

SPINAL-CORD INJURY

A Prototype "System" Model for the Prevention and Control of Severe Disability

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The overload imposed by disability upon our systems for health and social care is coming into view as a massive drain on material and productive resources. Standardization and centralization of the machinery for handling reimbursement provides (along with some efficiency) a demonstration of the dimensions of this burden which is consuming at least 7.5 percent of the gross national product (11, 12).

The threat of great and rising costs is just one more reason why easy acceptance of unnecessary disability is truly an unconscionable attitude in modern society. We need to ask ourselves if we can accept or tolerate it and still claim to retain the core values of our culture, values which converge on the charge to revere the individual. Will we remain a "caring" society, as Reverend Harold Wilke eloquently pleads that we do (14) or will we let all our values become economic? And to the extent that they did become purely economic, would we blunder still in our choices because we continued to misread even the economic facts about disability and rehabilitation?

If we misread the economics, we could in the name of hard-headed realism contrive to maximize both the ongoing waste of our economic resources and the waste of our human resources.

A Model for Response

Our heritage of uncontrolled disability stems from neurotrauma, from musculoskeletal illness and injury and defect, from the disabled aging person, or the retarded or defective child, the severely-burned child or adult, and from many other conditions. The inexorable growth in the numbers of such fellow inhabitants of our world of families and communities and farms will surely continue. As a model for response to so overwhelming a prospect, the authors propose the "system" concept as typified in spinal-cord-injury-related programs (and in such prototypes for other major disabled medical problem examples as the head-injured person). The authors believe that the "system" as they have experienced it has altered for them the commonly-held medical view that the prognosis is only for chronicity and long-term institutionalization. They offer instead the view that the "system" greatly influences the feasibility of successful modern spinal-cord-injury rehabilitation, with its concomitant potential benefits of purposeful survival and independent living.

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The Role of Comprehensive Management of Spinal-Cord-Injured Persons in Defining a "System"

Most physicians until recently considered survival with major SCI to be so rare in the civilian population as to be inconsequential (as well as obviously incurable). The typical incidence in the 1950s and 1960s in automobile injuries was 25-50 per million civilian population (10,000 to 15,000 per year). It was less well known that 10 times this number, or 100,000 to 150,000 individuals, survived and continued to need assistance. Since then the development of skilled emergency evacuation teams, better trauma care in emergencies, and the refinement of cardiopulmonary resuscitation have further improved opportunities for survival. Better management at the scene of injury and improvement in control of secondary effects of massive injury (with specialized trauma surgery and the use of antibiotic drugs) is saving and sustaining the lives of those who previously would have died.

But many physicians remain pessimistic about extensive neurotrauma. They still ask the question: "After the drama of lifesaving—what then? Is it possible to make the saved life worthwhile? Since the pathology of 'complete' spinal-cord injury is incurable, isn't the situation hopeless?" To this, the correct answer is that ever-increasing numbers of such persons now return to a satisfactory life—when modern specialized restorative medical treatment and rehabilitation are available. But where the dominant philosophy is still based on the "incurable...hopeless" viewpoint, the critical restorative phase of care is (usually) replaced by "chronic care" which (usually) turns out to be some form of that long-term institutionalization that can be so costly in human as well as economic terms.

How the Conceptual Foundation Grew.

The "system concept is the heart of the authors' message. It truly seems to be the key to the feasibility of modern spinal-cord-injury care. But it is at once the sum and the result of a series of developments. It seems wise, at this point, to describe the "system"

by means of a very brief recapitulation.

In the past three decades, the development of comprehensive rehabilitation started at a modest level with programs for the spinal-cord-injured in England at Stoke Mandeville, in Perth, Australia, and, the Veterans Administration Hospital at Long Beach.

Elsewhere in the United States, where scattered organized efforts could be found, they could often be traced back to experience with the poliomyelitis respiratory center development of the 1950s and 1960s. Those respiratory centers had been located in or near major existing rehabilitation facilities because successful management of the complex needs of the centers required the work, even the teamwork, of hospital-based physicians from a variety of specialties. In some cases, such special "centers" were supported as demonstration models by the Federal government: these put emphasis on the idea of teamwork among a broad spectrum of health professionals, and substantial specialized-care experience accrued.

Those respiratory centers of the 1950s and 1960s had been developed under the auspices of the National Foundation for Infantile Paralysis (NFIP) with funding from the Rehabilitation Services Administration (RSA). The effort expressed the belief that a response to a catastrophic medical problem of national importance could and should be on a national level, with research seen as a necessary element of the response. Support for research in the specific context of the spinal-cord-injury center entered the picture through RSA Research and Training Centers (RTCs) in respiratory centers where there was also, coincidentally, some substantial emphasis on spinal-cord injury. Later, the RTCs were funded by the National Institute of Handicapped Research.

The emergence of an organized body of rehabilitation research results, comprising both basic and clinical investigations and bearing upon both concepts and practices, boosted the effectiveness of the spinal-cord-injury centers—in some cases to unique levels. The resulting gains in ability to protect residual functions and restore function led to a gradual reorientation of rehabilitation goals. It had become possible to think in terms of fulfilling the re-

quirements for restoring the patient to the status of "person" in some kind of "natural" life setting, instead of limiting the horizon to custodial care.

Movement in that direction progressively revealed the fundamental importance of deliberately providing for the transition in roles and responsibilities between the caretakers and the patients. Such a transition diminished professional control and directiveness by shifting to the patient the opportunity for some autonomy with provision of real opportunity to practice it.

It is possible to see this transition as a forbiddingly complex psychological problem demanding superhuman ingenuity and sophistication on the part of those responsible for making it happen. Fortunately, the remarkable adaptability of the human brain was unleashed and made it possible for more and more persons to return to a satisfactory lifestyle in many different circumstances of living. The guiding ideal might have been summed up as follows: "Achievement of a healthful state free of disabling complications of inactivity, immobility, and dependency...moving the patient toward fuller participation in (and control of) his own life activities, with some assistance from technologies which often may be very simple."

In the last decade, the independent living movement was added to the arsenal of needed resources for control of disability. Independent living services and assistance first developed as noninstitutional peer counseling services or as "transitional" programs in association with spinal cord centers or rehabilitation units. Former patients, alone or aided by staff persons, provided training in self-help, in life adjustment, in equipment selection and maintenance, in transportation, and in home support services. Many offered, to the spinal-cord-injured person, training in selection and supervision of attendants, and in advocacy and coping skills. (The services were not restricted to the spinal-cord-injured.) Congregate living facilities and domiciles were developed in association with these programs, so that nonsegregated community-based housing opportunities could be established. Thus, the cycle was completed with return to community living with control of one's own lifestyle and future potential—similar to the goals of others.

Success Factors in the Creation of Spinal-Cord-Injury Systems of Care

The broadening of the goals of the center, as recounted above, led to the necessary concept of the "system." The system can be seen as the final phase of development to date, influencing both the feasibility of successful modern spinal-cord-injury care and patients' access to that service.

Obviously, some organization of facilities had to be established because many duplicated settings of care, intervention, and support cannot possibly exist in one place, and what was required was not likely to be put together in the typical acute hospital facility. The combination of anticipatory acute (first-phase) care had to be followed by function-oriented restorative care and comprehensive rehabilitation as soon as possible. Individualization had somehow to be accomplished within this organized and systematic effort. Only with some kind of area or regional structure could such a program be sustained, as the poliomyelitis experience had shown.

It is surprising that this concept of regionalization for care of the spinal-cord-injury condition was not established and working (as a demonstration model) in the United States until 1972. (The count by 1983 was 17 regional centers.) The efficacy of such centers had been well identified years before by individuals such as Donald Munro in this country, Botterell in Canada, Guttmann in England, and Bedbrook in Australia (1,2).

Our own Texas experiences are worth examining as a typical example. The Institute for Rehabilitation and Research (TIRR) had evolved a spinal-cord center modeled after its poliomyelitis respiratory center, in the interval between 1960 and 1962. Federal RSA grants supported the spinal-cord center. Clinical and basic research were added in a special medical rehabilitation research and training center (RT-4) with major emphasis on spinal-cord-injuries. Pressure-sore prevention was emphasized through technology research and development in a rehabilitation engineering center Baylor College of Medicine, Texas A&M University, and TIRR. In the 1970s a transitional program and then an independent-living model coalesced many relevant experiences, developments of needed concepts, and processes (3,4). These verified the importance of early intervention and followup, and of comprehensive restorative and rehabilitative care. The opportunity

existed to compare the effectiveness of early prevention as well as late control of disabling medical complications.

Ultimately, the evaluation of methods for control of disability with long-term followup became the purpose of a National Spinal Cord Injury database system. It was developed by Young at a hospital-based unit at Good Samaritan in Arizona. More than 15 regional centers provided data in the 1970s for this analysis, which generated substantial evidence of patient benefit and cost savings. The savings (as prevention of economic losses) were verified from decrease in repeated hospitalization (5, 6).

Most recently, a Texas Regional Spinal Cord Injury System has been initiated for a community of 1.9 million persons and a catchment area of 3.3 million in the Gulf Coast region. In 1980, out of an estimated 175-200 spinal-cord-injured trauma victims, 135 were admitted at onset to three acute hospital trauma centers (two in Houston and one in Galveston). Twenty-five percent of these patients were admitted for rehabilitation to TIRR and 10 percent to the Veterans Administration Hospital-based center in Houston, if veterans. (Thirty percent of those in need of rehabilitation did not receive it, largely because of the lack of funding sponsors!) (7, 8, 9).

The first "acute phase" in this system consists of cooperative trauma centers and emergency transport systems coupled with discrete acute-hospital-based bed units for spinal-cord patients. These have trained staff oriented to and practicing anticipatory care to prevent secondary pressure ulcers (10), metabolic, respiratory, circulatory, or genitourinary complications, intestinal bleeding, and overwhelming respiratory complications especially in quadriplegia. Consultation with rehabilitation center staff is used for initial care planning and to promote early transfer to intermediate restorative, subacute, medical and rehabilitation spinal-cord centers like TIRR's. Linkages for referral and follow-through to community support services such as independent living assistance are arranged. Independent living arrangements for congregate housing exist in Houston. Periodic re-evaluation and followup is arranged by center staff. Vocational and educational services, home modifications, technology support for mobility and self-care are available with state vocational rehabilitation agency support. Housing subsidies are from the local governmental and Housing and Urban Development (HUD) programs and

private donations.

The experiences of arranging more comprehensive care have defined our current concept of a "system":

A center is a defined bed unit operating with service and referral protocols with an experienced staff and equipment. A patient is attended by the same physicians and professional staff throughout his or her stay.

A system is a set of related and organized activities using a center as pivotal. The patient can be assisted appropriately in time of intervention, in duration, and in facility location according to his changing status, from serious medical problems to ultimate personal autonomy and independence from institutional living and professional directivity. The goal of self-choice among options of lifestyle and self-advocacy by handicapped persons promotes active inclusion in the life of the community.

Why Building A System of Coordinated Care Is Difficult.

The reasons why it is difficult to establish and operate a system are manifold. Solutions must be adjusted to a variety of regional circumstances, resources, capabilities, financing opportunities, etc. Still, centers confront some difficulties in common. These examples are typical.

1. There is often wide geographical separation between the locations for acute care and the centers where concentrated medical restorative and rehabilitative care are available. Mutual exchange of information and personal consultation are difficult and time-consuming for the limited number of experienced professionals who are available.
2. The acute-medical-care specialists have incomplete understanding of, and limited experience with, the total medical, functional, and psychosocial needs of the severely injured person. These complex needs are not caused solely by the injury of an isolated part of the anatomy. Dysfunction often follows in other organ systems and from secondary involvement or pathological changes in the central nervous system

such as involuntary movements (spasticity), etc. The integrative behavioral changes of personality, and environmental social conditions, affect prognosis and even adaptation.

3. There is conceptual confusion of a pathologically oriented "incurable" prognosis with the feasibility of prevention and control of disability obtainable by setting functional limitations.

4. Medical pathological prognoses lead the patient and family to a sense of hopelessness, and as a result of this feeling the vital appropriate early referral to specialized resources (which is so critical) may fail to occur.

5. There is literally "incredible" difficulty in arranging the timing and amount of public and private sponsorship of care within fragmented and incomplete eligibilities, limited benefits, and short duration of coverage. The lack of understanding by sponsors of the cost effectiveness of the social and economic losses prevented for the family and society, is widespread.

6. An array of disincentives are found in reimbursement systems that are based on criteria relevant to curative medicine and to self-limited conditions. Cost data derived from non-comparable care models (for example, average stay and average costs of acute hospital short-stay patients) are often used to set reimbursement limits for intensive restorative and rehabilitative services. Public and private purchasers' estimation of reasonableness of costs of intensive individualized restorative and rehabilitative care is not associated with long-term custodial care losses **prevented**—nor can rehabilitation be offered in a nursing home setting at long-term-care reimbursement levels.

7. There is social and political association of high technology intensive-care medical costs for terminally-ill, dying patients and the care costs of a severely-impaired person with intact brain function and curable disability. This augments the attitude that such care is too costly and unnecessary.

8. Aversive personal attitudes by lay persons, and especially among professionals, about severe handicaps and disability stereotype such individuals as hopeless, dependent, and "crippled" (8).

Hopeful Expectations

Overall, the evolution of the system concept, typified in spinal-cord-injury related programs (and such prototypes for other disabling medical problem examples as the head-injured person) has altered the unfortunately dismal medical view. Prognosis for chronicity and long-term institutionalization is changing. There is an awareness of the need for a very different societal evaluation and personal behavioral change towards the person with handicaps. This is a result of their increasing survival, visibility, self-advocacy, and the evident value of the contribution they can make to our society. Albeit probably fewer than 10 percent of those with a potential to benefit actually receive comprehensive assistance, their numbers are increasing. The amalgam of process and procedures pioneered in the last three decades is having a demonstrable effect on purposeful survival. The results of research, development, and new technologies, with the establishment of independent living resources and new institutional and consumer relationships, have yielded undeniable benefits and strengthened the prototype systems of care that we have.

It is truly a reason for optimism that such persons have attained far greater self-sufficiency as a result of these efforts, combined with the support of families and other community persons. These accomplishments, having demonstrated what can be done repeatedly and predictably without resort to exotic techniques or unique personnel, present us with some kind of an obligation to insure that the newly won ability to return these patients to independent living becomes more widely available in our communities. You might say that an "ethical awareness" has been generated that the handicapped person should have the opportunity (the right?) to succeed or fail in the work of living, and to reach for the quality of life pursued by others in our society. It is possible to perceive a new emphasis on greater understanding of the relationship between the person and the modern environment that will be needed to achieve physical and social inclusion.

Orderly growth and development of new resources, sufficient to provide restorative and rehabilitative capacity for hundreds of thousands of presently unassisted severely disabled persons of all ages—that is a challenge not just to our means but to our self-image as a society, nation, institutions and

culture. There must be cooperative planning involving both the public and private sectors of our society. There has to be inclusion of persons with severe handicaps. New service capacity must be created with dissemination of knowledge and technology through information embedded in education and training curricula.

There will have to be different arrangement for rational financing of the systems of care. The changes will have to be justified on the humanitarian grounds of the social value of the individual to others and the right of equity in opportunity to contribute to society and participate in its benefits. Also, justification for services to many will be more than covered by the economic private and public losses prevented: this will surely be a fair trade-off for the enormous losses from the costs of medical and financial assistance for disability (11).

This enlarged scope of the concept of "health" care reveals the need to stop relegating restorative and rehabilitative care to an orphan status or as an "optional" medical and social benefit. Far greater advocacy by handicapped groups will be required, and national leadership will be needed from councils evaluating the need for social changes and proper resourcing. Advocacy effectiveness has already been demonstrated in the movements for barrier reduction and access, but those gains have proved vulnerable to shifting economic and political winds, demonstrating that the economic, ethical, and indeed political support for any major development such as the one we are contemplating here must be put in place (and kept intact) with great care and completeness.

The international decade of the disabled, recently affirmed by a resolution of the Congress of the United States, is symbolic of a worldwide resolve to include persons with handicaps in daily life. But to achieve more widespread opportunities for the disabled person requires structural as well as attitudinal changes in our nation. The future planning and operation of health and social services will have to anticipate, explicitly, the potential social and economic contribution to our nation and its communities, everywhere. Practically, this means we have to change our behavior from patronization overlaid with pity in the name of charity, to affirmation of value of human dignity, and investment in the means to harvest individual worth and productivity. This a difficult task, but it is clearly unwise to ignore

the need to control the incredible costs and losses of disability, an enormous burden consuming at least 7.5 percent of the gross national profit ■

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APPENDIX

The brevity of the overview which has been presented seems to justify explanation of some broadly interpreted words and contextual assumptions used therein.

1. Disability: This word is distinguished from impairment. Impairment should be used to refer to pathology or pathophysiological manifestations of injury or disease. Commonly, physicians interchange these two words, as in "orthopedic disability" or "cardiac disability" when impairment better expresses their meaning.

The definition for disability implied in its use throughout this paper has been that commonly applied in the lexicon of persons active in rehabilitation, where disability refers to difficulty in **performance** of self-initiated activities of living. In a simplified conceptual way it might be described as "a form of inability or limitation of ability in performing roles or tasks expected of an individual within a social environment, including self-care, family and personal relations, education, recreation, and economic life and employment.....as a result of limitations in func-

tion," Nagi (1). Woods for WHO (2) chains the causal circumstances, pathology, impairment, disabilities, and handicap. He considers "handicap" as any restriction or lack of ability to perform in the manner (or within the range) considered normal for the human being if the individual is thereby put at a **disadvantage relative to others**, limiting or preventing fulfillment of a role that is "normal" for that individual.

Thus, Nagi's levels:

Active Pathology → Impairment → Functional Limitation → Disability

and Wood's levels:

Disease or Disorder (intrinsic) → Impairment (exteriorized) → Disability (objectified) → Handicap (socialized)



2. Restorative Care: This synonym for rehabilitative medicine is used to distinguish among preventive medicine, curative medicine, and restorative medicine. The different concepts and goals in these

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aspects of "health care" are discussed in this paper. Restorative care means the medical activity, usually physician-directed, intended to restore a healthful biological state, to protect or preserve residual functional capacities that are needed for purposeful activities, through medical, physical, technological, and other means. Restorative care emphasizes secondary prevention of physical, physiological, and behavioral complications leading to disability.

3. Rehabilitation:

This is usually a multidisciplinary, goal-oriented, integrated activity which individualizes physical treatment, behavioral and social assistance, counseling, training for self-care, and environmental modifications needed to convert functional capacities into capabilities for autonomous purposeful activities of daily living and life adjustment. Restorative and rehabilitative care are often referred to as "comprehensive rehabilitation," especially if independent noninstitutionalized living is achieved.

4. Handicaps: this term carries the meaning of those attitudes and behaviors of other persons which limit the acceptance, inclusion, and participation by the functionally limited and/or disabled person in social activities that are commonly available to and undertaken by "ordinary" persons. The term handicap thus reflects stigmas, stereotypes, and arbitrarily erected boundaries for social and interpersonal actions, resulting in exclusion.

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