to help alleviate neurogenic pain [25].

- Avoid TCA medications in older adult patients as it can cause confusion and orthostatic hypotension [27]. Therefore, Trazodone (Desyrel) may be a preferred option for the elderly patient due to its minimal side effects [27].
- The most common side effects with TCAs include anticholinergic reactions, such as urinary retention, dry mouth, dry eyes, blurred vision and constipation and sedative properties [25].
- If the patient is not staying asleep, adding a serotonin-selective reuptake inhibitor (SSRI) may be helpful. Selective serotonin reuptake inhibitors (SSRIs) such as citalopram hydrobromide (Celexa), escitalopram oxalate (Lexapro) and fluoxetine (Prozac) and sertaline hydrochloride (Zoloft), can be prescribed alone or in combination with TCAs for pain relief and depression [18, 27, 36]. However, the nurse should educate the patient that the SSRIs do not help alleviate fatigue [23].
- Fluoxetine (Prozac) should be the first antidepressant agent used to treat depression in children and adolescents; however, all of these medications should be used only with extreme caution and extensive parental education. Psychiatric consultation is recommended. The doses of all antidepressants should be individualized, based upon the symptoms and history.
- Over the years, there has been numerous literature cautioning health care professionals in prescribing antidepressants to children and adolescents. According to the National Institute of Mental Health (2009), in the FDA review, no completed suicides occurred among nearly 2,200 children treated with SSRI medications. However, about 4 percent of those taking SSRI medications experienced suicidal thinking or behavior, including actual suicide attempts – twice the rate of those taking placebos or sugar pills. In response, the FDA adopted a “black box” label warning indicating that antidepressants may increase the risk of suicidal thinking and behavior in some children and adolescents with major depressive disorder (MDD). A black-box warning is the most serious type of warning in prescription drug labeling. The warning also notes that children and adolescents taking SSRIs should be closely monitored for any worsening in depression, emergence of suicidal thinking or behavior, or unusual changes in behavior, such as sleeplessness, agitation or withdrawal from normal social situations. Close monitoring is especially important during the first four weeks of treatment. SSRI medications usually have few side effects in children and adolescents, but for unknown reasons, they may trigger agitation and abnormal behavior in certain individuals [37].
- The most common side effect of SSRIs is insomnia [25].
- Serotonin-norepinephrine (SNRI), Cymbalta (duloxetine hydrochloride) and Savella (milnacipran HCl).
- Anti-anxiety medications include antidepressants, such as SSRIs; paroxetine (Paxil), trazodone (Desyrel), benzodiazepines, nonbenzodiazepine sedatives, or L-dopa and carbidopa may be used in fibromyalgia syndrome, especially if the patient suffers sleep disturbances due to restless leg syndrome [36].
- Clonazepam (Klonopin) is an anticonvulsant/benzodiazepine that should never be confused with clonidine (Catapres) antihypertensive/cardiac medication. Clonazepam is ideal for the chronic fatigue/fibromyalgia patient with concomitant restless legs syndrome or mitral valve prolapsed (MVP). The starting dose is 0.125 or 0.25 mg and titrate the dose to the lowest effective dose. The nurse should instruct the patient to take it as prescribed, never take double doses or abruptly discontinue due to the risk of seizures. Side effects include, but are not limited to increased fatigue, bleeding, sore throat, fever, clay-colored stools, jaundice or behavioral changes [25].
- Corticosteroids are not useful in the treatment of fibromyalgia without concomitant rheumatic illness, such as joint, bursa or tendon inflammation [22, 36].
- Herbal supplements and vitamins are frequently used by people with chronic fatigue syndrome for symptom relief. Although there have been few clinical trials, many chronic fatigue syndrome patients report symptom relief with supplements. The potential danger is these products are unregulated, and information on potency and side effects is frequently unknown. Nurses and health care professional need to question patients about supplement use and OTC products to determine safety, efficacy and possible negative interactions with prescribed medications and therapies. The CDC (2008) discourages patient use of herbal remedies like comfrey, echinacea, ginseng, ginkgo, ginseng, saw palmetto, valerian, echinacea, ginseng, ginkgo, ginseng, saw palmetto, valerian, and any other supplements that are potentially dangerous [10].

Pain is the primary symptom, especially for the patient with fibromyalgia, and it needs to be addressed appropriately by the primary care provider. Ideally, patients should avoid the use of any pain medication if possible, but many endure excruciating, debilitating pain and it needs to be addressed. The goal is to ensure the patient is prescribed pain medications that alleviate the pain but are nonaddicting.

- Gabapentin (Neurontin) and zonisamide (Zonegran), (analgesics/anticonvulsants) are typically prescribed for neuropathic pain; however, they may be useful for fibromyalgia patients [18]. The typical dose is 100 mg/day and increased to 200 to 800 mg/day [49]. Nurses should assess the patient prescribed gabapentin (Neurontin) to discontinue gradually over one week as it may cause seizures. In addition, the patient should avoid taking it within two hours of an antacid. Women of childbearing age should speak with their doctor if they are contemplating a pregnancy and/or breastfeeding [25].
- Guainefesin (cold expectorant/cough medicine) is in some review of the literature demonstrating “significant benefits in decreasing pain, improving other symptoms as it works on the NMDA receptor” [1, 22]. At this time, there are no protocols, and the validity is questioned, so further research is needed on the true effectiveness of guaifenesin. Nurses should be aware of the potential use of guaifenesin and fibromyalgia, especially since it is available over the counter.
- Muscle relaxants, such as cyclobenzaprine (FLEXIRIL) 5 to 40 milligrams are typically prescribed to alleviate musculoskeletal pain, especially spasms; however they are also effective in improving sleep when taken at bedtime as well as providing relief the subsequent day [18]. Nurses should assess the patient for drowsiness, dizziness and blurred vision. In addition, muscle relaxants may cause anticholinergic side effects (urinary retention and dry mouth), especially in the elderly or if a patient is already prescribed a medication that induces anticholinergic side effects [25].
- Nonsteroidal anti-inflammatory drugs (NSAIDs), including COX-2 selective agents and acetaminophen are not effective analgesics when used alone, but when combined with a TCA they may provide a beneficial efficacy. Nurses should assess the patient for a history of hypersensitivity, bleeding disorders, gastrointestinal bleed and severe hepatic or cardiovascular diseases prior to administering [25]. The patient should be instructed to take NSAIDs with a full glass of water and to remain upright for a minimum of 15 to 30 minutes after administration to reduce the risk of ulcer formation [25].
- Opioid/narcotics, such as codeine, fentanyl, hydrocodone, methadone, oxycodone and tramadol (Ultram) should be avoided or used sparingly to avoid addiction and overdose.
- Tramadol (Ultram) (50 to 100 mg two or three times daily) is prescribed for pain relief in patients with fibromyalgia. The dose should be slowly tapered gradually when discontinued. Tramadol can be used alone or in combination with acetaminophen.
The combinatory regimen of physical therapy, exercise, cognitive behavioral therapy, and medication is the standard of care for chronic pain management. For fibromyalgia, nonsteroidal anti-inflammatory drugs (NSAIDs) can help reduce pain and inflammation. Antidepressants, particularly serotonin reuptake inhibitors (SSRIs), and alpha2-adrenergic agonists such as clonidine can also be effective. Medications are used to reduce pain, fibromyalgia symptoms, and comorbid conditions. Cognitive behavioral therapy, relaxation techniques, and physical therapy are integral to this treatment approach. Additional interventions include educational programs and psychosocial support networks. Exercise is crucial for patients with fibromyalgia as it helps reduce pain and fatigue. Mind-body techniques, such as yoga, tai chi, and meditation, can significantly improve pain and quality of life for fibromyalgia patients. It is essential to note that acute and chronic pain can coexist and should be managed accordingly. Treatment options for fibromyalgia are individualized, and patients are advised to consult with their healthcare provider for the most effective and suitable management plan.
CHRONIC FATIGUE AND FIBROMYALGIA SYNDROME
Self Evaluation Exercises
Choose True or False for questions 1 through 10 and check your answers at the bottom of the page.

You do not need to submit this self-evaluation exercise with your participant sheet.

1. Chronic fatigue and fibromyalgia are among the most complex and misdiagnosed syndromes.

   True    False

2. Chronic fatigue syndrome is a debilitating syndrome that involves multiple body systems. It is characterized by profound fatigue that is not improved by bed rest and may be exacerbated or re-kindled by physical or mental activity.

   True    False

3. Fibromyalgia is a disorder of unknown etiology characterized by widespread pain, abnormal pain processing, sleep disturbance, fatigue and often psychological distress.

   True    False

4. Chronic fatigue and fibromyalgia are syndromes that are all in the patient’s “head.”

   True    False

5. Men are more likely to be affected by chronic fatigue and fibromyalgia syndrome than women.

   True    False

6. There are studies that indicate that the development of fibromyalgia may be linked to the Borrelia burgdorferi, which causes Lyme disease, brucella and the parvovirus.

   True    False

7. Nurses should discourage patients with chronic fatigue and fibromyalgia to exercise.

   True    False

8. There is one FDA-approved medication for the treatment of fibromyalgia: Lyrica.

   True    False

9. The nurse should always assess a patient taking an antidepressant for suicidal ideations.

   True    False

10. The prognosis of chronic fatigue and fibromyalgia syndrome varies among each individual, but neither condition is progressive in nature with prompt, adequate diagnosis and appropriate/individualized treatment.

    True    False

CHAPTER 3
DEALING WITH THE ANGRY PATIENT/FAMILY MEMBER:
STRATEGIES FOR REDUCING THE RISK OF WORKPLACE VIOLENCE
(4 CONTACT HOURS)

Learning objectives

- Discuss the incidence and prevalence of violence in the workplace.
- Identify barriers to reporting incidents of workplace violence.
- Explain what factors trigger violence in healthcare work settings.
- Explain how communication affects the ability to reduce/prevent workplace violence in healthcare settings.
- Implement strategies to reduce the potential for workplace violence in healthcare settings.
- Identify education strategies that prepare staff to reduce the potential for workplace violence in healthcare settings.

Introduction

Serena is an RN who works 7 am to 7 pm in the Emergency Department (ED) of a 500-bed medical center. She arrives at work to find the department in a state of near chaos. People are crying and several police officers are attempting to restore order. It seems that a gunshot victim’s brother stabbed a physician and a nurse after shouting that no one cared if his brother lived or died.

Bob is a physical therapist who works in an outpatient clinic. He has a new patient that is scheduled for her initial evaluation and therapy session at 2 pm. Mrs. Gray has a rapidly progressing form of multiple sclerosis (MS). Her cognitive state and motor skills are quickly deteriorating. Unfortunately, another therapist has called in sick, and, in helping to cover her patients’ therapies, he is running late. Mrs. Gray and her husband have had to wait for 20 minutes. Mrs. Gray is tearful and Mr. Gray is furious. When Bob arrives Mr. Gray confronts him by stepping to within a few inches of Bob’s face and shouting, “How dare you make my wife sit and wait like this? She is a sick woman and you had better be prepared to deal with me!”

Hannah is an RN who works on the stroke rehabilitation unit. Her patient, Mrs. Clark, is running a slight fever and has developed a cough. Mrs. Clark is often confused as to time and place. As Hannah attempts to auscultate Mrs. Clark’s lungs Mrs. Clark screams, “What are you doing to me? You are trying to kill me!” She makes a fist and attempts to punch Hannah in the face.

The preceding scenarios could be taking place at any time in any healthcare facility throughout the country. Workplace violence in healthcare settings can affect anyone who works or volunteers in such settings. The violence can also affect other patients and families and visitors. It is imperative that persons who work in healthcare know what factors trigger violent behavior and what actions to take to reduce the potential for that violence. They must also know how to deal with violence, whether it is verbal or physical, if and when it does occur.

Incidence and prevalence of workplace violence

The prevention of workplace violence is a critical safety issue. Such violence can take many forms including verbal abuse, threats, physical battery, and even murder. The healthcare workplace, indeed all workplaces, must be made as safe as possible for employees, volunteers, patients, families, and visitors.

The good news regarding workplace violence in the U.S. is that from 2002 to 2009 the rate of non-fatal workplace violence has declined by 35 percent. This follows a 62 percent decline in the rate from 1993 to 2002. The bad news is that it still occurs. In fact workplace violence is responsible for about 900 deaths and 1.7 million non-fatal assaults every year in the U.S.

In March, 2011, the U.S. Department of Justice published a special report, Workplace Violence, 1993-2009. This report is a summary of the National Crime Victimization Survey and the Census of Fatal Occupational Injuries. In order to effectively implement measures to stop or reduce workplace violence it is important to understand the incidence and prevalence of such violence. Here is a summary of the key highlights of this report from findings related to the years 2005 through 2009.

- 2009 preliminary data indicate that 521 persons 16 or older were homicide victims in the workplace.
- The majority of workplace homicide victims were male and middle-aged. Four out of five workplace homicide victims were men, and 48 percent of all workplace homicide victims were between the ages of 35 and 54. Twenty-one percent were 55 or older, and about 10 percent of victims were between the ages of 16 to 24.
- About half of all workplace homicide victims were white. About a fifth of all victims were black, 16 percent were Hispanics, and 11 percent Asian.
- Healthcare practitioners accounted for 1.1 percent of workplace homicide victims 16 years of age or older.
- About 28 percent of workplace homicide victims worked in sales in related jobs. About 17 percent worked in protective service occupations.
- The majority of workplace homicides (70 percent) were committed by robbers and other assailants. About 21 percent were committed by work associates.
- Shootings were responsible for 80 percent of workplace homicides. Firearms were used in five percent of non-fatal workplace violence.
- Law enforcement officers, security guards, and bartenders experienced the highest rate of workplace violence.
- The highest number of non-fatal workplace violence events was committed by strangers against males (53 percent) and females (41 percent).

In the hospital setting, workplace violence occurs most often on psychiatric units, emergency departments (EDs), waiting rooms, and geriatric units. Research shows that 35 percent to 80 percent of hospital staff members have been physically assaulted at least once during their careers. In the ED, the vast majority of the people who commit violence are patients, their family members, and their visitors.

These statistics show that workplace violence is a significant occupational risk. There is a real need for employers to develop and implement workplace violence prevention policies and procedures. Both the Joint Commission and The Occupational Safety and Health Administration’s (OSHA) have made recommendations and identified strategies for the prevention and reduction of workplace violence. However, many organizations still struggle to develop and, more importantly, to properly implement such strategies. Compounding this problem is the issue of proper reporting of violence in the workplace. It is suspected that many occurrences of workplace violence are not reported because no significant harm came to the victim, or because the victim believed that such violence was just “part of the job.” Workplace violence is not something that should ever be considered a “normal” risk of certain occupations.

Barriers to the reporting of workplace violence

Charles is the chief executive officer (CEO) of a small rural community hospital. He and his administrative team are working to develop a policy regarding workplace violence based on OSHA recommendations. Even as they work, Charles does not feel that this is a major problem for his organization. “After all,” he thinks to himself, “we really don’t have much of a problem in our little town. Why the most serious problems the local police department faces are drunk driving and maybe a brawl at the only bar in town on Saturday nights!” Charles asks his team how they would define workplace violence. “What exactly is it we’re supposed to prepare to deal with? Are we talking about somebody coming in here with a gun or what?”

Melanie is a respiratory therapist. One of her patients is a 22-year-old man who developed pneumonia after being hospitalized for multiple fractures sustained in a motorcycle accident. He requires assessment and breathing treatments and Melanie dreads going into his room. He continually makes sexual comments and yesterday tried to grab Melanie’s breast du ring a treatment. Melanie is reluctant to report the incident. She tells herself that nothing “actually happened” and she is both embarrassed and afraid that no one will believe her. The man is the son of a prominent, wealthy businessman who is on the hospital’s board of directors.

Henry is a physical therapist who is working to improve the mobility skills of an 80-year-old lady who has suffered a stroke. She is occasionally confused and this morning she punched Henry in
the jaw as he attempted to help her transfer from bed to wheelchair. Henry decides not to report the incident. He doesn’t want to admit that a frail, elderly lady hit him.

Dana is an RN on a surgical unit. One of her patients, Mr. Henry, is continually complaining about the care he receives from the nurses, the food, his physician, and even how the volunteers deliver flowers and the mail. This afternoon he starts shouting loudly as she enters the room to give him his pain medication. He calls her “just a stupid nurse” and says he is tired of waiting for his medicine while all “you and the other lazy cows around here sit and do nothing! Someday I’ll make you all sorry.” Dana wants to report the incident as an adverse occurrence according to the hospital’s workplace violence policy. Her nurse manager tells her to forget about it. She tells Dana, “Words can’t hurt you!”

The preceding scenarios illustrate just how many barriers there are to the reporting of workplace violence. They range from a failure to comprehend the scope of the problem, inconsistency of definitions, embarrassment, fear, and a lack of managerial support.

**Defining workplace violence**

Statistical reports of workplace violence cannot be completely accurate because of inconsistencies and/or failure to report the problem. One of the most obvious inconsistencies is a lack of a standardized national definition of workplace violence. Despite the existence of policies and procedures, even employees of the same organization may define workplace violence differently. For example, does workplace violence include verbal aggression or is it limited to actual physical harm? Does the definition also include the threat of physical harm, even if actual harm does not occur? What level of verbal aggression is considered to be a type of workplace violence? If a patient shouts at a staff member, is this workplace violence? How “severe” does verbal abuse have to be to constitute workplace violence?

There are no simple answers to the preceding questions. Most people would agree that actions that cause physical harm are forms of workplace violence. However, what level of harm must exist? Compare a slight pinch of the skin to a black eye. Are both examples of workplace violence?

Ultimately, it is up to each organization to define and explain to employees what does and does not constitute workplace violence. It is likely that most organizations would include both verbal and physical aggression (including the threat of physical aggression) as part of the definition of workplace violence.

Policies and procedures concerning workplace violence should be written not only by management and/or administration, but by staff members. It is critical that the persons most likely to encounter violent situations, such as those who provide direct patient care, security guards, and secretaries and clerks who may be the first to greet or encounter patients and visitors, have input into such guidelines. By having input they will be more likely to follow, encourage others to follow, and to support policy and procedure implementation. However, no matter how committed employees are to stopping workplace violence, and no matter how well-written are the policies and procedures, a violence prevention program must have the support of management and administration to be effective.

**Failure to understand the scope of the problem**

In the first scenario at the beginning of this section, Charles, the CEO of a small rural community hospital, did not believe that workplace violence was a problem for him. This attitude, although not as common as it once was, still exists. And this attitude is not only a barrier to reporting workplace violence, but poses a danger to staff, visitors, and patients as well. If the CEO, and/or others at the executive level fail to understand that the possibility of workplace violence affects all healthcare organizations, staff members will not be prepared to prevent (whenever possible) and/or deal with it when it finally does occur.

Fortunately, both OSHA and the Joint Commission frequently address the problem of workplace violence. This generally means that administrative and managerial staff will support the development and implementation of policies and procedures that address the issue of workplace violence. However, it is not only administrative and managerial staff that need to understand the scope of the problem. Everyone who works in or volunteers for a healthcare organization must be taught how to prevent and deal with workplace violence.

Why would employees be reluctant to learn about the potential for violence in the workplace? Some employees (or volunteers) may believe that the threat of violence in healthcare settings is a problem that only direct patient care providers have to deal with. However, workplace violence can occur anywhere in the workplace and all employees need to be educated about the problem and how to deal with it.

Some employees may equate their risk of experiencing workplace violence with the types of patients they care for. For example, results of a recent study published in the *Journal of Nursing Administration (JONA)* concerning violence against nurses working in EDs, showed that nurses in pediatric EDs were less likely to experience frequent physical violence. But nurses who worked mostly at night and weekends were more likely to experience frequent physical violence.¹

Some employees may feel that their gender affects their likelihood to experience workplace violence. The JONA study also showed that female nurses were less likely than male nurses to report that they experienced frequent physical violence.¹ However, in other areas of healthcare settings, female nurses may feel more vulnerable to violence depending on the time of day they work, the specific setting in which they work (e.g. ED, inpatient units, etc.), and the types of patients they care for.³

Employees who fail to comprehend the scope and risk of workplace violence may be perceived as barriers to reporting its existence. They may not define violence according to hospital policy and procedure. They may choose to ignore coworkers’ concerns or reports of violence. They may simply, mistakenly, assume that violence is part of the job.⁴ Such attitudes are not only barriers to accurate reporting but are barriers to implementing an effective workplace violence prevention program.⁵

Managers may be part of the group of employees who fail to comprehend the scope of the workplace violence problem. In fact, they may have a significant impact on how willing their subordinates are to report incidents of workplace violence.

**Lack of managerial support and commitment**

OSHA, in its guidelines for a violence prevention plan, emphasizes the importance of managerial commitment to reducing and preventing the incidence of workplace violence. “Management commitment provides the motivation and resources to deal effectively with workplace violence...”¹⁰

Consider the scenario at the beginning of the section in which the RN Daria experienced escalating verbal abuse committed by a patient. Daria’s desire to report the problem per the hospital’s workplace violence policy was “squashed” by her nurse manager. The manager’s comment, “Words can’t hurt you” indicate not only a failure to understand the scope of the problem but an obvious lack of managerial support and commitment. Just how long is Daria supposed to wait to report escalating aggression? What, in the manager’s opinion, has to occur before it is deemed to be workplace violence?

Lack of managerial support and commitment has an adverse effect on employees. In this type of environment staff members may be reluctant to report what they believe to be workplace violence, even though, as in Daria’s case, the verbal aggression is escalating. Escalating behaviors often indicate that potential danger to employees is also escalating.⁸,⁹,¹² Suppose Daria’s concern and/or fear of Mr. Henry interferes with her ability to concentrate on her job responsibilities and she makes an error? Is Daria’s manager equally to blame since she did not support Daria? Or is Daria to blame since she had the option of filing a report and/or filing a grievance? These are difficult questions to answer, and there are probably no clear-cut right or wrong responses. The point is, lack of managerial commitment can impact the organization in a variety of ways. These include:
Increased potential for injury: If staff members are reluctant to or even prevented from reporting workplace violence no measures are taken to deal with the person or persons who are aggressive. This may increase the aggression until physical harm occurs.

Distrust of management: If management is seen as unwilling to support measures to increase the safety of the workplace, resent among staff members may grow. This leads to a hostile work environment.

Potential for increased filing of grievances: If employees feel that their legitimate concerns are ignored and organizational policy and procedures are being violated, there may be an increase in the number of employee grievances filed against management.

Legal consequences: Failure to provide a safe environment may have legal consequences for management. Deliberately failing to adhere to workplace violence policies and procedures may make the manager liable to legal action in the event of injury to employees.

Increased number of adverse occurrences: Staff members who are distracted by an unsafe work environment may find it more difficult to concentrate thereby increasing the risk for errors.

Difficulty with recruitment and retention activities: If an organization develops a reputation as a workplace that is unsafe or that does not support its employees there may be problems recruiting qualified personnel. There may also be problems retaining staff members.

Why would managers fail to adhere to workplace violence policies and procedures? Not understanding the scope of the problem may be only one reason. Others may include:

Belief that employees are exaggerating the danger: Some managers may honestly believe that certain employees exaggerate the danger of a given situation or may even be perceived as “troublemakers.” These are subjective feelings and should not interfere with a manager’s ability to provide a safe work environment.

Fear that reporting will acquire a negative reputation: Managers may fear that if a number of reports of workplace violence are filed administration will think that they cannot run their units/departments properly. Managers may not want their units/departments to be “known” as a dangerous place, which can hamper recruitment efforts.

Regardless of the reasons, managers need to understand the scope of the workplace violence problem, and be committed to doing everything possible to enhance safety and reduce the risk of aggression.

Embarrassment
Employees may be embarrassed that they cannot defuse an aggressive situation. Think of Henry, the physical therapist who was punched by a frail stroke patient. Henry may have been embarrassed that this frail, elderly woman was able to strike him. Nevertheless, verbal and physical violence should embarrass no employee. The danger for injury is real and all incidents of workplace violence should be reported.

Fear
A good example of fear is the scenario that describes why Melanie, a respiratory therapist, is reluctant to report the workplace violence she experienced. The person committing the violence, which consisted of inappropriate sexual comments and an attempt to grab her breast, was the son of a member of the hospital’s board of directors. Fear can have a number of causes. These include:

Fear of retribution: Some workplace violence may involve threats of future harm. For example, a staff member may be told: “If you tell anybody about this, I’ll make sure you’re sorry after I get out of here.” Intimidation may prevent a staff member from documenting workplace violence.

Fear of management disapproval: Some employees may fear that if they report incidents of workplace violence. It may appear that they cannot do their jobs, which may include dealing with aggressive patients, families, and visitors.

Fear of political consequences: As in Melanie’s case, some perpetrators of violence may be prominent members of the community or related to such people. Sadly, political ramifications may be a distinct possibility. However, protecting a violent person is never acceptable, regardless of how prominent or how much influence that person may have.

“It’s just part of the job”
There are some hospital employees who are more likely than others to be at risk for workplace violence. Security guards and emergency department personnel are a few examples. Even those employees who do not work in high-risk areas may believe that experiencing workplace violence is just “part of the job.”

Results of a study conducted on nurses working in emergency departments, intensive care units, and general units in a regional medical center showed that about 50 percent of participants stated that incidents of violence against nurses were never reported in writing. Explanation of this failure to report was based on the belief that such incidents were part of the job and that reporting the violence would not serve any helpful purpose. Other reasons given included feeling empathy for frightened, angry patients and family members and that if no physical injury actually occurred there was no reason to report attempted violence.

Why does workplace violence occur
An infant is born with numerous, severe congenital abnormalities. It is doubtful, even with supportive treatment, that the baby will live a year. The infant's pediatrician sits down with his parents to discuss options. He wants to present them with all possible options in light of the fact that their baby is seriously ill and suffering. The baby has developed an infection and the physician suggests supportive measures rather than aggressive antibiotic treatment. The baby's parents are distraught and the father attempts to punch the physician screaming, “You are a murderer! You want to kill my son! All life is sacred no matter what!”

Nancy is a speech therapist working with a closed head injury patient. The patient is quite disoriented and, when Nancy pauses to consult her notes, he reaches out and scratches her face, which begins to bleed.

Mark is a security guard in the emergency department. A teenager is helped into the department by two friends. He has been stabbed in the right arm. The boy’s friends begin to call out loudly for help and push and shove around the waiting room. As Mark approaches the boys, one of them pulls out a knife and tries to stab him. All three teenagers smell strongly of alcohol.

The preceding scenarios illustrate a number of reasons why violence occurs in healthcare settings. Fear, anger, confusion, values conflicts, and substance abuse all can contribute to violent behavior. It is important that healthcare workers comprehend the various factors that can trigger violence in healthcare work settings.

Joint commission findings
On June 3, 2010 the Joint Commission published some recommendations on preventing violence in the healthcare setting. An analysis of the Sentinel Event Data base concerning criminal events helped to identify the following causative factors that were most often identified in the last five years:

Flaws in leadership: In 62 percent of events, problems with policy and procedure development and implementation of such policies and procedures were cited as having contributed to the violence.

“Human resources-related factors:” In 60 percent of events factors such as the need for staff education regarding workplace violence and assessing (or failing to assess) the competency of staff to deal with or prevent workplace violence were cited.

Assessment: In 59 percent of events assessment was cited as a contributing factor to workplace violence events. Assessment involved such issues as lack of psychiatric assessment, failure to staff to adequately observe patients, and inadequate tools of assessment.

Failures in communication: In 53 percent of events safety deficiencies in the environment as well as deficiencies in security procedures and actions were cited as contributing factors.
Fear is a common reaction among hospitalized patients and their families. Lack of control over what is happening to them or, in the cases of families, of their loved ones, significantly contributes to fear and anxiety.23 These feelings are not limited to persons in the inpatient setting. Consider the patient who is receiving chemotherapy at an outpatient clinic or the patient who is receiving bad news about his/her health in a physicians’ office. Fear occurs in all healthcare settings.

Fear is often a normal response when dealing with the unknown, with pain, with the need to face the reality of a serious or terminal illness or injury. Fear lowers an individual’s tolerance and he/she may react angrily at even the slightest provocation such as failure to receive the proper breakfast or having to wait an extra 15 minutes for a treatment or outpatient visit.

By recognizing and acknowledging fear healthcare workers may be able to help reduce the emotion and reduce the potential for violence. Fear should never be dismissed as “over-reacting.” The need for diagnostic procedures and treatment affects each person (and each family member) differently. One person may stoically receive a diagnosis of cancer while another may weep hysterically. Objectivity on the part of healthcare workers is necessary. It is unfair and unrealistic to compare different patients’ responses or to compare a patient’s response with how the healthcare worker feels he/she should respond. Patients and families who sense that they are being judged by their healthcare providers may quickly become angry, and that anger may eventually escalate to violence.

Conflict of values
Values are beliefs about the “right” and “wrong” way to conduct one’s life including personal and career behaviors. Differences in values can lead to conflict.15 Such conflict can evolve into violence, verbal or physical behaviors, or both. Consider the scenario that described distraught parents whose infant was born with terminal congenital abnormalities. Their fear was compounded by a physician’s attempt to discuss difficult options for the baby’s care. The parents’ values, “all life is sacred” may be perceived by the parents as in conflict with the physician, who is attempting to present a variety of options to the parents.

Values are influenced by upbringing, religious beliefs, age, and culture. Medical options that come into conflict with the values of the patient and/or family can cause considerable stress and add to fear and anxiety. This kind of conflict can also deteriorate into violence.

Even something as “harmless” as mistakenly serving a meal containing meat to a vegetarian patient can incite conflict. The values of the vegetarian are offended by this mistake. If the person making the mistake apologizes and corrects the mistake by ordering another meal the issue will likely resolve itself. But if the staff person reacts by dismissing the patient’s concern conflict may escalate. Staff members must be alert to the patients’ values and not judge as to what values are “important” and what are not.

When a patient’s values come into conflict with the healthcare professional who is providing patient care it is up to the staff member to maintain objectivity. This may be challenging in some cases. Consider a patient with late-stage lung cancer values on quality of life. His treatments leave him sick and exhausted. He decides to stop treatment and instead opt for measures that will allow him to remain as comfortable as possible for as long as possible. A nurse who believes that every option for treatment should be utilized may be tempted to try to change the patient’s mind. Attempting to do so will cause not only stress but may lead to conflict. It is not appropriate to challenge a patient’s values. Once the healthcare team has presented all options to a patient it is up to the patient to direct his plan of care and the team must respect the patient’s values and decisions.

Even simply presenting options that threaten a patient’s values may lead to conflict, as in the scenario with the terminally ill infant. Physicians have an obligation to present all options and information about each option so that patients and families can make informed decisions. But presenting options must be done with compassion and respect. Patients and families should never be made to feel that there is a “right” and a “wrong” decision.

Culture
Cultural (and religious) values and customs are usually deeply important to persons embracing them. Healthcare workers should make every effort to respect the culture and religious beliefs of the patients they care for. For instance, some female Hispanic patients may defer to their husbands as the decision-maker in matters of health and wellness.5 This may contradict the values of a healthcare professional who believes that each patient should make her or his own decisions about treatment, follow-up care, etc. But the staff member must respect the patient’s own values and not attempt to change them. Attempting to do so may cause considerable conflict. But respecting such values and including the patient’s husband in all aspects of decision-making will more than likely facilitate patient care.

For example, suppose a young male patient is dealing with a diagnosis of diabetes. This will require changes in diet, exercise, and in many of his activities. He will need to take insulin. The patient is having a difficult time accepting the diagnosis and his physician believes that psychosocial counseling may be helpful. The patient and his family adamantly refuse. The family is of Middle Eastern descent and believe that personal problems are best taken care of within the family.6 The physician needs to work with the family, especially the family spokesperson, to help the patient receive the care that he needs while respecting the family’s cultural values.

Cultural and religious beliefs should always be respected. If the healthcare team is unfamiliar with a particular culture and/or religion they need to gather information about both and, if possible, ask for the assistance of representatives from that culture and/or religion to help provide culturally appropriate care. Failure to do so may lead to conflict and even instances of workplace violence.

Substance abuse
Having to deal with patients, families, and visitors who are under the influence of alcohol, prescription drugs, or illegal drugs is a fairly common problem in the healthcare setting. People under the influence of such substances may exhibit a wide range of behaviors, from being withdrawn, to euphoric, to depressed, to belligerent and combative.

When thinking of patients under the influence of alcohol or other drugs some healthcare professionals may picture an out-of-control patient or family member in the emergency department or a family member or visitor making a scene while visiting a hospitalized loved one. However, a review of some recent studies show that just as big a problem is the need to deal with patients who are going through alcohol withdrawal while hospitalized.14

Recent studies indicate that a significant number of hospitalized patients suffer from alcohol use disorder (AUD) such as alcohol abuse or dependence. Results of a 2008 study show that an estimated one in five patients admitted to a hospital suffer from an AUD.14 Additional data estimate that one in four medical-surgical hospitalized patients have some form of AUD.14

Staff members need to be alert to alcohol withdrawal signs and symptoms, which may mimic other illnesses or disorders. These signs and symptoms are indicative of declining alcohol blood levels and usually appear within a few hours to a few days after alcohol intake stops.14 These signs and symptoms may increase in severity as the time from when the last drink of alcohol increases. These signs and symptoms include:14

- Tremors.
- Anxiety.
- Headache.
- Palpitations.
- Diaphoresis.
- Nausea and vomiting.
- Seizures.
- Hallucinations.
- Delirium.
- Tachycardia.
- Hypertension.
- Fever.
It is important that healthcare professionals recognize the potential for alcohol withdrawal and know what signs and symptoms to look for. They should also anticipate potentially violent behavior. Early recognition and preparation for alcohol withdrawal will help to initiate appropriate treatment measures that help patients get through the withdrawal and to be prepared for potential violent outbursts.

**AUD Alert!** Remember that alcohol withdrawal is a stressful time for the patient's loved ones as well. Increase in stress and anxiety may also increase the risk of verbal and/or physical aggression!

**Side effects of prescription medications**

Mr. Bob Forrester is a 40 year-old business executive. He is hospitalized after having developed a severe, systemic fungal infection. He has been taking the antifungal drug Nizoral (ketoconazole). Mr. Forrester is sad and withdrawn and tells the nurses that he just wants to be left alone! His wife is tearful and stops at the nursing station to tell her primary nurse, Hannah, that, “I just don’t understand what is happening. Bob was always so upbeat and positive. Since he got this horrible infection he is so depressed and at times he just yells at me to leave him alone.” A pharmacist, who is a friend of the Forrester's, also happens to be present. At that moment Bob is heard shouting at another nurse. As Hannah, the pharmacist, and Mrs. Forrester hurry into the room Bob is seen throwing his water pitcher at the housekeeper and yelling, “Just get out. I want everyone to leave me alone. I don’t care if I live or die!” The pharmacist asks Hannah what medications Bob is taking and what potential side effects may occur. Using her iPad to consult her online drug reference Hannah finds that depression is a potential side effect of Nizoral.13

Sometimes it can be easy to forget that prescription medications have a wide variety of side effects, including changes in mental status. Mood changes, outbursts, agitation, and depression are just some of the side effects that can be caused by many common medications and that also can contribute to workplace violence.

If a patient is displaying unusual behaviors and outbursts of anger look up the side effects of medication he/she is taking. There are so many varied reasons for workplace violence that sometimes busy healthcare professionals forget to consider the effects of medications.

**Patient assessment**

The Joint Commissions sentinel event data base contains data pertaining to inadequate assessment as a contributing factor to workplace violence.8 As seen in the preceding section on prescription drugs, a thorough assessment of the medications Mr. Forrester was taking might have helped the nursing staff to more quickly identify his medication as a contributing factor to his behavior. A thorough patient assessment is critical to safe and appropriate patient care.

Think not only about the patient’s history and presenting clinical picture but about his home environment as well. Is there a family history of abusive behaviors? Does the patient feel safe in his/her own home? Has there been an incident in the patient’s past (e.g. experiencing a traumatic event such as rape or serving in the military in a war zone) that could affect how he/she responds to others? What pathophysiological changes have occurred that may have an adverse impact on a patient’s mental status or the ability to control anger?

Include the patient’s family in the health assessment as much as possible. They may be able to provide important information, especially if the patient is confused or incompetent. The family unit may also need to be assessed. Are they anxious and fearful? Have they been acting as the patient’s caregivers? If so, are they tired and under stress? Most families and other loved ones are worried about the patient. They (and the patient) feel a lack of control and may use aggression as a means to gain some control over a frightening situation.

Most hospital stays involve exposure to the unknown. Unpleasant, painful diagnostic tests and treatments, having to deal with a serious diagnosis, and feeling that nurses, therapists, doctors, and other healthcare professionals have “taken over” their lives definitely do not make for a calm experience. Assess patients and families for their levels of stress, coping mechanisms, and support systems.

Also, don’t forget to assess for alcohol and drug use. As pointed out in the previous section, such substances can have quite an impact on the behavior of patients and families. Equally important is to check for nicotine use. Hospitalized patients have few if any opportunities to smoke. Abrupt cessation of smoking can make for very irritating, and even aggressive, patients.

**Confused patients**

Mr. Wilson is a retired minister with a reputation as a kind, gentle man, who is a good husband and father. He recently suffered a stroke. He is confused and often verbally aggressive, cursing and shouting at staff members. His wife is heartbroken, telling nurses and therapists that her husband rarely raises his voice at home and never uses “ foul” language. Staff members try to comfort Mrs. Wilson, explaining that these behaviors can be part of the pathophysiology of stroke.

Many illnesses and injuries contribute or cause confusion, fear, and belligerence. Persons who were polite, well-mannered, and gentle may become aggressive and physically abusive. It is important to explain to families and loved ones about the reasons for these types of behaviors. It is also important to help staff members who may not have a good understanding of the pathophysiology of conditions that contribute to such behaviors. For example, dietary aids, students, housekeepers, and maintenance personnel may all come into contact with persons who are confused and belligerent. It is important that these staff members be educated about the effects problems such as stroke, dementia, and head injury can have on behavior. In fact, education concerning workplace violence and its causes should be offered to all employees, not just direct patient care providers and security guards. Workplace violence can affect any and all employees!

**Change**

Change can be seen as either positive or negative. A promotion, buying a new house, losing weight, having surgery or treatment that cures an illness may all be viewed as a positive change. Diagnosis of a serious illness, experiencing painful and otherwise difficult treatments, and hospitalization all involve change of a less pleasant nature.

Change has often been a source of conflict. Changes in policies and procedures, changes in personnel, changes in job expectations may all be greeted with distrust and even hostility.8 Patients, especially those who are inpatients or who are dealing with serious or chronic conditions, are forced to deal with a multitude of changes on an almost daily basis. Compounding the problem is that patients and their families often have no control over what is happening to them. Feelings of loss of control compounded by change can be an explosive combination.13

Consider how healthcare employees feel when changes in routine or policy are mandated without their input. This comparison can help healthcare employees to empathize with patients and families and acquire a better understanding of how they feel when confronted by the changes that occur as the result of illness or injury. Expressions of empathy and acknowledging just how difficult change can be can help to calm a patient and defuse a potentially violent situation.

**Communication**

The Joint Commission has cited inadequate communication as a potential cause of workplace violence.8 But what exactly does inadequate communication mean? Inadequate communication can mean that:

- Patients receive incorrect or contradictory information from various members of the healthcare team.
- Patients receive information in terms that they do not understand. Perhaps information contains a great deal of technical terms that are not defined. Perhaps English is not their first language and information in their native language is inadequate or not available.
- Patients are “told” what to do or what decision to make without being given enough information to make an informed decision or to provide informed consent.
- Patients are given “biased” information. In other words the healthcare professional providing information allows his/her personal beliefs and values to influence how they communicate with the patients.
 Patients are not given the opportunity to ask questions or to think about what they have been told.

 Patients overhear staff members talking about them and even ridiculing questions they ask or decisions they make.

 Patients get the impression that healthcare professionals are not really “listening” to them.

 Patients get the impression that healthcare professionals do not have time to discuss information with them.

 Patients get the impression that healthcare professionals are bored or disinterested in their health and well-being.

 Whether or not any or all of the preceding concerns are truly accurate, what matters is if the patients and/or their families think they are accurate. Failure to communicate effectively leads to feelings of fear, frustration, and, possibly anger. This anger can contribute to incidences of workplace violence.

 **Lack of a safe environment**

 All employees should ask themselves if they believe that their work environment is safe. Joint Commission findings show that 36 percent of reported workplace violence events in the sentinel event data base were due to a lack of safety in the work environment. Some deficiencies that contribute to workplace violence include:

 - Lack of effective policies and procedures that address the issue of workplace violence.
 - Lack of management commitment.
 - Lack of trained security guards.
 - Lack of sufficient numbers of security guards.
 - Inadequate system of staff and visitor identification.
 - Failure of staff members to wear employee identification.
 - Lack of education and training for employees on the topic of workplace violence and how to reduce and/or prevent it.

 **Belief that healthcare professionals don’t care about them**

 It is important that all staff members who come into contact with patients (and this includes housekeepers, volunteers, secretaries, etc.) convey the attitude that they genuinely care about all patients and their families. It is easy to become complacent about interacting with patients. And there may be some patients and family members that staff members actually dislike. It is not expected that all staff members like every patient and every patient’s family members and visitors. What is expected is that all staff members treat all patients, families, and visitors with respect and objectively do their best to promote the patients’ maximum health and wellness.

 It is not necessary to like someone to provide safe and appropriate care and to convey an attitude of compassion and empathy. If patients and their loved ones believe that the persons who are responsible for their very lives genuinely care about their welfare, chances are they will be,

 at least, minimally cooperative. If these same patients and their loved ones believe that no one cares if they get well or not, aggression is a distinct possibility.

 **Violence as part of the patient’s lifestyle**

 There are patients (and families and friends) whose lifestyle is violent. Violence is part of their everyday existence. Examples include persons who are victims of and/or perpetrators of domestic violence, gang members, persons who are involved in criminal activities, and those who have grown up in a family where verbal and/or physical violence was the norm.

 These individuals are more likely to behave in a violent manner because this is what is “normal” for them. Assessing a patient for a violent lifestyle will help to prepare staff members to deal with persons who are verbally aggressive and possibly physically aggressive.

 **Taking patient aggression personally**

 Jasmine is a nursing assistant who is Asian-American. She is taking care of an elderly patient who has dementia. The patient is usually confused and often verbally aggressive. When she sees Jasmine she screams, “Get away from me! I’m sick of all you foreigners taking over my country.” Jasmine becomes upset and begins to shout back at the patient. The situation escalates and the patient attempts to strike Jasmine.

 Most patients and families are not being deliberately aggressive. In the preceding scenario, Jasmine takes the patient’s comments personally. It can be difficult to remain calm and objective when someone is making hurtful comments. However, Jasmine’s patient is confused and suffering from dementia. It is unlikely that she has any idea of what she is saying.

 It is important that all staff members be taught ways to remain calm even in the midst of verbal aggression. It is important that all staff members be taught about the effects of disease and injury and how fear and other reasons for aggression are often due to feelings of loss of control and anxiety. Of course, there are instances when patients, families, and visitors are deliberately aggressive. Fortunately, this is usually the exception, not the norm.

 The important thing to focus on is not to take behavior personally. No matter how difficult, the first thing to do is to help healthcare workers establish an objective therapeutic relationship with patients. Understanding how and why patients behave the way they do is a foundation for establishing such a relationship.

 **Communication as the foundation for reducing/preventing workplace violence in healthcare settings**

 Communication is the foundation of practice for any healthcare organization. It is an issue that can enhance patient care and workplace safety or increase the risk for poor patient care outcomes and workplace violence. There are many aspects of communication to discuss. A good place to start is with communication among those who work in healthcare settings.

 **Communication among staff members**

 Raymond is a pharmacist making rounds with the interdisciplinary rehabilitation team on the spinal cord rehabilitation unit. He and the team are discussing concerns about one of the patients, whom they are carefully monitoring for symptoms of worsening depression. The patient has just been started on an antidepressant, and, as an 18-year-old, is at risk for an increase in suicidal thoughts when beginning antidepressant therapy. They are satisfied that he shows no evidence of such an increase. However, the housekeeper stops them in the hallway. “You had better pay more attention to that young man. His girlfriend just broke up with him last week and when no one is around I see him crying and muttering about killing himself or someone else. I told the doctor about this but she told me I was just here to clean rooms and to mind my own business!”

 This scenario is a good example of communication failure among staff members. A housekeeper’s observations can be critical to the health and well-being of patients. The willingness of physicians, nurses, pharmacists, and therapists to respectfully listen to each other cannot be stressed enough. All employees need education about preventing workplace violence and the importance of communication among all who work in the organization. Discounting important observations based on the role someone fulfills can be a dangerous mistake.

 Communication among staff members does not have to be verbal. Consider documentation. Team members do not always have the ability to discuss a patient’s status face-to-face. Patient’s lengths of stay are shorter and shorter and opportunities to communicate seem to decrease as well. Think about the pharmacist who fills prescriptions and sends medications to various patient units but must rely primarily on the patient’s medical record as a means of communication. Or the physical therapist who sees patients in the gym but seldom has an opportunity to interact with the nurses in person. Documentation must be concise and accurate and easily accessible to all. The implementation of electronic medical records has helped with accessibility. But if documentation is not complete, timely, and accurate, accessibility means nothing.

 Finally, think about how healthcare professionals communicate with each other. Do they treat each other with respect? Do they actively listen to each other? Do they take the time to relay important information? If face-to-face communication is not possible do they make time to telephone each other to relay essential information quickly? If the answer to any of these questions is “no” then changes need to be made to the way communication among staff members takes place. Active listening, genuine interest in the observations of colleagues, and the willingness to treat each other with respect are the focus of good communication among staff members.
**Good communication between staff members and patients/families**

Andy is an RN on a medical floor. He has an unusually heavy patient load today because several colleagues have called in sick. A family member wants to talk to him about her mother’s medication. Andy pauses on his way down the hall to answer her questions. The conversation is conducted in the hallway, neither of them sit down, and other staff members are constantly rushing by them. As Andy answers her questions he glances at his watch every few minutes. Finally, the family member becomes angry and says loudly, “Don’t bother with me anymore. It’s obvious you couldn’t care less. But I’ll tell you that I am not leaving here tonight until someone answers my questions properly. And I don’t want you taking care of my mother any more either!” Her voice carries down the hall and people stop and stare and listen to the confrontation.

Andy is busy and it was not the best time for him to attempt to answer the woman’s questions. But he violated almost every principle of good communication. He conducted an important conversation in a public hallway. Neither of the persons involved were in a comfortable environment. Andy kept glancing at his watch, indicating a lack of interest and/or being anxious to finish the conversation.

Failure to communicate adequately can and does increase the likelihood of workplace violence. Here are some verbal communication guidelines to help prevent patient/family anger and to defuse an angry confrontation if it does occur.1,2,9,12

- **Listen actively.** Show interest and a desire to assist the patient or family member. Maintain eye contact if culturally appropriate. Don’t indicate impatience by checking a wristwatch. If it is not understood what the patient or family member is asking, ask for clarification. Check if the patient or family member understands what is being said to her/him.

- **Listen in a timely fashion.** Consider Andy’s actions in the preceding scenario. It would have been better if he explained to his patient’s daughter that he needed to do something urgently for another patient but would return in 15 minutes (if that time frame is realistic) to talk with her. It is better to delay a conversation and set a time limit for return rather than rush through a conversation.

- **Show respect.** All human beings deserve respect. A visitor may arrive in dirty jeans and unshaven, but he still deserves to be treated with respect. Lack of respect will almost always lead to animosity. Address patients and visitors as Mr., Mrs., Ms., etc. unless invited to use first names. Never address adult patients and visitors as “honey,” “dear,” “sweetie,” or other demeaning term. They are not children. Some healthcare professionals seem to feel that patients and visitors, especially elderly patients and visitors, should be addressed as though they are children. This is demeaning and will not facilitate good communication. This principle holds true for patients who have dementia or are confused. Respect is always important and always appropriate! Say please and thank you.

- **Use a calm tone of voice.** This is always appropriate and could make the difference between calming an angry patient or family member or triggering an instance of verbal or physical aggression. Don’t be drawn into an argument. Don’t raise your voice. Try to avoid telling someone who is upset to “calm down.” This may cause the situation to escalate. Instead, ask the angry person to, “please speak more slowly so that I can understand what you are saying.”

- **Avoid public confrontations.** Do not have difficult conversations in a public place. Such conversations are best conducted in a private patient room, a private lounge, an office, etc. If family members or other visitors are involved in a conflict direct them to separate waiting areas. Do not allow quarrels and other confrontations to occur in front of patients. If patients are quarreling with visitors it may be necessary to ask the visitors to leave. Never hesitate to call for the assistance of security guards.

- **Offer options.** For example, suppose a patient is away from the nursing unit for a diagnostic test and a family member is becoming increasingly anxious. Offer the family member the choice of having a seat in the waiting room or remaining in the patient’s room. If the test will last for any length of time it may be appropriate to suggest that the family member get a snack or cup of coffee in the coffee shop.

- **Help patients/families to maintain or regain control.** Comments such as, “I understand you’re upset, what can I do to help?” Or “Take some deep breaths” or “Please sit down and breathe slowly” are simple instructions that will help them to focus on something other than fear or anger.

Monica is a 36-year-old breast cancer survivor. She has arrived at her doctor’s office for the results of some additional diagnostic tests that were conducted to determine if there is any evidence of metastasis. The office is crowded and Monica has been waiting for over 30 minutes past her scheduled appointment time. When the nurse finally escorts Monica to an exam room she apologizes to Monica for the delay. Monica responds by saying that “I know you are busy. I am sure that everything will be OK.” Monica is clenching and unclenching her fists and breathing quickly. As the doctor enters the room she shouts, “How dare you keep me waiting like this!” Both the nurse and the doctor are surprised. The nurse tells the doctor that “Monica wasn’t upset. She said she understood the delay!” Monica has “missed” important non-verbal cues that the patient was upset.

Non-verbal communication is every bit as important as verbal communication. Some sources point out that over 90 percent of communication is actually non-verbal. Here are some important guidelines for non-verbal communication.1,2,9,12

- **Be alert to early warning signs of agitation.** Early signs of increased anxiety and agitation are rapid breathing, sighing, and wringing of hands.

- **Look for discrepancies between what is said and what body language indicates.** For example, in the preceding scenario Monica says that it was OK that she had to wait and that she believed that everything would be OK. But her body language indicated otherwise. She was breathing rapidly and clenching and unclenching her fists. Pay attention to any differences between what is said and non-verbal behaviors.

- **Maintain eye contact.** When culturally appropriate maintain good eye contact. Do not “overdo” eye contact however. This can make some people uncomfortable. Experts suggest that eye contact should be made at intervals that last about four to five seconds.

- **Maintain open body language when talking to patients, families, and visitors.** Keep hands and arms at your sides or resting on a table. Lean forward slightly to show interest.

- **Avoid closed body language.** Do not cross your arms, clench your fists, or turn away from the person you are speaking to.

- **Be objective.** Do not show amusement, disdain, or disgust. Do not judge what the patient says or believes.

- **Do not interrupt.** Allow patients, family members, and visitors to finish their sentences. Avoid assuming you know what they are going to say or ask.

**Communication reminder! Aggression should not be taken personally!**

**Cultural awareness**

Joseph is a 20-year-old college student of Middle Eastern ancestry. He is hospitalized following a car accident during which he sustained multiple fractures. His female nurse asks him if he would prefer a male nurse and if he would like his bed turned to face east so that he can pray. The nurse assumes that a man of Middle Eastern ancestry is Muslim and prefers a member of the same sex as a care provider. Joseph looks puzzled and a little annoyed. He is a fourth generation American and a Christian. “Why are you assuming what I am just because of my ethnic background?”

Elizabeth is a Japanese citizen who is in the United States on a work visa. She is hospitalized...
because of a septic infection that developed after removal of an ovarian cyst. During a patient education session her nurse, a man, uses hand gestures to explain some points of care. Elizabeth is offended since, in her culture, the use of hand gestures can be insulting. It is important that culture be considered and respected when attempting to provide a safe environment for patients, families, visitors, and staff members. It is important to avoid assumptions. Cultural generalizations can be made but all persons are unique. Avoid assuming that all persons of a particular race, religion, or ethnicity will behave in the same way and have the same values and religious beliefs. But be aware of generalizations that can help reduce the risk of workplace aggression. Even some seemingly simple behaviors like eye contact and a handshake can have cultural implications. Here are some tips for ensuring cultural sensitivity:

- **Handshake:** In Western cultures the right hand is extended with the thumb up. The handshake is firm but should not cause discomfort. The hand is shaken two or three times and then released. Handshakes often differ in other cultures. For example, the Chinese and Japanese may grasp hands less firmly but hold the hand for a longer period of time. Muslim men generally do not shake the hand of a woman.

- **Eye Contact:** In the United States eye contact demonstrates interest and is part of active listening. It indicates honesty and confidence. However, in many Asian countries direct eye contact may be interpreted as disrespectful. Looking away may be an indication of respect. In Mexico direct eye contact may be interpreted as aggressive behavior while in France, eye contact may be maintained so intensely that Americans may become uncomfortable.

- **Personal Space:** Personal space varies among countries and cultures. In the U.S. personal space is usually about three feet. In Italy and South American countries the distance is closer, but in Asian countries the distance is often greater. Be guided by the other person’s body language. If they seem uncomfortable, allow a greater amount of personal space.

- **Facial Expressions:** A smile in most Western countries indicates pleasure. Americans in particular smile easily. However, people in some Asian countries may actually conceal annoyance or other negative emotions with a smile. Japanese may smile less often, believing that if one is really happy, a smile is not necessary.

- **Hand Gestures:** Hand gestures, a common practice in American culture, may be seen as signs of aggression in other countries. For example, in China and some other Asian countries hand gestures can be considered rude. Hand gestures in general are easily misunderstood. For example the thumbs up sign, an indication of approval or victory in the U.S. is considered crude in the Arab world. Winking at someone is considered rude in Australia and Taiwan. Standing with hands on hips can be interpreted as aggressive in many countries.

The preceding generalizations help to illustrate just how varied cultural considerations can be. Facial expressions, hand gestures, eye contact, and personal space are just a few of the behaviors that can offend others or help to enhance communication.

**Ensuring personal safety**

It is important to ensure personal safety when dealing with aggressive patients, families, or visitors. Violence rarely takes place without some warning such as raising one’s voice, clenching fists, and violating personal space. Part of controlling the problem of workplace violence includes ensuring your personal safety.

Here are some recommendations for maintaining personal safety:

- **Trust your instincts.** If you feel uncomfortable, recognize early warning signs of violence, or just have a “feeling” that you are in danger, trust your instincts. Use good communication techniques to defuse the situation. If this does not work, take protective measures.

- **Tell someone else of potential difficult situations.** If you know in advance that a meeting with a patient or family member is going to be or may become problematic tell at least one other co-worker where you will be meeting and how long you anticipate the meeting will take.

- **Maintain an exit pathway.** Never allow a patient, family member, visitor, etc. to get between you and an exit. Always position yourself between the person you are talking to and the exit.

- **Evaluate your environment.** Remove items that could be used as weapons such as syringes, scissors, knives from meal trays, etc. from the environment. Assess the likelihood that someone could use a chair, bedpan, meal tray, or other object as a weapon.

- **Dress appropriately.** Be aware of your appearance and what, if any, articles of clothing that could be used as weapons. Avoid tight fitting clothing that accentuate breasts and/or hips. Avoid clothing that shows cleavage. Such clothing may encourage some persons to make inappropriate remarks or sexual gestures. Avoid wearing jewelry or accessories that can be used to injure you. For example, a scarf or necklace can be pulled tight around the throat. Keys worn around the neck can be grabbed and used as a weapon. Long earrings can be pulled off, causing injury. Avoid high heels that can prevent you from moving quickly if you need to get away from a dangerous situation.

- **Know how to get help.** Know what to do in case of an emergency. Know how to quickly contact security guards. Do not be afraid to shout for help if necessary.

**Suggestions for implementing a strategic plan for preventing workplace violence**

OSHA and the Joint Commission have made a number of suggestions for the development of a strategic plan for preventing workplace violence. Some practical suggestions include the following factors:

- All healthcare organizations should have a violence prevention program in place. The program should be based on policies and procedures that are developed with input from all levels of staff and who represent all departments.

- All employees should have the opportunity to review policies and procedures and support their implementation.

- All administrators and managers must support the implementation of policies and procedures that guide the implementation of a workplace violence prevention program.

- A written plan should be in place that describes the various types of workplace violence, how to prevent their occurrence, how to deal with them if they do occur, and how to document their occurrence.

- All employees should receive education and training concerning a violence prevention program.

- The written plan should make it clear that there is zero tolerance for violence, verbal and nonverbal threats, and physical violence.

- The written plan should clearly state that no reprisals will be taken against any employee who report or experience workplace violence.

- The written plan should include a plan for establishing and maintaining security such as the hiring of security guards, mandating that all employees wear organization-mandated identification, and how to report instances of violence.

- An analysis of the workplace for the potential for violence and how well each department is equipped to deal with violent behavior should be conducted. An analysis should include:
  - Review of risk management and other data that document occurrences of workplace violence.
  - Evaluation of the physical environment for safety issues such as are fire and security doors secure, are medications secured, are employees wearing identification, are objects that could be used as weapons easily accessible to patients and visitors, and availability of security guards throughout the organization.
  - The work environment should be free from clutter so that items such as books, keys, pens, etc. cannot be used as weapons.
  - Assessment of employees’ knowledge of how to prevent and/or deal with workplace violence.
  - A system that allows for additional security precautions in high risk areas such as the emergency department should be established.

- Assessment of risk factors for violence such as substance abuse, history of domestic abuse, of domestic violence, and drug or alcohol abuse should be determined.
A system of documenting instances of workplace violence should be clearly established.

The workplace violence prevention program should include medical intervention, follow-up counseling, support groups, stress management, and employee assistance programs to help victims of workplace violence deal with the aftermath of violence.

The workplace violence prevention program should include a mechanism to analyze trends, assess strengths and weaknesses of the program, measure improvements, and maintain current knowledge of strategies to reduce the occurrence of workplace violence.

Periodic, unannounced assessments of the organization for violations of security and staff members' ability to deal with aggressive or potentially aggressive patients should be conducted.

Appropriate staff members, such as security guards and emergency department personnel, should receive training in responding to agitated, violent persons. Such training may include ways to physically restrain agitated, violent persons without causing them injury.

**Education and training**

No strategic plan can be implemented successfully unless all employees receive ongoing education and training concerning the incidence of workplace violence, how to prevent it, how to deal with it when it occurs, how to document it, and how to receive necessary follow-up help if they become victims of such violence.

Appropriate education is ongoing. A one-time discussion of policies and procedures is not enough to ensure a culture of safety. Establishing and maintaining a workplace environment that helps employees to prevent and/or reduce the incidence of workplace violence requires continuing education endeavors. The organization’s professional development/staff development department and human resource department should work with administration, management, and staff members to plan, implement, and evaluate education offerings pertaining to workplace violence prevention.

Here are some strategies for the implementation of ongoing education and training.

**Orientation**

Workplace violence prevention strategies should be part of the orientation of every employee. Topics to include are:

- A discussion of policies and procedures related to workplace violence.
- An explanation that the organization has a zero tolerance toward workplace violence.
- An explanation that there will be no reprisals or disciplinary action taken against employees who report workplace violence.
- A review of data pertaining to the occurrence of workplace violence and the organization’s response to these occurrences.
- Conditions that can predispose patients, families, and visitors to become violent.
- Reasons for the occurrence of workplace violence.
- Warning signs of escalating anger and aggression.
- Techniques to calm angry and/or agitated persons.
- How to deal with verbally and/or physically violent persons.
- How to document occurrences of workplace violence.
- How to access employee assistance if workplace violence is experienced.
- As appropriate, physical restraint and crisis management techniques to subdue violent persons.

Employees should be given the opportunity to express concerns and ask questions. The purpose of addressing workplace violence during orientation is to frighten employees but to prepare them to help prevent the problem and deal with it if they experience it.

**Education Alert! The depth and specifics of interventions will vary depending on the role of the employee in the organization. For example, a security guard or emergency department nurse may receive training in the physical restraint of violent patients. A member of the housekeeping department would most likely not receive such training.**

**Annual mandatory training**

All healthcare employees are required to participate in mandatory training on an annual basis. Common topics are infection control, safety, and risk management. As part of safety training, prevention of and dealing with workplace violence should be addressed.

Time for such training is limited. Numerous topics must be addressed within a limited time frame. Case studies, role play, and computer-based training are all ways to incorporate prevention of and dealing with workplace violence as part of annual mandatory training. Competency of staff members regarding workplace violence should be assessed. Ways to assess competency include demonstrating effective communication as part of a role play demonstration and written quizzes.

**Continuing education**

Continuing education involves offering additional information beyond what is provided during orientation and annual mandatory training. Such information might include:

- Current statistics on the incidence and prevalence of workplace violence.
- Information regarding new techniques to help calm patients, family members, and visitors.
- Data pertaining to incidence and prevalence of workplace violence occurrences within the organization including strengths and weaknesses of the organization’s workplace violence prevention program.
- Current techniques (as appropriate depending on the employee’s role in the organization) for the restraint of violent persons that can be implemented without harming those persons. Such training should be offered by educators who are trained in physical crisis management techniques.

**Simulation of workplace violence**

Simulation of clinical situations has been used as an education technique for a considerable length of time. Simulation of workplace violence can be used to prepare staff members to defuse such situations. Simulation can also be used to help staff react if violence actually occurs.

Various scenarios such as a visitor who is under the influence of alcohol, a confused patient, or a family member who is angry about the care a loved one received can be simulated.

Simulations can be conducted in a classroom setting or spontaneously enacted in the actual work setting. The focus of simulation is to help prepare staff members to better cope with the problem of workplace violence. Simulation can also be used to assess competency of staff members to defuse potentially violent situations as well as their ability to deal with actual violence.

**Summary**

In summary, violence in the workplace is a problem that must be dealt with by every organization. A zero tolerance for such violence must be clearly established and upheld by all members of the administrative and management staff. A workplace violence prevention program must be developed and implemented with the cooperation and support of all employees. Barriers to the reporting of workplace violence must be identified and eliminated, and reasons for the occurrence of such violence discussed.

All employees, including administrators and managers, must receive ongoing training and continuing education about the incidence and prevalence of workplace violence, how to prevent such violence, and how to deal with it if it occurs. Competency of the ability to help prevent and deal with workplace violence should be assessed. Workplace violence should be part of the annual mandatory training that all employees receive.

Data pertaining to the organization’s specific record of incidence and prevalence of workplace violence as well as the violence prevention program’s strengths and weaknesses should be shared with employees. Employees have the right to know just how safe their workplace is. Employees also have the responsibility to help enhance the safety of their work environment. Responsibilities include helping to write and evaluate relevant policies and procedures, participating in continuing education and training pertaining to workplace violence, and reporting unsafe conditions including documenting incidents of workplace violence. Workplace safety is the responsibility of all employees!
### DEALING WITH THE ANGRY PATIENT/FAMILY MEMBER: STRATEGIES FOR REDUCING THE RISK OF WORKPLACE VIOLENCE

#### Self Evaluation Exercises

Choose True or False for questions 1 through 10 and check your answers at the bottom of the page.

You do not need to submit this self-evaluation exercise with your participant sheet.

<table>
<thead>
<tr>
<th>Question</th>
<th>True</th>
<th>False</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Workplace violence is responsible for about 900 deaths every year in the U.S.</td>
<td>True</td>
<td>False</td>
</tr>
<tr>
<td>2. There is a consistent definition of workplace violence according to the Joint Commission.</td>
<td>True</td>
<td>False</td>
</tr>
<tr>
<td>3. Managers may discourage the reporting of workplace violence because they do not want their departments/units to acquire a negative reputation.</td>
<td>True</td>
<td>False</td>
</tr>
<tr>
<td>4. Employees may not report violence because they believe that it is just part of the job.</td>
<td>True</td>
<td>False</td>
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<tr>
<td>5. Recent studies show that patients with AUD are likely to become less aggressive as they withdraw from alcohol.</td>
<td>True</td>
<td>False</td>
</tr>
<tr>
<td>6. Prescription drugs are not likely to make a patient aggressive.</td>
<td>True</td>
<td>False</td>
</tr>
<tr>
<td>7. When attempting to calm an angry visitor it is best to speak loudly to get his/her attention.</td>
<td>True</td>
<td>False</td>
</tr>
<tr>
<td>8. It is best to maintain direct eye contact with a Mexican patient.</td>
<td>True</td>
<td>False</td>
</tr>
<tr>
<td>9. Staff members should have input into the development of workplace violence policies and procedures.</td>
<td>True</td>
<td>False</td>
</tr>
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#### References

CHAPTER 4
HORIZONTAL VIOLENCE IN HEALTH CARE ORGANIZATIONS: WHY PEERS BULLY PEERS
(5 CONTACT HOURS)

Learning objectives
- Describe the phenomenon of horizontal violence.
- Discuss the incidence and prevalence of horizontal violence.
- Discuss how horizontal violence victims are chosen by their abusers.
- Identify the characteristics of persons who commit horizontal violence.
- Explain the causes of horizontal violence.
- Analyze the impact of horizontal violence.
- Implement strategies to reduce and prevent horizontal violence.

Introduction
What first comes to mind when health care employees hear the words “violence” and “workplace”?

Many might say they think of an out-of-control emergency department patient under the influence of drugs or alcohol who attempts to harm staff members. Others may remember a confused, frightened patient who tried to strike them. Still others may think about an angry visitor who verbally abused them.

These scenarios are not uncommon and are understandable. In fact, a 2011 U.S. Department of Justice special report published findings that showed workplace violence in this country is responsible for about 900 deaths and 1.7 million nonfatal assaults annually.21 In the hospital setting, research shows that 35 percent to 80 percent of hospital staff members have been physically assaulted at least once during their careers.9

However, there is another type of violence, commonly referred to as horizontal violence, which also has far-reaching, serious consequences. These consequences affect recruitment and retention, can increase the risk of errors, decrease patient outcomes, and adversely affect the health and well-being of its victims.2,19,20 Horizontal violence, also known as HV, is aggression against peers, co-workers who are on the same hierarchical level of an organization.2,20 And some researchers believe that this type of violence has reached epidemic proportions.

HV is sometimes referred to as lateral violence, and it causes more harm than any other type of aggression in the workplace, including bullying of nurses and other health care professionals by physicians, supervisors and subordinates.2,3

The phenomenon of horizontal violence
Jackie is the nurse manager for two surgical units in a 500-bed medical center. She has been a manager for nearly three years and has been able to initiate unit-based councils on both of her units. Jackie is grooming her staff to become more autonomous, assume more responsibility for identifying goals and objectives to advance patient outcomes, and to initiate and participate in nursing research.

Members of her nursing staff excel at their jobs and have worked with the medical center’s nurse researchers on studies that have strengthened evidence-based practice and led to improved patient outcomes. When vacancies are posted for Jackie’s units, she receives numerous applications from nurses already employed at the medical center who want to transfer to her units.

However, Jackie has noticed that the more her nurses grow professionally and patient outcomes improve, the more she feels isolated from and ostracized by her fellow nurse managers. If she passes fellow managers in the hallway or in elevators, they do not speak to her and avoid eye contact. During management meetings, her comments or ideas are either ignored or ridiculed.

Jackie approaches one of her colleagues who was once a good friend and asks why she is being treated in this fashion. The former friend replies, “How do you expect us to act? You with all of your new ideas showing us up when we’ve been managers a lot longer than you have! You’re either with us or against us, and it seems to me that you’re more concerned with making yourself look good than in being one of us! And you’re stealing nurses from other units. You better stop this stuff, or you’re going to be sorry you ever took a management job!”

***

Adam is a physical therapist. He works at a prestigious rehabilitation hospital where he specializes in the therapy of patients who have suffered neurological impairment caused by spinal cord injury, brain injury and stroke. Adam is respected by his colleagues and his manager as a hard worker who is progressive in his ideas and innovative in developing plans of patient care.

He is very interested in clinical research and evidence-based practice. Because of his interest in research and his innovative clinical skills, Adam is asked to serve as the clinical research coordinator on the interdisciplinary neurologic research committee. Adam is eager to learn more about clinical research and participate in clinical research investigations.

At first, his co-workers share Adam’s enthusiasm. However, once a month Adam attends a research committee meeting, during which time his patients are covered by another therapist. As part of his duties as a member of the research committee, Adam must also, in conjunction with his manager and co-workers, schedule time to teach peers about research and participate in research projects. His peers begin to resent the time Adam is “given” for such projects, even though his new responsibilities require significant work on Adam’s part.

Adam’s peers begin to complain about him, making comments that he is not “pulling his weight” as a patient-care provider. They start to avoid Adam and often fail to include him in off-duty social activities. Adam attempts to discuss these problems with his peers, but they only comment that they are tired of doing his work. One of them explains, “You’ve so into this research thing that you are forgetting that you are just a therapist like the rest of us. You think you’re better than we are.”

Adam is shocked and asks his manager for guidance. The manager replies, “Just try not to take it personally. They’ll get over it after some time has passed and they have more chances to participate in research. Just don’t let it get to you.” Adam is upset, however, and begins to have trouble concentrating on his work.

***

Bernadette is a newly licensed RN. She is thrilled to have been hired to work on a large inpatient pediatric unit. Bernadette is assigned to work with Christine, an RN with 10 years of experience as a pediatric nurse, who will be her preceptor. Christine is an excellent clinician and has the respect of her co-workers. The nurse manager of the unit often refers to Christine as “my best nurse.”

However, as Bernadette’s orientation progresses, she finds that her co-workers not only respect Christine’s clinical knowledge but are intimidated by her as well. Christine has a reputation for criticizing her peers and subordinates in front of others if she feels that they are “asking stupid questions” or “just don’t know as much as they should.”

Christine constantly criticizes Bernadette as well, making negative comments in front of patients and telling co-workers that “I have my work cut out for me with this new nurse. They come out of school with all these fancy ideas but can’t carry a full patient load for weeks.” One of her colleagues tells Bernadette, “We’re sorry you’re going through this, but that’s just Christine. If we try to help you, she’ll turn on us, too.”

Bernadette makes an effort to talk to Christine privately about these kinds of comments. But Christine walks away from her and stops the nurse manager in the hallway. Rolling her eyes and laughing, Christine says, “I guess I’m in trouble. Our new little nurse has hurt feelings!”

Bernadette has had enough and quietly walks up to Christine and her manager. “I am willing to work hard and learn. However, Christine’s actions are interfering with my ability to learn and provide my best patient care. If these behaviors do not stop immediately, I expect to be assigned another preceptor. If this does not happen, I will file a grievance.”

Christine is astonished. No one has ever had the courage to confront her like this. The manager looks embarrassed and says that perhaps assigning another preceptor would be best.

The preceding scenarios illustrate some of the behaviors associated with HV. Horizontal
violence, as already noted, is aggressive behavior directed toward one’s peers. Such behavior can involve verbal abuse, interfering with ability to work effectively, attempts to embarrass a peer, derogatory facial expressions, and attempts to undermine a peer.2,20

The following definitions help to clarify HV and just how destructive the phenomenon can be. Some of these behaviors occur in other types of workplace violence, but for the purpose of this program, these definitions are written within the context of HV. Note that some behaviors can overlap and may fall under more than one category.

- **Assigning unrealistic patient assignments:** This involves assigning certain nurses to the most difficult patients on an ongoing basis or to an unfair workload and then refusing to help when needed.20
- **Backstabbing:** Backstabbing occurs when someone complains about a peer to others instead of speaking directly to that person about a concern or problem. This type of behavior undermines trust and confidence.19
- **Bullying:** Bullying is a set of behaviors designed to make a victim feel threatened, humiliated, insulted and helpless. These behaviors can be verbal, suggest the threat of physical harm, or even be physical actions designed to intimidate or cause physical harm. Bullying is not an isolated event. It is usually persistent, ongoing and systematic.2,19
- **Covert behaviors:** The word covert means something that is concealed or disguised. As it relates to HV, covert behaviors refer to those behaviors that are not obviously aggressive or threatening.2 Examples include being “too busy” to show a new employee where supplies are kept, excluding a colleague from social gatherings, and “forgetting” to tell a colleague about a schedule change. These kinds of behaviors can be especially hard to pinpoint because they can often easily be explained as innocent oversights. The victim of covert HV may have a hard time convincing a manager that he/she is experiencing HV if the majority of the behaviors are covert.
- **Disruptive behaviors:** Disruptive behaviors are designed to interfere with a peer’s job performance, which can increase the risk for errors and patient harm.16 Disruptive behaviors can include all types of verbal and physical aggression and threaten the safety of both its victims and patients alike.16
- **Overt behaviors:** Overt behaviors are those actions that are obviously aggressive and can be seen or heard. Overt behaviors include disgusted facial expressions, rolling of eyes, shouting, laughing at someone, criticism, fault-finding, gossiping, ridiculing and arguing.2,16
- **Sabotage:** Sabotage is behavior designed to deliberately undermine or prevent someone else from succeeding.2,18
- **The silent treatment:** Refusing to speak to a colleague, speaking abruptly, and withholding information are all behaviors that fall under the umbrella of the silent treatment.20
- **Taking the credit:** Taking credit occurs when the perpetrator of HV takes credit for someone else’s work.20
- **Verbal abuse:** Verbal abuse consists of spoken words that are meant to be unkind, belittling or humiliating. Verbal abuse is meant to cause distress, embarrassment and suffering.2

Consider how these various behaviors are presented in the scenarios at the beginning of this section. Jackie, the nurse manager, is an innovative leader whose actions have helped to establish a work environment in which her staff thrives and patient outcomes are achieved. These accomplishments have angered her peers to the point that they instigate a number of behaviors that qualify as HV.

They avoid speaking to her and avoid making eye contact. Such behaviors may be classified as covert because it can be difficult to prove that they are deliberately not speaking to her and avoiding eye contact. However, some of their other actions verge on verbal threats and intimidation. They ridicule her ideas, accuse her of “stealing” their staff nurses, and come close to overtly threatening her with the statement, “You better stop this stuff or you’re going to be sorry you ever took a management job!”

Some staff members may not realize that managers are also victims of HV. They may assume that the phenomenon only exists at the staff level. Sadly, HV occurs at all levels of the organization. Jackie’s peers may be jealous, fearful that her success threatens their own jobs, or simply resentful of change.

Whatever the reason or reasons, Jackie is dealing with HV at its worst. If she appeases her peers, it is likely that patient outcomes and job performance may be compromised. If she continues to fulfill her management role as she believes best, her peers may make it difficult for her to continue working within this organization.

Now evaluate the situation that Adam, the physical therapist interested in clinical research, finds himself facing. At first, his colleagues are supportive and share his enthusiasm for the research process. Then, as workload increases related to research participation, his peers begin to resent Adam, claiming that he now thinks he is “better” than the rest of them.

Adam’s manager seems to want to ignore the problem, telling him, “Just don’t let it get to you.” This type of managerial response is one reason that HV exists and a reason that victims fail to report it. Because of the HV, Adam is starting to have trouble concentrating on his work, which increases the possibility of error. What began as an exciting career opportunity has turned into a frustrating barrier to job satisfaction and the potential for compromised patient care.

Finally, review the scenario that describes the problems a newly licensed nurse had to deal with during her orientation. HV committed by a preceptor and other, more experienced colleagues, is one of the most common occurrences of HV. An experienced nurse, reported to be an excellent clinician, is acting as the preceptor for a new nurse. This preceptor intimidates her co-workers, and probably her nurse manager as well.

Bernadette, the new nurse, confronts the preceptor and the manager about the HV. Bernadette took action that all too few victims of HV have the courage to do: She confronted the perpetrator and the manager who seems to be willing to ignore the HV and the impact it has.

The preceding examples show just a few of the many ways that HV is committed. Note that persons who witness or know about HV and fail to do anything to stop it are just as responsible for the continuance of the problem as are those who directly commit HV.

Incidence and prevalence of horizontal violence

Diana and her husband have recently relocated across the country so that her husband can take advantage of a work-related promotion. She is a social worker with several years of experience in the acute hospital setting. Diana interviews for a position in a large community hospital, hoping to continue working with intensive care unit (ICU) patients and their families. She has heard rumors that the social workers who work in the ICU are a close-knit group who do not necessarily welcome newcomers.

During her interview with the director of the department, Diana asks about the orientation process and the hospital’s policies relating to HV. The department director laughs and says, “That’s a problem pretty much confined to nursing. You don’t see it in other departments.” Diana wonders if the director is naive or just reluctant to address the issue.

Edward is an information technology (IT) specialist in a large urban medical center. He notices that one of his colleagues seems to make it especially tough on new employees. Frank is one of the best IT specialists Edward has ever worked with, but he has the reputation of being a bully, and more than one employee has resigned because of his intimidating manner.

Edward discusses the issue with his wife, a nurse, who tells him that Frank is committing HV and needs to be stopped. Edward admits that he never thought much about the effects of Frank’s behavior until now. He always thought it was just Frank’s personality, but now wonders if it’s a lot more serious than that.

HV is not a new phenomenon, and as the preceding examples show, it can affect any and all health care professions. In fact, its occurrence and negative impact seems to be growing.2 It is difficult to objectively determine whether this
growth indicates an actual increase in occurrence or an increase in reporting by victims.

What research has been conducted on the phenomenon of HV? To date, the majority of published findings deals with research conducted on nurses, and much of that research was initiated in the United Kingdom and Australia. However, American experts such as Kathleen Bartholomew are swiftly becoming well known and have published articles and books that deal with incidence and prevalence of HV, why it occurs, and what can be done to stop it.

The following information on incidence and prevalence of HV and other types of bullying was obtained from nursing investigations. As of this writing, Internet searches regarding HV and other health care professions produced only a few articles on the topic, and those dealt primarily with how to deal with its occurrence. Estimates of HV in the nursing workplace range from 46 percent-100 percent.

Results from one nursing study showed that one-third of the nurse respondents perceived that they experienced emotional abuse during the last five shifts they worked. International studies indicate that one in three nurses intends to leave her present position because of HV.

The results of a United Kingdom study of 4,500 nurses showed that one in six had experienced what was described as “workplace mistreatment,” and 33 percent planned to resign from their present jobs because of being verbally abused.

A survey of 1,100 nurses employed by a National Health Service Community Trust in England reported that 30 percent of those nurses reported being victims of HV on a daily or near daily basis.

A study of emergency department nurses indicated that about 27 percent of participants had experienced workplace bullying within the last six months.

The staff of the professional journal Nursing 2011 conducted a survey of 950 nurses, asking them to identify the frequency with which nurses experience or witness HV. Eighty-two per cent of respondents reported experiencing or witnessing at least one type of HV on a weekly or daily basis.

Despite the growing incidence and prevalence of HV or lateral violence, some administrators, managers, and even staff members fail to recognize or acknowledge it as a serious problem. Amazingly, even some perpetrators do not realize that their behaviors are actually a form of workplace violence. This lack of recognition makes it even more difficult to control HV. As Bartholomew, one of the experts in this field, points out, “Bullying behaviors are like gangrene – when tolerated from a few physicians or nurses with strong personalities, the behaviors spread and infect the entire team – and eventually, the patient.”

Choosing victims

How does one become a victim of HV? How are victims chosen by those who commit HV? Consciously or unconsciously, victims are usually carefully selected by their perpetrators. Victims are usually among the most vulnerable of staff members. They may be newly licensed professionals or newly hired colleagues who lack confidence and are without power or workplace friends who could help them adjust to their new environment or protect them from those who commit HV.

Researchers have identified certain factors that may make someone more vulnerable to HV. These include being:

- A new graduate or newly hired staff member.
- Someone who has received a promotion or honor that causes resentment or envy among co-workers.
- A person who has problems working well with others or who has trouble acquiring new skills.
- Someone who receives special attention or recognition from supervisors or physicians.
- Someone who appears to lack confidence.

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- Someone who appears to lack confidence.

HV Warning! Severe or chronic understaffing contributes to the risk of HV.

Characteristics of persons who commit horizontal violence

Roseanne is a pediatric nurse who has extensive knowledge and expertise in this specialty. She has a reputation for being “hard” on her colleagues. She is quick to criticize her colleagues, and the new nurses she helps to orient often resign before completing orientation.

Roseanne does not see herself as intimidating. She sincerely believes that she is acting in the best interest of the patients by “protecting” them from nurses who are not as “smart” as she is.

When Roseanne arrives at work, the nurse manager asks to speak to her in private. He tells Roseanne that she has been named in a grievance filed by one of her colleagues who recently requested transfer to another unit. Both the manager and Roseanne have been named in the grievance as committing HV. Roseanne for her HV behaviors and the manager for failing to stop the behaviors even after the nurse brought them to his attention.

Roseanne is outraged. “I’m only doing my job! I haven’t done anything wrong!”

Most people, especially victims of HV, assume that those who commit HV know exactly what they are doing when they bully and intimidate others. However, many of those perpetrators of HV do not acknowledge their behaviors as damaging nor do they see themselves as bullies. In fact, many abusive, disruptive actions are committed without awareness; persons committing HV often do so without awareness.

Consider the many causes of HV discussed earlier in this program. These reasons give clues to the characteristics of those who commit HV.

These characteristics include:

- A need for power and control. Persons who have power and control at work are often willing to behave disruptively in order to maintain them. Persons who aspire to have power and control may likewise use aggressive tactics to acquire them.
- Fear. Persons who are fearful of being overshadowed by younger, less experienced colleagues may target these colleagues to secure their own places within an organization.
- Unhappiness at work or at home. Persons who are unhappy at work or at home may treat others badly. Without knowing it, they may be trying to make others as unhappy as they are.
- Inability to see the effects of their behaviors. Perpetrators of HV often refuse to see that their behavior has a negative impact on co-workers, patient outcomes and the work environment.

The preceding characteristics are not all-inclusive. They do, however, offer some awareness of the types of persons who are likely to commit HV.

Possible causes of horizontal violence

There are numerous possible causes of HV. They vary depending on the person committing the violence and the workplace environment. There may be more than one trigger of HV. In fact, it is usual to have several factors that come together to instigate HV.

Envy

Lisa is a highly skilled critical care nurse. She is accustomed to being seen as the “expert” by her colleagues. About two years ago, Lisa helped to orient Sophie, a nurse who is now referred to as “one of the best nurses” by colleagues, the manager and physicians alike. Lisa liked Sophie when she was a new nurse who was in awe of Lisa and her clinical skills. Now Lisa is afraid that Sophie is taking her place as the clinical leader on the intensive care unit. The two women are assigned to work on developing a research proposal. The day the proposal is to be presented to the institutional review board (IRB), Sophie is sick. Lisa presents the proposal as entirely her own work and implies that Sophie did nothing to help with its development.

The preceding example illustrates one possible cause of HV: envy. Envy or jealousy is an attitude that is usually accompanied by bitterness and resentment. Envy may be related, as in Lisa’s case, to jealousy of a colleague’s clinical skills and the fear that the role of acknowledged clinical expert is going to be lost. Other work-related reasons for
envy that leads to HV may include jealousy of persons who seem to have developed professional friendships with managers or other administrative personnel, jealousy of persons who have received promotions or other career advancement opportunities, and jealousy of persons who have the opportunity to pursue education opportunities such as graduate education.

But envy does not have to be limited to jealousy of work-related issues. Perpetrators of HV may be jealous of a peer’s personal life. They may envy someone who has a loving spouse or significant other, children, or a close circle of friends. This envy may cause them to retaliate by committing HV against those whom they envy.

Control and power

Jason is the manager of a physical therapy department in a small rural hospital. He has been the manager for more than 15 years and has more managerial experience than most of the managers of other departments. Seniority and experience are greatly valued in this hospital, and the chief executive officer (CEO) supports Jason as one of the key decision-makers of the organization. Jason is confident in his ability and in the professional rapport he has established with the CEO. Jason gets a lot of satisfaction knowing that his experience is valued.

He controls his department strictly and is rather autocratic in his management style. Jason discourages change and innovation, and most of the other managers would rather agree with him than “get on his bad side.” He believes that his way is best because his department has a record of achieving patient outcomes, the respect of the physicians, and a low incidence of adverse occurrences.

Turnover is low, and Jason knows it is likely to remain low because his hospital is the only one in the immediate geographic area. However, things start to change when the CEO retires and a new administrator assumes responsibility for fulfilling a mandate from the board of directors: expand outpatient services by establishing an outpatient therapy clinic. Several new managers are hired for various departments, including occupational therapy, nursing and cardiac rehabilitation. These managers are eager to initiate planned changes to fulfill the board of directors’ mandate. They have skills and ideas that are openly praised by the new CEO.

Jason believes he is losing control over the organization that he has helped to guide for many years. In an effort to maintain this control, Jason begins to target the new managers by complaining about them behind their backs and telling the new CEO that “these new people don’t know what they’re doing.” Jason’s behavior causes a great deal of dissention among the management staff and effectively slows progress on development of the outpatient services.

The need for control often co-exists with envy. In Jason’s case, he may be envious of the new managers’ skills and ideas that are obviously valued by the new CEO. He is also determined not to lose control over his work situation. He is equally determined not to lose the power he has had for many years, thanks to his seniority and friendship with the former CEO.

The need for power and control often go hand-in-hand. Jason has lost sight of the goals of the organization. He commits HV in order to try to maintain his sense of control and power over others, which, if left unchecked, can become the defining characteristic of his organization.

Fear

JoAnne is an RN who has an associate degree. She has been a nurse for five years and consistently receives excellent performance evaluations. Recently, the health care system for which she works has announced that beginning immediately, RN vacancies will be filled only with nurses who have BSNs. Nurses who do not have BSNs will not be terminated, but they will not be eligible for promotion to certain levels of staff nurse, nor will they be eligible to apply for managerial positions. The health care system offers tuition reimbursement, and some college courses will be offered at the hospital in an effort to facilitate nurses’ ability to obtain their BSN degrees.

JoAnne is very angry. She does not want to go back to school and is afraid that her job will eventually be in jeopardy. As her resentment grows, she starts to encourage other nurses who do not have BSNs to avoid colleagues who do. She instigates a campaign of “silent treatment” toward these colleagues, and as nurses with BSN degrees are hired, JoAnne makes sure to spread gossip about their lack of knowledge and skill.

Fear is a powerful motivator. Fear of change, fear of loss of respect, and, as in JoAnne’s case, fear of job loss all contribute to fear as a cause of HV. Fear is closely aligned with envy and a need for control. Some perpetrators of HV commit aggressive acts in an effort to gain or maintain control over situations that they perceive to be threatening or harmful.

The need to belong

Henry is an occupational therapist who works at a prestigious spinal cord injury center. He is a member of an interdisciplinary team that has a national reputation for excellence. The work is hard but rewarding, and there are multiple applicants for every vacancy that is posted.

When Henry was hired almost two years ago, he had to struggle long and hard to be accepted by the team. He experienced a variety of HV actions committed by members from the occupational therapy, physical therapy and nursing departments. He tries to convince himself that his colleagues’ behaviors made him a better therapist because he had to excel to prove himself to be a competent member of the team. Henry is relieved that after nearly two years, he is an accepted member of the team.

Recently, a new occupational therapist joined the organization, and Henry observes that many of the colleagues who were “hard” on him are bullying and intimidating the new therapist. Henry would like to help his new colleague but is afraid that if he does, he will lose the acceptance he worked so hard to gain. He tells himself that his new colleague will survive and that this is just something all new hires must go through. But he feels guilty and a bit ashamed of his own failure to try to put a stop to the aggressive actions of others.

The need to belong is powerful and, as in Henry’s situation, it is often accompanied by fear. This can be fear of loss of friendship, fear of not being “part of the team,” and fear of retaliation. If Henry would try to help his new colleague, would he once again become a victim of HV?

Some former victims of HV may participate in it in an effort to appease the person or persons who commit HV. Persons like Henry may ignore or go along with HV in an effort to avoid becoming victims again.

HV Warning! Persons who ignore HV are just as guilty of aggression as those who actually commit this type of aggression.

Blaming the victim for the occurrence of horizontal violence

Stephanie is a critical care nurse who works in a large trauma center emergency room. The work is extremely challenging, and only those nurses with excellent trauma skills and stamina survive the hectic pace and demanding work schedule.

Stephanie is assigned to participate in the orientation of most newly hired nurses. She criticizes them in public and ridicules them for asking “too many questions.” She also criticizes even her experienced peers in this manner. The turnover rate is quite high and many of those who resign mention that Stephanie’s behavior was a major factor in their decision to leave.

Stephanie’s manager asks to speak to her in private. The manager shows Stephanie documentation that links her behavior to the resignation of 10 highly qualified nurses during the past 12 months. Stephanie responds by rolling her eyes and saying “If they can’t stand the pressure and a little honest criticism, then they don’t belong here. They deserved what they got. I’m not here to babysit new nurses!”
This scenario is a good example of blaming the victim, a justification sometimes used by those who commit HV. In other words, it’s the victim’s fault that he or she was subjected to HV. 2,5,20 Persons who commit HV may justify their behavior with excuses such as:

- These people who are complaining that they are too poorly treated are just looking for ways to excuse the fact that they can’t do the jobs they were hired for.
- Some people just can’t take criticism.
- I was just kidding around. They can’t take a joke.
- If they can’t take the pressure of working here, then they should just leave. It’s their fault if they can’t work up to my standards.

In the minds of these perpetrators, their victims were “asking for it.” They truly believe that the victims, not the persons who commit HV, are at fault. In other words, “they brought it on themselves.”

**Initiation or rite of passage**

Sarah is a new social worker. She works in an outpatient oncology clinic. After another hard day at work during which she was assigned the most difficult patients, ignored by her co-workers, and asked to work on Saturday even though this should have been her weekend off, Sarah thinks, “I feel as though I’m back at college and going through ‘hazing’ week in order to be initiated into my sorority. I didn’t think people acted like this in the real world.”

Initiation or rite of passage as an excuse for HV may seem, as Sarah thinks, like going through the hazing process conducted by college fraternities and sororities. Viewed by some who commit HV as “paying your dues,” this concept justifies HV as something that every employee must go through to work on a particular unit, assigned to them and that they “have what it takes” to work on a particular unit, in a certain department or for a specific organization.

Persons who use rite of passage or initiation as an excuse to commit HV have probably had to go through a similar “initiation” themselves. Therefore, in their minds, because they were once treated poorly, everyone who follows them must also be treated poorly. 5,20

**Opposition to change**

Louis is a respiratory therapist. He has worked at a large, long-term care facility for several years. Louis enjoys his job and likes having the chance to get to know patients and families as opposed to the hectic pace of acute care.

When he arrives at work one morning, his manager tells him that the owners of the facility have decided to build an addition to the building. This addition will be the location of a new program that will offer short-term stays for patients needing rehabilitation after suffering a stroke and other debilitating conditions. Louis is told that he and the other therapists will need to “rotate” through this unit to provide respiratory care to these short-term patients.

Louis is annoyed and immediately begins to wonder whether this change will lead to more change and more “problems.” He worries that his job responsibilities will change and that he may not be able to deal with acute patient rehabilitation needs. How will these changes affect his work schedule? Will his job be in jeopardy?

Several of Louis’ colleagues are enthusiastic about the new rehabilitation program and talk about taking some continuing education courses to prepare for the new patient population. Now Louis begins to worry that these colleagues will outshine him when the new program is implemented. Louis begins to ridicule his colleagues’ enthusiasm. He opposes their ideas in staff meetings and complains to his manager that they are so busy preparing for new types of patients that they are neglecting their current job responsibilities. Louis’ fear of change is triggering HV.

The workplace literature is filled with references on change and how much opposition change triggers. Change often triggers worry and fear. 2,3,17 The preceding scenario shows that people like Louis react to change (and their own fears and concerns) by lashing out at co-workers and committing HV.

**Generational differences**

The term “generation gap” has been around for a very long time. Conflicts among generations come from differences in upbringing, education and experiences of world events. For example, older adults remember a time when homes and cars could safely remain unlocked, while young colleagues can’t imagine a world in which not only homes and cars must be secured but even school buildings as well.

Baby boomers entered a workplace in which employees saw themselves in terms of the organizations for which they worked. Succeeding generations who saw their parents downsized, sometimes after years of working for one organization, developed a loyalty to themselves, not to their places of employment. They are usually accustomed to change and consider it the norm, not the exception.

Professionally, they see themselves in terms of their professions, not in terms of their employers. The newest members of the workforce expect flexibility in work hours and a work environment that offers time for “fun” as well as time for serious discussion. They are accustomed to conducting life at breakneck speed, thanks to the instant means of communication (e.g.,

Internet, texting, iPads and so on) and learning opportunities now available. 1

No matter what generation an employee represents, there are certain principles that apply to everyone when it comes to a healthy work environment and to the reduction of HV. Here are some guidelines to help bridge the generation gap. 1

- Remember not to generalize about people because of their age, education or work experience. For example, don’t assume that an older colleague is computer illiterate. He or she may thrive on technology. Don’t assume that younger colleagues automatically adapt well to change. They may be significantly opposed to change!

- All adults, no matter their age or professional experience, bring an abundance of life experiences with them to the work setting. These experiences usually enhance an adult’s ability to fulfill their role responsibilities.

- All adults, no matter their age, background or professional experience, deserve to be treated with respect.

- HV is not limited to an older colleague victimizing a younger colleague. HV can be committed by a member of any generation against members of any other generation, including their own generational peers.

**Oppression theory**

Oppression theory is based on the belief that whenever two or more groups co-exist and one group has more power than another, a power imbalance exists. This imbalance leads to the development of a dominant group and a subordinate group. When the values of the subordinate group are ignored, ridiculed or repressed, oppression occurs. 2

Experts in the field of HV often apply oppression theory to HV in the nursing profession. Why is this so? Some believe that from its conception, the members of the nursing profession were told to assume a subordinate position, which almost automatically predisposed them to oppression. 2

Some experts believe that academic education may be ineffectual in preparing nurses to deal with bullying at all levels. It is imperative that, as part of their basic education preparation, nurses be taught to project confidence and deal with conflict effectively. 20 Without this preparation, nurses are in danger of completing their entry level education feeling uncertain and dependent.

When nursing was initially established as a profession, all or nearly all of its practitioners were women at a time when women had few, if any, legal rights. In most countries they could not vote, own property, or in some cases, even inherit money or property. Women were not
expected to work unless absolutely necessary, and work opportunities were limited to domestic service, teaching and other jobs that were deemed “acceptable” for women.

Nursing offered another opportunity for women to earn their own livings, but, again, in order to be considered respectable, nursing was advertised as a “calling” or a desire to do “God’s work.” Such beliefs led to the image of nurses as: 2

- Always caring and compassionate.
- Being “angels of mercy.”
- Willing to work long hours without reward.
- Never complaining.
- Fulfilling a subordinate role.

Although the preceding beliefs, thanks to advancements in nursing education and training, are beginning to fade, research shows that some people, even health care colleagues in other disciplines, continue to uphold these beliefs. This prolongs what is sometimes referred to as the culture of oppression in nursing. 2

Persons who believe that they are members of a subordinate group may feel that they are oppressed and powerless. According to oppression theorists, these feelings lead to hostility, anger and the desire for control. One way of gaining control is to oppress others, whether it be out of frustration, anger or simply the desire to subordinate others as a way of responding to subordination that HV perpetrators are experiencing themselves.2

It is wrong to assume, however, that other disciplines do not experience oppression. It is also wrong to assume that male nurses do not experience oppression. This phenomenon can affect anyone depending on the work environment and other factors that contribute to the development of HV. It has been suggested that one reason for a lack of HV research in professions other than nursing is a failure to admit that HV exists. Sadly, some health care managers and staff members ignore the problem, try to hide its existence, or simply refuse to believe that HV behaviors are harmful. Consider just how powerful this failure can be as a trigger for HV.

Failure to admit that HV exists
Paula is an RN who has worked on various oncology units for the last seven years. She recently relocated from a small city to a large urban area. She interviews at several hospitals. Two questions Paula routinely asks the manager and staff members are “How do you deal with horizontal violence? And “What hospital policies and procedures are in place to discourage workplace violence, including HV?” If either a manager or his/her staff members deny that HV exists, Paula knows that she does not want to work for their organizations. She knows that HV exists, to varying degrees, in all organizations. Paula expects an honest appraisal of the problem and information about hospital policies and procedures pertaining to HV. Having experienced HV in the past, Paula has learned to evaluate how potential employers work to reduce or eliminate the problem.

There are many reasons that HV is not recognized or acknowledged and even some excuses for its occurrence. Here are some managerial reasons and excuses for allowing the problem to continue.2,5,10,20

- Managers may be reluctant to implement policies and procedures on HV because they are afraid that their departments may acquire a reputation for unpleasant working conditions, which may interfere with recruitment efforts.
- Managers may ignore or downplay the problem of HV for fear of offending the perpetrators. Persons who commit HV may be some of the most experienced clinicians. Some managers are willing to put up with bullies who instigate HV if they are valued by management for their clinical expertise or other job-related skills.
- Managers may fail to acknowledge HV for fear that their supervisors and administrative staff will believe that they cannot deal with personnel problems.
- Managers may believe that a certain amount of bullying is necessary to identify employees who lack confidence and assertiveness.
- Managers may be unaware of the adverse effects of HV and assume that it is not a serious problem.
- Managers may actually believe that employees must go through a rite of passage to work in their departments.

The preceding are a few examples of reasons management staff may give for failure to admit that HV exists. Here are some reasons staff members and peers may give for failing to admit that HV is a significant problem.2,5,10,20

- Claiming that HV exists is just an excuse for weak or ineffectual staff members to make trouble. As previously noted, persons most vulnerable to HV are those who are new to the organization, lack confidence or seem unsure of themselves.
- Having to deal with HV is just part of the job. “If people can’t deal with criticism, then they don’t belong here!”
- “I had to go through it, and so should everybody else.” This idea correlates with the belief that bullying is part of the initiation process new employees must go through.
- “I feel bad when I see new people getting abused. But if I say something, I’m afraid they’ll go after me too.” Fear is a powerful motivator for ignoring HV.

Finally, one reason for ignoring the problem of HV or dismissing it as unimportant may be that managers and staff members alike do not realize the serious impact HV can have on its victims, patients and the organization.

The impact of horizontal violence
The impact of HV is toxic to patients, victims and the organization in which it takes place.3

HV takes a toll on the physical and mental health of its victims, puts patients’ safety at risk by increasing the potential for error, and costs the organization thousands upon thousands of dollars.3,20 Any plan to reduce and prevent the occurrence of HV must begin with an analysis of the impact of HV.

Impact on patients
Veronica is a physical therapist with several years of experience in acute care settings. She has worked with orthopedic patients for several years but has always been especially interested in the physical rehabilitation of stroke patients. She works in a large health system that consists of a large acute care hospital, several outpatient clinic, and a rehabilitation hospital.

A vacancy in the rehabilitation hospital would allow her the opportunity to work with stroke patients and expand her knowledge of neurologic physical therapy. She applies for and is hired to fill the position in the rehabilitation hospital. However, her new colleagues are less than welcoming. She receives little orientation to her new duties, and her co-workers are always “too busy” to help her adjust to her new job. She overhears them complaining about her. Apparently, they wanted another candidate to fill the vacancy for which Veronica was hired. She hears them conspire to make things difficult for her so that she will “go back to orthopedics where she belongs.”

Part of making things difficult includes failing to communicate some essential patient information about one of Veronica’s patients. This patient began a new medication that may cause him to have trouble concentrating until he adapts to its effects. Not knowing about the medication, Veronica continues to teach the patient how to transfer from wheelchair to toilet. The patient is unable to concentrate and loses his balance. Veronica is able to stop him from falling, and as she attempts to lower him back to his wheelchair she calls out for help. Her colleagues take their time coming to her assistance, and when they arrive, they find both Veronica and the patient on the floor. The patient has a laceration of her forehead and Veronica suffers muscle damage to her lower back.

HV interferes with effective communication among colleagues. Experts agree that inadequate communication interferes with the exchange of information critical to the safety and well-being of patients.3,5,10 The potential for errors increases, and if errors occur, patients can be injured and desired outcomes compromised. The preceding scenario may seem extreme, but, unfortunately, similar situations have been known to take place. It is doubtful that Veronica’s colleagues wanted to see either her or her patient suffer injury. But sometimes those who commit HV are so intent on intimidating their victims, they fail to consider just how serious the consequences of HV can be.

The Joint Commission has made references about the impact of HV on patient care and safety. The blog The Joint Commission Journal on Quality and Patient Safety noted that “Whether conflicts openly threaten a major disruption of hospital operations or whether unresolved conflicts
lurk beneath the surface of daily interactions, unaddressed conflict can undermine a hospital’s efforts to ensure safe, high-quality patient care.”

Communication breakdown is not the only factor that can lead to patient harm. If victims of HV are flustered, uncertain and experience a decrease in confidence, they are more likely to make mistakes. HV perpetrators may not want their victims to succeed at work. However, what they often fail to understand is that setting up a peer for failure can also set up a patient for serious harm.

The point is, HV violence creates a workplace environment that is dangerous to victims and patients alike. In fact, HV victims may experience damage to their physical and mental health and well-being.

Impact on physical health

Leslie is an occupational therapist who works in a large medical center. The occupational therapy (OT) department is divided into units, and each unit is responsible for specific specialty areas. Leslie was just promoted to the position of manager of OT for the spinal cord center. She is excited about this new career opportunity. However, her managerial peers are less than welcoming, and she becomes a victim of their HV.

Leslie becomes anxious and stressed, and in her words, “I seem to ‘catch’ every cold and virus that is going around.” One of her peers comments that “Leslie sure takes a lot of sick time. And when she is at work, she always seems to have a cold or a sore throat or something. I don’t even like to be around someone who is sick all of the time!”

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Tim is a nurse on the pediatric unit. He has five years of experience in the specialty, and his performance evaluations are consistently excellent. However, one of his peers, Kathy, a nurse with 30 years of experience as a pediatric nurse, dislikes Tim. She believes that it is “unnatural” for a man to want to work in pediatrics but is careful not to say so at work. She rolls her eyes when he speaks during staff meetings and goes out of her way to make sarcastic “jokes” about him to their peers.

Tim has attempted to discuss her behavior with her, but she claims she isn’t doing anything wrong. Their nurse manager tells Tim that unless Kathy does something that can be proven as HV, there is nothing that can be done. Tim begins to avoid Kathy as much as possible.

He notices that he is experiencing a rapid heart rate and some “skipped beats” that he attributes to caffeine intake, even though he rarely drinks caffeinated beverages. His wife encourages him to see his physician. Tim reluctantly does so. After a thorough physical exam, his physician begins to suspect that Tim’s rapid heart rate and minor arrhythmia are stress related.

The preceding scenarios show that HV has a physical impact on those who experience it. HV causes stress and anxiety. The health care literature is filled with references to stress and its impact on the body. The stress triggered by HV can have detrimental effects on physical health.

A review of the literature shows that the following physical effects are found in many victims of HV:

- **Decrease in the effectiveness of the immune system.** When the immune system is compromised, the body’s resistance to infection is decreased, and the affected person is more vulnerable to illness.
- **Increased likelihood of accidents and injury.** Stress interferes with a person’s ability to concentrate and focus on tasks. Lack of focus and concentration makes a person more likely to make mistakes, have accidents and suffer injury.
- **Increase in the incidence of cardiac arrhythmias.** Stress can have an adverse effect on the cardiovascular system, causing problems such as elevating blood pressure and heart rate and causing arrhythmias.
- **Increase in sick days taken.** The negative impact on the immune system and the cardiovascular system as well as the increased likelihood of accidents and injury all contribute to an increase in the number of sick days taken from work.

**HV Warning! Sick days not only have an impact on the person who is ill but on the organization as well. Sick days cost the organization a considerable amount of money, and research suggests that this amount could run into many thousands of dollars annually. Results from an Australian study show that 34 percent of nurses who experience HV take more than 50 sick days per year.”

Impact on psychosocial health

Jay is a neuropsychologist who works in a prestigious medical center in a large American city. The work environment is quite competitive, and the incidence of HV is high as Jay and his colleagues compete for career advancement. Jay, the youngest member of the staff, is often subjected to HV by his older colleagues who resent their younger, highly skilled colleague.

Jay finds himself becoming quite irritable and is increasingly short-tempered with his wife and children. One evening Jay’s 5-year-old son forgets to put his toys away as he has been learning to do. Jay shouts at the boy and tells him that as a punishment he is going to give away the boy’s new tricycle. The boy bursts into tears and runs to his room. Jay’s wife is furious and tells him, “I’ve had enough! It’s the horrible people at work who are giving you trouble, not me or the kids! Either figure out a way to solve the problem or you can find someplace else to live!”

***

Wendy is a nurse practitioner who works in a large outpatient clinic. She exerts at her job and has the respect of her supervisors and peers.

Five years ago, Wendy was the victim of HV so severe that she filed a lawsuit against her former employer. Wendy still has nightmares about the HV and sometimes finds herself suffering from periods of severe anxiety when she remembers the abuse she suffered.

***

Raymond is an RN working in a neurologic intensive care unit. The work environment is quite stressful. There is little trust among members of the nursing staff, who always seem ready to discredit a colleague in an attempt to gain the attention of the physicians and nurse manager.

Raymond usually has a couple of glasses of scotch every evening to “relax” after work. Lately, his friends notice that instead of “a couple” of drinks, Raymond has taken to drinking so much that he has to be driven home because he is too drunk to safely drive.

HV can cause serious psychosocial problems as well as physical illness. These problems can range from slight anxiety to major depression, substance abuse and damage to interpersonal relationships. The following psychosocial effects have been reported by some victims of HV:

- **Feelings of anger, irritability and aggression.** Victims of HV often find themselves experiencing and displaying anger and irritability to an unusual degree. Aggressive behaviors such as road rage and arguing with friends and family over trivialities to an excessive degree may also occur. The first scenario in this section describes how Jay’s anger and frustration are being taken out on his family at home.

- **Damage to interpersonal relationships.** The first scenario also shows that Jay’s aggressive behaviors at home are having a damaging impact on his relationships with his wife and children. This kind of damage does not have to be limited to spouse and children. All types of interpersonal relationships can suffer, including those with a significant other, friends, parents and siblings.

- **Depression.** Clinical depression may also occur as a result of HV. Depression can impact all facets of a person’s life. Depression can become so severe that the person loses interest in work, leisure activities and interpersonal relationships. Suicidal thoughts may even occur.

- **Decreased self-esteem and self worth.** Feelings of worthlessness may occur. The victim of HV may begin to believe that he or she is unable to live a productive life. Confidence is destroyed. These kinds of feelings are also symptomatic of depression.

- **Feelings of loss of control over many aspects of life.** These feelings may begin with a loss of control over their work environment as the perpetrators of HV assume toxic control over the workplace. These feelings may spread into the victim’s personal life as well.

- **Decrease in motivation.** The victim of HV may lose interest in work. He or she believes
that the workplace is so toxic that there is no point in trying to do a good job. This lack of motivation may also affect the victim’s personal life. Family and friends may notice that the affected individual has no interest in home and family or in the pursuit of leisure activities. He or she may seem lethargic and apathetic and have no interest in their normal activities. These feelings and behaviors can also be symptomatic of depression.

- **Substance abuse.** Raymond, in the preceding third scenario, has begun to use alcohol to relax and forget about his problems at work. There are a variety of substances that can be abused. In addition to alcohol, prescription drugs and illegal drugs may also be abused. Food is another substance that can be abused. Over-eating may be a coping mechanism when trying to deal with the effects of HV.

Post-traumatic stress disorder (PTSD) is a mental health disorder that can develop as a result of experiencing a traumatic event such as HV. PTSD is characterized by ongoing anxiety, panic attacks, aggressive outbursts, having nightmares about the traumatic event, having “flashbacks” during which the event is relived, and avoiding situations and activities that remind the person of the stressful event. To qualify as PTSD, these symptoms must last for at least one month following the traumatic event.  

**HV Warning!** As in the case of Wendy in the second scenario at the beginning of this section, PTSD can continue to affect people for years after experiencing the traumatic event that triggered the disorder. Some researcher shows that 50 percent of persons who experienced HV suffer from stress and PTSD for as long as five years after the event.

### Impact on the organization

**Cheryl** is a nurse manager who has been having trouble managing her unit’s budget. She is summoned to the director of nursing’s office. The director tells her that her unit is significantly over budget. Turnover is high, and the unit is developing a reputation for conflict among staff members. It is estimated that Cheryl spends as much as 30 percent of her time dealing with conflict and that this is costing many tens of thousands of dollars.

The preceding scenario is, unfortunately, not fictitious. A study conducted by the American Management Association on the cost of conflict in the workplace estimates that managers spend about 20 percent to 50 percent of their time dealing with conflict in the work place. This translates to hundreds of thousands to even a million dollars annually depending on the workplace and the extent of conflict.

Costs are associated with many factors of management and organizational effectiveness. Here are some of the factors that seem most closely associated with HV.

- **Recruitment and retention**
  
  **Amanda** is a newly licensed RN who is interviewing for her first job as a registered nurse. During the interview she asks questions about turnover and the policies and procedures that are in place to deal with HV. The human resources director and nurse manager are surprised. They are not prepared to answer questions about these sensitive issues.

  Health care organizations can quickly acquire a reputation for having a dysfunctional work environment. Word of mouth and social networking sites all contribute to the ease with which information about an organization can spread.

  Health care professionals are becoming more knowledgeable about asking questions concerning work environment, including the occurrence of workplace violence. If managers and human resources personnel deny the problem exists or are unable to explain the policies and procedures that govern the problem, candidates may very well choose to work elsewhere.

  As of this writing, information regarding recruitment and retention and HV was found only in the nursing literature. Here are some statistics from the nursing literature pertaining to recruitment and retention and HV.

  - The turnover rate for clinical practicing nurses is between 33 percent and 37 percent in the United States.
  - The turnover rate for newly licensed RNs in the United States ranges from 55 percent to 61 percent.
  - It is estimated that about 60 percent of newly licensed nurses in the United States resign from their first positions within the first six months of employment because of some type of HV.
  - Job dissatisfaction contributes to both turnover and HV. A study of 43,329 nurses from Canada, England, Germany, Scotland and the United States showed that job dissatisfaction was high in all countries represented except for Germany.

  The preceding statistics indicate that turnover related to HV is a significant problem. The costs associated with recruiting, orienting and retaining health care professionals can range from tens of thousands to hundreds of thousands depending on the organization. Additional costs include paying staff members overtime to ensure adequate staffing, advertising job openings, and interviewing and selecting candidates to fill vacancies. All of these add up to huge budgetary expenses that can force an organization to cut spending throughout the organization.

- **Sick time**

  As previously noted, HV has an adverse effect on physical and mental health.

  Deterioration of physical and mental health leads to illness and an increased number of sick days. The organization must not only pay sick time but also pay overtime for employees who must cover until the employee who is ill can return to work.

  **HV Warning!** If the employee can show a link between his or her illness and HV, there may be legal consequences for the organization.

- **Quality and appropriateness of patient care**

  Research shows that the effects of HV interfere with concentration and focus as well as communication among staff members. These issues contribute to an unsafe environment for staff members and patients alike. Research also shows that in this type of environment there are increases in adverse occurrences, such as medication errors and patient complaints, and a decrease in desired patient outcomes.

- **Legal ramifications**

  HV also makes an organization more vulnerable to malpractice lawsuits. If there is an increase in errors, patient dissatisfaction and patient injury, there also may be a corresponding increase in malpractice lawsuits. Lawsuits or the threat of lawsuits increase employee stress and increase the financial burdens that face health care organizations.

  Employees who are victims of HV and commit errors that result in patient harm may try to establish a link between their malpractice and the committing of errors. For example, suppose organizational policies and procedures pertaining to HV exist but are not followed. This failure to follow organizational mandates may increase the risk for legal action against an organization and its administrators and managers.

  Victims of HV may attempt to show that HV contributed directly to any errors that were made, and that the organization failed to follow its own mandates.

  As of this writing, few laws specific to bullying exist, although there are laws against harassment. However, as the public becomes more and more aware of the effects of HV, interest in legal protection grows. Some states’ legislators are proposing laws that would allow workers to sue for physical, psychological or economic injury from abusive treatment at work.

  Managers and administrators have a legal and ethical duty to their employees. Consider how the four elements of malpractice might be applied to a situation in which HV exists. In the clinical setting, elements of malpractice for health care professionals include duty to the patient, breach of duty owed to the patient, injury or harm to the patient, and causation, meaning that there is a direct
link between the breach of duty and the injury or harm experienced by the patient.\textsuperscript{23} Consider how these elements may apply to administrators and managers in relation to their employees.

\begin{itemize}
  \item **Duty to the employee:** An organization, via its administrators and managers, assumes a duty and responsibility for employees. Part of this duty and responsibility is an obligation to provide a workplace environment that is safe and appropriate.
  \item **Breach of duty to the employee:** A breach of duty might exist if an employer fails to provide a safe and appropriate work environment. An example of such a failure might be a failure to follow policies and procedures related to HV.
  \item **Harm or injury to the employee:** A victim of HV may experience physical or mental illness or injury.
  \item **Causation:** Causation indicates an ability to demonstrate a direct link between the harm or injury experienced by the employee, the occurrence of HV, and the organization’s failure to follow policies and procedures established to stop the occurrence of HV.
\end{itemize}

\textbf{(LEGAL WARNING: THIS EDUCATION PROGRAM IS NOT INTENDED TO SERVE AS LEGAL ADVICE OR COUNSEL. QUESTIONS CONCERNING THE LEGAL RAMIFICATIONS OF HV SHOULD BE DISCUSSED WITH QUALIFIED LEGAL COUNSELORS. AS OF THIS WRITING, LEGISLATION SPECIFIC TO HV HAS NOT BEEN ENACTED.)}

\section*{Strategies to reduce or prevent horizontal violence}

\subsection*{Communication tips}

\textit{Ellen} is just completing her first year of employment as an RN. She is a rather shy person and has been subjected to HV throughout this first year. HV behaviors consisted mostly of criticism in front of co-workers and gossip behind her back.

Ellen recently enrolled in an assertiveness training course. Instead of quietly trying to ignore the behaviors of her peers, Ellen now confronts them. She stands erect and maintains eye contact. She speaks clearly and firmly. Ellen tells colleagues who are criticizing her that she is as willing to learn as anyone but will not tolerate being embarrassed in front of others. When she learns of the gossip being spread about her, she confronts those who are responsible. Her peers are surprised at her newfound confidence and the HV begins to stop.

Earlier in this education program, information about who were the most likely targets of HV was offered. It is important to project an air of confidence. How one communicates with others has a lot to do with stopping or preventing HV. But communicating assertively is not the only means of communication designed to stop HV. Active listening is also an important part of reducing this type of workplace violence. Here are some suggestions for projecting both an attitude of confidence and willingness to listen to what others have to say.\textsuperscript{5,12,13}

\begin{itemize}
  \item **Posture:** Stand or sit erect with arms at your sides. Avoid crossing your arms or clenching your fists. These actions give the impression of anger and being closed to the ideas of others.
  \item **Eye contact:** Maintain eye contact as culturally appropriate. For most Americans, eye contact indicates an interest in what the other person is saying.
  \item **Tone of voice:** Speak clearly. Speak loudly enough and slowly enough to be understood easily. Don’t speak too rapidly.
  \item **Facial expressions:** Don’t frown or roll your eyes. Maintain a pleasant expression. Avoid showing amusement unless the person with whom you are communicating is genuinely trying to be funny. Laughing at someone is never appropriate.
  \item **Self-analysis:** Be aware of your communication style. Do you cross your arms without being aware of doing so? Are you maintaining eye contact? What about tone of voice? Record yourself speaking and really listen to what you sound like. Do you speak too quickly? Too softly? Too loudly?
  \item **Personal space:** Personal space varies among countries and cultures. In the U.S., personal space is usually about three feet. Be aware of how closely you sit or stand next to someone.
  \item **Active listening:** In addition to maintaining eye contact, respond to what someone else is saying. Nodding your head, asking for clarification and making comments such as, “I understand that you are concerned about the work schedule,” or “I am interested in your ideas about purchasing new IV pumps,” show that you are really listening to the concerns and ideas of others. Never appear to be bored or in a hurry. Don’t tap your foot, glance at your wristwatch or stand with one hand on the doorknob when talking to someone else.
  \item **Willingness to learn:** Always show that you are willing to learn. No one knows all there is to know about a particular profession. The fact that you are willing to learn (and say you are willing to learn) will go a long way to enhancing professional rapport with colleagues.
  \item **Willingness to help:** Help a colleague whenever possible. In general, peers will remember who came to their rescue on a bad day and will reciprocate when needed.
\end{itemize}

The preceding tips are good suggestions for projecting confidence as well as a desire to listen to what others have to say. Good communication does help to reduce the incidence of HV. However, there are always colleagues, for whatever reason, who seem to be the primary instigators of HV. It is important to be prepared to deal directly with those who commit HV.

\section*{Dealing directly with persons who commit HV}

\textit{Sarah} is an RN who works on one of several medical/surgical units in a large community hospital. This morning she is asked to “float” to another medical/surgical unit that is short-staffed. As soon as she arrives, she asks for a brief orientation to the unit and a report on the patients she will care for. An older, more experienced colleague, Norma, rolls her eyes and complains that if Sarah doesn’t know what she’s doing, “she might as well go back to her own unit.”

The nurse manager intervenes and tells Norma to provide Sarah with the information she needs. Norma does so, but reluctantly. She tells a patient that Sarah “doesn’t usually work on this unit, but I guess she’ll know how to take care of you.” Norma walks out of the room and Sarah overhears her tell other nurses that “This nurse they sent us is really a pain. She expects to be treated like royalty.”

Sarah finishes providing care to the patient and leaves the room. She asks to speak to Norma privately. Norma rolls her eyes and steps into the nurses’ lounge. “Hurry up, I don’t have all day.” Sarah responds by saying, “I am more than willing to help take care of patients since you are short-staffed. However, I will not tolerate the comments you are making about me in front of patients and to other nurses. This must stop now.”

It is not easy to talk to the person who is committing HV. The encounter will be difficult and, most likely, emotional. It is important that a victim of HV remain calm and address the problem without shouting or crying. If you are a victim of HV, it may be helpful to practice what you will say and how you will say it.

The most important strategy to combat HV is to deal with the problem the first time it occurs. Do not ignore it. Ignoring the problem will only make the perpetrator believe that he or she can get away with it, and the problem will probably escalate. It is critically important that the victim of HV makes it clear that this behavior will not be tolerated. In the preceding scenario, Sarah confronts Norma as soon as possible.

Here are some suggestions when confronting persons who commit HV.\textsuperscript{4,7,10,11,12,13,14,15,16}

\begin{itemize}
  \item **Stay calm.** If you become angry, defensive or cry, the persons committing HV will assume that you can’t defend yourself. In this case, the HV will more than likely continue.
  \item **Confront the perpetrator in private.** Don’t address the issue in front of an audience. If the person committing HV refuses to speak to you in a private location, you may need to speak to him or her in a more public setting, but NEVER in front of patients. Refusing to speak in a private setting may be a bully’s way of avoiding having to deal with the problem. If forced to confront the person in a hallway, do so as quietly as possible.
  \item **Deal with the situation as soon as possible.** Obviously, patients cannot be left unattended in order to confront a bully. But do not allow an entire shift or longer to go by. The longer the perpetrator gets away with it, the longer...
and more virulent the HV will become. HV often continues because its instigators are so seldom confronted about it.

*Set boundaries.* Sarah, in the preceding scenario, calmly explains what will not be tolerated. Notice that it is best to start by indicating an appropriate action. Sarah starts by saying she is willing to help during a period of short staffing. A new orientee might start by saying that he or she is willing and eager to learn. The next sentence should be a calm, definite statement that the HV will not be tolerated. Be specific. For instance, Sarah states that she will not tolerate the negative statements being made in front of patients. In some circumstances, it may be necessary to say what steps will be taken if the behaviors do not stop. For instance, a new employee may say that if behaviors do not stop, she or he will request a new preceptor. Don’t threaten. Start by saying what behaviors have occurred and that they will not be tolerated. If they continue, another confrontation will be necessary, and at that time, you should indicate what the next step will be (e.g., ask for a new preceptor, file a grievance).

*Focus on behaviors, not personalities.* When setting boundaries, talk about the behaviors that are not acceptable. Avoid “you” statements, such as “you are making fun of me,” or “you are criticizing me in front of other nurses.” Instead, give examples, such as “Comments that I don’t know what I am doing in front of patients upset the patients and embarrass me. I will not tolerate these comments.”

It’s never easy to have these types of conversations. But the person instigating the HV must be confronted as soon as possible after it occurs.

**Documentation**

Persons who experience HV should keep a documentation record of the events. These are personal records, and HV should not be documented in a patient’s medical record. Note the date, time and location of the event. Document what was said or done and who was responsible for the HV behaviors.

It is important to be objective. For example, don’t document that on “July 1, 2012, at 10 a.m. my preceptor embarrassed me in front of a patient.” Instead, document that on “July 1, 2012, at 10 a.m. in room 228, I was changing a sterile dressing, under the supervision of my preceptor, Karen Saunders, on Ms. Evens, a patient who had undergone an abdominal hysterectomy. During the procedure, Ms. Saunders rolled her eyes and commented, ‘I guess we’ll be here all day since you’re so slow.’” She then addressed Ms. Evens directly and stated, ‘You have to understand that these new nurses just don’t know as much as they should.’”

By being objective and specific an accurate account is recorded. This type of personal record may be needed if it becomes necessary to approach a nurse manager or to file a grievance in accordance with organizational policies and procedures.

**Zero tolerance HV policies and procedures**

It is important that all employees, including managers and administrators, be aware of policies and procedures that deal with HV and other types of workplace violence. If someone is a victim of HV and confronting the abusers directly fails to stop the abuse, it is important that policies and procedures be followed. In many cases, the next step (if confronting the perpetrator does not put an end to the problem) is for the victim to meet with his or her immediate supervisor. When doing so, it is probably helpful to bring the written record of the HV to the meeting. This helps to keep the meeting objective and prevent displays of emotion, such as anger or tears, that may interfere with coming to a satisfactory conclusion on how to stop the problem. The Joint Commission has published guidelines for the prevention of disruptive workplace behaviors. These guidelines include the following recommendations.29

- All employees should receive education about disruptive behaviors to be avoided as well as those appropriate behaviors that foster respect and professionalism in the workplace.
- It should be made clear, as part of written standards such as policies and procedures, that all employees and others who work within the organization are accountable and responsible for their own behavior.
- There should be written policies and procedures that guarantee zero tolerance for behaviors that are disruptive or intimidating and adversely affect the organization.
- Persons who report disruptive or intimidating behaviors must not be reprimanded or subjected to any form of retaliation for doing so.
- Organizational leaders must be trained and educated to recognize disruptive, intimidating behaviors, to stop such behaviors, and to uphold standards of acceptable behavior.
- Organizational leaders must establish a system for dealing with disruptive, intimidating behaviors. This system must include a process for monitoring and reporting such behaviors.
- Any and all actions taken to stop disruptive, intimidating behaviors must be documented.
- A code of conduct must be written. This code must define what are considered to be acceptable behaviors and what behaviors are disruptive and intimidating.

**Conflict management styles**

It is important that all employees be helped to recognize the various conflicting management styles and what styles are appropriate under what conditions. Here are examples of some of the most common styles.31,31

Thomas is a member of an interdisciplinary research committee. He is one of the committee’s newest members. The group is discussing sample selection for a research project. Thomas respectfully questions the proposal for sample selection currently under review. He believes that it lacks objectivity and may have an adverse impact on the reliability of the results of the research. However, the person who proposed the selection is a colleague who has served on the committee for many years and has the respect of the group. There is significant support for the proposal as it is currently written. Thomas apologizes and agrees to go along with the group’s recommendations even though he believes the proposal will hamper effective research.

This is an example of accommodation. Accommodation exists when one person or group gives in to the demands of another person or group. “Giving in” may compromise patient care, organizational standards, or other important factors. Accommodation is appropriate only if the person who gives in realizes that he/she has made an error. Giving in to avoid conflict may be seen as weak and ineffective by others.

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**Stella and Maureen** are senior physical therapists. They have a friendly rivalry for the respect and attention of their less experienced colleagues. During a staff meeting, they take opposite sides of a discussion pertaining to a new scheduling format. Neither is willing to discuss or listen to the other’s viewpoint.

This is an example of competition. This is a negative approach to resolving conflict. With competition, neither involved party is concerned with achieving the best possible outcome. The only concern is winning. In completion, there is always a winner and always a loser.

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**Arlene** is the nurse manager of several medical units. She knows that there is conflict among the units about staffing and the budgetary allotment for unit resources. Staff members have asked for a multi-unit staff meeting to resolve the issues. Arlene is reluctant to schedule a meeting that she fears will further disrupt professional rapport. She hopes that eventually each unit will determine a way to deal with the resources they have.

This is an example of avoidance. Avoidance means that the conflict is being completely ignored in the hope that it will eventually resolve itself or even disappear entirely. But ignoring conflict seldom, if ever, results in a happy ending. Avoiding conflict usually prolongs it and often causes it to escalate.

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**Linda and Victor** are social workers whose patient population is primarily elderly persons who have had strokes or other debilitating conditions. Linda believes that Mrs. Burns, a stroke patient, should be taken in by one of her many children after discharge. Victor believes that her care is so extensive that she should be discharged to a long-term care facility. They cannot come to an agreement, and family
members are arguing among themselves about what to do. Linda and Victor decide to present the option that each of the children take turns having Mrs. Burns in their homes on a trial basis. If none of them are able to care for her, she will then go to a long-term care facility. Neither social worker is happy with this option.

This scenario is an example of compromise, which means that all parties involved in the conflict give up something in order to resolve it. Since neither party is really comfortable with the outcome, compromise is usually only a temporary resolution of the problem and conflict still exists to some extent. ***

The nurses who work on a busy surgical unit are forming a unit-based council. One of their first projects is to initiate self-scheduling. It is a difficult process, but all agree that the first consideration must be adequate staffing. After discussing, sometimes forcibly, a variety of options, the group comes up with a way of scheduling that allows nurses to work only one weekend a month as well as a system that has each nurse taking her turn to work overtime or additional shifts when needed without scrambling at the last minute to find coverage.

This scenario is an example of collaboration. It is also referred to as negotiation and results in a win-win situation. Collaboration means that a solution that is satisfactory to everyone involved is found. When working with diverse groups of colleagues, it is helpful to identify one’s personal conflict management style. In this way, collaboration, rather than styles that often escalate conflict, can be implemented.

Education

Education is essential to the reduction and elimination of HV. All employees, including administrators and managers, must participate in education and training about HV. Remember that this phenomenon occurs in all departments, not just those whose staff members are direct patient care providers, and at every level in the hierarchy. Work with the organization’s professional development department (also known as staff development or education) to plan, implement and evaluate such education.

Before education can take place, effective policies and procedures must be written with a statement that there is zero tolerance for disruptive behaviors, including HV. (See the recommendations for these policies and procedures above). Every employee should be required to read these documents, agree to uphold them, and sign a documentation record that they have done so.

What should HV education consist of? How should it be presented? Everyone is busy and finds it hard to leave their departments to attend education. But attendance should be facilitated and should also be mandatory. Remember that all such education and training does not have to be done entirely in a classroom. Computer-based learning, staff meeting presentations and distribution of case studies can all be used so that the actual time in the classroom is limited to manageable amounts.

Information to be presented should include: 2,5,8,6

- An explanation of what HV is and what it is not. Role play, case studies and actual examples, preferably from situations that have been witnessed within an organization, are good ways of making the HV “real” and not just a theory. But be sure that scenarios used as examples do not include names, specific units or other items that would specifically identify the victims or those who commit it. This will embarrass some and make others angry and only escalate the problem.

- An overview of the organization’s policies and procedures that deal with disruptive behaviors.

- How to deal with HV. Use a variety of strategies to show how to deal with HV. Don’t just have people listen to a lecture or read a policy. Role play and case studies should show effective and non-effective ways of dealing with the problem. This type of contrast can show what works and what does not.

- Presentation of organizational data related to HV. This could include statistics about turnover, the effects of HV, and the cost of the problem to the organization. On a department level, actual data showing how HV has impacted patient care, recruitment and retention could be presented. HV must be made “real” to the employees, especially those who don’t believe it exists.

- How to recognize HV when it is seen or when it is committed. Remember that earlier in this program it was mentioned that some people don’t even realize that their behaviors constitute workplace violence. Every employee should have to perform a self-analysis of his/her own behavior.

These are just some ideas to “kick off” an education campaign to stop HV. But a one-time education session is not enough. HV education must be ongoing and occur during various points in employees’ careers, such as, during:

- Orientation: The topic of HV should be addressed during orientation of all new staff members and include information as described above. Some may argue that this will scare new employees and give them a bad impression of the organization. On the contrary, knowing about HV and what to do about it only empowers a new employee. It also shows that the organization has a commitment to put a stop to disruptive behaviors.

- Mandatory training: All health care organizations have some type of mandatory training. Updates on HV, how to recognize it and how to stop it should be part of every employee’s annual mandatory training.

- Continuing education: Ongoing information about HV and other types of workplace violence should be part of every organization’s continuing education endeavors. Education could include updates from the literature, information based on analysis of the organization’s own efforts to stop HV and other forms of workplace violence, and how successful the organization has been in stopping HV.

**HV warning!** Ask employees for input on the kind of education they need about HV. Do they want more opportunities for role play and discussion? Is there interest in conducting research about HV? What is it, from their viewpoints, that should be done to help stop HV and to help employees deal with it when it does occur?

**Conclusion**

HV is not a new phenomenon, but it is one that is becoming more well-known and more openly acknowledged by accrediting bodies. All persons who work within the health care field must take responsibility for putting a stop to HV. To provide a safe work environment for employees and an environment that is conducive to the best possible patient care, HV must be recognized and a zero tolerance for its occurrence be upheld by administration, management and staff.

Education is a critical part of developing and maintaining such an environment, and education must be mandatory for everyone who works in health care. It is essential that the leadership of the organization serve as role models for appropriate behavior, and that those who commit HV, no matter what their role in the organization, be held accountable for their actions.

**References**


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**HORIZONTAL VIOLENCE IN HEALTH CARE ORGANIZATIONS: WHY PEERS BULLY PEERS**

**Self Evaluation Exercises**

Choose True or False for questions 1 through 10 and check your answers at the bottom of the page.

You do not need to submit this self-evaluation exercise with your participant sheet.

1. Horizontal violence is generally committed by managers against their subordinates.
   - True  
   - False

2. Estimates of HV in the nursing workplace range from 46-100 percent.
   - True  
   - False

3. Among the most vulnerable to HV are those who are older workers with many years of experience.
   - True  
   - False

4. The need to belong to a certain group or team can be a cause of HV.
   - True  
   - False

5. Persons who ignore HV are just as guilty of aggression as those who actually commit this type of aggression.
   - True  
   - False

6. Oppression theory as a cause of HV is most often linked to the discipline of physical therapy.
   - True  
   - False

7. Persons who experience HV often experience a decrease in the effectiveness of their immune systems.
   - True  
   - False

8. If a person experiences PTSD as a result of HV, the symptoms of PTSD end as soon as the victim finds another job.
   - True  
   - False

9. When confronting someone who is committing HV, it is best to avoid eye contact.
   - True  
   - False

10. The most important strategy to combat HV is to deal with the problem the first time it occurs.
    - True  
    - False

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CHAPTER 5
Mental Disorders in Children
(10 Contact Hours)

Learning Objectives
- List the characteristics inherent in people who have schizophrenia.
- Identify and list the signs and common symptoms of people with schizophrenia.
- Distinguish the causal factors attributed to schizophrenia.
- Understand when the onset of schizophrenia occurs and how it affects different populations.
- Distinguish between brain function in healthy people and brain function in people with schizophrenia.
- Describe treatment implications and currently recognized methods of treatment for schizophrenia.
- Identify the importance of family engagement in the care-giving of people with schizophrenia.
- List the common signs and symptoms of Asperger’s syndrome.
- Know the history of Asperger’s syndrome.
- List diagnostic criteria for Asperger’s syndrome.
- Describe the onset of Asperger’s syndrome.
- Describe the etiology (pathophysiology) of Asperger’s syndrome.
- Identify the prevalence (epidemiology) of Asperger’s syndrome in the general population.
- Describe the difference between Asperger’s syndrome and high functioning autism.
- List characteristics of Asperger’s syndrome in adolescence and adulthood.
- Describe assessment for Asperger’s syndrome.
- List comorbid illnesses associated with Asperger’s syndrome.
- List treatments for Asperger’s syndrome.
- Describe the prognosis for individuals with Asperger’s syndrome.
- List the five disorders found within the autism spectrum.
- Identify shared autism spectrum disorder (ASD) characteristics.
- Describe the range of impairment within ASD.
- List current ASD interventions.

Section 1
What is schizophrenia?
Schizophrenia is a chronic, severe and disabling brain disorder that has been recognized throughout recorded history. It affects about 1 percent of Americans.1

People with schizophrenia may hear voices other people don’t hear, or they may believe that others are reading their minds, controlling their thoughts or plotting to harm them. These experiences are terrifying and can cause fearfulness, withdrawal or extreme agitation. People with schizophrenia may not make much sense when they talk, may sit for hours without moving or talking much, or may seem perfectly fine until they talk about what they are really thinking. Because many people with schizophrenia have difficulty holding a job or caring for themselves, the burden on their families and society is significant as well.

Available treatments can relieve many of the disorder’s symptoms, but most people who have schizophrenia must cope with some residual symptoms as long as they live. Nevertheless, this is a time of hope for people with schizophrenia and their families. Many people with the disorder now lead rewarding and meaningful lives in their communities. Researchers are developing more effective medications and using new research tools to understand the causes of schizophrenia and to find ways to prevent and treat it.

This course presents information on the symptoms of schizophrenia, when the symptoms appear, how the disease develops, current treatments, support for patients and their loved ones, and new directions in research.

Symptoms of Schizophrenia
What are the symptoms of schizophrenia?
The symptoms of schizophrenia fall into three broad categories:

- **Positive symptoms** are unusual thoughts or perceptions, including hallucinations, delusions, thought disorder and disorders of movement.
- **Negative symptoms** represent a loss or a decrease in the ability to initiate plans, speak, express emotion or find pleasure in everyday life. These symptoms are harder to recognize as part of the disorder and can be mistaken for laziness or depression.
- **Cognitive symptoms** (or cognitive deficits) are problems with attention, certain types of memory and the executive functions that allow us to plan and organize. Cognitive deficits can also be difficult to recognize as part of the disorder but are the most disabling in terms of leading a normal life.

Positive symptoms
Positive symptoms are easy-to-spot behaviors not seen in healthy people and usually involve a loss of contact with reality. They include hallucinations, delusions, thought disorder and disorders of movement. Positive symptoms can come and go. Sometimes they are severe, and at other times hardly noticeable, depending on whether the individual is receiving treatment.

Hallucinations. A hallucination is something a person sees, hears, smells or feels that no one else can see, hear, smell or feel. “Voices” are the most common type of hallucination in schizophrenia. Many people with the disorder hear voices that may comment on their behavior, order them to do things, warn them of impending danger, or talk to each other (usually about the patient). They may hear these voices for a long time before family and friends notice that something is wrong. Other types of hallucinations include seeing people or objects that are not there, smelling odors that no one else detects (although this can also be a symptom of certain brain tumors), and feeling things like invisible fingers touching their bodies when no one is near.

Delusions. Delusions are false personal beliefs that are not part of the person’s culture and do not change, even when other people present proof that the beliefs are not true or logical. People with schizophrenia can have delusions that are quite bizarre, such as believing that neighbors can control their behavior with magnetic waves, people on television are directing special messages to them, or radio stations are broadcasting their thoughts aloud to others. They may also have delusions of grandeur and think they are famous historical figures. People with paranoid schizophrenia can believe that others are deliberately cheating, harassing, poisoning, spying upon, or plotting against them or the people they care about. These beliefs are called delusions of persecution.

Thought disorders. People with schizophrenia often have unusual thought processes. One dramatic form is disorganized thinking, in which the person has difficulty organizing his or her thoughts or connecting them logically. Speech may be garbled or hard to understand. Another is “thought blocking,” in which the person stops abruptly in the middle of a thought. When asked why, the person may say that it felt as if the thought had been taken out of his or her head. Finally, the individual might make up unintelligible words, or “neologisms.”

Disorders of movement. People with schizophrenia can be clumsy and uncoordinated. They may also exhibit involuntary movements and may grimace or exhibit unusual mannerisms. They may repeat certain motions over and over or, in extreme cases, may become catatonic. Catatonia is a state of immobility and unresponsiveness. It was more common when treatment for schizophrenia was not available; fortunately, it is now rare.2

Negative symptoms
The term “negative symptoms” refers to reductions in normal emotional and behavioral states. These include the following:

- Flat affect (immobile facial expression, monotonous voice).
- Lack of pleasure in everyday life.
- Diminished ability to initiate and sustain planned activity.
- Speaking infrequently, even when forced to interact.

People with schizophrenia often neglect basic hygiene and need help with everyday activities. Because it is not as obvious that negative symptoms are part of psychiatric illness, people with schizophrenia are often perceived as lazy and unwilling to better their lives.

Cognitive symptoms
Cognitive symptoms are subtle and are often detected only when neuropsychological tests are performed. They include the following:

- Poor “executive functioning” (the ability to absorb and interpret information and make decisions based on that information).
Causal factors and onset

When does it start and who gets it?
Psychotic symptoms (such as hallucinations and delusions) usually emerge in men in their late teens and early 20s and in women in their mid-20s to early 30s. They seldom occur after age 45 and only rarely before puberty, although cases of schizophrenia in children as young as 5 have been reported. In adolescents, the first signs can include a change of friends, a drop in grades, sleep problems and irritability. Because many normal adolescents exhibit these behaviors as well, a diagnosis can be difficult to make at this stage. In young people who go on to develop the disease, this is called the “prodromal” period.

Research has shown that schizophrenia affects men and women equally and occurs at similar rates in all ethnic groups around the world.1 People with schizophrenia are not especially prone to violence and often prefer to be left alone. Studies show that if people have no record of criminal violence before they develop schizophrenia and are not substance abusers, they are unlikely to commit crimes after they become ill. Most violent crimes are not committed by people with schizophrenia, and most people with schizophrenia do not commit violent crimes. Substance abuse always increases violent behavior, regardless of the presence of schizophrenia. If someone with paranoid schizophrenia becomes violent, the violence is most often directed at family members and takes place at home.

What about suicide?
People with schizophrenia attempt suicide much more often than people in the general population. About 10 percent 4,5 (especially young adult males) succeed. It is hard to predict which people with schizophrenia are prone to suicide, so if someone talks about or tries to commit suicide, professional help should be sought right away.

What about substance abuse?
Some people who abuse drugs show symptoms similar to those of schizophrenia, and people with schizophrenia may be mistaken for people who are high on drugs. While most researchers do not believe that substance abuse causes schizophrenia, people who have schizophrenia abuse alcohol and/or drugs more often than the general population. Substance abuse can reduce the effectiveness of treatment for schizophrenia. Stimulants (such as amphetamines or cocaine), PCP and marijuana may make the symptoms of schizophrenia worse, and substance abuse also makes it more likely that patients will not follow their treatment plan.

Schizophrenia and nicotine
The most common form of substance abuse in people with schizophrenia is an addiction to nicotine. People with schizophrenia are addicted to nicotine at three times the rate of the general population (75-90 percent vs. 25-30 percent).4

Research has revealed that the relationship between smoking and schizophrenia is complex. People with schizophrenia seem to be driven to smoke, and researchers are exploring whether there is a biological basis for this need. In addition to its known health hazards, several studies have found that smoking interferes with the action of anti-psychotic drugs. People with schizophrenia who smoke may need higher doses of their medication.

Quitting smoking may be especially difficult for people with schizophrenia because nicotine withdrawal may cause their psychotic symptoms to temporarily get worse. Smoking cessation strategies that include nicotine replacement methods may be better tolerated. Doctors who treat people with schizophrenia should carefully monitor their patient’s response to anti-psychotic medication if the patient decides to either start or stop smoking.

What causes schizophrenia?
Like many other illnesses, schizophrenia is believed to result from a combination of environmental and genetic factors. All the tools of modern science are being used to search for the causes of this disorder.

Can schizophrenia be inherited?
Scientists have long known that schizophrenia runs in families. It occurs in 1 percent of the general population, but is seen in 10 percent of people with a first-degree relative (a parent, brother or sister) with the disorder. People who have second-degree relatives (aunts, uncles, grandparents or cousins) with the disorder also develop schizophrenia more often than the general population. The identical twin of a person with schizophrenia is most at risk, with a 40 to 65 percent chance of developing the disorder.7

Our genes are located on 23 pairs of chromosomes that are found in each cell. We inherit two copies of each gene, one from each parent. Several of these genes are thought to be associated with an increased risk of schizophrenia, but scientists believe that each gene has a very small effect and is not responsible for causing the disease by itself. It is still not possible to predict who will develop the disease by looking at genetic material.

Although there is a genetic risk for schizophrenia, it is not likely that genes alone are sufficient to cause the disorder. Interactions between genes and the environment are thought to be necessary for schizophrenia to develop. Many environmental factors have been suggested as risk factors, such as exposure to viruses or malnutrition in the womb, problems during birth and psychosocial factors, such as stressful environmental conditions.

Schizophrenia and the brain
Do people with schizophrenia have faulty brain chemistry?
It is likely that an imbalance in the complex, interrelated chemical reactions of the brain involving the neurotransmitters dopamine and glutamate (and possibly others) play a role in schizophrenia. Neurotransmitters are substances that allow brain cells to communicate with one another. Basic knowledge about brain chemistry and its link to schizophrenia is expanding rapidly and is a promising area of research.

Do the brains of people with schizophrenia look different?
The brains of people with schizophrenia look a little different than the brains of healthy people, but the differences are small. Sometimes the fluid-filled cavities at the center of the brain, called ventricles, are larger in people with schizophrenia; overall gray matter volume is lower; and some areas of the brain have less or more metabolic activity. Three microscopic studies of brain tissue after death have also revealed small changes in the distribution of characteristics of brain cells in people with schizophrenia. It appears that many of these changes were prenatal because they are not accompanied by glial cells, which are always present when a brain injury occurs after birth. One theory suggests that problems during brain development lead to faulty connections that lie dormant until puberty. The brain undergoes major changes during puberty, and these changes could trigger psychotic symptoms.

The only way to answer these questions is to conduct more research. Scientists in the United States and around the world are studying schizophrenia and trying to develop new ways to prevent and treat the disorder.

Treatment implications

How is schizophrenia treated?
Because the causes of schizophrenia are still unknown, current treatments focus on eliminating the symptoms of the disease.

Antipsychotic medications
Antipsychotic medications have been available since the mid-1950s. They effectively alleviate the positive symptoms of schizophrenia. While these drugs have greatly improved the lives of many patients, they do not cure schizophrenia.

Everyone responds differently to antipsychotic medication. Sometimes several different drugs must be tried before the right one is found. People with schizophrenia should work in partnership with their doctors to find the medications that control their symptoms best with the fewest side effects.

The older antipsychotic medications include chlorpromazine (Thorazine), haloperidol (haldol), perphenazine (etrifon, trifalon), and fluphenazine (prolixin). The older medications can cause extrapyramidal side effects, such as...
rigidity, persistent muscle spasms, tremors and restlessness.

In the 1990s, new drugs, called atypical antipsychotics, were developed that rarely produced these side effects. The first of these new drugs was clozapine (clozaril). It treats psychotic symptoms effectively even in people who do not respond to other medications, but it can produce a serious problem called agranulocytosis, a loss of the white blood cells that fight infection. Therefore, patients who take clozapine must have their white blood cell counts monitored every week or two. The inconvenience and cost of both the blood tests and the medication itself has made treatment with clozapine difficult for many people, but it is the drug of choice for those whose symptoms do not respond to the other antipsychotic medications, old or new.

Some of the drugs that were developed after clozapine was introduced – such as risperidone (risperdal), olanzapine (zyprexa), quetiapine (seroquel), sertindole (serdolert), and ziprasidone (geodon) – are effective and rarely produce extrapyramidal symptoms and do not cause agranulocytosis; but they can cause weight gain and metabolic changes associated with an increased risk of diabetes and high cholesterol. People respond individually to antipsychotic medication, although agitation and hallucinations usually improve within days, and delusions usually improve within a few weeks. Many people see substantial improvement in both types of symptoms by the sixth week of treatment. No one can tell beforehand exactly how a medication will affect a particular individual, and sometimes several medications must be tried before the right one is found.

When people first start to take atypical antipsychotics, they may become drowsy, experience dizziness when they change positions, have blurred vision, develop a rapid heartbeat, when people need to take their pills, and pairing medication with routine daily events, like meals, can both help patients remember to take their medication every day. If they don’t like the side effects of one medication, they may stop taking it without trying a different medication.

Substance abuse can also interfere with treatment effectiveness. Doctors should ask patients how often they take their medication and be sensitive to a patient’s request to change dosages or to try new medications to eliminate unwelcome side effects.

There are many strategies to help people with schizophrenia take their drugs regularly. Some medications are available in long-acting, injectable forms, which eliminate the need to take a pill every day. Medication calendars or pillboxes labeled with the days of the week can help patients remember to take their medications and let caregivers know whether medication has been taken. Electronic timers on clocks or watches can be programmed to beep when people need to take their pills, and pairing medication with routine daily events, like meals, can help patients adhere to dosing schedules.

Medication interactions
Antipsychotic medications can produce unpleasant or dangerous side effects when taken with certain other drugs. For this reason, the doctor who prescribes the antipsychotics should be told about all medications (over-the-counter and prescription) and all vitamins, minerals and herbal supplements the patient takes. Alcohol or other drug use should also be discussed.

Psychosocial treatment
Numerous studies have found that psychosocial treatments can help patients who are already stabilized on antipsychotic medication deal with certain aspects of schizophrenia, such as difficulty with communication, motivation, self-care, work and establishing and maintaining relationships with others. Learning and using coping mechanisms to address these problems allows people with schizophrenia to attend school, work and socialize. Patients who receive regular psychosocial treatment also adhere better to their medication schedule and have fewer relapses and hospitalizations. A positive relationship with a therapist or a case manager gives the patient a reliable source of information, sympathy, encouragement and hope, all of which are essential for managing the disease. The therapist can help patients better understand and adjust to living with schizophrenia by educating them about the causes of the disorder, common symptoms or problems they may experience, and the importance of staying on medications.

Illness management skills
People with schizophrenia can take an active role in managing their own illness. Once they learn basic facts about schizophrenia and the principles of schizophrenia treatment, they can make informed decisions about their care. If they are taught how to monitor the early warning signs of relapse and make a plan to respond to these signs, they can learn to prevent relapses. Patients can also be taught more effective coping skills to deal with persistent symptoms.

Integrated treatment for co-occurring substance abuse
Substance abuse is the most common co-occurring disorder in people with schizophrenia, but ordinary substance abuse treatment programs usually do not address this population’s special needs. Integrating schizophrenia treatment programs with drug treatment programs produces better outcomes.

Rehabilitation
Rehabilitation emphasizes social and vocational training to help people with schizophrenia function more effectively in their communities. Because people with schizophrenia frequently become ill during the critical career-forming years of life (ages 18-35) and because the disease often interferes with normal cognitive functioning, most patients do not receive the training required for skilled work. Rehabilitation programs can include vocational counseling, job training, money management counseling, assistance in learning to use public transportation, and opportunities to practice social and workplace communication skills.

Family education
Patients with schizophrenia are often discharged from the hospital into the care of their families, so it is important that family members know as much as possible about the disease to prevent relapses. Family members should be able to use different kinds of treatment adherence programs and have an arsenal of coping strategies and problem-solving skills to manage their ill relatives effectively. Knowing where to find outpatient and family services that support people with schizophrenia and their caregivers is also valuable.

Cognitive-behavioral therapy
Cognitive behavioral therapy is useful for patients with symptoms that persist even when they take medication. The cognitive therapist teaches people with schizophrenia how to test the reality of their thoughts and perceptions, how to “not listen” to their voices, and how to shake off the apathy that often immobilizes them. This
treatment appears to be effective in reducing the severity of symptoms and decreasing the risk of relapses.

**Self-help groups**

Self-help groups for people with schizophrenia and their families are becoming increasingly common. Although professional therapists are not involved, the group members are a continuing source of mutual support and comfort for each other, which is also therapeutic. People in self-help groups know that others are facing the same problems they face and no longer feel isolated by their illness or the illness of their loved one. The networking that takes place in self-help groups can also generate social action. Families working together can advocate for research and more hospital and community treatment programs, and patients acting as a group may be able to draw public attention to the discrimination many people with mental illnesses still face in today’s world.

Support groups and advocacy groups are excellent resources for people with many types of mental disorders.

**What is the role of the patient’s support system?**

Support for those with mental disorders can come from families, professional residential or day program caregivers, shelter operators, friends or roommates, professional case managers, or others in the communities or places of worship who are concerned about their welfare. There are many situations in which people with schizophrenia will need help from other people.

**Getting treatment**

People with schizophrenia often resist treatment, believing that their delusions or hallucinations are real and psychiatric help is not required. If a crisis occurs, family and friends may need to take action to keep their loved one safe.

The issue of civil rights enters into any attempt to provide treatment. Laws protecting patients from involuntary commitment have become very strict, and trying to get help for someone who is mentally ill can be frustrating. These laws vary from state to state, but, generally, when people are dangerous to themselves or others because of mental illness and refuse to seek treatment, family members or friends may have to call the police to transport them to the hospital.

In the emergency room, a mental health professional will assess the patient and determine whether a voluntary or involuntary admission is needed.

A person with mental illness who does not want treatment may hide strange behavior or ideas from a professional, therefore, family members and friends should ask to speak privately with the person conducting the patient’s examination and explain what has been happening at home. The professionals will then be able to question the patient and hear the patient’s distorted thinking for themselves. Professionals must personally witness bizarre behavior and hear delusional thoughts before they can legally recommend commitment, and family and friends can give them the information they need to do so.

**Caregiving**

Ensuring that people with schizophrenia continue to get treatment and take their medication after they leave the hospital is also important. If patients stop taking their medication or stop going for follow-up appointments, their psychotic symptoms will return. If these symptoms become severe, they may become unable to care for their own basic needs for food, clothing and shelter; they may neglect personal hygiene; and they may end up on the street or in jail, where they rarely receive the kind of help they need.

Family and friends can also help patients set realistic goals and regain their ability to function in the world. Each step toward these goals should be small enough to be attainable, and the patient should pursue them in an atmosphere of support. People with mental illness who are pressured and criticized usually regress and their symptoms worsen. Telling them what they are doing right is the best way to help them move forward.

How should you respond when someone with schizophrenia makes statements that are strange or clearly false? Because these bizarre beliefs or hallucinations are real to the patient, it will not be useful to say they are wrong or imaginary. Going along with the delusions will not be helpful, either. It is best to calmly say that you see things differently than the patient does, but that you acknowledge that everyone has the right to see things in his or her own way. Being respectful, supportive and kind without tolerating dangerous or inappropriate behavior is the most helpful way to approach people with this disorder.

**What is the outlook for the future?**

The outlook for people with schizophrenia has improved over the last 30 years or so. Although there still is no cure, effective treatments have been developed, and many people with schizophrenia improve enough to lead independent, satisfying lives.

This is an interesting time in schizophrenic research. The explosion of knowledge in genetics, neuroscience and behavioral research will enable a better understanding of the causes of the disorder, how to prevent it, and how to develop better treatments to allow those with schizophrenia to achieve their full potential.

**How can a person participate in schizophrenia research?**

Scientists worldwide are studying schizophrenia so they will be able to develop new ways to prevent and treat the disorder. The only way it can be understood is for researchers to study the illness as it presents itself in those who suffer from it. There are many different kinds of studies. Some studies require that medication be changed; others, like genetic studies, require no change at all in medications.

To receive online information about federally and privately supported schizophrenia research, visit [this site](http://clinicaltrials.gov). This site describes an extensive list of studies being conducted across the United States. The information provided should be used in conjunction with advice from a health care professional.

NIMH conducts a schizophrenia research program at the National Institute of Mental Health in Bethesda, Md. Travel assistance and study compensation are available for some studies. A list of outpatient and inpatient studies conducted at NIMH can be found at [this site](http://patientinfo.nimh.nih.gov). In addition, NIMH staff members can speak with you and help you determine whether their current studies are suitable for you and your family member.

Simply call the toll-free line at 1-888-674-6464. You can also indicate your interest in research participation by sending an e-mail to Schizophrenia@intra.nimh.nih.gov. All calls remain confidential.

**Addendum 2007**

Aripiprazole (Abilify) is another atypical antipsychotic medication used to treat the symptoms of schizophrenia and manic or mixed (manic and depressive) episodes of bipolar I disorder. Aripiprazole is in tablet and liquid form. An injectable form is used in the treatment of symptoms of agitation in schizophrenia and manic or mixed episodes of bipolar I disorder.

**Section 2**

**Introduction: What is Asperger’s syndrome?**

Asperger’s syndrome (AS), a developmental disorder, is one of a series of autism spectrum disorders (ASD). Autism spectrum disorders are a distinct group of congenital-neurological conditions characterized by:

- Impairment in language and communication skills including:
  - Semantics.
  - Pragmatics.
  - Prosody (volume, intonation, inflection, and rhythm).

- Impairment in the use of nonverbal behaviors:
  - Eye contact.
  - Facial expression.
  - Body posture.
  - Body gestures.

- Repetitive or restrictive patterns of thought.

- Inflexible adherence to routines, rituals.

- Socially or emotionally inappropriate behavior.

- Difficulty with sensory integration issues:
  - Motor clumsiness.
  - Sensitivity to:
    - Noises.
    - Food.
    - Clothing.
    - Smell.

Children with AS often exhibit:

- A limited capacity for empathy.
- A failure to develop friendships.
- A limited number of intense and highly focused interests.

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**Elite**
Superior rote memory.
Extensive vocabulary.

Other ASDs include:
- Classic autism.
- Rett’s syndrome.
- Childhood disintegrative disorder.
- Pervasive developmental disorder, not otherwise specified (usually referred to as PDD-NOS).

Unlike children with classic autism, children with AS tend to retain their early language skills, often having large vocabularies for their age. Individuals with AS also tend not to experience severe intellectual impairments as compared to individuals with other ASDs. Testing of individuals with AS tends to reveal IQ’s in the normal to superior range, although some persons with AS have been reported to be mildly retarded. There are some similarities with classic autism without the diagnosis of mental retardation (higher functioning autism or HFA), and the issue of whether Asperger’s syndrome and HFA are different conditions has not been adequately resolved.

Parents and caregivers are usually able to detect signs that there is something unusual about a child with AS by the time of his or her third birthday, although some children may display signs and symptoms of AS as early as infancy. Unlike children with classic autism, children with AS will retain their early language abilities.

Sometimes the earliest indicators of AS are motor development delays. The child may sometimes have difficulty crawling, walk late, and may be seen as clumsy, both in articulation and gross motor behavior. Sensory integration issues are often evident in this population. Difficulties with clumsiness are exhibited in a variety of areas including:
- Locomotion.
- Basic skills (catching, throwing, and kicking).
- Balance.
- Manual dexterity issues (such as handwriting).
- Inability to take slow, considered approaches to activities.
- Lax joints.
- Rhythm.

Many individuals with AS are at risk for developing a wide range of mood disorders, including anxiety or depression, especially during the emotionally difficult years of adolescence.

In terms of strengths, individuals with AS can have normal or superior intelligence, and they are often able to make great intellectual contributions despite severe social problems such as insensitivity or indifference toward others. Basic noted that there are case reports and studies of men with AS that suggest the ability to accomplish cutting-edge research in fields such as computer science, mathematics and physics. Many individuals with AS can and have experienced positive outcomes, especially in areas not dependent solely upon social interaction. Outstanding skills in mathematics and computer science are sometimes seen in persons with AS, and these individuals are often extremely good on rote memory skills such as dates, facts and figures.

**History of Asperger’s syndrome**

As a diagnosis, AS has been known in Europe since the 1940s when it was described by Viennese pediatrician Hans Asperger. Dr. Asperger reported observing four children in his practice who had difficulty in social situations. Although appearing normal in terms of intelligence, these children appeared to lack nonverbal communication skills, failed to demonstrate empathy for their peer group, and were physically clumsy.

Dr. Leo Kanner first published a paper in 1943 identifying autistic children. Kanner noted that these children (eight boys and three girls) often demonstrated capabilities that did not seem to fit the patterns of other emotionally disturbed children. Although Dr. Asperger was unaware of Leo Kanner’s work on autism, he did use the term “autistic psychopathy” to describe the social deficits he observed in a group of boys. His original description, in German, was essentially unknown in the English literature for many years. The work of Lorna Wing increased interest in the condition here in the United States. Since that time, the use of the term Asperger’s syndrome and the number of research studies on AS have increased steadily.

While AS was recognized in Europe nearly 60 years ago, it was first recognized as a unique diagnosis by the American Psychiatric Association in the Diagnostic and Statistical Manual of Mental Disorders in the fourth edition published in 1994. Recognition in the DSM followed an international field trial involving over 1,000 children with classic autism and related disorders. The field trials provided evidence justifying the addition of Asperger’s syndrome as a diagnostic category separate from autism, under the diagnostic class of pervasive developmental disorders (PDD). Before the diagnostic standards were published by the World Health Organization (1990) and the American Psychiatric Association (1994), the main diagnostic criteria was provided by either Gillberg and Gillberg, or Szatmari et al, both published in 1989.

**DSM-IV-TR diagnostic criteria for Asperger’s syndrome**

The DSM-IV-TR criteria for diagnosis of Asperger’s disorder (299.80) are similar to that for autistic disorder except they do not include the communication problem areas seen frequently in autistic populations. Official DSM-IV-TR criteria include the presence of:
- Qualitative impairment in social interaction, as manifested by at least two of the following:
  - Marked impairment in the use of multiple nonverbal behaviors such as eye-to-eye gaze, facial expression, body postures, and gestures to regulate social interaction.
- Failure to develop peer relationships appropriate to developmental level.
- A lack of spontaneous seeking to share enjoyment, interests or achievements with other people (e.g., by a lack of showing, bringing or pointing out objects of interest to other people).
- Lack of social or emotional reciprocity.
- Restricted repetitive and stereotyped patterns of behavior, interests and activities, as manifested by at least one of the following:
  - Encompassing preoccupation with one or more stereotyped and restricted patterns of interest that is abnormal either in intensity or focus.
  - Apparently inflexible adherence to specific, nonfunctional routines or rituals.
  - Stereotyped and repetitive motor mannerisms (e.g., hand or finger flapping or twisting, or complex whole-body movements).
  - Persistent preoccupation with parts of objects.
- The disturbance causes clinically significant impairment in social, occupational or other important areas of functioning.
- There is no clinically significant general delay in language (e.g., single words used by age 2 years, communicative phrases used by age 3 years).
- There is no clinically significant delay in cognitive development or in the development of age-appropriate self-help skills, adaptive behavior (other than in social interaction), and curiosity about the environment in childhood.
- Criteria is not met for another specific pervasive developmental disorder or schizophrenia.

**ICD-10 Criteria for Asperger’s syndrome**

The following information is reproduced verbatim from the ICD-10 Classification of Mental and Behavioral Disorders, World Health Organization, Geneva, 1992.

**F84.5 Asperger’s syndrome**

A disorder of uncertain nosological validity, characterized by the same kind of qualitative abnormalities of reciprocal social interaction that typify autism, together with a restricted, stereotyped, repetitive repertoire of interests and activities. The disorder differs from autism primarily in that there is no general delay or retardation in language or in cognitive development. Most individuals are of normal general intelligence, but it is common for them to be markedly clumsy; the condition occurs predominately in boys (in a ratio of about eight boys to one girl). It seems highly likely that at least some cases represent mild varieties of autism, but it is uncertain whether or not that is so for all. There is a strong tendency for the abnormalities to persist into adolescence and adult life, and it seems that they represent individual characteristics that are not greatly affected by environmental influences. Psychotic episodes occasionally occur in early adult life.
Diagnostic guidelines
Diagnosis is based on the combination of a lack of any clinically significant general delay in language or cognitive development plus, as with autism, the presence of qualitative deficiencies in reciprocal social interaction and restricted, repetitive, stereotyped patterns of behavior, interests, and activities. There may or may not be problems in communication similar to those associated with autism, but significant language retardation would rule out the diagnosis.

Includes:
- Autistic psychopathy.
- Schizoid disorder of childhood.

Excludes:
- Anakastic personality disorder (excessive doubt and caution, preoccupied with rules and organization, perfectionism that leads to failure in task completion, pedantic, rigid and stubborn).
- Attachment disorders of childhood.
- Obsessive-compulsive disorder.
- Schizotypal disorder.
- Simple schizophrenia.

Onset
The apparent onset of the condition, or at least its recognition, is probably somewhat later than classic autism. According to the information provided by the Asperger’s Syndrome Coalition of the United States, a large number of children are diagnosed after the age of 3, with most diagnosed between the ages of 5 and 9. The delay in diagnosis has been attributed to the relatively more preserved language skills and cognitive functioning found in individuals with AS.

Etiology (pathophysiology)
The pathophysiology of Asperger’s disorder is unknown. At this juncture, the medical community has been unable to agree on the causes of AS, though there is a growing body of evidence (generally though twin and family studies) that suggest a strong genetic component. It is somewhat likely that multiple genetic factors cause AS. It has been hypothesized that events in early development may play a role in the development of Asperger’s disorder. At present, it is uncertain whether AS and classic autism are genetically related.

Some studies have linked AS to structural abnormalities in the brain, specifically neural circuits that have an impact on thought and behavior. A recent study by the University of California suggests that AS stems from abnormal changes that happen in the brain during critical stages of fetal development. One study is using functional magnetic resonance imaging (fMRI) to show how abnormalities in particular areas of the brain cause changes in brain function that result in the symptoms of AS and ASDs. There is no evidence to suggest that AS is caused by emotional deprivation, maltreatment or neglect.

Prevalence (epidemiology)
The incidence of AS has not been well established. Estimates of the prevalence of AS vary widely in the United States. Studies suggest that between 2 to 36 children out of every 10,000 have this disorder, with 4 of every 10,000 as the most quoted statistic. Although the condition was originally reported only in boys, reports of girls with the syndrome have now appeared. Nonetheless, boys are significantly more likely to be affected. It is estimated that boys are four times more likely than girls to have AS. However, it is speculated that girls are under-diagnosed. There is no race predilection related to the prevalence of AS. It is estimated that more than 400,000 families in the United States are affected by AS.

There is no evidence that suggests that individuals with AS have less than normal life spans.

Asperger’s syndrome vs. high functioning autism (HFA)
In some circles AS has been described as high functioning autism (HFA). More recent work has gone into differentiating the two diagnoses. It is believed that in Asperger’s disorder:
- Onset is usually later than with HFA.
- Outcome is usually more positive, with many individuals able to function on their own upon reaching adulthood.
- Social and communication deficits are less severe than with HFA.
- Restricted patterns of interest are generally more prominent with AS.
- Verbal IQ is usually higher than performance IQ (in most cases of autism, the case is usually the reverse).
- Motor clumsiness is more frequently seen in AS.
- Neurological disorders are less common.

Assessment of Asperger’s syndrome
In order to properly assess and diagnose the presence of AS in an individual, the clinician must complete a detailed history and assessment including:

Development history:
- Prenatal history.
- Maternal health factors.
- Beginning from birth, an evaluation of:
  - Social behaviors.
  - Language.
  - Interests.
  - Routines.
  - Physical coordination (often learning to walk a few months later than expected).
  - Sensory sensitivity issues.
- Social history:
  - Difficulty with peer relationships.
  - Rejection by other children.
  - Inappropriate attempts to initiate social interaction and to make friends.
  - May not display affection to family members.
  - Separations, divorce and other changes may be particularly stressful.
  - May have difficulty in dating, marriage and intimate relationships.
- May exhibit socially inappropriate behavior.
- Failure to understand social cues may be reported.
- May not understand why people become upset when he or she violates social rules and norms.

Communication issues:
- Use of gestures is frequently limited.
- Body language (nonverbal communication) may be awkward and/or inappropriate.
- Facial expressions may be absent or at times, inappropriate.
- Problems with language pragmatics (social use of language).
- At times may interpret language literally.
- Has difficulty with:
  - Idioms.
  - Double meanings.
  - Sarcasm.

Speech and hearing functioning:
- Demonstrates several abnormalities in speech, including:
  - Pendantic speech.
  - Oddities in:
    - Pitch.
    - Intonation.
    - Pronunciation.
    - Rhythm.

Sensory integration issues:
- May be sensitive to:
  - Sound.
  - Touch.
  - Taste.
  - Sight.
  - Smell.
  - Pain.
  - Temperature.

Activities assessment:
- Peculiar and narrow interests.
- Interests may be so focused that the individual does not develop normal relationships.

Physical issues:
- Lax joints (exhibited as immature or unusual grasp).
- Clumsiness (though not unique to individuals with AS).
- Odd motor mannerisms such as:
  - Hand flapping.
  - Awkward body movements.
  - Abnormalities of:
    - Basic skills.
    - Locomotion.
    - Balance.
    - Manual dexterity.
    - Handwriting.
    - Rapid movements.
    - Rhythm.
    - Imitation of movements.

There are several instruments in use to diagnose the presence of AS in individuals. The adult Asperger’s assessment (AAA), the childhood Asperger’s syndrome test (CAST), the Asperger’s syndrome diagnostic scale (ASDS), the Gilliam Asperger’s disorder scale (GADS), and a variety
of autism tests can be used to diagnose the presence of AS.

Characteristics of Asperger's syndrome in adolescence
It can be difficult to recognize, assess and diagnose symptoms of AS during the adolescent years. This may be due in part to the considerable co-morbidity issues that may arise during the adolescent years. Teenagers with AS may have major problems with daily life such as:

- Personal hygiene – General refusal to manage personal hygiene to socially accepted standards. Often refuses to wash, bathe, shower and brush teeth often due to sensory issues such as the water, soap, shampoo and toothpaste not “feeling right.” Hair and nail cutting may be a major problem for caregivers.
- Dressing – Often wears the same clothes and shoes for days, weeks or months. Again, sensory issues come into play as they will often complain that their clothes don’t “feel right” after they have been laundered. Others may change clothes obsessively, sometimes several times a day.
- School work – Often the adolescent with AS will not realize the importance of school and related work. Work in groups can cause considerable difficulty for the AS adolescent due to his communication and social impairments. Teasing and bullying of the adolescent with AS remains a problem throughout the school years.
- Eating – The individual with AS may be quite choosy about food preferences. Largely this also seems to be due mainly to sensory integration issues, where not only the taste but also the temperature and texture of the food become an issue. For others, the issue of food selection or rejection may be due to the individual’s beliefs about the food in question.
- Sleeping – For reasons that remain uncertain, many individuals with AS begin having problems with sleep during the adolescent years.

Characteristics of Asperger’s syndrome in adulthood:

- Childhood onset.
- Limited social relationships – social isolation:
  - Few/no sustained relationship and relationships that vary from too distant to too intense.
  - Awkward interaction with peers.
  - Unusual egocentricity, with little concern for others or awareness of their viewpoint; little empathy or sensitivity.
  - Lack of awareness of social rules; social blunders.
- Problems in communication:
  - An odd voice, monotonous, perhaps at an unusual volume.
  - Talking “at” (rather than to) others, with little concern about their response.
  - Superficially good language, but too formal/stilted/pedantic; difficulty in catching any meaning other than the literal.
- Lack of non-verbal communicative behavior: a wooden, impassive appearance with few gestures; a poorly coordinated gaze that may avoid the other’s eyes or look through them.
- An awkward or odd posture and body language.
- Absorbing and narrow interests:
  - Obsessively pursued interests.
  - Very circumscribed interests that contribute little to a wider life, e.g., collecting facts and figures of little practical or social value.
  - Unusual routines or rituals; change is often upsetting.

Bauer does not preclude the potential for a more “normal” life in adults with AS. He indicates that these individuals will often gravitate to professions that relate to their own areas of interest.

Gillberg has estimated that between 30 and 50 percent of all adults with AS are never evaluated or correctly diagnosed.

Co-morbidity
Persons with AS may be vulnerable to mental health problems. Few studies have systematically addressed these issues, although children with developmental disabilities are thought to have a two-to-six-times greater risk of experiencing co-morbid psychiatric conditions than their developmentally normal peers. These problems often evidence themselves in adolescence and early adulthood. One research report indicates that up to 65 percent of individuals with AS presented with symptoms of one or more psychiatric disorders. It is worth noting that symptoms of psychiatric problems, especially mood disorders, can be masked by observed behaviors of individuals with AS.

Individuals with AS can exhibit psychological conditions including:
- Attention deficit hyperactivity disorder.
- Conduct disorder.
- Oppositional defiant disorder.
- Major depressive disorder.
- Dysthymic disorder.
- Adjustment disorder with depressed mood.
- Bipolar disorder.
- Generalized anxiety disorder.
- Obsessive compulsive disorder.
- Substance abuse issues.

Depression
The presence of depressive symptoms in individuals with AS is fairly common. This depression may be related to the individual’s increasing awareness of his disability as he goes through the adolescent and early adult years. The inability to form and maintain relationships and engage in meaningful social activities is often at the root of the depression. At times the individual’s depression may be so severe that he begins to experience suicidal thoughts. These seem to be most frequent in adolescence and early adult life. Children with AS may speak of death and suicide, and adolescents with AS may act upon their suicidal thoughts. Gillberg noted that individuals with AS tend to respond well to the simple suggestion (from a professional) that attempting suicide is not good for them.

Anxiety
Anxiety is also common in individuals with AS. The inability to handle normal changes in school, home and work often exacerbates feelings of anxiety. As with depression, the social demands of adolescence and adulthood may generate extreme levels of anxiety.

Obsessive-compulsive disorder
OCD does appear often to coincide with Asperger’s syndrome, with as many as 8 percent of individuals with AS exhibiting signs of OCD. Care must be taken to differentiate between the narrow interests of a person with AS and the obsessive nature of persons with OCD.

Substance abuse issues
It is not uncommon for individuals with AS to start using and abusing alcohol toward the end of adolescence. To some degree, this may be related to normal peer pressure experienced by every teenager. For others, the process of intoxication may ease feelings of social discomfort, allowing the AS individual to feel more “normal.” Several studies have suggested that alcohol abuse rates may be extremely high in individuals with AS. As with suicide attempts, some individuals with AS tend to respond positively to the suggestion that they not use alcohol or drugs.

Treatment of Asperger’s syndrome
It is thought that the core symptoms of AS cannot be cured. Nonetheless, children and adults with AS can benefit from a variety of specialized interventions that focus on behavior management, social skills training and management of co-morbid symptomatology.

Any treatment program for AS should begin with a thorough assessment of the individual’s strengths and deficits. After a complete evaluation, a diagnosis can be made and a treatment plan developed that focuses on addressing the needs of the client, while at the same time reducing symptoms of the disorder and embracing the client’s individual strengths.

Due to the multi-modal nature of treatment for individuals with AS, it is very important that all members of the treatment team are aware of all the interventions under way and have the ability to communicate with one another as needed.

Communication and social skills training
Communication and social skills training is central to the treatment of AS. That said, the practice of communication and social skills does not imply that the individuals with AS will acquire normal communication skills. It does, however, better prepare the individual with AS to deal with the inherent difficulties with social and interpersonal interactions in everyday life.

- Skills training needs to be conducted in a fashion that is explicit, verbal and rote in...
nature. Both training and repeated exercise are often needed to facilitate long-term retention of the material.

- Training cannot rely on instruction that is subtle, uses metaphors, similes, humor, sarcasm or analogies because the individual with AS may take these communications in a literal sense.
- Problem-solving strategies can teach identification of the problems people with AS frequently experience and provide strategies to deal with them in a socially acceptable manner.
- The client should be taught, if possible, to self-monitor elements of his/her speech for volume, rhythm, naturalness, proximity to the audience and context.
- It is important that individuals with AS be able to evaluate themselves so they will become aware of situations that are potentially troublesome. Individuals with AS often have many cognitive strengths and interests that can be used to their advantage in these situations.

**Behavior management**

Individuals with AS often display a wide range of problematic behaviors that others often view as willful and malicious. Far from being willful, these behaviors, though challenging, must be viewed in the context of the individual’s disability and treated accordingly. Klin and Volkmar suggest that behavior management strategies include:

- The appropriate use of limit setting that is explicit, clear and consistent.
- Help the individual with AS make appropriate choices. This involves exploring the full range of choices available to the individual, not just what the person likes or dislikes.

**Cognitive behavior therapy**

Focused and structured cognitive-behavioral psychotherapy can be useful in dealing with the symptoms of AS. The cognitive style of treatment is heavily biased toward addressing and improving verbal functioning and addressing and working through real-life problems experienced by the client. This involves listening closely to the client, ferreting out issues that are problematic, and at times, offering advice to overcome these issues. People with AS particularly need cognitive therapy during periods of distress or transition, although regular contact offers the best possible insurance against psychological decompensation. Group cognitive sessions (with other AS individuals) may be helpful for older adolescents and adults with AS. Sessions will often focus on social skills and communication issues. Again, as with other interventions, therapy is not curative in nature, but works toward maximizing the client’s ability to function in society.

**Parent education and training**

It is very important that parents of children with AS be fully informed as to the nature and symptoms of AS. Often, without this knowledge, parents can easily see the child’s behavior as willful and malicious. In other cases, parents who lack an understanding of the illness can excuse the child’s behavior away as due to intellectual brightness or individual eccentricities.

**Educational considerations**

AS children seem to do best in highly structured educational environments. In these settings they can learn practical problem-solving and social skills, as well as academic coursework. Children with AS often require protection from the teasing and bullying of other children, and they often prosper when paired with a slightly older teenager who can serve as a mentor. Formal social skills training can also take place in the classroom as well as in other therapeutic individualized settings.

**Medication management (psychopharmacotherapy)**

Little information regarding pharmacotherapy and the AS individual is available. It is generally thought that a conservative approach to medication management should be used in dealing with AS clients.

In general, medications can be used to deal with co-morbid disorders frequently seen with AS:

- Depression and OCD-like symptoms such as obsessions, compulsions, rituals, and preoccupations:
  - SSRIs.
  - Tricyclic antidepressants.
- Anxiety:
  - SSRIs.
  - Tricyclic antidepressants.
- Irritability and aggression:
  - Mood stabilizers.
  - Beta blockers.
  - Neuroleptics.
- Thought disorders:
  - Antipsychotics.
- Hyperactivity, inattention and impulsivity:
  - Psychostimulants.
  - Tricyclic antidepressants.

**Occupational/vocational training and therapy (sensory integration training)**

Individuals with AS, particularly those in mid- to late adolescence or early adulthood, can prosper from a variety of vocational training strategies.

- Clients with AS should generally not be placed in jobs that require manual labor as the individual’s lack of motor coordination will be a significant factor in job success.
- Likewise, jobs that require a high degree of social interaction are probably not advised for the individual with AS.
- Occupational therapy may address strategies for motor clumsiness including:
  - Developing better body awareness and postural security.
  - Improving tactile discrimination.
  - Improving balance.
  - Improving motor planning.
  - Improving fine motor skills.
  - Reducing gravitational insecurity.
  - Improving ocular control and visual-spatial perception.

**Prognosis**

While individuals with AS may be taught specific skills to compensate for the disorder, it is believed that the underlying impairment is lifelong. The prognosis will vary according to the severity of the disorder and the interventions used to ameliorate existing symptoms. In general, the prognosis for persons with AS is better than those who have been diagnosed with classic autism. Social situations and personal relationships will likely be a lifelong challenge. Although social difficulties may persist, many individuals, with the proper care and treatment, will be able to achieve self-sufficiency as an adult. Individuals with AS tend to do better in the presence of supportive family members who, while encouraging, also have an adequate grasp of the disorder.

**Conclusion**

Asperger’s syndrome was first described by Hans Asperger in 1943. His research was largely unknown in English-speaking countries until 1981 after Lorna Wing published a paper on AS in 1981. Since then, interest and research on AS has grown steadily.

Asperger’s syndrome is a complex and often confounding disorder that often goes undiagnosed or misdiagnosed. When evaluated and diagnosed correctly, the individual with AS will show symptoms affecting language, communication skills, thought and social/emotional behavior. Children with AS often exhibit a limited capacity for empathy, problems developing appropriate friendships, and will often display a limited number of intense and highly focused interests.

Asperger’s syndrome can be diagnosed only with observation of a variety of impairments including qualitative impairment in social interactions, as well as restricted repetitive and stereotyped patterns of behavior, interests and activities. These symptoms must cause significant impairment in social, occupational or other important areas of functioning. There must be no clinically significant general delay in language, cognition or adaptive behavior.

It is thought that most children with AS are diagnosed between the ages of 3 and 9. Adults with AS are often diagnosed at the behest of family members, generally in response to marital, social, occupational or other types of adaptive malfunction.

The etiology of AS is unknown at this juncture. The medical and psychological community has been unable to agree on the causes of AS, though there is evidence suggesting a genetic component to the illness. It is also thought that events in early development may play a role in the development of AS.

To properly assess and diagnose the presence of AS in an individual, the clinician must complete a detailed history and assessment focusing on elements of developmental history, social history, communication skills, speech/ hearing functioning, sensory integration issues
and numerous physical issues. There are several psychological instruments that can be used in the assessment of AS.

Persons with AS are particularly vulnerable to other mental health problems, including depression, anxiety, behavior disorders, ADHD and thought disorders. These co-morbid issues can be addressed in the course of treatment for AS and often respond to a mix of cognitive behavioral therapy and medication management.

Due to the intelligent nature of many individuals with AS, they tend to respond to a mix of therapeutic interventions. These multi-modal interventions should include communication skills training, behavior management, cognitive behavioral therapy, parent education and training, medication management (for certain symptoms), and occupational / vocational training and therapy to address sensory integration issues.

The prognosis for AS is generally good if detected, diagnosed and treated early. Individuals can lead full and productive lives when given proper care and support.

### Section 3

**Autism spectrum disorders in children**

Introduction

A growing number of children are being diagnosed with autism spectrum disorders (ASD), prompting a need for mental health professionals to learn more about these developmental disorders. As a matter of fact, they are the fastest growing serious developmental disabilities in the United States. They are five times more common than Down syndrome and three times more common than juvenile diabetes, affecting an estimated 48 million people worldwide.

Autism was formerly a “catch-all” term that include a range of autistic disorders. The current term for autism is autism spectrum disorders (ASD). ASD is one of the invisible disabilities and is extremely complex with many different symptoms that can occur in various combinations. These symptoms or characteristics range from mild to severe. At the mild end of the ASD spectrum, a youngster is able to participate in typical classroom activity and, with appropriate support, may no longer show symptoms of autism at an older age. On the severe end of the spectrum, a child may need continuous supervision and basic needs care. Mental health practitioners know that each child with ASD is unique and distinctive with his or her own traits.

The five developmental disorders within the autism spectrum include:

1. Autistic disorder.
2. Asperger’s disorder.
3. Childhood disintegrative disorder.
4. Rett’s disorder.
5. Pervasive developmental disorder – not otherwise specified (PDD-NOS).

This course will provide readers with a brief history on ASD, discuss shared ASD characteristics, impart ASD statistics, as well as describe current ASD treatment.

### ASD statistics

According to a public awareness organization called Autism Speaks:

- Every 20 minutes a new case of autism is diagnosed.
- There are 24,000 new autism cases in the United States each year.
- The annual cost of ASD is $90 billion and 90 percent of those costs occur in services to adults with ASD.
- It is estimated that in 10 years, the estimated cost of ASD will be between $200 billion and $400 billion.

The Centers for Disease Control and Prevention reports that the median age of earliest ASD diagnosis ranges from 4 years, 1 month to 5 years, 6 months. However, developmental concerns had been recorded before age 3 for 51-91 percent of children later diagnosed with ASD.

In addition, research shows that possibly half of all children with ASD can recover enough to form relationships, be mainstreamed in school, hold jobs and lead full lives when they receive early intensive intervention.

### Defining autism

The word “autism” is derived from Greek and means “autos or self.”

There are earlier published descriptions, but a Swiss psychiatrist named Eugene Bleuler coined the term in 1911 with schizophrenic patients. These patients were observed to be isolated from the outside world and excessively self-absorbed.

Two doctors, Dr. Leo Kanner in the United States and Dr. Hans Asperger in Austria, working separately during the same time period, (1943 and 1944), conducted research in which they both described the same autistic characteristics. Drs. Kanner and Asperger are now considered to be the pioneers in what is identified as autism today. Through their work, both physicians described children with similar characteristics.

ASD is a developmental disorder and not a disease. It is a condition where a youngster’s usual stage in typical physical and/or psychological development is disturbed. This disturbance retards development and generally appears in a child’s first years of life.

The condition can affect a child’s ability to:
- Connect with other people.
- Socialize.
- Display normal behavior patterns.
- Experience sensory stimulation normally.
- Communicate.
- Use imagination.

Decades ago, ASD was considered quite rare. Only one in 10,000 children was diagnosed. According to the Centers for Disease Control, (CDC), ASD now affects one out of 166 children. The overall ratio of boys to girls with ASD is four to one. One possible reason for this ratio may be that girls with normal IQ’s and ASD are not being recognized and diagnosed.

Throughout the 1990s, new cases of ASD were increasingly reported to the CDC. In 2002, the U.S. Department of Education reported that autism rates nationwide had increased 556 percent in just one decade.

It is popularly theorized that those numbers indicated that ASD is now better understood and defined, prompting greater reporting, diagnosing and intervention. Physicians are more aware and able to assess and diagnose the disorder.

### ASD and brain function

Neural research has discovered that children with ASD experience a circuitry disruption within their brains. Some parts of the their brains are over-connected while others are under-connected. In addition, people with ASD process information in different parts of the brain than those people who do not have ASD. In other words, they may identify alphabet letters in a part of their brains that typically identifies shapes.

Early developmental cues in ASD children identify certain brain abnormalities, such as smaller head size at birth, followed by a period of excessive head growth between 6 months to 2 years of age. During this period, the frontal lobes, responsible for social reasoning and decision making, experience the greatest increase even though they are normally the last regions of the brain to develop. Consequently, children with ASD generally have problems in social reasoning and decision-making.

According to the DSM-IV, “imaging studies (in ASD children) may be abnormal in some cases, but no specific pattern has been clearly identified. EEG abnormalities are common even in the absence of seizure disorders.”

### Sharing normal growth guidelines with caregivers

It benefits mental health professionals to understand normal growth in children in order to guide parents when they share concerns.

These simple child growth guidelines have been printed by the Centers for Disease Control (www.cdc.gov/actearly-1-800-CDC-INFO). Mental health practitioners can make them available for clients and use as a handy reference. Remember that children are very different, and their milestones may occur slightly before or after other children their own age.

- **By the end of 7 months, many children are able to:**
  - Turn head when name is called.
  - Smile back at another person.
  - Respond to sound with sounds.
  - Enjoy social play (such as peek-a-boo).
- **By the end of 1 year (12 months), many children are able to:**
  - Use simple gestures (waving “bye-bye”).
  - Make sounds such as “ma” and “da.”
  - Imitate actions in their play (clap when you clap).
  - Respond when told “no.”
By the end of 1 1/2 (18 months), many children are able to:
- Do simple pretend play (“talk” on a play phone).
- Point to interesting objects.
- Look at object when you point at it and tell them “look!”
- Use several single words unprompted.

By the end of 2 years (24 months), many children are able to:
- Use two- to four-word phrases.
- Follow simple instructions.
- Become more interested in other children.
- Point to an object or picture when named.

By the end of 3 years (36 months), many children are able to:
- Show affection for playmates.
- Use four- to five-word sentences.
- Imitate adults and playmates (run when other children run).
- Play make-believe with dolls, animals, and people (“feed” a teddy bear).

By the end of 4 years (48 months), many children are able to:
- Use five- to six-word sentences.
- Follow three-step commands (“Get dressed. Comb your hair. Wash your face.”).
- Cooperate with other children.

**ASD causal theories**

**Genetics**

One specific genetic connection with ASD is the fragile X syndrome, which is the most common cause of genetically inherited mental retardation. Recently, a specific mutation called MeCP2 has been identified to cause the majority of cases of Rett’s syndrome.

Research has also discovered that if a parent gives birth to a child with an ASD, there is a one in 20 chance that she will give birth to another child with an ASD. And if one identical twin has an ASD, there is a 90 percent chance that the other twin will have an ASD as well. There is a 3 percent chance if the twins are fraternal twins or siblings.

Researchers have also identified a number of genes that may play a role in ASD “onset.” Some of these genes might be responsible for inherited traits that don’t cause ASD but are associated with them. These traits are being identified in family members of children with ASD and include large head size, abnormal brain processing of faces and existence of mindblindness.

Mindblindness is the inability of a person to empathize or understand that people think or feel differently. Mindblindness has nothing to do with intelligence.

**Environment**

It has been suggested that children may be born with a genetic predisposition to ASD whose onset is then triggered by an environmental factor.

Immune disorders

Another theory suggests that certain disorders of the immune system may prompt ASD onset as well.

**Pregnancy**

Scientific speculation connects pregnant women and ASD to the labor-inducing drug pitocin, yeast infections, viral infections in the placenta, poor diet and hormonal or immune system changes during pregnancy.

**Immunizations**

There has also been speculation that immunizations may contribute to the onset of ASD although to date, no scientific study has discovered beyond a doubt that a link exists.

Is there a cure of autism spectrum disorders?

Currently there is no cure for ASD, although research is rapidly progressing to identify its causes. However, early diagnosis and intense intervention can greatly benefit children.

**Shared ASD characteristics**

The five disorders within the ASD spectrum are described in “The Diagnostic and Statistical Manual, Fourth Edition, Text Revision,” (DSM-IV) published by the American Psychiatric Association under the “pervasive developmental disorders” heading, and are described as “characterized by several deficits and pervasive impairment in multiple areas of development. These include impairment in reciprocal social interaction, impairment in communication, and the presence of stereotyped behavior, interests, and activities.”

The term “pervasive” indicates that a child’s overall behavior and development is affected, and a “developmental disorder” refers to the disordered or disorganized way in which a child is developing.

A child with any of the five ASD diagnoses will exhibit the following behaviors before the age of 3:

- **Qualitative impairment in social interaction.**
  - Children with ASD frequently show an intense interest in objects, rather than other children. They maintain little to no eye contact, unemotional facial expressions, and demonstrate little real empathy.

- **Qualitative impairments in communication.**
  - Children with ASD may have no speech, delayed speech, or idiosyncratic or repetitive speech. Many do not speak at all, and those who do speak may be unable to initiate or hold a two-way conversation, or engage in make-believe play.

  One type of impaired communication includes “echolalia.” It is speech repetition without comprehension – repeating words, phrases or songs that can mean nothing to the child with ASD.

- **Restricted, repetitive and stereotyped patterns of behavior, interests, and activities**
  - Children with ASD obsess on objects and topics to the extent that nothing else exists. They may exhibit repetitive actions or movements such as hand flapping or rocking called “stereotypes.” And they can fixate on a specific routine or ritual, such as closing all the doors when entering or leaving a house.

**Food allergies, gastrointestinal problems, metabolic errors**

Many children with ASD suffer from enhanced behavior problems and lack of focus due to the inability of their bodies to break down certain proteins. They also suffer from food allergies, gastrointestinal problems and higher yeast levels. In addition, some children can suffer from metabolic errors that may be treated with larger amounts of vitamins.

**The five ASD categories**

Mentioned earlier in this course, there are five ASD categories that include autistic disorder, Asperger’s disorder, childhood disintegrative disorder, Rett’s disorder, and pervasive developmental disorder – not specified (PDD-NOS). Brief descriptions of each follow:

1. **Autistic disorder**
   - The DSM-IV describes the essential features of autistic disorder as “The presence of markedly abnormal or impaired development in social interaction and communication, and a markedly restricted repertoire of activity and interests.”
   - By definition, if there is a period of normal development, it cannot extend past age 3.

   In the past, the autistic disorder was referred to as autism, infantile autism and Kanner’s syndrome.

   The three most prevalent early symptoms in autistic children are:
   - 1. Non-responsiveness.
   - 3. A lack of eye contact.

2. **Later, autistic disordered children:**
   - Have problems communicating.
   - Demonstrate rigid behavior in their routines, rituals and mannerisms.
   - Engage in atypical play. For example, they do not pretend play, but focus on parts of objects or their toys, and “flip toys” rather than actually play with them.
   - Do not share their interests.

   Autistic youngsters can function at varying levels that include low to high functioning. At the lower functioning level, a child has mental retardation, is non-verbal, and exhibits disruptive and problematic behaviors. At the higher functioning range a child may be verbal, fall within the average IQ and even superior range, and does not express significant problem behaviors.

   Behavioral symptoms in autistic children include temper tantrums, hyperactivity, short attention span, impulsivity, aggressiveness and self-injurious behaviors.
Sometimes children with autism disorder display special skills and characteristics. Two of these include:
- Calendar calculation – the prodigious ability to calculate dates.
- Hyperlexia - decoding written materials with minimal understanding of the meaning of what has been read.

Mental retardation is diagnosed in individuals with an IQ below 70 who also have significant limitations in self-help skills. Mental retardation can range from mild to profound.

The relationship between autism and parenting stress
A study conducted by Shieve, Blumberg, Rice, Visser and Boyle for the Centers for Disease Control and Prevention, concluded that parents of children with autism were more likely to score in the high aggravation range (55 percent) than parents of children with developmental problems other than autism (44 percent), parents of special health care needs children without developmental problems (12 percent), and parents of children without special health care needs (11 percent).

However, within the autism group, the proportion of parents with high aggravation was 66 percent for those whose child recently needed special services, and 28 percent for those whose child did not. The parents of children with autism and recent special service needs were substantially more likely to have high aggravation than parents of children with recent special service needs in each of the three comparison groups.

Conversely, parents of children with autism but without recent special service needs were not more likely to have high aggravation than parents of children with other developmental problems. Therefore, parenting a child with autism with recent special service needs seems to be associated with unique stresses.

2. Asperger’s disorder
The DSM-IV describes the essential features of Asperger’s disorder to be “severe and sustained impairment in social interaction and the development of restricted, repetitive patterns of behavior, interests and activities. The disturbance must cause clinically significant impairment in social, occupational or other important areas of functioning.”

Because Hans Asperger’s research was not translated into English until years later, Asperger’s disorder, also referred to as AD, Asperger’s or Asperger’s syndrome, is a relatively new diagnosis within the United States.

Asperger’s disorder is different from autism disorder for the following reasons:
- Autism signs surface much earlier than Asperger’s disorders (AD) signs.
- AD symptoms are less apparent than autism signs.
- AD children do not display clinically significant delays in cognitive development or age appropriate self-help skills, adaptive behavior (other than social), and curiosity about their environment in childhood.
- AD children seek out others for one-sided conversation and play.
- AD children can engage in limited imaginative play.
- AD children’s IQ’s are normal to superior, whereas autistic children have mid-range to lower IQ’s.

Like many children with ASD, AD is found more often in boys than in girls, with a 15 to 1 ratio. Again, this may be attributed to the fact that girls are being under-diagnosed.

While children with AD are usually diagnosed later than children with autism disorder, around school age, early indicators include:
- Little or no interest in play with other kids.
- The inability to engage in two-way conversations.
- Obsessive interest in specific topics that include fact memorization.
- Unusual or odd use of speech.
- Awkward motor coordination.
- Lack of empathy.

Mental retardation is not generally observed in Asperger’s disorder, and occasionally mild mental retardation is present and becomes apparent only in the school years, but there appears to be no apparent cognitive or language delay in the first years of life.

3. Childhood disintegrative disorder
The DSM-IV describes the essential features of childhood disintegrative disorder (CDD) as “a marked regression in multiple areas of functioning following a period of at least two years of apparently normal development.”

CDD is far more rare than autistic disorder, occurring 100 times less often. Described first in 1908 by a special education teacher named Theodore Heller, it is sometimes referred to as Heller’s syndrome.

CDD usually affects children later than autistic disorder, between the ages of 2 and 5, with the onset of their decline occurring by the age of 10. Children with CDD develop typically for the first two years and then experience marked regression through:
- Loss of speech and the ability to have conversation.
- Everyday functioning.
- Social interaction.

Shared autism traits include hand flapping and behavior repetition. Children also experience a high frequency of seizure disorders, accompanied by profound mental retardation. Bladder and bowel control are often lost.

4. Rett’s disorder
The DSM-IV describes the essential feature of Rett’s disorder as “the development of multiple specific deficits following a period of normal functioning after birth.”

Unlike other ASDs, Rett’s disorder is diagnosed almost exclusively in girls and was described by Dr. Andreas Rett in 1966. Worldwide, it occurs in 1 in 10,000 to 1 in 23,000 females.

Children with Rett’s disorder generally develop normally until 5 to 18 months of age, and then their development either stagnates or regresses. Onset of symptoms can begin as early as 5 months. Mentioned earlier in this course, there is now a genetic test for a mutated gene, MeCP2, that has been found in most of these girls and in some boys. However, the disorder is more often fatal in boys.

Rett’s disorder symptoms include:
- Slower head and body growth (between 5 and 58 months, head growth decelerates).
- Difficulty walking and poor coordination.
- Seizures.
- Sleep disturbances.
- Difficulty with breathing.
- Lack of communication skills.
- Loss of purposeful hand skills, and stereotyped hand movements such as hand-wringing.
- Severe or profound mental retardation.

5. Pervasive developmental disorder – not otherwise specified (PDD-NOS)
According to the DSM-IV, “this category should be used when there is a severe and pervasive impairment in the development of reciprocal social interaction associated with impairment in either verbal or nonverbal communication skills or with the presence of stereotyped behavior, interests and activities, but the criteria are not met for pervasive developmental disorder, schizophrenia, schizotypal personality disorder, or avoidant personality disorder.”

PDD-NOS can also be referred to as “atypical PDD” or “atypical autism.” Children with PDD-NOS demonstrate some but not all of the criteria for the other ASDs. The PDD-NOS diagnosis may be given when physicians have not established a clear diagnosis and/or when a child exhibits shared ASD characteristics.

ASD definition check-in
- Aphasia: The loss of ability to implement or comprehend language.
- Apraxia: A disorder in which persons suffer partial or total loss of voluntary movement while retaining muscular power and coordination. (The disorder most often affects speech.)
- Autistic savant: A person who expresses exceptional mental abilities, occurring most often in the fields of numerical calculation, art or music.
- Central auditory processing disorder: While retaining hearing, a person experiences difficulty understanding and/or processing spoken language.
- Dysfluency: An interruption in the flow of speech, such as stuttering.
- Dyslexia: A learning disability that affects one’s ability to read.
- Echolalia: A condition in which a person repeats previously heard words or phrases with diminished understanding of their
meaning. Delayed echolalia can occur days or weeks after initially hearing the word or phrase.

- **Hyperlexia**: An ability for a person to read at an early age without total comprehension.
- **Pedantic speech**: Tiresome speaking that emphasizes self-absorption more than salient fact.
- **Pica**: Ingestion of non-food items.
- **Pincer grasp**: The use of thumb and forefinger to grasp small objects.
- **Prosody**: The style of speech identified by intonation, pitch, loudness and tempo of spoken words.
- **Tactile defensiveness**: A marked overreaction to touch.

**Autistic spectrum disorder interventions**
While there is no known cure, treatment for ASD is rapidly changing and progressively getting better. Research continues that may help to detect and treat ASDs before age 1 as researchers are studying the visual, social and verbal skills of infant siblings of children with ASDs to see whether early detection can be developed.

Intensive early intervention builds on a child’s rate of learning and helps to minimize problem behaviors. Included here are brief descriptions of some of the more practiced interventions.

**Applied behavior analysis (ABA)**
ABA has been well researched and documented as an intervention to assist children with ASD. It builds important skills and reduces problematic behaviors. In addition to teaching basic skills, it also focuses on play, social skills, communication, and relationship building.

ABA was pioneered by Dr. Ivar Lovaas and was based on B.F. Skinner’s conditioning theories to reward and reinforce behavior without punishment. It incorporates different procedures that break down tasks for children so they can learn them more easily.

There are different models for implementing ABA, and they are usually customized to meet each child’s specific need. ABA sessions are generally structured, and caregivers participate with their children as well.

**Medications**
Medications are prescribed for children with ASD in order to alleviate specific symptoms. To date, there is no ASD antidote, but most of the medications prescribed address:

- Depression.
- Anxiety.
- Attention disorders.
- Behavior problems.

In addition, many children with ASD have acquired other medical conditions and may take several different medications. Regular assessments and re-evaluation of medications is necessary with ASD youngsters.

**Occupational and sensory integration therapies**
Occupational therapy (OT) can be an important intervention in helping children with ASD because OT helps build their neuromuscular, visual, sensory and gross/fine motor skills. Often used with sensory integration therapy, it works to help children absorb and process sensory information, especially when children have sensory system dysfunction that over-responds or under-responds to environmental stimulation. Through OT, children learn how to complete daily living tasks, respond to touch, communicate and balance their weight. OT can also help a child draw or write.

OT techniques are reinforced in the child’s home setting, and they include joint compression, wearing weighted vests and deep pressure. One form of sensory integration is called auditory integration training. (Physical or speech therapy is used with sensory integration as well.)

**Floortime**
Floortime literally occurs on the floor in order for a child and caregiver or therapist to engage and spontaneously interact with one another. Floortime is also known as DIR or developmental-individual-difference-relationship based, and focuses on assisting children with ASD to learn building blocks of communication and thinking.

Floortime was developed by Dr. Stanley Greenspan and capitalizes on a child’s motivations and interests. It entices a child to play with another person rather than perpetuation of self-absorption through self-play. Utilizing floortime creates “circles of communication.” (For example, a parent may line up a truck with her/his child’s lined cars.)

**Physical therapy**
Physical therapy (PT) helps children with their gross and fine motor skills, and enhances their physical capabilities because children with ASD often struggle with body awareness, diminished coordination, poor posture and muscle tone, as well as balance.

Individual PT sessions are the norm, and include:
- Muscle strength and endurance exercises.
- Breathing exercises.
- Aerobic exercises.
- Aquatic exercises.
- Passive, active and resistance exercises.

**Social skills training**
Social skills training teaches appropriate social interactions. A trained social skills facilitator uses a variety of activities to promote friendships and appropriate social behavior in children with ASD. They are taught in groups, peer or video modeling sessions, and one-on-one.

Short narrative stories can assist parents in teaching children how to appropriately respond in a social setting. Other activities include games, role-play, discussion and targeted activities that promote two-way communication, understanding and empathy.

**Pivotal response training**
Pivotal response training (PRT) works to improve pivotal behaviors such as responses to cues and stimulation as well as motivation in children. PRT is designed to work with a child’s everyday life at home and school. Consequently, parent involvement is crucial.

PRT focuses on the natural interests of a child to build skills and includes changing and correcting behaviors, positive reinforcement and working with a child’s preferences. It also helps to create effective social interactions and lengthen attention spans.

Drs. Lynn and Robert Koegel worked to develop this comprehensive approach as an outgrowth of applied behavioral analysis.

**TEACCH**
TEACCH, or treatment and education of autistic and related communication for handicapped children, was developed during the 1970s at the University of North Carolina’s School of Medicine.

TEACCH is a structured and comprehensive teaching intervention that incorporates several techniques and methodologies to address social, coping and communication needs of children with ASD.

TEACCH was the first statewide program to diagnose, treat and educate children with ASD and works on the premise that a child’s environment should be modified to meet her/his needs and not the other way around.

**Speech and language therapy**
Speech and language therapy is administered by a speech and language pathologist. Through this intervention, children learn how to use language to initiate and sustain conversation as well as improve oral motor abilities.

Speech and language therapy utilizes language-based exercise, games and activities to help a child communicate verbally and nonverbally through words and/or body language. (Auditory treatment examples include music therapy, earobics and use of Fast ForWord.)

**Alternative treatments**
Conventional ASD treatments are frequently partnered with alternative interventions that can include:

- Dietary supplements such as Vitamin B-6, cod liver oil supplements, calcium and other vitamins, as well as mixtures of magnesium.
- Body manipulation such as acupuncture, energetic or massage therapy.
- Music therapy.
- Animal therapy.
- Art therapy.
- Dietary intervention – As noted, many ASD children suffer from food allergies and the inability to break down certain proteins. Consequently their diet removes foods containing wheat, oats, gluten, rye and dairy products. One known diet for children with ASD is the GF/CF, or gluten-free/casein-free diet.
- Osteopathy.
In her book, “The Autism Sourcebook,” author Karen Siff Exkorn states that she used a variety of interventions for her son. In her case, “when he was 2, we used the more conventional treatments (one-on-one sessions of ABA, speech therapy, and OT) as the foundation for his treatment regimen, and added on others that may be considered alternative and complementary (cranial-sacral osteopathy, gluten-free/casein-free diet, vitamin supplements such as B6/magnesium, homeopathy, and even energetic therapy).”

Ms. Exkorn further explains in the book that as her son became older, his treatment/ intervention regimen was modified to meet his emerging needs. Some of her son’s interventions were discontinued or lessened as others were introduced.

**Conclusion**

Autism spectrum disorders (ASD) include five classifications described under the pervasive developmental disorders section within the DSM-IV. These disorders are characterized by varying degrees of shared impairment and range from mild to severe. There is no single cure for ASD, but early detection and intervention greatly enhances the quality of life for children.

**Professional organizations with autism information for mental health practitioners**

Mental health practitioners can provide to their clients the following list of organizations that report on child development research, as well as best practice for children with ASD. They include:

- Autism Connect.
- Autism Society of America.
- American Academy of Child and Adolescent Psychiatry (AACAP).
- American Academy of Family Physicians (AAFP).
- American Neurological Association.
- American Psychiatric Association.
- Association for Behavior Analysis International.
- Center for Disease Control Autism Information Center.
- Child Neurology Society.
- National Association of Pediatric Nurse Practitioners (NAPNP).
- National Institute for Mental Health.
- Parent Information and Resource Center.
- Society for Research on Child Development.
- The Studies to Advance Autism Research and Treatment Network.

References, bibliographies & endnotes


**For More Information on Schizophrenia:**

- The National Library of Medicine, a service of the U.S. Library of Medicine and the National Institute of Health, provides updated information on many health topics, including schizophrenia. It also lists mental health organizations that provide useful information. If you have Internet access, search for schizophrenia at http://medlineplus.gov. In Spanish at http://medlineplus.gov/SPA.html
- Information from NIMH is available in multiple formats. You can browse online, download documents in PDF, and order paper brochures through the mail. If you would like to have NIMH publications, you can order them online at http://www.nimh.nih.gov. If you do not have Internet access and wish to have information that supplements this publication, please contact the NIMH Information Center at the numbers listed below:

**For Further Information:**


**Section 2**

- DSM-IV American Psychiatric Association...

**Section 3**


**Section 4**

- Ashley, Susan, Ph.D., Asperger’s Answer Book (2007), Sourcebooks Inc, Naperville, Ill.
- Centers for Disease Control. Autism, Resources for practitioners, Centers for Disease Control, Atlanta, GA www.cdc.gov/actually
- Mears, Catherine, Let Me Hear Your Voice (1994), Ballantine Books, New York, NY
- Murphy, Tamra, M.D., University of Florida, Gainesville, Florida.

**Mental Disorders in Children**

**Self Evaluation Exercises**

1. Schizophrenia has only been recognized in the last century.

   True  False

2. Interactions between genes and the environment are thought to be necessary for schizophrenia to develop.

   True  False

3. There is only one proven strategy to help people with schizophrenia take their medications.

   True  False

4. Asperger’s syndrome is one of a series of schizophrenia spectrum disorders.

   True  False

5. Males are thought to be four times more likely to have Asperger’s syndrome than females.

   True  False

6. Individuals with Asperger’s syndrome are rarely diagnosed with other psychological problems such as depression and anxiety.

   True  False

7. ASD is five times more common than Down syndrome and three times more common than juvenile diabetes.

   True  False

8. Currently there is no cure for ASD, although research is rapidly progressing to identify its causes.

   True  False

9. Rett’s disorder is diagnosed almost exclusively in girls.

   True  False

10. Physical therapy should never be used with children who are diagnosed with ASD.

    True  False
CHAPTER 6
STROKE RISK FACTORS: RECOGNITION AND MANAGEMENT
(3 CONTACT HOURS)

Learning objectives
- Identify stroke risk factors.
- Differentiate between controllable and uncontrollable stroke risk factors.
- Describe strategies to manage stroke risk factors.

Introduction
Stroke (cerebrovascular accident or CVA) occurs when cerebral circulation is abruptly impaired causing an interruption in, or reduction of, the oxygen supply to the brain. The impact of stroke is significant. Approximately 795,000 Americans suffer a new or recurrent stroke annually, and stroke kills more than 137,000 people every year. In fact, stroke is the number four cause of death in this country, and costs billions of dollars every year for medical and disability-related expenses.

There are a number of stroke-related risk factors, some of which are controllable while others are not. It is important for members of the stroke team to be able to recognize the various risk factors of stroke, work with patients and families to reduce the potential impact of these risk factors, and help to prevent, whenever possible, the occurrence of stroke.

Uncontrollable risk factors
Age
Age is a risk factor that cannot be controlled. Although a stroke can occur at any age, the risk increases with age. Unfortunately, the risk of stroke doubles for every decade someone is alive after the age of 55.

Although age cannot be altered, patients can be taught to recognize that as they age their risk for stroke increases. The healthcare community is obligated to help healthcare consumers work to achieve and maintain a maximum state of wellness. This work includes recognition of risk factors that are uncontrollable and effectively managing those that can be controlled.

Family history of stroke
Genetics is recognized as having a major impact on disease development. Persons whose family members have had a stroke are at higher risk of stroke. More than genetics may be involved in the family history aspect of risk factors. Family lifestyle issues such as diet, physical activity, and ways of coping with stress may also have an impact. When counseling patients and families about risk factor management it is important to not only ask about what family members have had strokes, but to also inquire about lifestyle issues.

Race
Research shows that African-Americans have twice the risk of stroke compared to Caucasians. Hispanics, Native Americans, Alaska Natives, and Asian/Pacific Islanders also have a higher risk than Caucasians.

“One-half of all African-American women will die from stroke or heart disease.” Why are so many African-Americans affected by stroke? Genetics may play a factor, but other risk factors may also play a role in its development. For instance, African-Americans also have a higher incidence of:
- Hypertension.
- Smoking.
- Obesity.
- Diabetes.

The stroke risk in this population is impacted by the number of risk factors they experience.

History of previous stroke or TIA
It is estimated that five to 14 percent of persons who suffer a stroke this year will experience a second one. Within the next five years 24 percent of women and 42 percent of men will have a recurrence of stroke.

These statistics show how important it is to manage controllable risk factors and prevent stroke recurrence.

Transient ischemic attacks (TIAs) are episodes of neurologic deficits that last from seconds to 24 hours but usually cause no permanent damage or disability. TIAs are caused by a temporary interruption in cerebral blood flow when microemboli are released from a thrombus and are serious warning signs of an impending stroke. In fact; nearly 40 percent of those who experience TIAs are likely to have strokes.

Patients and families must be taught preventive measures such as lifestyle changes and medication regimens and/or even surgical options (such as carotid endarterectomy for the removal of plaque buildup in the carotid arteries).

Fibromuscular dysplasia (FMD)
Fibromuscular dysplasia (FMD) is a disorder characterized by failure of some of the body’s arteries to properly develop. Fibrous tissue growing within the arterial walls leads to narrowing of the arteries and restricted blood flow. In the majority of cases (75 percent of patients) this disorder affects the arteries that transport blood to the kidneys (renal arteries). However, FMD can also affect the carotid arteries, interfering with blood supply to the brain, and other arteries throughout the body. FMD is three times as common in women as in men, but many people with the disease do not know that they have it.

Some people have no symptoms associated with FMD. Others may experience symptoms based on the arteries affected. For example, if FMD affects the arteries in the legs, leg pain may occur. Affected renal arteries may lead to hypertension or kidney failure. Affected cerebral circulation may lead to headaches, dizziness, or, if arterial damage leads to diminished blood flow to the brain, to stroke.

The cause of FMD is unknown, but family history of the disorder, tobacco use, and hormonal factors may predispose people to its development. There is no cure, but there are treatment strategies based on the arteries affected.

Angioplasty may be performed to open arteries. Those who have minimal narrowing may be prescribed anticoagulant therapy to reduce the changes of clot formation. Patients should be helped to stop smoking since use of tobacco products makes the disorder worse. Further information on FMD can be found at http://www.fmdsa.org (FMD Society of America).

Patient foramen ovale (PFO)
Patent foramen ovale (PFO) is commonly referred to as a “hole” in the heart. At birth, all people have flap-like openings in their hearts. These openings usually close by themselves soon after birth. However, sometimes the opening remains between the left and right atria, the upper chambers of the heart. Such an opening can allow blood clots to travel from various parts of the body to the heart, through the open flap, and then to the brain, leading to stroke.

PFO often causes no symptoms. It is estimated that about one in five Americans has a PFO. Many of them have no idea that they have this problem until a TIA or stroke occurs. If the existence of PFO is known, the condition may be treated with medication or possible surgical closure of the opening.

Gender: Female
Stroke is the third leading cause of death in women (after heart disease and cancer) and is the major cause of disability. In fact, 425,000 women experience a stroke every year. This is 5,500 more women than men. Since, on average, women live about five years longer than men, they have more time to have a stroke and to develop diseases and conditions that further increase their stroke risk. Despite the serious risk of stroke in women, many women, and even many healthcare professionals, are not aware of this risk.

Here are some statistics that further illustrate the significance of stroke risk in women:
- One in five women will experience a stroke at some point in their lives. This compares to one in six men.
- Nearly 25 percent of women who have a stroke die within the first year post-stroke.
- In the last 20 years the incidence of women who have a mid-life stroke has tripled.
- In general, only 25 percent to 30 percent of women can identify more than two symptoms of stroke.
- About 60 percent more women will die from a stroke than will men.
- Results from a survey commissioned by Healthy Women in partnership with the National Stroke Association and the American College of Emergency Physicians show that seven out of 10 women were unaware that they are more likely than men to have a stroke.
- African-American women have a significantly higher incidence of stroke than Caucasian women and are less likely to be able to accurately identify the causes of stroke.
Pregnancy can also increase stroke risk in women. When pregnant, women experience changes in the body such as alterations in hormone levels, possible increase in blood pressure, and increased stress on the cardiac system.13

Women who suffer from migraine headaches are also at increased risk for stroke. Research suggests that migraines can increase stroke risk by as much as three to six times.13 Study findings further suggest that women who experience migraines with aura (temporary visual, sensory, or speech disturbance associated with the headache) are at higher risk than those who have migraines without aura. The reason that migraines increase stroke risk is not known, but it may be that the vascular effects of migraines may be responsible for the increase.15

Depression is also linked to increased risk of stroke. Results from the Women’s Health Initiative research program show that women who were depressed experienced more strokes than those who were not. Possible explanations for this increase may be that depression is linked to changes in dopamine, norepinephrine, and serotonin levels.15

Waist size is also linked to stroke risk in women. Postmenopausal women whose waist size is more than 35.2 inches may have a significantly greater risk than women with a smaller waist size.13

**Controllable risk factors**

**Hypertension**

Hypertension, commonly referred to as high blood pressure, is defined as intermittent or a sustained increase in diastolic or systolic blood pressure. Hypertension is a major cause of cardiac disease, stroke, and renal failure.6 The risk of stroke actually starts to increase at blood pressure readings greater than 120/80 mm Hg.7 The first reading (sometimes referred to as the “top” number) measures the pressure when the heart is pumping blood through the arteries. The second reading (sometimes referred to as the “bottom” number), measures pressure within the arteries when the heart is receiving blood that is returning from the body.8

In the United States, hypertension affects 25 percent of the adult population.8 There are a number of risk factors for hypertension including:6

- Family history.
- Race (most common in African-Americans).
- Obesity.
- Stress.
- Lack of exercise.
- Age.
- Diet high in saturated fats and/or sodium.
- Use of tobacco products.

Current blood pressure guidelines regarding categories and readings in mm Hg are:8

- **Normal**: Systolic <120 and Diastolic <80.
- **Pre-Hypertension**: Systolic 121-139 or Diastolic 80-89.
- **Hypertension Stage I**: Systolic 140-159 or Diastolic 90-99.
- **Hypertension Stage II**: Systolic >160 or Diastolic >100.

Hypertension is commonly called the “silent killer” because in the early stages it produces no symptoms.8 What pathological changes does hypertension cause, and how do these effects increase the risk for stroke?

Hypertension is generally classified as essential (also referred to as primary or idiopathic) or secondary. Essential hypertension is the most common type. It begins insidiously and, if untreated, can cause major complications such as stroke and even death. Secondary hypertension is caused by a systemic disease that increases peripheral vascular resistance or cardiac output. Examples of diseases that can cause secondary hypertension include renal vascular disease, thyroid disease, and Cushing’s syndrome. Malignant hypertension is a dangerous, severe form of hypertension that can result from either essential or secondary hypertension.8,14

What causes hypertension? The exact cause is not clear, but it can arise from:6,14

- Alterations in the arteries leading to increased arterial resistance.
- Unusual increase in the tone of the sensory nervous system leading to increased peripheral vascular resistance.
- Renal or hormonal abnormalities that cause an increase in blood volume.
- Abnormal arteriolar thickening due to genetic influence that causes increased peripheral vascular resistance.
- Abnormal release of renin that leads to the formation of angiotensin II, which causes arteriole constriction and increased blood volume.

Hypertension does not produce signs and symptoms until vascular changes cause damage to the heart, brain, and/or kidneys. Prolonged hypertension damages the inner layers of small blood vessels, causing fibrin to accumulate, local edema to develop, and possibly, the formation of intravascular clots.14

Hypertensive signs and symptoms depend on the location of the damaged blood vessels. For instance, damaged retinal blood vessels can cause blindness. Damaged cerebral blood vessels can lead to stroke, and impaired cardiac blood vessels can cause heart attack. If the circulation to the kidneys is damaged the patient may develop proteinuria, edema, and renal failure.14

Hypertension increases the workload of the heart. As the heart attempts to deal with this extra work the left ventricle eventually hypertrophies, which eventually can lead to left sided heart failure, pulmonary edema, and right sided heart failure.14

There is no cure for hypertension, but with early identification and ongoing treatment prognosis can be good. Diet, exercise, and medication are the foundations of treatment.8

**Medication**

Mrs. Mrs. was prescribed Benicar 20 mg daily and Lasix 20 mg daily as part of a treatment plan.
for hypertension. However, when she returns to her physician’s office for a follow-up appointment the nurse notices a significant amount of edema in both of Mrs. Mason’s ankles. When asked if she were taking her medication as prescribed Mrs. Mason admits, “These pills are a real nuisance. Ever since I started taking them I spend so much time in the bathroom I am afraid to leave the house. There must be something wrong. Why am I passing my water so often? I stopped taking these stupid pills two weeks ago!”

The preceding scenario is, unfortunately, not uncommon. When medications are prescribed it is imperative that patients be taught about the purpose and effects (including possible adverse reactions) of any and all medications. Patients need to be helped to anticipate effects (such as increased urination) and how to deal with them. They also need information about why these effects are necessary to help control their hypertension and prevent adverse complications such as stroke.

Medications, prescribed in isolation or in combination, often prescribed for hypertension include:3,4

- **Angiotensin receptor blockers**: Affect renin, angiotensin, vasopressin, and aldosterone, hormones that are linked to blood pressure and kidney control. These types of medications cause arteries to dilate and influence the secretion of vasopressin and aldosterone.
- **Beta blockers**: Block beta adrenaline receptors in the blood vessels as well as the heart. These medications relax the arterial wall smooth muscle, which decreases the diastolic pressure.
- **Calcium channel blockers**: Block calcium movement in and out of the cardiac cells. This reduces the force of the contractions of the heart and decrease the systolic pressure.
- **Diuretics**: Stimulate the kidneys to make more urine, decrease the amount of fluid in the body, and reduce blood pressure. Some diuretics promote potassium depletion, thereby making it necessary for the patient to take potassium supplements per physician’s orders.

When educating patients and families about medications, be sure to include:

- The name of each medication and how it works to reduce blood pressure.
- When to take the medication.
- The proper dose of medication.
- How to take the medication (e.g. with food, in the morning, etc.).
- Side effects and what to do if side effects occur.
- Any known drug or food interactions with prescribed medications.

Patients should also provide their healthcare providers with a list of all medications they are currently taking. This includes prescription, over the counter, vitamins, herbal preparations, and other supplements. Any of these substances can interact with each other and cause dangerous side effects.

There are a number of other treatment initiatives necessary for the control of hypertension. These include:5,6

- Maintain or achieve a healthy weight. Excessive weight can increase blood pressure. Losing weight lowers blood pressure.
- Participate in regular physical exercise. The American Heart Association defines regular physical activity as moderate to vigorous exercise for 30 to 60 minutes a day on most or all days of the week. A lack of physical activity can lead to weight gain, elevated blood pressure, and increased cholesterol levels. Lack of physical activity is a risk factor for diabetes, which, in turn, is a risk factor for stroke.
- Reduce salt intake. The intake of salt should be about 1.5 g per day. Decreasing the amount of salt in the diet can reduce blood pressure. However, helping patients to reduce the amount of salt may not be a simple process. It must involve the entire family, since dietary changes will impact all of those who live in the same house as the patient. A dietary consult is a must. Written guidelines written in terms that the patient and family can understand should be provided. At the start of the process, the patient’s normal diet should be assessed.
  - Is salt used when cooking?
  - Is additional salt added to prepared foods?
  - Is the patient aware of the salt content in foods?
  - Does the patient eat items like canned soups, microwavable dinners, preserved foods, and other products that are usually high in sodium?
  - If the patient likes the convenience of such foods how can he/she be taught to substitute similar products that are lower in sodium?
  - Can the patient and family be taught to read the labels of food products to evaluate the sodium content?
  - If they are accustomed to eating a diet high in sodium how can they be realistically helped to lower their salt intake? They may be unable or unwilling to make abrupt, drastic reductions in sodium.
  - Can they be helped to gradually reduce their salt intake?

Some patients are overwhelmed at the thought of making drastic reductions “all at once.” A more successful realistic approach may be to initiate a gradual, steady reduction that patients can adhere to. The entire stroke team needs to be supportive as the patient works to make lifestyle changes. Remember that diet is probably not the only change the patient is being asked to make!

- Consider increasing potassium intake. Some experts promote an increased potassium intake in the form of eating eight to ten servings of fruits and vegetables every day. Potassium can help to reduce blood pressure. However, potassium intake should not be increased in persons with kidney disease or heart failure. Potassium should not be increased without the knowledge and approval of the patient’s physician.
- Ask about the feasibility of following the DASH diet. DASH is the acronym for Dietary Approaches to Stop Hypertension. It promotes the intake of fruits, vegetables, low-fat dairy products, whole grains, fish, poultry, and nuts. Proponents of the diet discourage the intake of fats, red meat, sweets, and beverages that contain sugar. However, as with any dietary changes, the patients’ physicians should be consulted before starting the DASH or any other diet. This diet is high in potassium so it is not recommended for persons with impaired kidney function or heart failure.
- Limit intake of alcohol. Excessive intake of alcohol can elevate blood pressure as well as increase levels of triglycerides, a form of cholesterol. Persons who drink more than two drinks a day are at particular risk.
- Stop tobacco use. Nicotine products injure blood vessels and increase the rate of plaque build-up in the arteries. Persons exposed to secondhand smoke are also at increased risk of damage due to the effects of tobacco products.
- Implement strategies to effectively manage stress. Stress is associated with increased alcohol consumption, overeating, smoking, and other behaviors that increase stroke risk. Stress reduction strategies such as meditation and deep breathing exercises may be helpful as part of a stress reduction regimen.

### Atrial fibrillation

Atrial fibrillation (AF) is the rapid (can reach rates of more than 400 beats per minute), irregular beating (fibrillation) of the atria, the two upper chambers of the heart.5,10-23 AF is a major risk factor for stroke. In fact, a person with AF is five times more likely to have a stroke, and approximately 15 percent of all people who have strokes also have AF.10

AF affects about 2.2 million Americans. In persons over 80 years of age, AF is the direct cause of one in four strokes. Effective treatment with agents such as warfarin decreases the rate of stroke for persons with AF by about one-half to two-thirds.9

AF can occur rarely, occasionally, or become an ongoing problem.23 Its cause may not be known or may be due to:1-2,4

- Heart failure.
- Chronic obstructive pulmonary disease.
- Pericarditis.
- Ischemic heart disease.
Pulmonary embolism.
Hyperthyroidism.
Hypertension.
Mitral stenosis.
Atrial irritation.
Complication of heart surgery.
Alcohol use.
Medications such as digoxin.
Pneumonia.

How does the existence of atrial fibrillation increase the risk of stroke? First, it is important to understand the pathophysiology of AF.

The electrical system of the heart controls the rate and rhythm of the heartbeat. As the heart beats, an electrical signal moves through the heart from top to bottom causing the heart to contract and pump blood to the body.23

The heart’s electrical signal originates in the sinus or sinoatrial node (SA node), which is located in the right atrium.23 As the electrical impulse travels through the atria; it causes the atria to contract. The electrical impulse reaches the atrioventricular (AV) node, located in the muscular wall between the two ventricles. The impulse pauses at the AV node so that the blood from the atria can enter the ventricles. Finally, the impulse moves into the ventricles, causing them to contract and move blood out of the heart. This completes a single heartbeat.24 In a healthy adult; the SA node sends an electrical signal to initiate a new heartbeat 60 to 100 times a minute.23

In AF, the electrical signals of the heart do not begin in the SA node. Instead, multiple sources of electrical impulses exist. These signals cause the atria to beat in an irregular, disorganized, very rapid way. These atrial contractions may occur at a rate as high as 400-600 beats per minute. This interferes with proper blood flow from the atria to the ventricles.23,24

The irregular, faulty impulses arrive at the AV node, but not all of them are able to travel beyond the node. So the ventricles beat more slowly than the atria and in an irregular fashion. This rapid, irregular heartbeat can cause symptoms such as:

- A sensation of palpitations or rapid, irregular heartbeats.
- A sensation of fluttering in the chest.
- Feeling light-headed or faint.
- Weakness.
- Shortness of breath.
- Chest pain.

Symptoms vary from person to person. Some people have no symptoms at all.24

The relationship between AF and stroke is linked to the pooling of blood in the heart due to ineffective cardiac output. As blood pools, it is likely to form clots, which can travel to the brain, leading to stroke.10

There are several types of AF. These include:

- **Intermittent or paroxysmal AF**: This type of AF is characterized by an onset of AF that typically converts back to normal heart rhythm (normal sinus rhythm) without treatment. Intermittent AF may last from just seconds to days.
- **Persistent AF**: The AF occurs in episodes but does not return to normal sinus rhythm without treatment.
- **Permanent AF**: This arrhythmia is characterized by a heart that is constantly in AF. Conversion to normal sinus rhythm is not possible or is determined to be inappropriate for medical reasons. In cases such as these, heart rate is decreased by medication. It is also necessary that the patients be placed on anticoagulants for as long as they live.

AF treatment goals focus on reducing the heart rate, re-establishing and maintaining normal sinus rhythm, and preventing the formation of blood clots that can lead to strokes.24

**Reduction of heart rate**
Reducing the heart rate slows the rate of ventricular contractions, allowing more time for the ventricles to fill with blood and improving blood flow and cardiac output.23 Reduction of heart rate is usually accomplished by the administration of oral medications such as:

- Digoxin.
- Beta blockers such as Inderal and Lopressor.
- Calcium channel blockers such as Verapamil.

These drugs slow the heart rate but do not usually convert the AF to normal sinus rhythm. Other medications or treatments are needed to accomplish this.25

In emergency situations during which the patient is experiencing serious symptoms such as chest pain or difficulty breathing, medications may be given intravenously. This allows for more rapid reduction of the patient’s heart rate than can be achieved via oral medications.24

**Prevention of clot formation**
Warfarin (Coumadin) is an anticoagulant administered to prevent blood clot formation.22,23 Research shows that, in patients with chronic sustained AF as well as paroxysmal AF, warfarin reduces the incidence of strokes.25

Candidates for warfarin therapy include:

- Patients 65 years of age or older with paroxysmal or chronic sustained AF. This is because older patients are at highest risk for stroke.
- Patients less than 65 years of age with a history of cardiovascular disease, hypertension, diabetes mellitus, and/or prior strokes due to emboli.

Since warfarin increases the risk of excessive bleeding, warfarin therapy is not recommended in patients who:

- Are at increased risk of bleeding such as persons with active gastric ulcers.
- Elderly patients at risk for falls or other trauma that can lead to excessive bleeding.
- Patients who are unable or unwilling to undergo the stringent monitoring necessary while on anticoagulant therapy.

Side effects of warfarin therapy include hemorrhage, bleeding ulcers, and dizziness.22

**Conversion of atrial fibrillation to normal sinus rhythm**
About 50 percent of patients who are newly diagnosed with AF convert spontaneously to normal sinus rhythm within 24-48 hours. Unfortunately, AF often returns in many patients.24

How often AF returns, the symptoms it causes, and the adverse effects it produces determine how conversion of AF to normal sinus rhythm is accomplished. Patients who are less than 65 years of age, have had AF for a period of less than 12 months, have normal-sized atria and ventricles, and are having their first episode of AF are most likely to experience successful conversion with either medication or electrical cardioversion.25 Some antiarrhythmics medications used to help patients attain and maintain normal heart rhythm include:

- Quinidine (Quinaglute).
- Procainamide (Procan SR).
- Sotalol (Betapace).
- Disopyramide (Norpace).
- Amiodarone (Cordarone).

Although these types of medications have a 50 percent success rate in converting AF to normal sinus rhythm they do have some possibly significant side effects. For example, even though they may control AF they may cause other types of cardiac arrhythmias that can be more dangerous than AF. Each medication must be evaluated for the possibility of side effects and the benefits of therapy weighed against the risks.22,25

Cardioversion is another option for conversion from AF to normal sinus rhythm. This procedure uses an electrical current to literally “shock” the heart back to a normal rhythm. The patient is sedated and an external defibrillator is used to deliver the electrical current. Cardioversion is successful in more than 90 percent of cases. However, it is not always a permanent solution, and AF often returns.24

In a small number of patients a pacemaker is implanted to correct AF. A pacemaker is an electronic device that takes the place of the body’s natural pacemaker, the SA node. The artificial pacemaker emits electrical impulses to help the heart maintain a normal rhythm.24

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Lab tests such as Activated Clotting Time (ACT), Prothrombin Time (PT), and International Normalized Ratio (INR) are used to monitor patients for excessively increased clotting time.22,25

For younger patients, or patients who are not good candidates for warfarin therapy, aspirin may be recommended. Aspirin, an anti-platelet drug, has milder effects than warfarin. However, it is not as effective as warfarin in preventing strokes in patients with AF. Aspirin may be prescribed for patients who are at significant risk of complications from warfarin, or for those who are unwilling to take warfarin.25
Regardless of the treatment initiatives employed, it is important that patients see their physicians on a regular basis for follow-up. Since AF, even after correction often returns, long-term monitoring is often necessary.

**Smoking and exposure to second hand smoke**

Tony has been a pack a day cigarette smoker for 30 years. Now in his 50’s, Tony is beginning, for the first time, to seriously consider quitting this habit. His mother died from a heart attack when she was 58, and his father died at 60 from a stroke. Realizing that smoking increases his already high risk for stroke, Tony schedules an appointment with a nurse at his physician’s office to get some tips to help change this behavior. The nurse arrives for their first counseling session smelling strongly of cigarette smoke. As they sit down in her office the office manager stops outside the door and asks, “When will you be ready to take our next cigarette break? I want to grab a smoke before it starts to rain since we have to go outside to smoke.” The nurse looks embarrassed, and Tony wonders how another smoker is going to help him stop when she is still smoking herself.

The adverse effects of tobacco use and exposure to second hand smoke are well documented. One of these adverse effects is increased risk for stroke. As noted in the earlier section on hypertension, nicotine products injure blood vessels and increase the rate of plaque build-up in the arteries. Persons exposed to secondhand smoke are also at increased risk of damage due to the effects of tobacco products.1

It is important to consider how smokers are helped to quit the habit. It is a poor strategy to have someone who smells of cigarette smoke counsel a patient about the risks of smoking. Here are some suggestions to follow when helping patients to stop smoking.

- Remain objective. Don’t judge. Scolding or ridiculing will destroy professional rapport and make it even more difficult for the patient to change his/her behavior.
- Work with the physician if medications such as nicotine patches are prescribed. Make sure the patient knows how to use or take medication, what side effects may occur, and what to do if side effects are experienced.
- Be prepared to offer the patient information about local support groups. Some people find it easier to stop smoking if they are working with others facing the same or similar problems.
- Be prepared to offer the patient information about online support groups. Some persons prefer finding their sources of support online rather than in person.
- Investigate online resources about smoking cessation. There is so much information of widely varying reliability about all types of health topics. Make sure that patients have access to resources that are accurate and helpful.

**High cholesterol**

David is a third generation dairy farmer. He works hard from early in the morning to late in the afternoon. He is accustomed to eating a hearty breakfast of bacon and eggs almost every morning. Recently, David was told by his physician that his cholesterol was significantly elevated and that he must modify his diet. David meets with a young dietician who told him in no uncertain terms that he must change his daily intake of bacon and eggs. She discusses substituting “egg beaters” and whole grain cereals instead. David listens politely but tells himself that he is not going to stop his usual breakfast routine.

Dietary changes are among the most difficult to make. In David’s case a bit of discussion with some realistic goals was in order. It is important to remember that the overall goal is to make dietary changes that can be willingly implemented in order to help lower David’s cholesterol. A good starting point would be to explain why lowering his cholesterol is such a high priority.

A total cholesterol level should be less than 200 milligrams per deciliter.2 When working with patients who have high cholesterol it is important to remember that the patient is the most important member of the healthcare team. If he/she is not in agreement with goals and how to achieve them the plan of care will never succeed.

Some persons are able to achieve desired cholesterol levels by modifying their diet, weight, and patterns of physical activity. Others need to add medication to these types of modification. If patients are prescribed cholesterol-lowering drugs it is important that all members of the healthcare team are aware of what is prescribed, how the medication works, how it should be taken, potential side effects, and any ongoing monitoring that is necessary. A physical therapist may be the first to recognize or hear about side effects. A patient may tell an occupational therapist that he is not having his blood drawn as ordered to check for potential adverse effects.

When the team is working with a patient and family to help with cholesterol control, it is important to implement the following actions.

- Work to facilitate compliance with medication regimen. Be sure that patients know when and how to take their medications and what side effects (and what to do about them if they happen) may occur. Facilitate on-going monitoring. For example, some cholesterol medications have the potential to interfere with liver functioning and need to have their blood drawn periodically to check for liver impairment. Does the patient have transportation to a lab to have the blood drawn? Is the patient home bound? Can arrangements be made to have blood drawn in the home? How does the patient obtain medication? Can he afford it? If not, is financial assistance available?
- Be supportive as patients make changes in their diet. It is also important to be realistic.

As in the case of David in the preceding scenario, it is unlikely that he will abruptly remove eggs and bacon from his breakfast ritual. Can a compromise be made? Can eggs and bacon be part of his breakfast a few times a week and incorporate more healthy options on the other days? What foods does the patient like? Fruit? Cereals? How can realistic goals be set that will support the lowering of cholesterol?

- Is the patient aware of the dangers of high cholesterol? It is important that he/she understands why it is necessary to lower cholesterol.

In addition to medication and dietary modifications, exercise and weight control can help to lower cholesterol and the risk of stroke.

**Overweight or obesity**

Carolyn had a TIA about six months ago and has, since then, worked to reduce her risk for stroke. Part of that goal is weight reduction. Carolyn is obese and needs to lose about 100 pounds. She is taking daily walks and is progressively modifying her diet. To date, she has lost 45 pounds, a rate of about two pounds per week. Carolyn is very proud of her accomplishment. Over the weekend she attended a wedding and was thrilled with the compliments people paid her on her weight loss. Today, she is visiting her doctor’s office for follow-up. Carolyn is wearing a new dress and a jaunty hat in preparation for visiting a tea room for afternoon tea with friends. She knows that instead of losing two pounds this week she gained two pounds. She thinks, “I know I ‘cheated’ a bit at the wedding but will get back on track this week. No sweets at the tea for me! I know they have fresh fruit and that will suit me just fine!” Carolyn usually sees the nurse practitioner, who has been very supportive and encouraging. Unfortunately, the nurse practitioner is ill, and Carolyn will be seen by the nurse manager of the practice. As he enters the exam room after weighing Carolyn he shakes his head sadly and tells her that she has gained two pounds instead of losing the two pounds required. “If you don’t continue to lose weight you’ll be at serious risk for stroke. What have you done to gain weight?” Carolyn is embarrassed and feels like a failure. As she leaves the office her buoyant mood evaporates. She sadly removes her cherished new hat and uses her cell phone to call her friends. Carolyn tells them she won’t be able to join them for tea and heads home.

Being overweight or obese increases the risk of stroke.2 Therefore, a goal for all patients is to achieve and/or maintain a healthy weight. But, as with all healthy initiatives, it is so important to maintain a supportive, encouraging attitude with patients. The preceding scenario shows that a negative approach is not effective. If Carolyn had been consistently gaining weight, a more firm approach would certainly be warranted. However, a two pound gain is not cause for censure under these circumstances. This example may seem an impossible exaggeration, but it is not uncommon. Sometimes the healthcare team members forget
just how important it is to be both realistic and supportive.

When establishing a weight loss program, consider these issues.

- What is the patient’s current diet? What positive dietary habits exist? What negative habits exist?
- What are the patient’s favorite foods? What are the least favorite foods?
- Are there any concurrent health problems (such as thyroid disease) that affect the patient’s ability to lose weight? How are these problems being addressed?
- What support will the patient receive from other members who live in the same household? It is harder to lose weight if other members of the household are eating foods high in fat and calories and the patient must eat a “special” meal that is different from everyone else’s.
- Have realistic weight loss goals been set? About two to three pounds per week is usually desirable. Patients who need to lose a great deal of weight must be helped to realize that it is not a quick process. It is best to gradually lose weight while adapting new behaviors that will not only help the patient to lose weight but will also help to maintain the desired weight after it is achieved.

Increased physical activity is usually combined with diet as part of a weight loss program. Physical activity is also an important component of reducing stroke risk.

Lack of physical activity

Lack of physical activity is also a stroke risk factor. Additionally, lack of exercise can lead to weight gain, elevated blood pressure, and increased cholesterol levels. It is also a risk factor for diabetes. The American Heart Association defines regular physical activity as moderate to vigorous exercise for 30 to 60 minutes a day on most days of the week. However, persons who are generally sedentary may need to “work up” to this goal gradually. Any new exercise program should be implemented in conjunction with physician approval.

There are a variety of ways to increase physical activity. Patients may be overwhelmed by the thought of going to a gym. They don’t need to. Here are some suggestions.

- Find physical activities that patients enjoy. Is there a sport they enjoy? Do they like to dance? Can they find someone to walk with during lunchtime at work or after work?
- There are a number of exercise facilities that are relatively inexpensive (such as the Y.W.C.A.) that have a variety of exercise options such as treadmills, stationary bikes, and aerobics classes. This may be a good option for persons who enjoy going to a specific location to exercise.
- Identify ways to add physical activity throughout the day. Take the stairs instead of the elevator. Park as far away as possible from the entrance to the mall or the grocery store.
- Find someone with whom to exercise. It can make the activity more pleasant.

Cardiovascular disease and diabetes

Persons with existing cardiovascular disease and diabetes are at increased risk for stroke. Cardiovascular disease can put extra pressure on blood vessels and/or promote the buildup of plaque in the arteries. This can diminish circulation to the brain or lead to the formation of clots that can travel to the cerebral blood vessels and lead to stroke. Persons with diabetes often have concurrent health problems that increase stroke risk. These problems include hypertension and elevated cholesterol. Additionally, brain damage may be more severe and extensive if glucose levels are high when a stroke occurs.

Persons with cardiovascular disease and/or diabetes must manage their conditions with great care. The healthcare team must work vigilantly to help with the management of these life-long conditions. It can be overwhelming for patients and families who are dealing with cardiovascular conditions or diabetes to realize that the risk for stroke is significant.

Obstructive sleep apnea

Research indicates that obstructive sleep apnea more than doubles the risk of stroke in men and increases the risk in women as well. Results of the Sleep Heart Health Study showed that the risk of stroke shows up in men with mild sleep apnea and increases with the severity of sleep apnea. The risk from sleep apnea is independent of other risk factors. Results also showed that women with sleep apnea are also at increased risk for stroke. Experts believe that men with sleep apnea may be at more risk for stroke than women because they develop sleep apnea at younger ages and may go untreated for longer periods of time.

Sleep apnea also seems to be linked to an increased risk of hypertension, heart attack, cardiac arrhythmias, and heart failure. Untreated sleep apnea has also been associated with obesity, diabetes, and injuries due to daytime drowsiness.

Treatment initiatives for obstructive sleep apnea include wearing mouthpieces, breathing devices such as continuous positive airway pressure or CPAP, surgery, and, if needed, weight loss.

Alcohol intake

Excessive alcohol intake, including binge drinking, increases the risk of stroke. Alcohol can elevate blood pressure and cholesterol, known stroke risk factors. When assessing alcohol intake remember that:

- Patients of all ages need to be counseled about alcohol intake. Binge drinking is particularly prominent among young adults such as those in college. Young adults need to know that they, too, can suffer strokes.
- Patients should be referred to support groups such as Alcoholics Anonymous as needed for help with alcohol abuse.

Use of illicit drugs

The use of illicit drugs such as cocaine and methamphetamine is a risk for stroke. These drugs can lead to stroke by:
- Elevating blood pressure to dangerous levels, levels high enough to cause stroke.
- Exerting extra pressure on blood vessels causing them to rupture and cause cerebral hemorrhage.
- Narrowing blood vessels, which obstructs cerebral blood flow and causes stroke.

Even someone who uses an illicit drug for the first time can suffer a stroke. It is important that persons who abuse drugs be identified and referred to the appropriate rehabilitation facilities.

Conclusion

There are a significant number of factors that increase the risk for stroke. Some are controllable, while others are not. The healthcare team must be knowledgeable about all factors and be able to work with patients to identify their own particular risk factors and how to manage and reduce them whenever possible.

It is very important that the patients and families participate in developing the plan of care for stroke risk factor management. In fact, remember that the patient is the most important member of the healthcare team.

Goals for risk factor management must be measurable, realistic, and achievable. Placing unrealistic demands on patients will not only lead to frustration but will almost certainly lead to noncompliance.

Patients need encouragement and support. Occasional “slips” in complying with the plan of care should not be condemned. Instead, help the patient to determine what went wrong and revise the plan of care as needed.

Finally, offer praise for a job well done. Everyone needs encouragement. Share positive results promptly with patients. Lowered cholesterol, reduction in blood pressure, weight loss, etc. should all be acknowledged and appropriate positive feedback given. Most patients will have to work on managing risk factors throughout their lifetimes. A positive, supportive environment will go a long way toward achieving goals and making healthy lifestyle choices!

References

STROKE RISK FACTORS: RECOGNITION AND MANAGEMENT

Self Evaluation Exercises

Choose True or False for questions 1 through 10 and check your answers at the bottom of the page.

You do not need to submit this self-evaluation exercise with your participant sheet.

1. The risk of stroke doubles for every decade someone is alive after the age of 55.
   True  False

2. Research shows that Caucasians have twice the risk of stroke compared to African-Americans.
   True  False

3. Fibromuscular dysplasia is a disorder characterized by failure of some of the fibrous tissues to properly develop.
   True  False

4. Men and women are at equal risk for stroke.
   True  False

5. Research findings from the Women’s Health Initiative showed that there was a 40 percent to 50 percent increase risk of stroke in postmenopausal women on estrogen therapy regardless of whether or not the estrogen was combined with progestin.
   True  False

6. Normal blood pressure is defined as Systolic <120 and Diastolic < 80.
   True  False

7. The relationship between AF and stroke is linked to the pooling of blood in the heart due to ineffective cardiac output.
   True  False

8. During cardioversion a pacemaker is implanted to take the place of the body’s natural pacemaker.
   True  False

9. Persons who are exposed to second hand smoke are also at increased risk for stroke.
   True  False


10. Treatment initiatives for obstructive sleep apnea include wearing mouthpieces, breathing devices such as continuous positive airway pressure or CPAP, surgery, and, if needed, weight loss.
    True  False