

The consumer's perspective and the professional literature: What do persons with spinal cord injury want?

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Abstract—Different motives and purposes drive research. New knowledge advances any discipline, and use of the information obtained from careful scientific study as the basis for clinical practice promotes patient care. It is important to consider the preferences of persons with spinal cord injury (SCI) and use this as the framework in formulating research questions and clinical applications of discoveries made in the laboratory. A literature review of articles related to the interests and concerns of persons with SCI was conducted through the National Library of Medicine resource. Patient interest in finding a “cure” for SCI was not directly ascertained by any of the studies reviewed. Mobility remains the area of greatest interest, and decreased mobility has been rated as the most difficult consequence to deal with after the injury. This review indicates a congruence of the interests of both patients and researchers. However, the methodology most often used to ascertain the preferences of persons with SCI may need to be supplemented with different approaches. In addition, these preferences and the factors that influence them should be longitudinally assessed.

Key words: consumer preference, rehabilitation research, spinal cord injury.

INTRODUCTION

Different motives and purposes drive research activities. In the academic community, respect is often

accorded to persons steadily engaged in research activities. Moreover, research is often stated as part of an institution's “academic mission.” Research activity has also become an invaluable means to supplement a steadily shrinking clinical revenue base. However, if the pursuit of research is based solely on the above motives, that pursuit will be short-lived and fraught with frustration. Moreover, in the absence of proper motives or vision, the merit of the research product will be poor and its use subsequently limited.

The excellence of any basic science or clinical discipline is based on the desire of its scientists and practitioners to ask questions and diligently seek answers. The benefit of any discoveries made from this process accrues not only to the researcher but also to others—namely, the consumer. Clinical practices obtained in this manner improve patient care and advance the knowledge base of the field. However, the benefits that consumers derive are directly related to the relevance of these developments to their lives. If any scientific and clinical discoveries are to

Abbreviations: MSCIS = Model Spinal Cord Injury Systems, NLM = National Library of Medicine, SCI = spinal cord injury. Address all correspondence and requests for reprints to Irene M. Estores, MD; University of Miami School of Medicine, Lois Pope LIFE Center, 1095 NW 14th Terrace (R-48), Miami, FL 33136; 305-243-4739; fax: 305-243-3395; email: irene.estores@med.va.gov.

translate into better care and quality of life for the patient, research efforts must consider patient priorities. These priorities must be used as a framework not only for formulating questions, but even more so for envisioning applications of any knowledge gained from basic research.

The primary objective of this article is to determine if persons with SCI express a high interest in the topic of neurological recovery after injury, which is the desired application of current basic science research. The secondary objective of this article is to summarize the topics of interest and areas of concern expressed by persons with SCI. Quality of life and pain have been extensively studied elsewhere and thus are not included in this review.

A review of the literature was conducted based on material from the National Library of Medicine (NLM). Additional information was obtained using cited references from the initial articles reviewed.

RESULTS

One would intuitively expect persons with SCI to express great interest in research related to neurologic recovery following acute injury. This is certainly observed in the clinical setting. However, this was not a question that was posed directly in any of the studies reviewed for this article. Interestingly, Hart, Rintala, and Fuhrer [1] mentioned that a topic of interest not included in their survey, but frequently added by the participants, was the topic of a “cure” for SCI.

There is, however, substantial literature on SCI patients’ overall concerns and interests, and a summary of these studies is provided in the **Table**. The literature also indicates that many social issues, such as finances [2], transportation, equipment, accessible housing [3], and employment [4], are areas of concern for persons with SCI.

In each of the studies reviewed, several variables affected the ranking of need and topics/areas of interest. These variables include gender, ethnicity, education, duration of injury, extent of motor impairment, and presence of caregiver support (spouse or paid attendant services).

Motor Impairment

The motor abnormality following incomplete SCI typically manifests itself as an initial period of spinal shock, followed by early and late phases of recovery and hyperreflexia [5]. As such, the motor consequences following injury include both decreased mobility and spasticity.

The work of Hart, Rintala, and Fuhrer [1] shows that 53.1 percent of their subjects ranked exercise programs as the most important educational topic of interest. Testing of nerve and muscle function followed in the ranking, with 51.4 percent. A significant proportion of subjects (62.6%) studied by Widerström-Noga and associates [6] likewise reported that mobility impairment was very hard to deal with postinjury. Cox and associates [7] reported that physical changes, including strength, neurological function, and mobility skills, were rated most frequently as an area of high need (31%). Moreover, 13 percent of their participants also rated mobility, fitness, and exercise as an area of great importance.

On the other hand, spasticity was not perceived as an issue of high need by either of the two groups studied by Widerström-Noga (30.2%) and Cox (9%). Spasticity was ranked only sixth as a topic of interest by participants in the Hart study [1].

Sensory Impairment

Pain is a very distressing sensory consequence following SCI [8,9]. It is highly prevalent and associated with more depressive symptoms, perceived stress, and poor self-assessed health [10]. It ranked fourth among the five top educational topic areas reported by respondents in the study by Hart and associates [1]. Chronic pain was rated as particularly hard to deal with by 37.2 percent of subjects in a study conducted by Widerström-Noga et al [6], an observation consistent with other studies [11,12].

In contrast, pressure ulcers, a consequence of sensory loss following SCI, was not rated with the same importance. Pressure ulcer prevention and management has received much attention and has been the subject of substantial research [13]. The prevalence of this medical condition is high, estimated at 50 to 80 percent of SCI patients [14], and the personal and financial costs associated with its care are significant [15]. However, few participants—only 6 percent in the Cox study [7] and 11.4 percent in the Widerström-Noga study [6]—rated this as an area of high need or difficulty. It was ranked ninth in terms of interest by the participants the Hart study [1].

Autonomic Dysfunction

Sexual, bowel and bladder dysfunctions were mentioned as other topics of concern. The results of two studies conducted by White and colleagues [16,17] are shown in the **Table**. It is important to point out the apparent gender differences, not only in the way this concern is ranked, but also in that the specific areas of concern are

Table.

Summary of research studies assessing concerns and interests of people with spinal cord injury.

Authors	Title	N	Population Description	Study Design	Results
Hart KA, Rintala DH, Fuhrer MJ	Educational Interests of Individuals with Spinal Cord Injury Living in the Community	590	Selected randomly*	Area of interest inventory on 3 topics: • Medical • Sexuality • Wellness	Five topics of greatest interest: • Exercise programs • Muscle nerve function testing • Bladder or kidney problems • Pain • Sexuality
White MJ, Rintala DH, Hart KA, et al.	Sexual Activities, Concerns and Interests of Men with Spinal Cord Injury	79	Selected randomly*	Questionnaire rating scales	Importance of life areas ranked as— 1. General health 2. Family relationships 3. Emotional well-being 4. Money matters 5. Sex life 6. Daily living tasks 7. Spiritual life 8. Employment 9. Social life 10. Recreational activities 11. Housing 12. Transportation
White MJ, Rintala DH, Hart KA, et al.	Sexual Activities, Concerns and Interests of Women with Spinal Cord Injury Living in the Community	40	Selected randomly*	Questionnaire rating scales	Importance of life areas ranked as— 1. Spiritual life 2. Tasks of daily living 3. Emotional well-being 4. Family relationships 5. Transportation 6. Social life 7. General health 8. Recreational activities 9. Housing 10. Sex life 11. Money matters 12. Employment
Widerstrom-Noga, Felipe-Cuervo, et al.	Perceived Difficulty in Dealing With Consequences of Spinal Cord Injury	430	The Miami Project to Cure Paralysis database	Postal survey (430 respondents), telephone survey (19 of 447 nonrespon- dents). All subjects were asked to rate 5 consequences of SCI.	Consequences of SCI, percentage of subjects who found these consequences “very hard to deal with”: 1. Decreased ability to walk or move = 62.6% 2. Decreased bladder control = 44.9% 3. Decreased bowel control = 43.5% 4. Decreased sexual function = 42.1% 5. Pain = 37.2%
Pentland W, Walker J, et al.	Women With Spinal Cord Injury and the Impact of Aging	29	Focus groups: <i>n</i> = 10 key informant interviews: <i>n</i> = 19 31–70 years old, rural and urban Canada	Focus groups, key informant inter- views	Most common concerns: • Psychological issues • Sexual issues • Bowel/bladder issues Other concerns: • Declining health • Increasing dependency • Financial stresses

Table. (Continued)

Summary of research studies assessing concerns and interests of people with spinal cord injury.

Authors	Title	N	Population Description	Study Design	Results
Cox RJ, Amsters DI, Pershouse KJ	The Need for a Multidisciplinary Outreach Service for People with Spinal Cord Injury Living in the Community	54	Different postinjury durations. Subjects aged from 19 to 79, average age = 38.7, selected by random sampling	Telephone interviews	Main items of interest/concerns: <ul style="list-style-type: none"> • High need for followup care • High needs in area of mobility • High interest in areas of transport, fitness, and exercise

N = number of respondents.

*Patients selected from a community sampling frame in Houston and Galveston, Texas. Inclusion criteria: 18 years old or older, 9 months postinjury, and residual motor disability.

different for men and women. Decreased sexual function was reported as very difficult to deal with by 42.1 percent of subjects studied by Widerström-Noga [6]. Interest in bowel and bladder management was ranked third by Hart's subjects [1]. It was similarly reported as a consequence that was difficult to deal with by 44.9 percent (bladder) and 43.5 percent (bowel) of Widerström-Noga's subjects [6].

Physical Health and Aging

Advances in medical care have increased the survival rate and life expectancy of persons with SCI [18]. Consequently, one of the emerging concerns expressed by persons with SCI relates to the physical changes brought about by aging and the development of medical comorbidities [19]. Aging and duration of SCI amplified the male subjects' concerns about financial security and threats to health [19]. Although these concerns were also reported by female subjects, the authors also report that more women fear that aging with SCI will lead to isolation and neglect from health care and rehabilitation professionals, as well as from the social service system [20].

Methodological Considerations

With the exception of the Pentland study [20], which used focus groups in addition to interviews, data were collected for these studies through questionnaires and interviews. The inherent limitations in using this study design include a possible positive or negative bias due to differences between responders and nonresponders. In addition, it has also been suggested that people who have experienced constant deprivation may have lowered perceptions of their needs [21]. Another important consideration relates to the questionnaire's design and choice of words.

The use of focus groups as a qualitative method of data collection supplements information obtained from

quantitative (i.e., questionnaire) methods. The synergism provided by focus groups uncovers data or ideas that may not arise in an individual interview [22]. In addition, ideas expressed by the group can be used to generate research hypotheses and instruments for future quantitative testing. The potential for moderator bias in the conduct of focus groups certainly exists. Practices that can reduce this bias include proper selection and training of moderators, provision of a nonthreatening or nonjudgmental atmosphere during group interaction, and the use of more than one moderator [23].

Information regarding consumer preferences may be obtained in a game setting, which does not rely heavily on moderator facilitation, as a means to decrease moderator bias. A Features-Resource Trade-Off Game, initially proposed by Stineman [24], used groups to obtain consumer and clinician consensus for recovery among the 18 functional status items that make up the Functional Independence Measure. Each member of the group was given identical instruction and information on the principles involved in making their choices. These choices required trading levels of independence across different items. This game approach has been adapted by Patrick et al [25] to obtain pilot data regarding consumer versus staff preferences for walking after SCI. The use of groups requires more time and staff resources compared to surveys, which limits its use for obtaining large amounts of data.

CURRENT AND FUTURE RESEARCH

And so we now ask ourselves, are we answering our patients' questions? It is certain that research in SCI neuroprotection and neuroregeneration, with the end of finding a "cure" for SCI, is multiplying [26–28]. Research in motor retraining following SCI is likewise expanding

[29,30]. It is also clear that SCI rehabilitation research is continuously evolving to meet the needs of persons with SCI. The Model Spinal Cord Injury Systems (MSCIS) program, now in its third decade, has produced a significant body of information related to assessment and treatment, classification systems, methods of restoration of functional independence, adapted technology, and psychosocial factors affecting quality of life for persons with SCI [31]. Future areas of research will be pharmacological intervention, neuroscience and nerve regeneration, subjective well-being and consumer satisfaction, preventive health and wellness, bioethics, health care models, bioneurotechnology, and bioinformatics [31].

CONCLUSIONS AND RECOMMENDATIONS

This review suggests the following:

1. There is a need to directly ascertain patient interest in finding a "cure" for SCI. To avoid omitting relevant areas of study, researchers should invite persons with SCI to participate in the development of survey topics.
2. The areas of greatest concern and interest remain mobility issues. This implies the need for continued research in restoration of motion and ambulation, seating and assistive technology, and environmental adaptation.
3. Consumer priorities are affected by demographic factors (age, gender, ethnicity, location of residence, marital status), medical factors (duration of injury, level and completeness of injury), and social factors (presence of attendant care, level of education, employment status). Therefore, these factors should be considered in the analysis and interpretation of consumer priorities in cross-sectional, as well as longitudinal, research.
4. Concerns are emerging related to maintaining physical health during aging with chronic SCI, and these concerns should be addressed in future investigations.
5. Current SCI research does address the concerns and needs expressed by persons with SCI. However, the use of other qualitative methods (i.e., focus groups, tradeoff models), in addition to current quantitative methods to elicit patient preferences, should be included in future investigations.

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