

Prevention of Secondary Disabilities after Brain Injury and Spinal Cord Injury: Implications for Future Research¹

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Over the past decade there has been increased emphasis upon prevention of disability. Although it is obvious that preventing a disability is the most desirable approach, disabilities will nonetheless occur. When they do, we must treat them and prevent additional disabilities from following the original ones. Indeed, this separation of disabilities has led to a clearer understanding of their prevention, namely primary, secondary, and tertiary prevention. © 1994

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INTRODUCTION

Primary Prevention

Primary prevention seeks to avoid the occurrence of the original problem, for example, policies followed at a local swimming pool to prevent people from diving into shallow water and thereby fracturing their necks and becoming paralyzed. Another example is mandatory wearing of helmets while riding motor cycles or bikes and, thus, reducing the incidence of head injury resulting from biking accidents. However, once an injury has occurred, the focus changes to simultaneous treatment of the injury and prevention of secondary disabilities which can arise from the initial problem. An example of a secondary prevention strategy is education which reduces the incidence of pressure sores of insensitive skin which occurs in many people with spinal paralysis. Another example is the interventions and education which prevent joint contractures which can result from skeletal muscle spasticity caused by brain damage. In order to fully define prevention, one must also consider tertiary prevention which is the treatment of additional problems which complicate the secondary disability. An example is preventing osteomyelitis from developing at the base of a pressure sore which is the secondary disability described above. Another example is the treatment of immobility resulting from contractures which have already occurred as a

result of the spasticity caused by the original brain injury. These are not irrelevant distinctions. In order to focus on prevention strategies, one must have a clear understanding of where in the disabling process the patient's or the client's status is being considered.

Secondary Prevention

Fuhrer has set the conceptual landscape for understanding secondary disabilities (1). He distinguishes between health complications (secondary complications) and secondary disabilities. A complication is a pathological condition that appears in the course of another pathological condition and may or may not be a result of that condition. Secondary disability goes beyond the limited definition of complication by focusing upon a loss of human function rather than being limited to a further alteration of physiology. The secondary disability may be acute or it may be chronic, that is, of long duration. Whether acute or chronic, the secondary disability must be directly related to the primary health problem, in this case, spinal cord or head injury. We must not lose sight of the fact that these two injuries of the central nervous system usually leave life-long deficits in human function. It is possible and likely that the (former) patient will be vulnerable to secondary disabilities at any point in his or her life and for the rest of their life. Therefore, health care practitioners must prepare to fend off secondary disabilities on a continuing basis. Health status fluctuates with age, and it changes with exposure to normal life processes such as aging, pregnancy, work, etc. It is apparent that the system of health care should attend to the prevention of secondary disabilities occurring after spinal cord and head injury and for the rest of the person's life. The system should recognize risk factors and modulate its approach to prevention depending upon an interaction between health status and risk factors over the lifespan.

Pope and Tarlov wrote extensively on disability. In a report undertaken by the Institute of Medicine, they developed a national agenda for the prevention of dis-

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abilities (2). They defined the relationship between the primary disabling condition and the secondary condition as a causal one; the second condition would not occur without the existence of the primary condition. However, they point out that the causal relationship can be direct or indirect. It is in the area of indirect causality that the traditional health care system may miss opportunities to intervene and prevent secondary disabilities. An example of an indirect relationship is a disabling condition that causes new stress—uncertainty about the future, changes in living environments and social relationships, and frustrations from being unable to enter or leave a building—that can lead to other stress-related disorders. Marge listed some common secondary conditions that may threaten the individual with spinal cord or brain injury (3). These include decubitus ulcers, genitourinary tract disorders, cardiovascular disorders, stroke, musculoskeletal problems, arthritis, respiratory problems, speech and language problems, losses of sensory function, and emotional problems.

In 1986 the International Center for the Disabled, in cooperation with the National Council on the Handicapped, produced the first major national survey of the attitudes and experiences of disabled people. It was the first nationwide survey to ask disabled people about their self perceptions and how their lives have changed (4). It asked about their experiences with employment, education, social life, and what they think must be done to increase their participation in the mainstream of U.S./North American society. The answers they got to these questions are of considerable relevance to the subject of secondary disabilities. There is evidence, at least in the group of people with spinal cord injury, that persons who exhibited greater handicap in terms of poorer vocational adjustment and less social involvement were less likely to be alive 10 years after injury than were persons who were better adjusted vocationally and socially (5). The following observations from the survey point to ways in which people with disabilities could be better able to access the resources in our country, reduce their dependency, and improve their health. Attention to these factors might lead to a reduction of secondary disability over the lifespan.

Survey Observations

The survey observations include.

- There is need for improved transportation services and access to public areas which would help many disabled people get around easier and enter buildings and bathrooms without trouble. The survey also revealed a need for more personal care attendants or assistance services.

- There is a fear or self-consciousness among disabled persons. Fear and self-consciousness may be an

impediment to good health habits and is very difficult to alleviate.

- More than a third of all disabled people who face barriers in their lives related to their disability say that nothing could be done to help them. Apparently they look upon their situation as a personal trial and not a responsibility which they and society should face together.

- Although a core of disabled persons of unknown size will never be able to enter the workforce, others who were surveyed identify limitations in activities and need for care as barriers to employment. These same people do not know about rehabilitation and the medical services available to them. Their ignorance is a clear barrier to receiving vital services.

- Contrary to popular belief that loss of disability benefits is one of the most common reasons why so many disabled people do not return to work, the survey showed that the need for continued medical treatment, current employer attitudes, lack of education and skills, and transportation problems bar many more disabled persons from the workplace.

- The survey also provides implications for bringing more disabled persons into the work force. A greater willingness by employers to make accommodations will allow many more disabled persons to enter or re-enter the work force.

Just as in the areas of public health and prevention, interested individuals and organizations need to develop a common understanding of injury and disability so that they may communicate with one another. It is appropriate to review the work of several groups who, over the past decade, have worked to develop and refine a language and set of definitions which would describe disability in its various forms. With such an understanding the public and professionals can see where the prevention of disability, especially prevention of secondary disabilities, can favorably affect the emerging paradigm of disability. From the foregoing, it is clear that there are many impairments that can result from spinal cord or head injury. It is also clear that many secondary disabilities can result from these primary injuries and that they can occur over a lifetime. A complete picture of disability will help to focus upon the myriad of specific problems that can arise. Toward this end, the National Center on Medical Rehabilitation Research (NCMRR) modified and expanded a classification scheme proposed by several organizations and individuals (6).

NCMRR's Model of Disability

The NCMRR proposes a paradigm for understanding disability which is based upon earlier work by the World Health Organization (7), Nagi (8), and Wood (9). The National Advisory Board to the NCMRR devel-

oped a modification which further extends the previous constructs (10). In this model of disability, there are five separate definitions which together embody the entire spectrum of disability and its affects on people. (a) It begins with pathophysiology which is the underlying cause of the disease or injury. Pathophysiology focuses on the cells and tissues. It is the interruption of or interference with normal physiological and developmental processes or structures. Pathophysiology may produce impairment which focuses on the level of the organ. (b) Impairment is the loss or abnormality of cognitive, emotional, physiological or anatomical structure or function, not just those attributable to the initial pathophysiology. Impairment may produce functional limitation(s). The focus of functional limitation is on the whole person who is affected by loss or abnormality. (c) Functional limitation is a restriction or lack of ability to perform an action in the manner or within the range consistent with the purpose of an organ or organ system. The functional limitation may yield a disability which is the interface between an individual and his or her environment. (d) A disability is the inability or limitation in performing tasks, activities and roles to levels expected within physical and social context. The NCMRR's unique contribution was in defining a fifth level of disability, namely societal limitation. (e) Societal limitation is restriction attributable to social policy or barriers (structural or attitudinal) which limits fulfillment of roles or denies access to services and opportunities that are associated with full participation in society. With such a broad and sweeping definition of disability and its accompaniments, one can see that secondary disability can occur at many levels. Using this terminology in disability classification, there is clear relevance of the points made in the ICD survey of disabled Americans. The absence or inadequacy of our present knowledge of services and policies which impact disabled people at all levels can and does produce secondary disabilities.

Quadriplegia, with its injury to cells and tracks within the cervical spinal cord as the pathophysiology, illustrates this classification system. The impairment is the primary damage to the central and autonomic nervous systems with secondary effects on lungs, bladder, and bowel, for example. The functional limitation is the absent or limited movement of the extremities, limited ability to cough, and neurogenic dysfunction of bowel and bladder. The disability is seen when bodily functions require more time and assistance, there is a change of job status or the individual is unable to perform hobby and recreational activities as previously had been done. Societal limitations occur where the individual has difficulty finding employment or cannot obtain health insurance which will pay for assistive devices or cover costs of a suitably modified automobile. Society further limits the person by the presence

of inaccessible public buildings which reduce the individual's involvement in social activities.

Clearly, lack of access to appropriate and adequate health care will be a key contributor to the proliferation of secondary disabilities in people with spinal cord injury and head injury. However, there is another, more pervasive, yet subtle, aspect of societal limitation which deserves special mention here. Once an individual is disabled, there should be the expectation that a knowledgeable and sophisticated system exists to deal with the primary disability and prevent the secondary disabilities. However, the disabled person may have difficulty in accessing customary and usual medical services, for example, primary health care. There is a woeful lack of availability and quality of customary health services and primary care. In addition, there are too few practitioners of health care who are willing or able to serve the disabled community. Few understand how the spinal cord injury or head injury produces problems or influences existing or intercurrent acute illnesses. Not only are many primary health care facilities inaccessible to people with functional limitations, but the staff who work there often have little experience with the health care needs of paralyzed people, who may have cognitive or emotional impairments or other organ system dysfunctions which result from central nervous system injury. A recurring complaint among former rehabilitation patients is that they must constantly educate their primary care physicians about the idiosyncrasies of their impairments (11). A primary care physician may refer the disabled person inappropriately to the care of a specialist or send an individual to a hospital emergency room, thus further fragmenting health service, causing a delay in treatment, and leading to unnecessary hospitalizations and potential further disability.

Primary Health Care and the Disabled

DeJong and others reviewed the primary health care complaints of persons with physical disabilities in a conference conducted in 1989 by the National Rehabilitation Hospital Research Center and the National Institute on Disability and Rehabilitation Research (NIDRR) (12). McGinnis *et al.* further substantiated these complaints in their report of 240 patients discharged from three Boston-area medical rehabilitation programs (13). Patients often used numerous providers in attempting to resolve a single health problem. They concluded that there is little effective case management to resolve the basic health problems of persons with major physical disabilities. Litvak and co-workers reported that many persons with disabilities require the services of a personal attendant to assist them with their basic physical needs (14). They found that self-care whether performed by the disabled person or a

personal attendant is a major part of preventive health care for many people with disabilities. Attendants can often assist the disabled person in creating good health habits, including exercise and nutrition, and they are frequently the early observers of health problems such as impending skin sores. The lack of access to personal care assistants may increase the disabled person's vulnerability toward further secondary disabilities. Furthermore, when a person with a physical disability incurs a new health problem, often the consequences are worse than for an able-bodied counterpart. New health problems often increase the functional dependence and further compromise the person's ability to work and to live independently. Whereas able-bodied people can employ many strategies to offset acute illness and can utilize community resources, the disabled person frequently cannot independently pursue optimum health habits such as independent exercise and healthy social interactions. If avoidable stress is coupled with avoidable nutritional problems and avoidable social isolation, further secondary disabilities may ensue. Thus, there is a need to provide primary care services to people with disabilities.

Early workers in primary health care have been trying to provide managed health care services to working age disabled people for the past decade (15). Recently the Rehabilitation Institute of Michigan has been participating in a state-wide project to evaluate the effectiveness of a primary health care clinic wherein physicians and internists combine to meet patients' medical and rehabilitative needs for primary care. The effectiveness of these programs is yet to be fully understood. They will be measured by their ability to satisfy patients' and families' needs for primary health care while avoiding unnecessary hospitalizations and medical procedures, as well as social and vocational deterioration which could otherwise be prevented.

One could develop an extensive and expensive research agenda from the potential for problems which have been described above. Much of this has already been done and has begun appearing in the medical literature since the mid-1980s. When one focuses upon a comprehensive prevention program, a logical research agenda emerges. Tarlov and Pope (2) outlined such a program to prevent secondary disabilities. They caution, however, that there is as yet little evidence on the effectiveness of such preventive approaches. They lack valid and reliable assessments to determine what works and what does not in virtually all areas of health care, not just disability. Furthermore, it is likely that gender, socioeconomic status, or minority status may influence the risk factors for certain secondary disabilities. Second, it is commonly believed that disabling conditions are stable or, worse still, progressively deteriorating, thus, discouraging health providers from attending to this area of prevention of secondary dis-

ability. Marge (3) and later Tarlov and Pope (2) propose that secondary disabilities are best prevented with a five-stage program which (a) organizes and delivers services, (b) provides appropriate assistive technologies and trains individuals in their use, (c) promotes adoption of good health behaviors, (d) provides education to those in need, and (e) approaches environmental factors which affect people with disabilities.

A comprehensive approach to preventing secondary disabilities would first attend to a better organization of health services delivery and avoidance of the modern day fragmented approach. It would change health care funding policies in order to make useful services available to people with disabilities on the basis of approved medical need. Sadly, current insurance practices frequently deny such services to people with disabilities in the belief that these services are not medically necessary or are for convenience only and, thus, not reimbursable. A sophisticated health care system would also emphasize the role of independent living centers composed of people with disabilities who have learned to do peer counseling and education for healthier life habits. Independent living centers provide housing assistance, advice on transportation, and computerized information referral systems to community-based people with disabilities.

A second piece in a comprehensive program would address assistive technologies and provide devices and techniques that can eliminate or compensate for functional limitations. Such devices fall into three categories: (i) personal technologies such as tools used for self care, (ii) activity-specific technologies such as devices to assist in eating and writing, and (iii) environmental technologies that maximize access to society and its resources.

The comprehensive prevention program would include the third component, a process for health promotion. It would include advice and assistance on nutrition, exercise, and medication as well as lifestyle alterations that would reduce stress and increase healthy habits.

A fourth component would be education and information. It would be directed not only to the public but to that 14% of the public who have physically disabling conditions and live in the communities. In addition, health care professionals would be further educated to recognize and be skilled at treating problems and secondary disabilities which are predictable risk factors faced by disabled people on a daily basis. For example, we need specific accreditation criteria for assessing if medical schools provide adequate education on the prevention of disability and secondary conditions and on the rehabilitation of people with physical or mental disability. In addition, medical specialists should be similarly trained as should graduates of nursing and allied health professional schools.

A fifth component is an attack upon environmental considerations such as access to health services and facilities, meaningful employment, access to community parks and recreational establishments as well as public transportation, and availability of housing. Tarlov and Pope outline protocols for the prevention of secondary disabilities (2). Four categories or prevention protocols are defined. They include services, education, research and surveillance, and coordination and oversight. However, the needs of the community of disabled people go well beyond the availability of these four categories. A cursory listing of some of the protocols to prevent secondary disability would include:

- (a) Payment for assistive technology.
- (b) Development of screening instruments to identify, prevent, and treat secondary disabilities.
- (c) The addition of appropriate training in medical and allied health training programs in physiatric and psychiatric principles appropriate to physical disability.
- (d) Education of the public and targeted subsets of the public, including postgraduate education and education for policy-making bodies on the nature of physical disability and the secondary disabilities which it can produce.
- (e) Disability surveillance systems to better understand incidence and prevalence of secondary disabilities and effective modalities for their treatment.
- (f) Establishment of an interagency council to coordinate the prevention activities of all federal agencies. Oversight should stress and maximize the emphasis upon multidisciplinary approaches to prevention (16).

CONCLUSIONS

Trauma-induced central nervous system injury will lead predictably to secondary and tertiary disabilities, many of which are preventable. An improved health care system which addresses prevention will include: (a) a better educated population of people with disabilities, (b) a better trained community of health practitioners who evaluate and treat people with disabilities, (c) better availability of personal assistance and technological services focused on the needs of people with disabilities, (d) a more accessible environment with which the disabled person interacts, (e) more accommodation to the unique needs of disabled people in the workplace, (f) revisions of social and health policies affecting people with disabilities, and (g) a pervasive societal effort to enhance the self-esteem of disabled people in order that they utilize these proposed improvements in our health care system. The research agenda which is responsive to these prevention needs will measure the effectiveness of these strategies and study the structure under which services are provided. It will attend to uniqueness of population subsets

whose needs relate to gender, socioeconomic status, or minority status as well as the nature of the disability itself. The agenda lends itself to involvement of a myriad of health workers whose coordination will be critical to success. The funding for this research is still lacking but national attention, more than ever before, has been drawn to the social and monetary costs of disability in our society. The problems associated with disability are common to the contemporary needs of other disadvantaged segments of our society. Opportunities abound for mutual gain through implementation of these concepts of disability, prevention, and research.

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