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INTRODUCTORY REMARKS

by

William A. Spencer, M.D.

THE SPINAL CORD INJURY MANAGEMENT CONTINUUM "SHORT-TERM CARE AND LONG-TERM OUTCOMES"

Your attendance at this comprehensive overview of the management of spinal cord injured persons is most hopeful. Spinal Cord Injury (SCI) is thought to be uncommon. This is statistically accurate since the typical incidence is 35-50 per million civilian population, or 10,000 to 15,000 newly injured persons per year in the United States. Less well known is the likelihood that ten times this number, or 100,000 to 150,000 persons are on hand at all times. This number is increasing because of the effectiveness of our trauma systems and emergency ambulance systems. After the drama of the life-saving first hours or days, what then? Is it possible to make the life saved worthwhile? Isn't the 'complete' spinal cord injury incurable and therefore the situation hopeless? Of course not! Now, legions of persons with spinal cord injury are returning to a satisfactory life. They have succeeded through the indomitable adaptability of the intact human brain and the benefits of anticipatory, acute (first-phase) care. Systematic follow-up, with function oriented restorative care and comprehensive rehabilitation, insures participation in many aspects of a productive daily life and increasing opportunity to exercise options of self direction.

The mystique persists that this uncommon condition is relatively unimportant. How untrue this is in respect to personal, family, and societal impact, medical and related costs, and national consequences of loss of productivity. This low incidence problem is a huge socio-economic catastrophe, although it is often unrecognized as such and ignored on statistical grounds of numbers affected. Taking an overall lifetime cost estimate of $500,000, which is low by worker's compensation insurance experience, and underestimating family, financial, and societal productivity losses - expected future years' obligations are in the range of $75.0 billion! What does this mean personally?

Recently, costs of motor vehicle injuries (MVI) alone were second to cancer and above heart disease and stroke in direct and indirect costs. $23.1 billion was spent for cancer and $14.4 billion was spent for MVI. Since MVI causes only one-third of all trauma deaths and 7% of all injuries, these figures are shocking. The SCI data base from the spinal cord injury system of centers reveals that less than one-half of all spinal cord injury must be caused by MVI. Thus, spinal cord injury, along with head injury, is a large cause of severe disability and accounts for a large proportion of the expenses incurred from accidents of all causes.

What is the impact of the incredibly small, current investment in control of severe disability - the personal consequences of such an impairment and the resulting loss of function?

(1) Under-resourcing in facilities and manpower;

(2) Tardy application of the knowledge of management methods and use of technology produced by research and 'model' systems in the last decade;

(3) Fragmented, incomplete, multi-party, roller-coaster financing of comprehensive care; and

(4) Lack of access to services by many persons who could benefit. Instead, at present, many such persons face a miserable dependency and the family and the public face costly, long-term, institutional care or premature death from preventable or controllable complications.

Isn't it tragic that we largely ignore control of all severe disability, a socio-eocnomic problem which collectively consumes at least 7.5% of the Gross National Product? Proportionately, we spend less than 1% of this on restorative and rehabilitative care for all persons with severe disability. This includes the spinal cord injured person.

In all of the research, development, and special model systems, we invest less than $10 to $12 million per year. For all causes of work disability, loss of self care and socialization, we spend 1,000 times less on research and development and technology for control of disability than on 'cure' of disease or for prevention of injury.

Restorative care, like preventive care, will be the rising star of future health care practices as soon as we are able to demonstrate widely that beneficial outcomes are possible for persons like those with spinal cord injury. We also need to join in support of those affected and their friends in their effort at public awareness and political priority. Increased private and public investment in resources is needed. The cost effectiveness of this investment is staggering. Three of four lifetime dollars could be saved as a burden on all of us. One-third of the immediate early care costs can be saved by specialized spinal cord centers.

Your attendance here is a signal of the growing professional concern and and interest in this largely private, not-for-profit effort. You will share your experiences with us and we will share with you what has been learned from our experiences of some 25 years with more than 2,000 persons with spinal cord injury, including some followed for nearly two decades. You will see how specialized programs yielded special centers and how careful clinical observation, research, development and technology have helped anticipate disability and its preventable or controllable complications. To be effective in care, causes of disability and complications must be addressed from the time of injury. You will learn how these persons achieve independent living, personal productivity, and participation in life's responsibilities and rewards. You will hear and see the value of a system of relationships between trauma centers and spinal cord injury centers in restorative and rehabilitative facilities. We are giving greater emphasis upon preservation of residual functions, the encouragement of adaptive responses of mind and body, and ways to minimize environmental handicaps. These concepts and procedures will be yours to sample, discuss, and question.

We welcome your participation, trust you will further develop in your own settings this relatively new concept of centers for special problems like spinal cord injury. I, personally, look to you to further the demonstration of how competence depends upon carefully analyzed clinical experience and proper use of technology driven by the process of individualization of care. Finally, the provision of opportunity for the patient as a 'person' to develop increasing self reliance and independence without your assistance is an objective to have in the forefront of clinical decision making.

We will all share in the reduction of personal, social, and economic losses attending severe disability through these future developments. We need America's handicapped citizens because their real numbers currently equal at least the 10.8% of working age adults who are currently unemployed in a time of recession and depression. In spinal cord injured persons, we have, in trust, the future lives of young adults averaging 21 years of age who will show the value of their survival that many of you work so hard to accomplish. They, in turn, will not disappoint us if we comprehensively, personally, and competently assist them!

NAME	MANUFACTURER
Scimedics Laminaire	Scimedics
Scimedics Polyaire	Scimedics
Scimedics Postureform	Scimedics
Scimedics Lux Aire	Scimedics
Spenco Gel Flotation Pad	Spenco Medical Corp.
Stainless Comfy Foam	Stainless Medical Products
Stainless Ester Foam	Stainless Medical Products
Stryker Gel Flotation Wheelchair Cushion	Stryker Corp.
Sun Mate Dynafoam II	Dynamic Systems
Sun Mate Laminaire	Dynamic Systems
Sween Gel Float	Sween Corporation
Talley Rippleseat	Talley Surgical Instruments, Ltd.
Temper Foam	Kees Goebel/Ali Med.

FIGURE 8

Seating for Pressure Relief: the individual with insensitive skin

I. Statement of the Problem

- A. Pressure ulcers, decubitus ulcers, pressure sores are defined as localized areas of cellular necrosis. They are a frequent and potentially life-threatening complication for the individual with absent or diminished sensation.
- B. Levels of tissue deterioration are:
    - 1. First degree: Epidermal - outer epithelial portion of skin
    - 2. Second degree: Dermal - of or pertaining to the skin
    - 3. Third degree: Subcutaneous - beneath the skin
    - 4. Fourth degree: Intramuscular - within muscle
    - 5. Fifth degree: Osteoarticular - pertaining to or affecting bones or joints
- C. Etiology
    - 1. Pressure from oversitting, poor care in bed, worn out wheelchair, mattress or cushion
    - 2. Trauma during transfers, as the result of a fall or from riding over rough terraine for an extended period of time
    - 3. Psychological stress that results in physiological changes in tissue

II. Philosophy: Prevention

- A. Clinical guidelines
    - 1. Good personal hygiene
        - a. keep skin clean and dry: moisture from perspiration or incontinence can precipitate skin breakdown, especially on already stressed tissue
    - 2. Nutrition
        - a. eat a well balanced diet
        - b. adequate protein
        - c. if unable to tolerate 3 meals a day, try eating 6 smaller meals; do not miss a meal
    - 3. Skin assessment: skin checks at least twice a day - once in the morning and last thing at night
        - a. redness or skin color changes that do not disappear within 30-45 minutes should be considered potentially dangerous and the area free of pressure for up to 24 hours if possible

4. The mattress surface: In most situations, individuals with physical disabilities can sleep on a standard hospital or commercially available home-use mattress. Those individuals with specific pressure-related problems are advised of the various therapeutic mattress surfaces available for home use. In a recent study, several different therapeutic mattresses were evaluated for their pressure relief properties. The mattresses included one standard hospital mattress and the following therapeutic mattress surfaces:
   a. Egg Crate - 2 inch thickness
   b. Egg Crate - 4 inch thickness
   c. Gaymar Alternating Air Pressure Mattress
   d. Lapidus Alternating Air Pressure Mattress
   e. Roho Dry Flotation Mattress
   f. Stryker Gel Mattress Inserts
      1) From this study, it appeared that trochanteric pressure under the sidelying patient was lowest on the Roho, followed by the Egg Crate 4 Inch Mattress. It must be emphasized however, that no mattress surface should be used indiscriminately.
5. Weight shifts: a method to periodically relieve pressure and reduce the potential for skin breakdown. Weight shifts are performed either independently or with varying degrees of assistance depending on strength and range of motion of the patient. The following regimen is offered as a suggestion for a routine program of weight shifts.
   a. Paraplegics should perform a weight shift every 30 minutes for a duration of 15 seconds.
   b. Quadriplegics below the C-5 level should perform a weight shift every 60 minutes for a duration of 30 seconds.
   c. Quadriplegics above the C-5 level, who require full assistance to accomplish a weight shift may attempt the 60 minute/30 second regimen but may find it necessary to emphasize a program of building sitting tolerance rather than a program that emphasizes weight shifts.
   d. There is considerable controversy among rehabilitation professionals about the effectiveness of weight shifts in preventing pressure sores. Our philosophy advocates weight shifts as one aspect of a preventative program. The above regimen is only a suggestion. We realize that there will be some variation among patients.

6. The wheelchair is important in maintaining the skin's integrity. The wheelchair must be properly measured and prescribed and kept in good condition.
7. The wheelchair cushion, is perhaps, the most significant factor that influences pressure and its consequences for the individual with a physical disability. The type, condition, age, and usage of a cushion will greatly effect sitting tolerance and skin condition.
8. Education of the patient and his family: make the patient responsible for his own skin care.

III. Classification of Wheelchair Seating (Figure 1)

A. Purpose of cushions
   1. To relieve pressure
   2. To stabilize the body for balance and functional positioning
   3. To distribute weight, especially away from bony prominences

B. Categories of static cushions
   1. Air filled cushions (Figure 2)
   2. Floatation cushions - filled and gels (Figure 3)
   3. Polymer foams (Figure 4)

C. The "perfect" cushion
   1. Controls distribution of body weight, over the greatest available contact for sitting
   2. Relieves pressure under bony prominences (to below the capillary pressure)
   3. Stability - for wheelchair mobility, propulsion, transfers
   4. Ease of motion for weight shifting
   5. Does not impede independence-lightweight, easy to transfer
   6. Stabilizes temperature optimally
   7. Controls excessive moisture
   8. Permits air exchange
   9. Reliable, does not deteriorate, does not "bottom out"
   10. Comfort is very subjective and not the most important
   11. Reasonable cost

D. Wheelchair cushion cover is an important consideration in that it will effect the pressure relief properties of the cushion itself.
   1. It should be washable
   2. It should allow flow of air (breathable)

3. It should absorb moisture
4. A cotton knit material is a good fabric for cushion covers although a polyester knit would be acceptable

IV. Selection of Wheelchair Cushions: Individual Evaluation

A. Considerations
   1. Diagnosis
   2. Number of hours spent in wheelchair each day
   3. Kinds of activities done from the wheelchair
   4. Usage environment: climate, pollution, humidity, temperature, terrain, continence of individual
   5. Living arrangements: independent or dependent
   6. Individual's tissue history: pressure ulcers, surgery to correct ulcers, decreased sitting tolerance secondary to specific medical or social factors
   7. Body build: the pressure relief needs of thin patients are different from the needs of heavier individuals
   8. The wheelchair: impact loads and usage environment that effect wheelchair suspension systems
   9. Pressure and its distribution

B. Individual evaluation for pressure relief devices
   1. Use of pressure monitoring devices
      a. Pressure Evaluation Pad
      b. Scimedics
      c. Research prototypes
   2. Specialty items: alternatives to commerically available pressure relief wheelchair cushions
      a. Wedging (Figure 5)
      b. Laminants
      c. Cut-outs: Stanford cushions, Australian Cushions, South African Cushions

V. Tissue Pressure Management as a Comprehensive Program: Research, Education, Clinical Service (Figure 6)

A. Research - Research efforts have been mainly in the following category: design and fabrication of devices utilizing a wide variety of materials and techniques.

1. It would seem that several other directions for research would be useful. These include:
    a. Identifying the long-term effects of using a specific type of cushion or seating surface;
    b. Developing a mechanism for sharing developments in this field;
    c. Manufacturing of potentially promising devices;
    d. Developing and refining of clinically useful pressure evaluation devices.

B. The education of individuals with physical disability, their families and all members of the health-care delivery team is an essential part of tissue management
   1. Rap sessions for hospitalized patients
   2. Workshops
   3. Seminars
   4. Lectures

C. Tissue Management Clinic - to provide a multidisciplinary approach to the prevention and treatment of pressure-induced tissue trauma (Figure 7).

VI. Projection for the Future

A. Development, fabrication and modification of clinically useful evaluation tools

B. Cooperation and collaboration between industry (manufacturers and distributors of rehabilitation equipment) and rehabilitation and rehabilitation engineering professionals, in research and clinical practice to objectively, conscientiously and rationally develop products for use by individuals with physical disabilities

C. Development and evaluation of new materials to be employed in pressure relief devices (Figure 8)
   1. Flolite - Hanson Industries from ski-boot material
   2. Elasto gel - from Southwest Technologies, Inc.
   3. Foam-in-Place Systems

VII. Conclusion

Pressure sore prevention is a major concern for the rehabilitation and rehabilitation engineering teams. However, ongoing research efforts indicate that there is no single pressure relief device or material that is optimum for all groups of individuals with physical disability. In addition, it has been demonstrated that many factors, alone or in combination, are responsible for tissue breakdown. Therefore, comprehensive programs that offer clinical service and education, as well as the incorporation of technology into the tissue management of these individuals will greatly enhance their potential for achieving their highest level of functional independence.

Case Management: An Interdisciplinary Approach

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INTRODUCTION

The array of services available to the patient in a rehabilitation hospital setting has increased dramatically in the past several years. Along with the traditional medical and functional services, we now have specialties such as respiratory therapy, neurophysiology, recreational therapy, urodynamics, nursing education programs and a whole series of services aimed at addressing the independent living needs of persons with a disability. All of these services and programs make demands upon a patients daily schedule, often times in a haphazard and non productive way.

This burgeoning service system has led to a concurrent awareness of the need to develop new models of patient (case) management in order to insure individualized, prioritized and timely service provision. While physicians have traditionally been seen as the manager of a patient's case, and indeed, may be the most appropriate choice during the acute medical phase of care, other clinical persons should be utilized in the role as a patient moves toward a psychosocial, community living focus.

MODELS OF CASE MANAGEMENT

In 1980, The Institute for Rehabilitation and Research added a variety of educational independent living services to its rehabilitation delivery system. These new services are offered along with medical, functional, psychosocial and vocational services. They are provided at the 22 bed TIRR Annex which primarily serves persons with spinal cord injuries and multiple amputations. These patients are generally transferred to the Annex from the main hospital when they are medically stable and ready to pursue advanced functional and independent living skills training. They may also be admitted from the community setting specifically for the specialized services and/or follow up care. The problems of managing this complex and varied system of care to insure that a patient receives the services he needs when he needs them was recognized early in the planning process. A number of models of case management were considered in order to design a system which could be individualized according the unique needs of each patient. Three models received primary discussion.

The first involved the development of a special department which would provide only case management services. We felt, however that its two major drawbacks would outweigh the possible advantages. First, it would add another layer of management and administrative cost to an already complex system. Second, the removal from day to day clinical practice would reduce the awareness of the practicalities and actualities of providing services.

The second model under consideration was based on choosing a discipline already established to add this function to its normal service program. The disciplines within our setting which would seem to be logical choices were either social work or vocational counselors. However, the planning group thought that the inclusion of only one discipline would lend a bias to the process and perhaps narrow the focus of the management team.

The third model, and the one ultimately chosen, involves using clinicians from the departments of social work, physical therapy, vocational, occupational therapy and nursing to serve as case managers on a half time basis while continuing their clinical practice during the rest of the time. Billing for their case management services is handled through regular department structures.

This model has several advantages for our particular setting. It allows us to utilize a departmental and service structure which is already in place. The diversity in backgrounds among the case managers provides a rich source of experience and knowledge about the full spectrum of rehabilitation with a variety of perspectives about service provision. And, the continuance of clinical practice insures a working knowledge of the service delivery system and the feasibility of making changes in programming as needs are recognized.

Every patient at the Annex is assigned a case manager. These mangers are assigned according to the patient's primary physician and teams are organized around the physician's and case manager's patient load. The average case load per manager is five.

Supervision of the case managers is provided by the administrative personnel of the TIRR Annex. Weekly meetings with administrators and case managers provide a forum for discussion of individual cases, the development of assessment skills and procedures, the documentation of system problems which impede timely service delivery and the exchange of knowledge among the various disciplines in the performance of case management responsibilities.

QUALIFICATIONS OF CASE MANAGERS

There are several qualifications which we feel are necessary for effectively performing the functions of this role. First, the person must have three years experience within the rehabilitation field in a major clinical department with participation in team meetings and planning. Since each rehabilitation setting differs, we further require that the person has worked in our facility for at least one year. These clinicians are generally senior level therapists who have shown leadership abilities within their own disciplines. They must demonstrate the ability to understand the total process of rehabilitation in relation to a patient's needs for living within the community and be able to assess those needs. Consequently, they need to have good interpersonal skills in working with patients on their case load as well as with other staff members. Case managers must also be comfortable in assuming a leadership role within the team and be willing to bear the responsibility for taking an active role in insuring that service plans designed by the team are implemented to meet patient needs.

ROLE AND RESPONSIBILITIES

The case manager function is designed to facilitate integrative and individualized program and service planning for patients. A key component of this process is an assessment of patient life goals with care provision subsequently related to the attainment of these goals. Case managers carry both the responsibility and authority to insure team planning is relevant to a patient's goals and that service provision is prioritized to meet those goals. To accomplish this, the manager is designated leader of the team and continually reviews service plans in relation to desired outcome. Decisions are made at this level drawing on team expertise regarding changes of approach, service timing issues, patient progress and scheduling conflicts. Since the role of the case manager as practiced at TIRR is a relatively new concept for patients, it is important for the manager to clarify the role and establish a working relationship with the patient early in the process.

In accomplishing these various functions, the case manager must work at the individual patient level, within the team process, and at the systems maintainance and design level.

Assessment

The assessment process forms the cornerstone for effectively managing the process of rehabilitation for each patient. This multidimensional assessment is used to determine patient needs, establish goals and design service plans. Assessment information is categorized in six major areas: Health Status, Functional Abilities, Productivity, Living Arrangements, Financial Status and Psychological Well-Being. These categories have been chosen as they appear to relate closely with those areas which are important for successful functioning within the community. The case manager derives input from the patient, team members, referral information, history and physical, family members, past hospitalization records and sponsors. The role of the manager in the assessment process is to integrate the information from all sources to reduce fragmentation of care and to develop a total picture of the person with his unique needs in his community setting. Goals are established from the assessment and listed in priority order. Wherever possible, goals are stated in terms of patient outcomes rather than system process. The focus of the rehabilitation process is directed toward what the patient wants to accomplish in his home setting and the case manager needs to insure that this viewpoint is maintained. The goals are discussed with the patient and are mutually agreed upon. Service plans are then developed around the prioritized goals. It is important to note that needs to be addressed are defined by the patient and team. Service provision to meet those needs is designed by the team and manager and presented to the patient. This distinction is an important one in that we cannot expect a patient to be sophisticated enough about our system to know what services are available, how he might access them, or how the services might help meet his stated needs. Thus, while we encourage and expect active participation on the part of the patient in setting goals, determining needs, and participating in the program, the professional staff retains the responsibility for designing service packages to best address patient goals.

Leading Team Rounds

As manager of the rehabilitation process, a primary responsibility of the case manager is to lead patient/team rounds which occur once a week. The patients are included in this process. In our patient goal oriented format, the focus of rounds becomes an interdisciplinary sharing of information about progress toward the accomplishment of stated goals. The manager leads the discussion about service provision and draws on the teams expertise in laying out plans for the coming week. Documentation of this process serves as the major tracking tool for the patient's progress during the admission. Notes are dictated by the case manager.

Ongoing Service Planning

In addition to assessment and the leadership of team rounds, the case manager performs a number of ongoing monitoring and oversight functions. The manager is responsible for reviewing a patient's schedule to insure that appropriate services are indeed being scheduled to meet patient goals. If scheduling conflicts occur, the manager will decide which appointment takes priority. She may wish to consult with other team members in making this decision.

The case manager meets with the patient on a periodic basis to discuss the overall course of the rehabilitation program. When the patient has questions about care, the case manager can direct him to the appropriate person to provide the needed answers. An important function of the manager is to educate the patient about using the system to meet his needs.

Case managers may call for planning and problem solving meetings with team members whenever warranted. They may also need to work closely with consulting medical services to insure appropriate timing of service provision.

Follow Up Services

Follow up/monitoring services are provided by case managers for our patients. Timing and number of contacts is determined by individual patient need. Issues for follow up are determined in the last team meeting with the patient and recorded on the final progress note.

If the patient is experiencing problems in the community, he is directed to the appropriate TIRR service, community agency or contact person. It is not the responsibility of the case manager to solve problems but rather to insure the appropriate referral linkages for the patient are identified. Documentation of follow-up contacts aid in evaluating trouble spots within the rehabilitation service system.

CONCLUSIONS

The case management function has been in the developmental and impl~~i~~ementation phase for the past two years. With our experience several observations can be made regarding the successes and problems attached to both the model of management chosen and the day to day operations of the role itself. The use of practicing clinicians who split their time between case management and provision of services within their own disciplines has, indeed, had several advantages. One, the sharing of a number of different perspectives during the case management planning sessions has insured that all develop an awareness of the multifaceted nature of the rehabilitation process and the varied possibilities for service planning. Two, the managers stay abreast of new services which are offered as they are active members of clinical departments. Three, since clinical supervisors in all disciplines from which case managers are drawn assign patients to therapists in relation to case manager assignments, the managers have the opportunity to know their patients from both perspectives. Therefore there is an integration of roles which allows several functions to be accomplished during one scheduled appointment. In comparing those instances where a case manager is not seeing a patient as a practicing clinician to those where they are, it appears that in the latter situation there is a more thorough understanding of the patient, his goals and needs and his day-to-day accomplishments.

There are two areas within this model, however, which can cause difficulties unless carefully monitored. First, because of the joint assignment in most instances of case management and therapist roles, it often occurs that as one's patient load grows as a manager it also increases as a therapist. During peak periods where one physician may have a disproportionally large number of patients in the facility, managers must be switched from one team to another to prevent any one manager carrying more patients than can adequately be handled in either or or both roles. Therefore the system must be responsive to day-to-day fluctuations and each manager should be comfortable in working with a number of different teams. And, second, this model demands that managers be able to work successfully under two supervisors: Within their departments regarding clinical skills and under the administrative supervisor for case management functions. Cooperative and collaborative relationships must be maintained between these two supervisory levels to insure that the staff persons dually assigned are not caught in the middle of conflicting needs or expectations.

One advantage of the system relates to the documentation needs of the management function. In most cases, the existing systems for documentation have been used to prevent the addition of yet another level of record keeping. Assessments and progress notes are handled through the regular dictation system which has long been established for physician records. In order to meet accrediting requirements, these notes are signed by both the case manager and the physician, thereby eliminating the need for separate notations.

As case managers are supervised by administrative personnel who have direct authority for overall service provision and program structure, there is an immediate feedback loop as systems problems which impede appropriate delivery of services are documented. Changes can be made more quickly and directly in the rehabilitation system itself than would be possible if case management were a departmental function further removed from the administrative function.

And, finally, the use of case managers in our setting has: (1) increased the relevance of the service packages designed for individual patients, (2) insured that these services are delivered in a timely fashion, (3) reduced the fragmentation of care often found in a multidisciplinary setting (4) provided a level of accountability for the unfolding of the process of rehabilitation for individual patients and (5) improved the documentation records used by sponsors and community agencies who maintain ongoing contact with patients.

CONSUMER PUBLICATIONS

Accent On Living Magazine

News and information for disabled individuals with special emphasis on day-to-day needs. A continuous source of new ideas, time-saving reference, and source of information about products and services. Published quarterly. Cost: $5.00 a year. Also contains a computerized retrieval system with information on topical publications and addresses of manafacturers marketing products for the disabled.

Accent on Living, Inc.
P.O. Box 700
Bloomington, Ill. 61701
(309) 378-2961

Paraplegia News

Published by the Paralyzed Veterans of America in the interest and for the benefit of all paraplegic individuals. Dedicated to the presentation of all news concerning living in a wheelchair. Cost: $5.00 a year.

Paraplegia News
5201 N. 19th Ave., Suite 111
Phoenix, Arizona 85015
(602) 246-9426

Rehabilitation Gazette

Annual publication with news on equipment, devices, publications, employment, personal stories, education, and other articles of interest to consumers. Cost: $3.00 for disabled, $5.00 for nondisabled.

Rehabilitation Gazette
4502 Maryland Ave.
St. Louis, Missouri 63108
(314) 361-0475

Green Pages

National buyer's directory of products and services for the rehabilitation of handicapped individuals. Published annually.

Green Pages
Rehab Sourcebook
P.O. Box 1586
Winter Park, Fla. 32790
(305) 628-0545

Paraplegia Life

Published bimonthly by the National Spinal Cord Injury Foundation. Features articles on environmental barriers, sports, and recreation, new products, and research in spinal cord injury. Cost: $10.00 a year.

Paraplegia Life
369 Elliot Street
Newton Upper Falls, MA. 02164

Disabled USA

A publication designed to promote better employment opportunities for disabled persons. Published bimonthly by the Presidents' Committee on Employment of the Handicapped.

PCEH
Washington, D.C. 20210

ACCD News Net

Monthly newsletter with consumer information published by the American Coalition of Citizens with Disabilities. Cost: $15.00 a year.

ACCD, Inc.
1200 15th St. N.W.
Washington, D.C. 20005
(202) 785-4265

Sports 'N Spokes

Magazine published bimonthly by the National Wheelchair Athletic Association covering wheelchair competition sports and recreation. Cost: $5.00 a year.

Sports 'N Spokes
5201 N. 19th Ave. Suite 111
Phoenix, Arizona 85015

Mainstream, Inc.

A monthly magazine features articles on employment, health, independent living, and assistive devices. For all disabled and professional concerned with the disabled. Cost: $10.00 a year.

Mainstream, Inc.
1200 15th St. N.W.
Washington, D.C. 20005

National Resource Directory

A guide to services and opportunties for disabled persons in the United States. Published by:

National Spinal Cord Injury Foundation
369 Elliot Street
Newton Upper Falls, Massachusetts 02164

The foundation will send you a copy at no charge but asks that you consider becoming a member. Membership cost is as little as $5.00 a year.

The Rights of Physically Handicapped People

A handbook published by the American Civil Liberties Union in December 1979. It is a comprehensive guide to the legal rights of handicapped people that explains in understandable form the state and federal laws and the effect of these laws in the areas of education, employment, transportation and public access. It also explains what you can do if your rights are being violated. Available for a small cost through local ACLU offices. In Houston the office address is 1236 West Gray, Houston, 77019, phone 524-5925. Or write the National office - 22 E. 40th St., New York, New York 10016.

Achievement

A monthly newsletter format of articles pertaining to all disabled persons. Cost $3.00 a year.

C.J. Lampos, editor
925 N. E. 122nd Street
N. Miami, Flordia 33161

Up Front

A newspaper format of articles on legislation, travel and human interest; a multi-handicapped approach. Cost: $15.00 a year.

Up Front
90 Cherry Street
Box 519
Johnstown, Pa. 15907
1-800-458-0151

Handicapped American Report

Newsletter focusing on legislation and court decisions affecting disabled individuals. Cost: $40 a year

Helen Hoart, Exec. Ed.
1300 N. 17th Street
Arlington, VA 22209

Reprint from ARCHIVES OF PHYSICAL MEDICINE AND REHABILITATION. Vol. 63, November 1982

Trochanteric Pressure in Spinal Cord Injury

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ABSTRACT. Garber SL, Campion LJ, Krouskop TA: Trochanteric pressure in spinal cord injury. Arch Phys Med Rehabil 63:549-552, 1982.

• Pressure-induced tissue breakdown is a frequent and life-threatening complication for individuals with spinal cord injury. These patients are frequently positioned on their sides to relieve back and sacral pressure while they are in bed. This position causes high trochanteric pressure with the potential for the development of pressure ulcers. In addition, the individual with a spinal cord injury has accompanying absent or diminished sensation, and therefore is not aware of the pressure overload. In this study the positions that will reduce the possibility that trochanteric ulcers will develop are identified. The Pressure Evaluation Pad (PEP), a pneumatic pressure monitoring system, has been used to study the effect of different leg positions on trochanteric pressure. The pressure under the right trochanter was monitored as the contralateral leg was positioned in various degrees of hip and knee flexion or extension. The procedure was repeated for the left trochanter. A study of 50 subjects demonstrated that a position of 30° hip flexion and 35° knee flexion (with lower leg behind midpoint of the body) produced lower contralateral trochanteric pressure than the traditional position of hip and knee flexion across the body. Additionally, thinner patients were found to have higher trochanteric pressure than average weight or obese subjects. Standardizing a method for the positioning of patients on their side can be a significant deterrent to the tissue erosion that greatly interferes with the rehabilitation process.

The breakdown of skin that overlies bony prominences is a frequent and life-threatening complication for the patient with a spinal cord injury.[12] The trochanter is especially vulnerable to extremely high pressure and ultimate erosion when the patient is positioned in bed on his side after surgery, on the sacrum or ischium, or during routine side-back-side turning procedures. In fact, approximately 17% of all pressure sores seem to occur over the trochanter.[6]

Body positioning is a daily activity that is important for patients confined to bed.[10] A plan for positioning should include placing the patient in the position that is most likely to decrease pressure and diminish the risk of skin ulceration. Opinions differ on the best position to reduce pressure. Traditionally, there have been many techniques that were utilized to decrease tissue breakdown. Turning every 1 to 2 hours with gradual and individually increasing frequency between turns is a routine procedure for this purpose.[1-4,7,8]

In addition to turning, there are many well-known devices that are used to decrease pressure and tissue breakdown. These include therapeutic beds, mattresses, positioning aids such as sheepskins, pillows, wedges, foams, and alternating air mattresses, all of which are thought to distribute pressure more evenly and therefore decrease the risk of tissue breakdown.[1,2,4,9]

Variation in the magnitude and location of trochanteric pressure is accomplished by positioning the top leg in varying degrees of hip and knee flexion or hip and knee extension. However, there does not seem to be any data that describes the quantitative measurement of the pressure under the trochanter with variation in the position of the opposite leg. In this study trochanteric pressure was monitored in relationship to variation in position of the opposite leg.

METHOD

Subjects studied. Of the 50 subjects with spinal cord injury who participated in this study 47 were males and 3 were females ranging in age from 14 to 62 years. Twenty-three were paraplegic and 27 were quadriplegic individuals. All patients had been admitted to the hospital for a comprehensive rehabilitation program and none had had any surgical procedure for the correction of pressure sores.

Procedure. The pressure monitoring system used in this study consisted of a printed circuit containing a 12 x 12 matrix of pneumatically controlled contact switches.[5] The circuit was connected to a readout board containing 144 light emitting diodes that became illuminated with pressure in the corresponding switches (fig 1). Each subject was positioned on his side in bed on a standard hospital mattress with the pressure measuring device under his trochanter. Pressure was first recorded while the patient was in the traditional position (fig 2) in which the superior leg was positioned across the body in 55 or 65° of hip flexion and in 80° of knee flexion as measured with a goniometer. The bottom leg was in a neutral position. (The amount of hip flexion in this position was determined by the patient's joint mobility and comfort. Trochanteric pressure in this position was the same in either 55 or 65° of contralateral hip flexion). One pillow was placed lengthwise between the legs to prevent pressure at the knees. The patient was then repositioned so that the superior leg was placed in 30° of hip flexion and 35° of knee flexion, with the lower part of the superior leg behind the midpoint of the body and resting on a pillow. The bottom leg remained in a neutral position. For both positions a pillow was placed behind the back for stability. The magnitude of trochanteric pressure was recorded and the entire procedure was repeated on the opposite side.

Statistical methods. Calculated data are given in terms of the mean ± standard error of the mean (SEM) and are expressed in millimeters of mercury (mmHg). Statistical sig-

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Some of the data reported here were presented at the 56th Annual Session of the American Congress of Rehabilitation Medicine, Honolulu, November 12, 1979. Submitted for publication September 18, 1981, and accepted in revised form January 12, 1982.

Fig 1—Use of the Pressure Evaluation Pad (PEP) to monitor trochanteric pressure of patients in bed in the sidelying position.

nificance was assessed using the student *t* test (paired, 2-tailed) and analysis of variance as was appropriate.

RESULTS

In normal volunteers (table), subtrochanteric tissue pressures in the traditional sidelying position (hip and knee flexion) were determined. Similar pressures were also observed in spinal cord injured subjects. These similarities in magnitude of pressure, therefore, indicate that resulting ulceration cannot be explained solely on the basis of the spinal cord injury alone. This is further demonstrated by the similarities observed in the ischial pressure of normal volunteers and the spinal cord injured seated in wheelchairs on various foam cushions.[11]

Because of the observation of high subtrochanteric pressure in the spinal cord injured subjects, it was necessary to investigate a number of body and extremity positions which might produce a reduction in localized tissue pressure. The traditional position (fig 2), was studied first and was found to produce high trochanteric pressures. In preliminary studies (unpublished data), the extended position was found to produce the most consistent reduction in subtrochanteric pressure. This modified position (fig 3) consists of the subject lying on her/his left side. The lower leg (left) is positioned in a neutral position of minimal hip and knee flexion. The superior leg (right) is extended behind the lower leg and rests in 30° of hip flexion and 35° of knee flexion. Pillows are placed behind the back, under the head, and between the legs at the knees.

The effect of leg extension was then investigated in the spinal cord injured subjects (fig 4). Compared to the relatively high subtrochanteric pressures observed in these subjects when positioned in the traditional position of superior hip and knee flexion, the proposed extended position decreased subtrochanteric pressures by 21 to 34mm Hg ($p<0.001$). Therefore, it seems apparent that for these patients, traditional methods of positioning clearly produce inordinately high localized tissue pressure and may contribute, in part, to the high rate of tissue breakdown observed in these patients.

Subtrochanteric Pressures in Patients with Spinal Cord Injury and in Normal Volunteers in the Traditional Sidelying Position

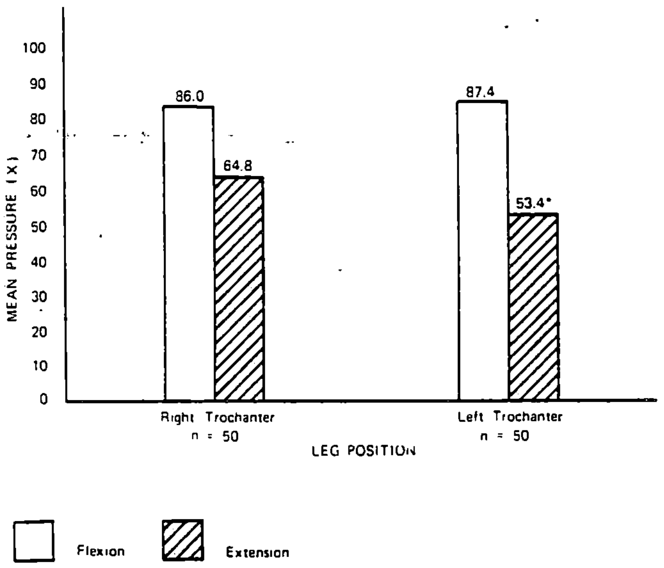
Subjects studied	n	Mean pressure ($\bar{X}$)* (mHg) Right side	Left side
Normal volunteers	30	80.3 ± 3.47	79.4 ± 4.49
Spinal cord injured	50	86.0 ± 3.57	87.4 ± 2.83

*Denotes mean ± SEM in mmHg

Fig 2—Traditional sidelying position; superior leg in hip and knee flexion across body.

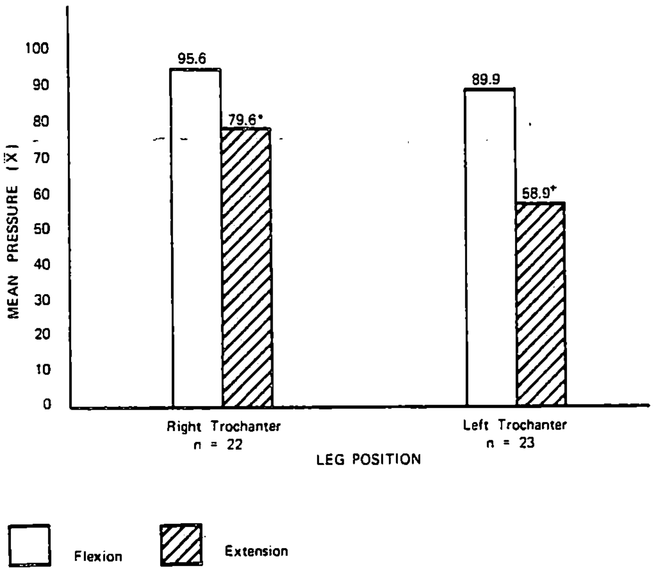
Possibly the effectiveness of the extended position may not be applicable for all immobilized patients with spinal cord injury. In order to investigate this possibility, it was necessary to investigate pressure in paraplegic (fig 5) and quadriplegic (fig 6) individuals. In the paraplegic individuals, subtrochanteric pressures in the traditional flexed position were significantly higher than those pressures observed in normal volunteers (table, $p<0.05$). These pressures, however, were

Fig 3—Position that produces lower trochanteric pressure; superior leg extended behind lower leg.



X = mean ± S.E.M. in mm/Hg
* = significantly different pressure in extension vs. flexion (p < .001)

Fig 4—Effect of leg position on trochanteric pressure in subjects with spinal cord injury.



X̄ = mean ± S.E.M. in mm/Hg
* = significantly different pressure in extension vs. flexion (p < .05)
+ = significantly different pressure in extension vs. flexion (p < .001)

Fig 5—Effect of leg position on trochanteric pressure in paraplegic subjects.

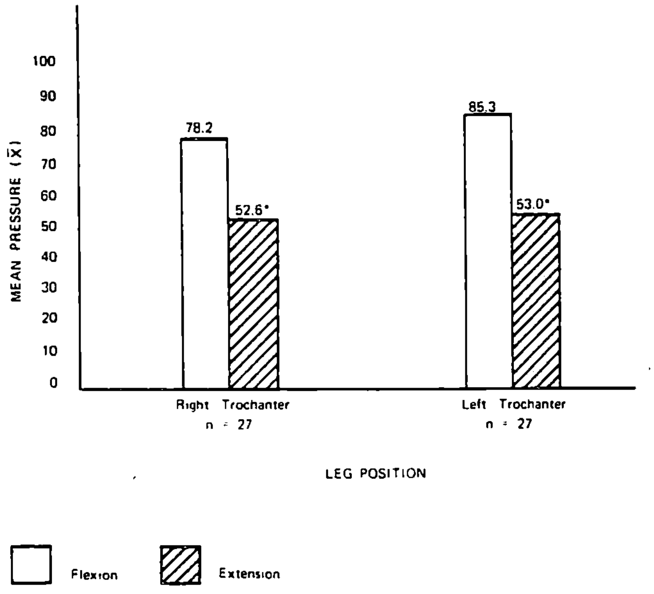
not significantly different from those observed in the overall population of spinal cord injured patients (table). Modification of leg position in the paraplegic individuals reduced subtrochanteric pressure 16 and 21mmHg on the right and left sides respectively.

Similar studies were also carried out in 27 quadriplegic individuals (fig 6). Pressures in the traditional position of hip and knee flexion in the quadriplegic individuals were as high as those observed in normal volunteers (table). Repositioning of the superior leg to the extended position reduced trochanteric pressure 26 and 32mmHg on the right and left sides respectively ($p<0.001$). Thus, it is apparent that the extended position is equally effective in quadriplegic subjects and paraplegic subjects.

DISCUSSION

It has been demonstrated that pressure exerted over a bony prominence, whether ischial in the person seated in a wheelchair or trochanteric in the person in the sidelying position in bed, is similarly high in both normal subjects and those with spinal cord injury. The effects of prolonged pressure over a bony prominence has been the breakdown and ulceration of that tissue that overrides the bone.

Until recently, there has not been a systematic investigation that compares patient positioning as a preventive measure in tissue breakdown. The Pressure Evaluation Pad (PEP) allows quantification of tissue pressure and has been used previously to evaluate pressure relief devices for the wheelchair and bed.[5] In this study, the nursing practices of turning and positioning of immobile patients have been investigated. Results of this study clearly demonstrate that the usual and customary sidelying position (hip and knee flexion across the body) in both paraplegic and quadriplegic individuals produced unacceptably high subtrochanteric tissue pressures.



X̄ = mean ± S.E.M. in mm/Hg
* = significantly different pressure in extension vs flexion (p < .001)

Fig 6—Effect of leg position on trochanteric pressure in quadriplegic subjects.

Reduction of trochanteric pressure is achieved by a redistribution of the pressure onto the larger ipsilateral gluteal surface. This arises from rotation of the pelvis posteriorly. Substantial reductions of 20 to 40% in these pressures can be produced by a simple modification of the position of the superior leg. Although this reduction in pressure is significant, the tissue that overlies the trochanter may still be vulnerable to breakdown if other pressure sore prevention techniques such as good hygiene, nutrition, and turning in bed are not also used.

CONCLUSION

The prevention of pressure sores is a major objective in the care of individuals with physical disabilities. Although there are numerous mattresses and devices to reduce pressure when in bed, spinal cord injured patients are still threatened with increased amounts of pressure on bony prominences that can lead to tissue compromise and a delayed rehabilitation program. Positioning and turning is therefore a vital component of the spinal cord injured patient's care. For the person confined to bed, the tissue over the trochanter is highly vulnerable to breakdown in the traditional sidelying positions. Modification of that position has resulted in a reduction of trochanteric pressures, thus reducing the potential for the tissue erosion that greatly interferes with the rehabilitation process.

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Early Psychosocial Intervention in Severe Trauma: Alliances for Treatment

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The individual who survives severe traumatic injury faces a complex, technical maze of medical and nursing care. Physical treatment in the acute period predominates as the activity primary for continued life support. But the physical treatments do not occur in isolation of the psyche. Since emotional stress accompanies any physical threat, emotional survival is also at stake following trauma.

Popularized concepts of the holistic health movement and ecological health models of person-in-environment now underline the importance of treating the person as a bio-psycho-social being. (1,2) There is fast-growing evidence that treating the whole person is not only humanitarian -- but that integrated physical and emotional care can promote positive outcomes in illness and disability. (3,4) Indeed, a patient's psychosocial experiences during acute care essentially lay the groundwork for long-term adjustment to physical disability.

The focus of this chapter is on patient and family experiences of severe trauma which result in catastrophic loss of physical function, i.e., the psychosocial aspects of injury and of the hospital environment. The dynamics of the treatment environment can powerfully influence coping and total outcome. (5,1) Methods and strategies are suggested for use in the acute-care environment to promote positive coping by patients and families. Finally, severe responses to injury are explored emphasizing indicators for psychiatric consultation.

Psychosocial Components of the Crisis

Survival Struggle The uncertainty of life and death confronts many traumatically injured persons following the accident. Immediate life threat may result from the severity of injury, and often occurs from delay or complications with rescue attempts.

> A 30 year old man sustained quadriplegia from trauma when his sports car overturned. He vividly recalls the near-death experience of waiting for hours for assistance, as he lay bleeding and helplessly trapped in the vehicle.
>
> A 20 year old man experienced immediate paralysis at the cervical level after diving into a sandy bank in Clear Lake. Floating face down, he expected his life to end from drowning. He was uncertain if his friends would pull him from the water -- of if he wanted them to.

Physical-Sensory Deprivation Trauma patients undergo a dramatic decrease in sensory and social stimulation during acute care. (4,6) The effects of the physical trauma itself, plus a combination of anesthesia, medication for pain, sleep disruption, and the disorienting bustle of intensive care unit (ICU) activities probably each contribute to a clouding of the sensorium. (7) Basic attempts at self-protection and coping may result in avoidance behavior, withdrawal, or emotional disassociation of the patient from his surroundings. (8) The ICU can literally become an incubator, shielding out familiar stimuli and inducing alienation.

Loss of Body Control Particularly for the patient population of physically active, independent adults, traumatic injury creates a stressful situation of forced dependency and physical helplessness. In spinal cord injury, motor functioning, sensation, bowel and bladder control and sexual functioning are likely to be lost or impaired; loss of essential function and phantom sensations typically accompany traumatic limb loss. Such drastic functional loss may trigger fear and confusion over the sense of disorientation with one's body. Physical loss of control represents an emotional threat because it limits one's ability to maintain personal control (8).

Interpersonal Relationships The hospitalized trauma patient is literally uprooted from his life-space. The person finds himself in an ICU or hospital ward, suddenly cut off from his family life, work activities, recreation. Particularly when internal coping resources are depleted from the crisis of injury, a person experiences intensified needs for emotional support, attention, and affection. Yet, these needs occur at a time when support from social and family contacts is greatly decreased. (1)

Furthermore, the ICU climate is generally not conducive to intimate communication about personal concerns -- which is the basis for mutual emotional support.

Besides the physical separation forced by hospitalization and restricted visiting, other factors may weaken the family support system, which normally provides protective and nurturing functions. Weller and Miller describe the helplessness and panic observed in families, noting common anxiety responses of excessive hovering or fleeing due to being overwhelmed. (9) Families and friends immobilized by stress may have difficulty providing appropriate support. Diminished internal and social supports consequently leave the patient with strong dependence on the acute-care staff to sustain his interpersonal needs.

Family Role Changes Another aspect of the isolation of the patient from family is disruption of role performance and role expectations. Family systems operate with varying degrees of interdependence for performing necessary tasks to maintain survival and family activities. With catastrophic injury and consequent prolonged hospitalization, there is typically an overwhelming shift in responsibilities to the spouse or other family members.

> The 19 year old wife of a young welder during initial hospitalization for C-5 quadriplegia was suddenly barraged with total family responsibilities following his injruy. Her part-time secretarial job 200 miles away was the only financial support for their family of 4. Her job was also necessary to maintain health insurance needed for his rehabilitation. She was faced with juggling priorities of producing income, managing child care, and arranging eventual relocation of the family -- while providing the major emotional support to her husband during his difficult hospitalization.

Social Stresses Other psychosocial factors of traumatic injury involve the concrete stresses on the social situation. Among the problems faced by patients and families after injury are loss of income, dilemmas with transportation, housing needs allowing accessibility to the hospital, and child care responsibilities. Due to increased expenses at a time when income may be decreased, financial stresses often limit the capacity to manage the other problems. Community resources for immediate personal and financial needs are inadequate and difficult to access. For many families, negotiating agency systems to obtain public assistance constitutes yet another stress of personal dignity and patience.

As prior to injury, families have varying capacities to cope with emotional and concrete stresses. Positive coping capacities usually include flexibility, good problem-solving skills, and abilities for developing and maintaining strong networks of social support. Those functioning with fewer personal resources may need emotional support and professional assistance from hospital staff. Intervention of direct-care staff by offering emotional support can be strengthened by initiating consultation with the social worker for full assessment and appropriate referrals which link families to additional resources.

Psychosocial Management of Trauma

The degree of emotional impact from these psychosocial components in traumatic injury must be considered unique to the individual patient and family system. Immediate psychological consequences have been conceptualized in terms of stages of emotional adjustment (8,9) and models of therapeutic management of trauma. (6) There is wide speculation that shock, depression and denial are necessary and universal reactions to sudden, catastropic injury. In her review of literature on the process of adjustment after injury, Trieschmann emphasizes that persons with traumatic injury are a heterogeneous group whose behaviors and emotional responses are highly individualized. (7) She notes there is not evidence at this time of classical stages of adjustment.(10) That is, positive adjustment can occur without depressive phase, and active denial may play a minor role with some patients. In fact, absence of these has been shown to correlate with positive outcomes. (7) The sequence and duration of adjustment responses are also believed to be variable for individual patients and families. (9,11)

Data does suggest that personality traits and coping styles tend to be maintained after traumatic injury. (7) In fact, there appears to be an intensification of pre-injury traits (12), such as self-blame or dependency. In view of individualized coping responses, it is wise to have no clear expectation that a patient or family must follow predictable response patterns.

It may be unrealistic for direct-care staff to fully assess and understand a patient's emotional experiences during acute care. Whatever the range of psychosocial responses, it is safe to assume the experiences surrounding injury constitute a life crisis by causing disruption in some aspect of lifestyle. Forces in the treatment environment will influence the patient and family and will shape their reaction to treatment, whether psychosocial functioning appears to be positive or poor. Positive patient-environment interactions can minimize negative aspects of trauma and treatment, as well as positively contribute to the process of returning to health.

How can the hospital environment and the staff as a dynamic part of the environment be responsive to patient and family needs? It is possible to glean some insights on environmental strategies from both crisis theory and the body of knowledge about coping with stress and illness.

Rapoport describes the tasks of effective crisis intervention in terms of the following goals:

1) establishing trust and engaging in an "alliance for treatment";
2) reestablishing a sense of autonomy;
3) mobilizing hope;
4) facilitating decisions and goals for action. (13)

The focus is on the immediate time and place, and primary strategies include clarification of basic information to diminish anxiety. The major objective of crisis intervention is to sustain and support the individual toward a state of equilibrium, in which he is self-sustained by usual coping resources.

Theories of coping and adaptation suggest that there are two modes of coping with stress, and influencing change in the social environment. (1,5) That is, internal coping within the individual, versus environmental alteration to minimize stress. While palliative efforts can be offered to the individual and family to enhance their coping, "fixing the person" remains an unrealistic and often ineffective objective. On the other hand, rich resources for supporting an adaptive emotional response to trauma lie in the person's external environment. The acute-care setting is complex and dynamic, with opportunities for positive emotional interactions which facilitate coping. The challenge becomes one of developing ways to use and modify the patient-care environment as a means of improving psychosocial functioning of the patient and family.

Many attempts have been made in the literature to describe what is essential for successful interactions with the environment, i.e., for coping. White suggests that adaptive behavior involves management of three variables: securing adequate information, maintaining autonomy and freedom of movement. (14) From an ecological perspective, Germain states that patients require certain "environmental nutriments" for effective coping with illness and disability:

1) opportunities for taking action and making decisions;
2) staff behaviors and patient services that regard patients' coping efforts and support their sense of dignity;
3) provision of necessary information in the appropriate amount and at the appropriate time;
4) organizational policies and procedures that respect patients' lifestyles, cultural values, and social supports. (5)

Using these concepts as a foundation, specific strategies and staff interactions within the hospital environment are proposed.

Environmental Strategies and Staff Responses

Establishing Trust: Building "Alliances for Treatment"

Develop good working relationships early with patient and family members, based on clear communication:

1) Active listening to needs and concerns.

INTERACTION PATTERNS -- STYLE I

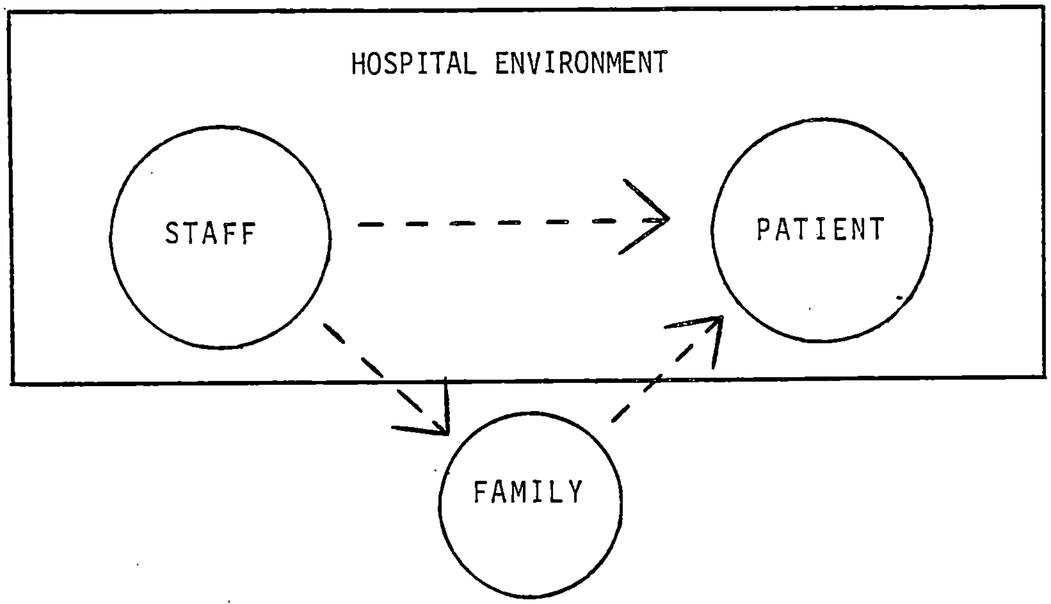

FIGURE 1

INTERACTION PATTERNS -- STYLE II

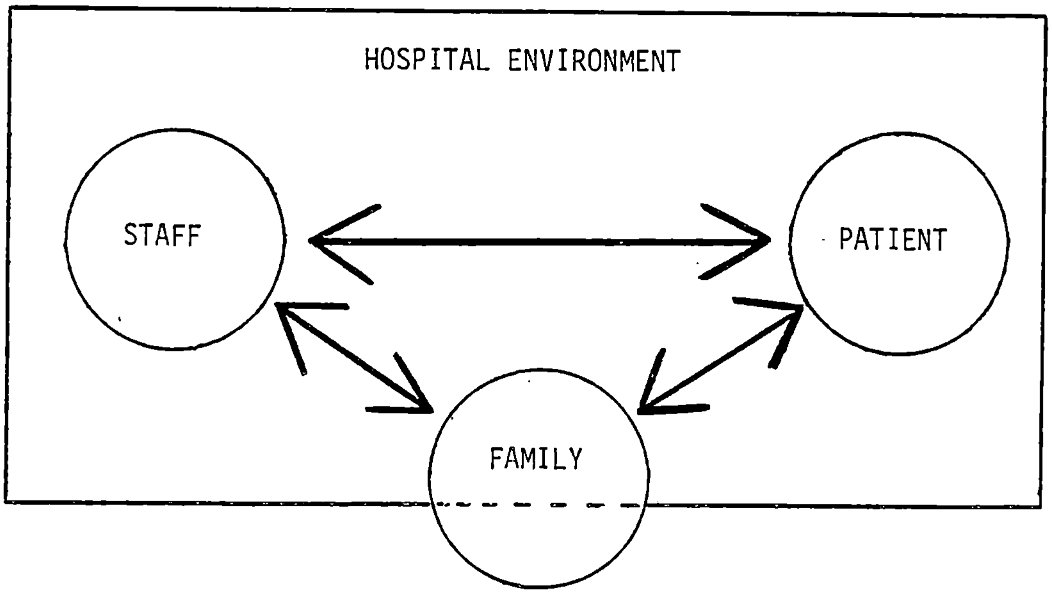

FIGURE 2

2) Giving information to welcome and orient patient and family to hospital system and introduce care procedures.

Effective Communication System

1) If patient is nonvocal, set up nonverbal communication system as soon as possible (e.g., blinking, clicking system).

2) Establish communication patterns to allow flow of information between patient, staff and family.

The systems-diagrams (Figures 1 and 2) illustrate two situations of interaction patterns occuring in the hospital environment. Broken lines depict unidirectional communication, and solid lines show two-way interactions. Figure 1 demonstrates a situation characteristic of the early period in acute care: one-way communication emanating primarily from staff to patient and family, with family interacting with patient from its place outside the system. As treatment alliances develop, ideally there should be movement toward Style II interaction patterns (Figure 2). The family is brought inside the system, now with strong two-way communication between all three essential elements -- the patient, family, and staff.

Opportunities for Control and Action

Staff responses in the acute-care environment traditionally foster learned helplessness by reinforcing helpless behavior, such as pain, calling for help, etc. Reinforcing independent behavior helps to improve treatment outcomes and long-term adjustment to disability. (7) Whenever possible, minimize helplessness and dependency of the patient by providing opportunities for decision-making, control and manipulation of the environment:

1) Establish care routines in which the patient can participate.

2) Allow patient decisions about negotiable aspects of his care, e.g., time of procedures, amount of family participation in care, etc.

3) Set up immediate environment to allow access to personal belongings and needed items, e.g., TV, telephone, cosmetics, etc.

4) Allow for patient privacy and ways to be alone if he needs quiet time.

5) Encourage physical movement and mobility within medical limitations.

6) Offer opportunities for daily decisions, e.g., regarding visiting times and number of visitors, menu choices, etc.

Providing Information

Providing clear, accurate information can reduce anxiety and helplessness:

1) Basic, simple information -- avoid technical, complex explanations.

2) Frequent, repetition of explanations of care procedures.

3) Clarification: Let the patient know:

   - what is happening to him,
   - what is being done to and for him, and why,
   - what he must do to cooperate with his care.

4) Reassurance -- calm, positive communication.

5) Accuracy (non-speculation): Offer and clarify the information you do have; resist pressures to supply answers to questions you cannot answer.

   (Giving inaccurate or misleading information may be more detrimental than saying "I don't know.")

Family Participation in Care Procedures

Build "alliances for treatment" with family members who can be essential sources of support. Involving family members in simple care procedures can reduce patient/family isolation, and minimize anxiety and helpless feelings:

1) Inform family of the care plan and allow them to participate in some aspect, e.g., feeding, positioning, personal hygiene.

2) Allow adequate space and time for visiting.

3) Encourage hospital policies and procedures that support family involvement, e.g., parking, family visiting area, minimized interruptions at visiting times.

Prognosis Information and Response to Denial

Giving prognosis information when it signifies "bad news" is a specialized aspect of communication with patients and families during acute care. Within the initial two weeks of hospitalization, a large percentage of patients actively desire information about implications of their injury. (10) Judgements by medical personnel about giving prognosis information may be difficult: how much to say, at what time, in what manner? In general, it is most helpful to provide truthful yet conservative predictions about outcomes in response to prognosis questions.

Basic concepts which may guide such judgements include:

1) People need information about their injuries, but only in the amount and at the appropriate timing that they can hear it.

2) It is as unfair to withhold information, as it is to bombard them with future predictions that cannot be proven so early.

3) It is possible to provide honest information without taking away hope.

A model for supportive use of prognosis information is shown below:

SUPPORTIVE USE OF PROGNOSIS INFORMATION

Appropriate Timing and
Amount of Information
↓
Hope -- Positive Expectancy
↓
Mobilization of Strengths
↓
Motivation for Rehabilitation

Sensitivity to preserving hope can foster positive patient expectations, which serve as the basis for mobilizing his strengths toward a positive outcome. In contrast, negative consequences of giving extreme predictions of prognosis are illustrated below:

PROGNOSIS INFORMATION: EXTREME PREDICTIONS

Positive Prognosis	Negative Prognosis
Reinforcement of Denial	Anger ↘ ↙ Hopelessness Despair
Unrealistic Expectations → Failure	
Unwillingness for Rehabilitation	Refusal to Cooperate with Treatment
Premature Return to Activity	Mistrust of Staff
	"Doctor-Shopping"

The use of denial as a coping mechanism in the acute phase of care is often viewed negatively. It may take the form of minimizing the injury or its implications;

in some patients, the possibility of permanence never occurs consciously. Denial of long-term disability in the early phase is a valid, useful, and healthy defense. (7-10,12) It serves to contain the flood of emotion that can immobilize any further coping. Since future-focused negative prognosis is likely to trigger stronger denial, a more effective approach is to assist the patient in focusing on the present reality in order to plan for the next step -- rehabilitation for maximizing what he has.

Indicators for Psychiatric Consultation

A range of emotional coping responses to trauma and acute care is natural and expected. Taking into account individual patient differences and limited assessment information during early care, it is important to note severe, dysfunctional reaction patterns that may indicate a need for psychiatric consultation. Indicators are outlined as follows:

1) Persistent lack of reality orientation, beyond a temporary disassociation or clouding of the sensorium.

2) Dysfunctional psychogenic symptoms, for which there may be a physiological basis, but diminished psycho-emotional tolerance of symptoms. For example,

   a. A non-medical appetite disorder in a young quadriplegic woman with extreme anxiety and GI problems. Her refusal to eat sabotaged her rehabilitation program.

   b. Pre-occupation with neurogenic pain in a C-5 quadriplegic male, whose back pain intensified with his depression, blocking participation in therapy.

3) Severe depression, with a history of depression precipated by loss. Pre-injury emotional loss is believed to be linked to severe depression as a syndrome after traumatic loss due to injury. (8) For example, loss of a parent or loved one early in life. This is distinguished from sadness or mourning as a natural response to loss.

4) Suicidal ideas that develop into a plan. This persistent preoccupation with suicidal thinking, or specific planning for suicide is distinguished from statements about not wanting to live, which may be in the normal range of emotional responses.

Conclusion

The person with severe trauma requires technical expertise, immediacy, and life-saving action. Such concentrated focus on emergency and critical care often obscures the broader need of treating the whole person. Management strategies which support emotional adjustment in the acute-care environment strongly influence positive long-term outcomes in rehabilitation.

The process of learning to live with one's disability begins at the moment of injury and continues through life. (7) Dynamics of the treatment environment affect this continuum: interactions with patients and families which encourage participation, hope and independence in a caring and enabling environment can mobilize strengths for rehabilitation and long-term adjustment to disability. Therefore, a traumatically injured person and his family require individualized, comprehensive care which is responsive to both physical and emotional needs. Maximizing a person's physical function becomes futile if psychosocial disability prevents him from using it.

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