Paraplegia

Toward a Health Services Research Capacity in Spinal Cord Injury

G. DeJong, PhD, A. I. Batavia, JD, MS

¹National Rehabilitation Hospital Research Center, Department of Community and Family Medicine, Georgetown University School of Medicine, Washington, D.C., USA.

Summary

Health services research (HSR) is the research field that seeks to examine systematically the organisation, provision, and financing of health care services. There currently is only a rudimentary HSR capacity in the area of spinal cord injury (SCI). To a large extent, the HSR community has not addressed issues concerning persons with SCI, and the disability research and medical rehabilitation communities have not considered issues of HSR that affect the SCI population. However, due to recent changes in (1) the clinical management of SCI; (2) the expectations of persons with SCI, and (3) health care delivery and finance, the time is now ripe for the development of a HSR capacity in SCI. This article summarises current efforts at HSR in SCI in the United States, which have been primarily in the areas of trauma care and medical rehabilitation. It considers an agenda for future health services research in SCI, which must include research on post-rehabilitation health care and personal assistance needs. Finally, this article suggests strategies for developing a comprehensive HSR capacity in SCI.

Key words: *Health services research; Spinal cord injury.*

Each year an estimated 8,000 individuals incur a traumatic spinal cord injury (SCI) in the United States alone. Almost 50% of these injuries result from motor vehicle accidents. The prevalence of persons with SCI in the United States (the number of persons with a physical disability resulting from a SCI at any given time) is estimated at 700 to 800 per one million population. Overall, spinal cord lesions of the cervical spine account for slightly more than one-half of all new injuries; thoracic vertebrae injuries account for more than one-third; and lumbar and sacral vertebrae injuries account for the remaining tenth (Stover and Fine, 1986).

These statistics convey the number of people who have sustained spinal cord injuries in the United States, but they do not convey the challenges facing persons with SCI or the issues affecting these individuals and their families, providers, payers and others. Not conveyed in the statistics are the substantial physiological, psycho-social and environmental factors that affect the spinal cord injured person's

(1) chances for long term survival and (2) prospects for living an independent and productive life. It is the contention of this article that these factors require a broadened research agenda.

Because persons with SCI are now living longer than ever before, it is no longer sufficient to focus research primarily on health care provided to save their lives at the time of injury or to restore their functional capacity shortly after injury. We must develop a broad research capacity to evaluate not only trauma care and medical rehabilitation (i.e., the front-end of SCI care), but also the ongoing health care needs of SCI persons well after their rehabilitation. In other words, we need to develop a comprehensive 'health services research' ('HSR') capacity on SCI. Persons with SCI have a specific constellation of ongoing health problems that are not being addressed by the mainstream of the American health care system, and that demand the attention of the HSR community.

This article focuses on health services research on SCI conducted in the United States. Similarly, it concentrates primarily on building the capacity in the United States for conducting such research. However, many of the problems highlighted in this article, and the need for good research on the health care services needed by persons with SCI generally, are relevant to the entire international community, not only the United States. Because the United States currently has one of the most highly developed capacities for HSR in the world, the issues delineated in this article are probably indicative of even greater problems in other countries. Thus, it is hoped that this article will draw attention to the need for HSR on SCI in the United States and throughout the world.

Health services research and SCI

What is health services research? It is the field of research that seeks to examine systematically the organisation, provision, and financing of health care services. HSR draws on the skills of many disciplines and professions, such as biostatistics, health care economics, epidemiology, health care finance, health law, medicine, political science, and medical sociology. Health services researchers commonly consider issues of cost, access, quality, and effectiveness of health care services (Flook and Sanazaro, 1973).

At present, there is only a rudimentary HSR capacity in the area of SCI management and its related discipline of medical rehabilitation (Fuhrer, 1988; DeJong, Batavia and Griss, 1989; Batavia and DeJong, 1990). The research community in the SCI and medical rehabilitation fields is comprised largely of physicians, allied health professionals, and persons trained in the behavioural sciences such as psychology. Notably in short supply are SCI and rehabilitation researchers who are trained in the disciplines that comprise the field of HSR (DeJong, Batavia and Griss, 1989; Batavia and DeJong, 1990).

By the same token, the HSR field has almost completely ignored the health care needs of persons with SCI and the field of medical rehabilitation. The HSR literature includes very few articles addressing the organisation, provision or financing of services for people with physical disabilities. Yet, this literature has addressed the concerns of various other subpopulations with special needs, such as elderly people, indigent people, and people living in underserved geographical areas. There is a real need for the HSR community to focus its efforts on the needs

of people with physical disabilities, such as SCI (DeJong, Batavia and Griss, 1989; Batavia and DeJong, 1990).

The development of a HSR capacity in SCI is particularly timely due to certain major changes that have occurred in the past two decades in (1) the clinical management of SCI; (2) the expectations of persons with SCI; and (3) the financing and provision of health care services generally. Changes in these areas provide valuable opportunities for the development of creative new ideas on how to meet the needs of persons with SCI. Collectively, these changes provide an important perspective on why a HSR capacity in SCI is long overdue.

Changes in clinical management of SCI

To understand the health care needs of persons with SCI today, it is valuable to have a historical perspective on the clinical management of SCI. Prior to the 1940s, the main issue in SCI management was mere survival. Persons who sustained a SCI often survived the original trauma, but later died because of secondary complications (such as urinary and respiratory tract infections) that could not be arrested. With the introduction of the sulfa drugs in the late 1930s and penicillin later, modern medicine dramatically improved the ability to control the complications of SCI. With the establishment of the medical specialty of physical medicine and rehabilitation in the late 1940s, medicine began to focus on reducing the functional limitations of persons with physical disabilities and increasing their capacities to live independently and productively.

However, even in the 1950's, most SCI rehabilitation patients were discharged to highly restrictive settings that limited their opportunities for independent and productive lives. Their ongoing health care and personal assistance needs were often managed in long term care institutions. Two developments in the clinical management of SCI altered this dependency-producing outcome. The first was the development of specialised SCI centres within the United States Veterans Administration (VA). The second was the development of specialised regional spinal cord injury systems within the civilian sector. These specialised systems created a new cadre of professionals with a clinical and research expertise that extended our thinking about the long term consequences of SCI. Both developments helped to bring a sharpened clinical focus to the ongoing needs of persons with SCI.

Changes in expectations of persons with SCI

Perhaps more than any other factor, the independent living movement of the 1970s (the IL movement) radically altered our expectations about the opportunities available to persons with disabilities. The IL movement was initiated by disabled persons in the United States who sought to remove environmental barriers that reduced their capacity for self-direction, independence and productivity (DeJong, 1979). It gave persons with SCI (and persons with other disabilities) a vision of how they could direct their own lives. In so doing, the IL movement also reshaped the relationship between physician and patient, and between rehabilitation professional and disabled consumer. With the advent of the movement, persons with SCI

served notice that they wanted to direct and manage their health care on their own terms (DeJong, 1981).

With respect to post-rehabilitation health services delivery, persons with SCI have sought to manage their own primary health care untethered to large medical centers. This often proved difficult, however, because there are relatively few primary care providers who are familiar with the health care needs of persons with physical disabilities. Many disabled veterans testify that they must seek out the expertise of a VA SCI service to meet their ongoing primary care needs, because they cannot locate such expertise in their own communities. Likewise, many non-veterans seek out the expertise of rehabilitation hospital outpatient clinics, because they have difficulty locating primary care providers knowledgeable of disability-related problems.

In short, specialised medical management of SCI has improved the health and functional capacity of persons with SCI, and the independent living movement has expanded the post-rehabilitation expectations of persons with SCI. With these advances, persons with SCI have developed new ideas about how they wish to have their ongoing health care needs and personal assistance needs met during the post-rehabilitation phase of their lives.

Changes in health care delivery and finance

Over the past decade, substantial changes have occurred in the delivery and financing of American health care. These changes fall into two categories. Firstly, there has been much experimentation in the payment of health care services, including the use of capitation payment,¹ diagnostic related groups (DRGs),² preferred provided arrangements (PPAs),³ and other payment mechanisms (Batavia, 1988). Secondly, these alternative methods of paying for health care often are accompanied by new health care delivery systems, including health maintenance organisations (HMOs),⁴ preferred provider organisations (PPOs),⁵ and various other systems of managed care (Batavia *et al.*, 1989). Many of the old assumptions about how health care should be financed and delivered have been cast aside. Cost-based reimbursement systems are clearly on the decline, and various providers have had to reposition themselves in a more competitive health care economy (Batavia, 1988; Batavia, 1989).

Clearly, the past 10 years have been an unusually fertile time for innovation and experimentation in health care. The challenge for SCI is this: How can we take advantage of these changes to accommodate the health care needs and expectations

¹ Capitation payment refers to paying a health care provider a pre-specified payment amount per patient for a set period of time (i.e., typically one year) to provide a comprehensive set of health care services, as needed, to the patient over that period.

² DRGs are payment categories in which patients are classified based primarily on diagnosis, and serve as the basis for payment of inpatient hospital care under the Medicare Prospective Payment System (PPS).

³ PPAs are contracting relationships between payors and providers in which the provider agrees to accept discounted fees for its services, and the payor agrees to provide incentives for its enrollees to use the preferred provider.

⁴ HMOs are health care organisations that provide managed care financed with pre-paid capitation payments.

⁵ PPOs are provider organisations that use preferred provider arrangements (see note no 3) and conform to certain additional agreements with payors such as utilisation review by payors.

of persons with SCI? We must evaluate different models of health care delivery and financing as to their ability to meet the needs and expectations of persons with disabilities. Approaches that appear promising should be tested before new political and economic constraints begin to limit the options available to persons with SCI. The present time is a historic opportunity that should not be missed.

Health services research in SCI today

As indicated above, currently there is a very limited HSR capacity in the area of SCI or physical disability generally. Researchers have not been drawn in substantial numbers to HSR issues concerning persons with SCI or other physical disabilities. One reason for this neglect is that persons with physical disabilities in our society have been a devalued population who, until recently, have not been considered worthy of serious research. Fortunately, this negative attitude toward disabled persons is changing, due in part to the successes of the IL movement (DeJong, Batavia and Griss, 1989).

To the extent that a HSR capacity in SCI exists, it is largely a result of data collected by the regional spinal cord injury systems and compiled in the National Spinal Cord Injury Database. The regional systems and national database are discussed in the next section. The areas of health care that have been considered most extensively by health services researchers in SCI have been trauma care and post-trauma acute care, and rehabilitative care. These areas are discussed in the sections that follow.

The national spinal cord injury database

The conventional wisdom among practitioners in SCI is that an integrated system of SCI management, beginning with trauma care, is essential to favourable outcomes. They argue that discontinuities in care can severely compromise the road to medical stability and successful rehabilitation. They further claim that early prevention of medical complications, such as pressure sores (i.e., decubitus ulcers) and urinary tract infections, expedites the rehabilitation process and improves the disabled individual's prospects for returning to the community. This wisdom is the cornerstone of the 14 regional SCI centres throughout the United States.

The regional SCI centres have long recognised that a good national data base is essential to conducting empirical research on SCI, and particularly to the ability to document the effectiveness of an integrated approach to SCI management. In 1975, the various model systems agreed to pool their resources to develop a common data base under the auspices of the National SCI Research Data Center (NSCIRDC) in Phoenix, Arizona, USA. In 1982, the data base (hereafter, the 'National SCI Database') was transferred to the National SCI Statistical Center (NSCISC) in Birmingham, Alabama, USA.

The National SCI Database has had a mixed history. On the one hand, it has compiled a rich source of uniform data to serve the research needs of its affiliates. The resources of the Database may represent the nation's most advanced capacity for HSR in SCI. It has data on more than 10 000 individuals collected over a decade or more. Some individual records include longitudinal data spanning more

than 10 years. Such longitudinal data contained in large data bases provide an excellent basis for methodologically sound empirical studies in HSR. The SCI research community, therefore, is very fortunate to have the resources of the National SCI Database.

On the other hand, the National SCI Database has experienced discontinuities in design and funding that limited its ability to service the information needs of the model systems and to support a broadened HSR agenda. While the Database represents, one of the best data bases in the field of medical rehabilitation today, its capacity has never been exploited fully for research purposes. We believe that the National SCI Database could support a fairly broad HSR agenda if it were not for two factors.

Firstly, and foremost, some of the participants in the National SCI Database system perceive their primary mission to be the conduct of analyses that will strengthen the merits of the regional SCI systems approach. While post-rehabilitation data are acquired by the National SCI Database, these data are evaluated primarily in terms of how they reflect on the efficacy of the original trauma and rehabilitation interventions. Discontinuities in post-rehabilitation health care that result in re-hospitalisations receive some attention, but it is insufficient relative to the scope of the problem. Moreover, such problems appear to be viewed by some of the participants as reflecting negatively on the regional systems approach, although the problems actually are widespread and are not specific to the model systems.

Secondly, participants in the National SCI Database have not adequately exploited the Database's potential for HSR research among third party investigators. The Database needs to be made more accessible to investigators outside the model SCI system network. Of course, there would have to be safeguards for maintaining patient and institutional confidentiality.

Areas of SCI care that have been addressed

While the National SCI Database has been the source of a significant amount of health services research in SCI, other HSR efforts related to SCI must also be mentioned. As suggested above, to the extent that a HSR capacity in SCI exists, it has been limited largely to the earlier stages of SCI management from trauma care through medical rehabilitation. The following sections consider the state of HSR in trauma care and rehabilitation as it relates to SCI.

Trauma care and post-trauma acute care

The point of entry into the health care system for the newly-injured person is some form of trauma care, whether it be at the ambulance entrance of a small rural hospital or at a highly triaged Level I trauma centre within a large urban medical complex. In recent years, the field of traumatology has emerged as a recognised discipline with a budding research capacity. Trauma researchers have developed a variety of tools by which to measure the severity of an injury, such as the Injury Severity Score (Baker *et al.*, 1974) and the Revised Trauma Score (Champion *et al.*, 1981). In evaluating the outcomes of trauma care, researchers seldom look beyond discharge from an acute care setting. Moreover, trauma researchers typically limit their outcome analysis to whether the patient simply lived or died.

However, as indicated above, it is important to look beyond mere survival. Trauma researchers have yet to examine how trauma care affects residual disabilities and functional losses. Thus, from the standpoint of HSR on SCI, the impact of trauma care should be evaluated in terms of: (1) How advances in emergency medical management and trauma care are changing the chances of survival for a person with SCI for a given level of injury severity; (2) How trauma care is affecting the degree of residual disability among survivors, especially among new survivors with high-level injuries (who earlier would have died); (3) How trauma care is altering the mix of patients with SCI seen by medical rehabilitation, such as the proportion of patients who require permanent use of a ventilator; and (4) How trauma care may be reshaping the post-rehabilitation health care needs of selected survivors.

To answer these kinds of questions, it is important that health services researchers in the field of rehabilitation collaborate with researchers in the field of trauma care. Each will benefit from the other's tools. For example, trauma researchers are largely unfamiliar with the functional status measures commonly used in rehabilitation research. Likewise, most rehabilitation researchers are unfamiliar with injury severity measures used in trauma research.

Medical rehabilitation

Since the demise of polio rehabilitation in the 1950s, SCI has been the 'model disability' in the field of medical rehabilitation. In other words, SCI has served as the clinical and analytic point of departure for much of medical rehabilitation practice. Only recently has SCI's preeminent role in medical rehabilitation been challenged by the compelling needs of persons with brain injury (DeJong and Batavia, 1989). By serving as medical rehabilitation's benchmark disability, SCI has been able to command resources for research not available to other diagnostic categories served by medical rehabilitation. As a result, the SCI research literature is perhaps the most extensive of any research literature generated by the medical rehabilitation community.

At the risk of great oversimplification, two categories of research dominate the research literature in SCI rehabilitation: (1) research related to physical restoration and (2) research related to psychosocial rehabilitation. Thus, although much rehabilitation research has focused on SCI, there have been relatively few efforts at HSR in the area of medical rehabilitation of SCI (Batavia, 1988). These efforts have been limited largely to issues of costs and cost-effectiveness. While these efforts have been significant in their own right, their findings remain less than fully conclusive (Johnston and Keith, 1983).

Many other HSR issues concerning the medical rehabilitation of persons with SCI have been largely overlooked or simply unfunded (Fuhrer, 1988). These include issues of access to rehabilitative care, the effects of payment mechanisms on rehabilitation utilisation and outcome, the relative effectiveness of various outpatient modalities, the impact of health maintenance education on subsequent health care utilisation, and others (Batavia, 1988). One can find scattered references to some of these topics in the literature, but one cannot discern a committed HSR capacity with which to tackle these kinds of issues.

What then are the capacities that comprise a HSR capability in the medical

rehabilitation phase of SCI? We would like to suggest the following: (1) A core group of researchers trained in several HSR-related disciplines (such as those cited above) and committed to disability issues; and (2) Longitudinal data bases that can track patient resource utilisation, patient progress, functional status, and patient outcome well into the post-rehabilitation period.

Longitudinal studies are labour intensive, and therefore very expensive, despite advances in computer-supported data base management.

While the first of these two capacities (i.e., a core group of researchers) is largely absent, the second (i.e., longitudinal data bases) is present to one degree or another. We have already noted the role of the National SCI Database. In addition, two factors have motivated medical rehabilitation providers to develop longitudinal data bases. The first is the requirements of the Commission on Accreditation of Rehabilitation Facilities (CARF) for a program evaluation capability that can assess patient outcomes in functional terms. The second is the requirements of changes emerging in the economics and financing of health care. As the health care market becomes more competitive, providers will be motivated to assemble data on patient outcomes and resource utilisation to convince payors that it is in their interest to cover the medical rehabilitation costs of their enrollees. These two factors have also led to the recent development of other data bases such as the Uniform Data System (UDS) for Medical Rehabilitation located at the State University of New York at Buffalo. UDS serves as a repository for medical rehabilitation outcome data and includes data on persons with SCI.

An agenda for health services research in SCI

Clearly, there is still much health services research that must be conducted in the areas of trauma care and medical rehabilitation. However, these areas have at least the beginnings of a HSR capacity; other areas have barely been considered by health services researchers. Among the most neglected health care needs of persons with SCI are those that surface after discharge from rehabilitation. At present, there is no system of primary care that is responsive to the particular constellation of health care problems commonly experienced by persons with SCI. Once a SCI person completes medical rehabilitation, he or she then has an 'orphaned condition' that is not the province of any one medical discipline (Batavia *et al.*, 1988). One reason for this state of affairs is that persons with SCI comprise a small part of the total population. A prevalence rate of about 700 to 800 persons with SCI per one million population is hardly enough to capture the interests of providers who might otherwise wish to specialise in this niche of the market. Potential providers may fail to recognise that persons with SCI use a disproportionately large share of health care resources, and thus will help them fill excess capacity in their practices. Alternatively, providers may fear that SCI patients will require a disproportionate share of their time, and that they will not be paid extra by third-party payors for the additional time allotted.

The provision of post-rehabilitation health care services has lagged behind the progress made by persons with SCI in living independently and becoming informed consumers of health care services. When persons with SCI remained primarily in institutional settings, the institution became the framework in which the person's health care needs were addressed. No comparable mechanism has

surfaced to meet the health care needs of persons with SCI now that they are living routinely in community settings.

Three health service issues dominate the SCI population following rehabilitation: (1) the very high rate of unscheduled rehospitalisation; (2) the lack of access to primary care; and (3) the development of new health problems as a result of aging with a disability. These health service problems require the consideration of new health service delivery models that are targeted more carefully to the needs of persons with SCI. Finally, there is also the problem of access to long term care, especially the availability of user directed community based long term care services (i.e., attendant care services). Each of these issues is considered below.

Rehospitalisation

Persons with SCI are not necessarily 'sick' by virtue of their disability. In fact, they must be medically stable even to participate in a rigorous medical rehabilitation program. Yet, it is known that a person with SCI has a very narrow margin of health that must be maintained scrupulously if serious medical problems are to be averted. In other words, SCI persons are highly vulnerable to a variety of acute conditions, such as pressure sores, urinary tract infections and respiratory tract infections. One of the primary goals of medical rehabilitation is to impart to the rehabilitation patient the health maintenance skills needed during the post-rehabilitation period.

However, research has shown repeatedly that many persons with SCI do not maintain their vital margin of health. Studies have shown that SCI persons experience a very high rate of post-rehabilitation rehospitalisation. Young and Northup (1979) analysed data on 383 persons with SCI who were discharged from model regional SCI centres. They report that about 50% had at least one rehospitalisation episode in their second year after discharge. Zook, Savickis and Moore (1980), in their study of rehospitalisation among persons discharged from six Boston area hospitals, report that persons with SCI had the highest rate of rehospitalisation of any diagnostic group. They report that, of the 86 persons discharged from a VA SCI centre, 70% were rehospitalised within a one-year period.

DeJong (1981) performed secondary data analysis on a sample of 111 persons with SCI discharged from 10 comprehensive medical rehabilitation centres. He reports that 55% were rehospitalised within a 12 month period approximately 2 to 3 years after discharge from medical rehabilitation. Young *et al.* (1982) report that, among persons represented in the National SCI Database, those persons with complete quadriplegia had the highest rates of rehospitalisation. The rehospitalisation rate ranged from a high of 61% in the second year following discharge to 32% in the sixth year. Meyers *et al.* (1985) conducted a health care utilisation study of 96 post-rehabilitation persons with SCI in eastern Massachusetts. They found that 57% were rehospitalised in a 12 month period.

The length of stay among SCI persons who have been rehospitalised is also striking. Young and Northup (1979) report a mean of 34 days once rehospitalised. DeJong (1981) reports a mean of 55 days. Meyers *et al.* (1985) report a mean of 45 days in their 12-month study period. Drawing on data from the National SCI Database, Stover and Fine (1986) report a mean of 33 days of rehospitalisation in the first year, and 28 days in the tenth year post discharge.

Finally, Batavia *et al.* (1989) surveyed over 600 persons living in the Washington, D.C., area who had at least one of ten specified conditions,⁶ and found that persons with SCI had the highest rate of hospitalisation (34% in the previous year). The study, which was not limited to persons recently discharged from rehabilitation, found that 54 per cent of persons with SCI (n=41) admitted in the previous year were hospitalised for a week or more in their most recent admission.

While these studies have been fairly consistent in reporting the seriousness of the problem, they have not been consistent in identifying the causes and predictors of rehospitalisation. In the Meyers *et al.* (1985) study, younger persons with low self-assessments of health and those who did not leave their residence at least once per day had higher rehospitalisation rates. In an earlier study of 70 persons with cervical level injuries, Burnside and Cook (1976) report that age and occupational status were significantly related to readmission. Younger patients who had worked in predominantly manual occupations exhibited higher rehospitalisation rates. They suggest that low intelligence (and inability to follow the doctor's orders) may promote rehospitalisation.

Other researchers such as DeJong (1981) and DeJong *et al.* (1987) are more reluctant to blame the victim. After two major studies, DeJong *et al.* (1987) report that they are unable to uncover any systematic predictors of rehospitalisation or to identify a consistent profile of the individual at greatest risk of rehospitalisation. However, DeJong and his team refuse to accept rehospitalisation as a random event, and suggest that we must give more careful attention to the responsiveness of the health care system to the particular needs of people with SCI as an explanatory factor.

We know that hospital costs comprise the single largest component of all health care costs. Further, Zook and Moore (1980) estimate that rehospitalisations (in all diagnostic categories) account for 60% of all hospital costs. To the extent that rehospitalisations account for a significant portion of all hospital costs, an understanding of the rehospitalisation phenomenon also can make a significant contribution in developing more highly-targeted cost management strategies in SCI health care.

Aside from the economic factors, rehospitalisation also exacts a high personal toll. Prolonged rehospitalisations disrupt a person's ability to live independently and productively. They result in absences from work, school, and family life. They can diminish the disabled individual's personal control over his or her life and increase reliance on others to make decisions during the individual's absence from community and family life. Finally, rehospitalisations can result in extended bed rest that can compromise many of the functional gains acquired during one's initial rehabilitation.

We know which conditions are most likely to precipitate a rehospitalisation episode—urinary tract infections, pressure sores, and lower respiratory tract problems. The great tragedy is that these conditions in the SCI population should not be nearly as prevalent as they are, because they are largely preventable. Hence, researchers have diligently sought out demographic and behavioural factors that might be contributing to the problem. Having failed to identify a clear

⁶ The conditions included in the study were amputation, cerebral palsy, cystic fibrosis, head injury, muscular dystrophy, multiple sclerosis, SCI, spina bifida, post-polio, and stroke (Batavia *et al.*, 1989).

demographic or behavioural explanation, we must look beyond the individual to the health care system, and particularly to the availability of timely primary health care.

Access to primary care

The conditions that precipitate rehospitalisation episodes usually start as relatively minor health problems that rapidly escalate into major medical crises if not detected and treated in a timely manner. Thus, timely access to primary care is essential if major problems are to be averted. Yet, many persons with SCI indicate that, once they sustained their SCI, they were no longer able to use their customary source of primary care for common health problems. A recurring complaint among persons with SCI is that, if they use a primary care physician, they must constantly educate their primary care physician about the idiosyncracies of their impairment and how it needs to be taken into account when prescribing treatment (Batavia *et al.*, 1988; Batavia *et al.*, 1989; DeJong, Batavia and Griss, 1989).

The family physician, the local internist, or the obstetrician/gynecologist is generally unaccustomed to treating patients with a major physical impairment. In the mind of the practitioner, the disability, not the present complaint, becomes the more important health issue. These perceptions of the patient's health often motivate the provider to refer the patient to a specialist. As a result, the person with SCI is likely to be sent to a urologist, a neurologist, a specialty hospital-based outpatient clinic, or an emergency room. The unfortunate outcome of such a referral pattern is often (1) an unnecessary hospitalisation or (2) delayed attention to an emerging health problem that will ultimately require hospitalisation (Batavia *et al.*, 1989).

These shortcomings in the United States primary health care system often lead persons with SCI to seek out a local physiatrist (i.e., a specialist in rehabilitation medicine) who is acquainted with the person's impairment and its implications for health management. Alternatively, the person with SCI may turn to the physiatrist he or she knew during the course of his or her rehabilitation program in a distant city. Although rehabilitation medicine has not viewed itself as a primary care specialty, some physiatrists are known to provide primary care services willingly to persons with SCI because of shortcomings elsewhere in the health care system (Batavia *et al.*, 1988).

The irony about the under supply of physicians knowledgeable of the health care needs of disabled persons is that there is an over supply of primary care physicians in many urban areas who could be addressing these unmet needs (Batavia *et al.*, 1988). While it is true that persons with SCI represent a very small part of the health care market, many other groups with physical disabilities experience similar health problems and similar problems with access to appropriate primary care (Batavia *et al.*, 1989; DeJong, Batavia and Griss, 1989).

Aging with a disability

The life expectancy of SCI survivors is beginning to approximate that of the general population. Thus, as persons with SCI become older, they are likely to experience many of the same kinds of chronic health conditions that are

experienced by the general population, such as arthritis, heart disease, cancer, and others (Mahoney, Estes and Heumann, 1986; Trieschmann, 1987). Four observations should be noted.

Firstly, persons with SCI are unable to undertake many of the same preventive measures available to the general population. For example, paralysed limbs limit the SCI person's capacity for aerobic exercise. Most adaptive devices for aerobic exercise have serious practical limitations. The use of arms for aerobic exercise is not available to persons with high cervical injuries. The use of a bicycle ergometer powered by electrically stimulated leg muscles requires expensive equipment and tedious set-up, and is difficult to integrate into the daily routine of a person with SCI. Moreover, we do not know the long term effects of such exercise. Secondly, persons with SCI may experience the onset of some chronic health conditions earlier in life than non-disabled persons experience such problems. Although we do not know this for certain, prolonged physical immobility and the use of compensatory muscles may aggravate certain body systems, and thus precipitate an earlier manifestation of certain health conditions. Thirdly, persons with SCI may be at risk of unknown new health problems. For example, the long term effects of regular urinary tract infections and long term exposure to antibiotics are not known (Ohry *et al.*, 1983). As Trieschmann (1987) observes, '... the true experts are those who have survived a disability ... or injury for 30, 40, or 50 years'. Fourthly, persons with SCI are likely to experience secondary functional losses because of a chronic health condition. For example, the presence of arthritis in one's fingers is likely to compromise what little dexterity remains. The onset of angina may limit the person's willingness to exert himself or herself physically when facing certain architectural barriers.

In responding to these needs, the health care system will have to take into account factors specific to the physical limitations experienced by persons with SCI: Firstly, early detection may be difficult because persons with SCI do not experience pain in many body regions. Secondly, secondary prevention may be difficult because of functional limitations, and thirdly, various kinds of therapy may be difficult because the disabled person may not be able to participate actively in the therapy.

At present, the health care system is not equipped to respond to these needs and limitations as persons with SCI become older. To respond adequately, new ways must be found in which primary care disciplines, rehabilitation medicine, and other specialty disciplines can work together on behalf of the patient. The challenges of aging with a disability are already evident at the VA, which serves a population of SCI cord injured veterans who served in World War II and the Korean War. Vietnam Veterans are also reaching middle age. In addition, there are many veterans with nonservice-connected spinal cord injuries. With its access to many older persons with SCI, the VA is in a strategic position to consider innovative approaches to meeting the needs of older persons with SCI.

New models of health care delivery

The unresponsiveness of the present health care system to the needs of persons with SCI and to persons with other physical disabilities compels us to search for new models of health care delivery that will be more responsive to their needs. We

must find models of care that will (1) avert unnecessary rehospitalisation; (2) offer access to timely primary care, and (3) respond to new health needs as persons with SCI become older.

One major shortcoming of the United States health care system is the manner in which it pays for health care. For example, rehabilitation providers have no direct financial incentive to enhance post-rehabilitation outcomes, such as the avoidance of complications that result in unscheduled rehospitalisations (Batavia, 1988). Likewise, third-party payors often are not willing to cover certain types of durable medical equipment when they know that this will attract high-cost disabled persons to their policies (a process known as adverse selection), or if their financial liability for the patient's care will soon end (Batavia, 1989). In short, the present health care financing system offers few financial incentives for both providers and payors to consider the long term needs of persons with SCI. It does not reward providers and payors to make the up-front investments needed to avert medical problems downstream (Batavia, 1988).

As noted in the opening sections of this article, the health care system is changing rapidly in the face of competition and the desire of payors to restrain the rapid growth of health care costs. These changes also provide an unusual window of opportunity in which to consider how to address the health care needs of persons with SCI. A few innovative approaches are being proposed. The common denominator among these approaches is the provision of managed care using an innovative financing mechanism. In San Francisco, the On Lok Senior Health Services program has been providing managed health care services to the frail elderly population since 1979. Since 1983, the On Lok program has been funded on a capitation basis under Medicare and Medicaid (Zawadski *et al.*, 1985). In Boston, the Urban Medical Group conducted a pilot project to evaluate the merits of a capitation-financed program for persons served by the Boston Center for Independent Living, many of whom had a SCI (Meyers *et al.*, 1987; Meyers *et al.*, 1988).

In Washington, D.C., the National Rehabilitation Hospital (NRH) conducted a feasibility study funded by The Robert Wood Johnson Foundation, which determined that a managed health care plan for working age (18–65 years) disabled persons in the metropolitan Washington, D.C., area should be developed and implemented (Batavia *et al.*, 1989). The NRH health plan will include, among other things, case management services and home visits by nurse practitioners in an effort to prevent unnecessary hospitalisations. The results of this project, and those discussed above, must be monitored carefully in order to evaluate their implications for the health management of persons with SCI. The needs of persons with SCI figured prominently in the development of both the Urban Medical Group project and the NRH project.

Attendant services

Immediately following discharge from a rehabilitation facility, many persons with SCI are faced with the need to find an affordable and reliable source of attendant services to assist them in personal care and various other in-home activities. Without some form of attendant care, the alternative for many would be

institutional care. Accordingly, attendant care is the premier long-term care issue for the population of people with SCI (DeJong and Wenker, 1983; Litvak, Zukas and Heumann, 1987).

When using the term 'attendant services' or 'attendant care', we are referring to a very specific model of in-home services that needs to be made explicit. In the attendant care model, as it is used here, the user of the service (e.g., a person with SCI) manages and directs his or her own attendant care employment relationship. The attendant is accountable to the consumer of the service, not to an outside agency as in the case of home health care. The attendant is not an extension of a home health agency that is usually managed by nurses who direct care in keeping with a physician's plan of treatment. The attendant is, in a sense, an extension of the disabled person, and does for the user what the disabled person ordinarily would do for himself or herself (DeJong and Wenker, 1983; Litvak, Zukas, and Heumann, 1987).

This conception of attendant services would appear to place attendant services outside the boundaries of health care and thus beyond the scope of HSR. However, we believe that attendant care is very much a health services issue as it is a social services issue for at least three reasons: Firstly, attendant care is, as noted above, a long term care issue that is widely viewed as a health service alternative to institutional care, secondly, attendant care is often financed using health-related payment systems such as Medicaid, and thirdly, an attendant also is an important aid to the user in carrying out health maintenance regimes and in detecting health problems at an early stage. Thus, attendant care must be viewed as an important adjunct to the user's overall program of health maintenance.

Despite the rather straightforward nature and scope of attendant services, the United States (and the vast majority of other developed countries) has yet to develop a coherent attendant services policy that can address the varied needs of potential users such as persons with SCI. Instead, we have a needlessly complex patchwork of programs that are extensions of various health and social service programs, and that are not responsive to the needs of users such as persons with SCI. In some states, disabled persons have no access to attendant services at all, unless they can afford to purchase their own attendant services. In a national study on publicly funded in-home service programs conducted by the World Institute on Disability, investigators found the following: 44% exclude certain disabling conditions; 42% do not cover both personal and domestic services; 22% do not cover services seven days per week; 50% do not serve persons with incomes above the poverty level and 67% do not allow attendants to assist in personal care involving medications, catheters, suppositories, or menstrual needs (Litvak, Zukas and Heumann, 1987). These findings indicate the extent to which most in-home service programs are not responsive to the attendant care needs of persons with SCI.

A major problem in the development of a coherent national attendant services policy is the absence of a good research base. We believe that the various skills that make up the HSR enterprise can advance significantly the policy agenda with respect to attendant services. The development of a national attendant services policy will require an aggressive HSR agenda that effectively can define the parameters of the debate with respect to the future of attendant services. Several major research questions remain to be addressed. For example:

1. How many and what types of persons need and want user-directed attendant services?
2. Can a user-directed model of attendant services foster a more independent and productive lifestyle?
3. Do user-directed models of attendant services foster health maintenance behaviours that help avert complications leading to hospitalisations?
4. Can user-defined criteria be developed by which (a) the quality of attendant service programs can be evaluated and (b) alternative models can be critiqued?
5. How do eligibility and income requirements for attendant services create disincentives for work, and how can such disincentives be averted?
6. How should attendant services be financed? For example, should they be financed within the framework of a health maintenance plan?
7. How much will a national attendant care program cost?

In addition, the VA has had its own attendant care program in the form the 'aids and attendants allowance' (Batavia, 1989). This program is viewed widely as an entitlement. There are no earned income restrictions for service-connected veterans. This long standing program needs to be evaluated in terms of its implications for the nonveteran population. The availability of affordable attendant care is the quintessential requirement for independent living. Without it, persons with SCI are relegated to an often destructive dependence on family members or on institutional care. Moreover, the SCI person's ability to maintain a dependable source of personal care is an important determinant of his or her long term health prospects.

Conclusion

Some elements of a core HSR capacity in SCI already exist in the United States. Among these are the various longitudinal data bases that sprinkle the disability and medical rehabilitation landscapes. The most formidable of the data bases is the National SCI Database discussed at length in this article. In addition, various medical rehabilitation facilities have emerging data bases within the scope of their respective program evaluation systems. The critical element, and the one most frequently missing, is the acquisition of post-discharge outcome and health utilisation data. Other elements of a HSR capacity in SCI are in very short supply. These include researchers trained in HSR disciplines, and HSR programs dedicated specifically to issues concerning SCI and physical disability.

The HSR issues in SCI and related disabilities are compelling. The knowledge gained by researchers in this field affects the assumptions and conclusions underlying federal and state legislation that allocates millions of dollars and impacts on hundreds of thousands of lives. We believe that once exposed to these issues, investigators will develop an enduring commitment to addressing them. Of course, these researchers will need to obtain financial support for pursuing their research agendas, and will need to find an institutional and academic home in which to base their research. Therefore, it is important that federal, state and local government, the philanthropic community, and the non-profit provider community develop strategies to foster this research.

We have noted the need for trained personnel in fields such as biostatistics,

health economics, epidemiology, health care finance, health policy, health law, medical sociology, political science, and social psychology. With respect to research funding sources, large grants for longitudinal research projects are less important than significant grants for individual dissertations, post-doctoral fellowships, research fellowships, visiting senior scientist awards, and other awards directed at individual investigators. These grants should be awarded to investigators with the training specified above, and should be designed to create an inflow of new researchers into the field. The Mary E. Switzer Research Fellowship Program of the United States National Institute on Disability and Rehabilitation Research (NIDRR) is one example of such a program. In addition, however, investigators who are attracted to the field must be assured of a reasonable probability of continued funding if they are to make a sustained commitment to this area of research.

We believe that the involvement of persons with SCI (and persons with other disabilities) in those HSR issues that effect their lives is particularly important. Thus, the disbursement of investigator awards should take into account the person's disability status as one relevant indicator of expertise. Moreover, financial support should be offered specifically to encourage persons with SCI (and other disabilities) to pursue HSR careers. Dissertation support for SCI persons in the disciplines indicated above would be one way to foster the intellectual commitment needed to make a significant contribution to the issues identified in this article.

Many of the HSR needs of the SCI population result from our medical successes in prolonging the lives of persons with SCI and assisting them to enhance their functional capacities. However, success brings with it new responsibilities and new problems to be solved. As more and more persons with SCI have come to live independently in the community, new health care needs have surfaced. The problem is that many of these needs have yet to be recognized fully. It is the task of health service researchers to conduct the studies that will document these new needs, and to help shape the agenda on how these needs will be met.

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