ARTICLE





Recovery target priorities of people with spinal cord injuries in Korea compared with other countries: a survey

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Abstract

Study design Cross-sectional survey.

Objectives To identify which functional areas are important in recovery and which psychosocial factors influence life quality among persons with spinal cord injuries in Korea and to compare our results with similar studies from other countries. **Setting** University-affiliated rehabilitation hospital.

Methods The survey was distributed to people with spinal cord injuries and captured their targeted functional recoveries and psychosocial goals that can affect life quality. The respondents were asked to place these in order of priority. Participants were also asked questions regarding factors they felt were important for restoring function, their expectations for recovery and to evaluate their health status and satisfaction with their quality of life.

Results Fifty-five people were tetraplegia and 45 people were paraplegia. The primary functional recovery goals included the recovery of upper extremity functions in tetraplegic persons and restoration of bladder and bowel functions in paraplegic persons. For psychosocial goals, stress management was the most important factor among both tetraplegic and paraplegic people. The two most important factors for restoring function were proper physical therapy and relationship with their clinician. About half of the respondents had no expectation of restoring their functions.

Conclusions Restoring upper extremity function, sexual function, and bladder and bowel function has been a common concern in previous studies. Our result, however, showed sexual function was less important. Coping with stress was important for life quality, another finding that differed from other studies. Thus, there may be cultural and social differences in the priorities of the target functions.

Introduction

Although no national data are available in Korea's spinal cord injury (SCI) registry, it is estimated that there are more than 67,000 people with SCI in Korea [1]. According to demographic data of 3076 Korean people with SCI, which were collected by the National Rehabilitation Center, 73% of such people were men and 27% were women. Traumatic

SCIs accounted for 81% of the collected cases, with traffic accidents (55%) being the most common cause and falls (32%) being the second most common cause. Furthermore, 19% of the collected cases were non-traumatic SCIs [2].

Tate et al. [3] reported that, compared with people without disabilities, those with SCI tended to have a lower quality of life. Estores [4] reviewed previous studies on quality of life among people with SCI and reported that bladder and bowel function, sexual function, pain, and mobility were the most important factors requiring attention in people with SCI. Lee et al. [5] noted that individuals with SCI in Korea suffered from quality of life-related problems as well as physical disabilities and that voiding and sexual function should be carefully considered for those with SCI.

Simpson et al. reviewed the priorities of those with SCI in terms of the functions to be restored. Several studies reported that arm and hand function was regarded as the highest restoration goal and that bladder and bowel function were regarded as the second-highest priority among people

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with tetraplegia [6–10]. Other studies reported that individuals with paraplegia regarded sexual function, locomotor function, and bladder and bowel function as the most important priorities [6–9]. Thus, it is possible to develop a rough understanding of the factors considered most important for quality of life among individuals with SCI; however, it is difficult to predict the priority accorded to these factors, which can influence quality of life under different social circumstances. People with SCI suffer from various physical limitations as well as psychosocial problems in everyday life. However, no study in Korea has investigated the recovery goal prioritization with regard to barriers in the physical function and psychosocial areas of people with SCI.

In Korea, all citizens receive medical care under the National Health Insurance program. Due to limited resources in terms of health and welfare services, it is always important to prioritize the distribution of resources. Therefore, in order to achieve optimal distribution, the service provider should know how to prioritize the aspects and levels of satisfaction in currently offered rehabilitation services that are considered most urgent by persons with SCI. Several previous studies have shown that functional goals may vary based on the time since injury, sex, the neurological level of the injury, and injury completeness [6, 7, 11– 13]. However, we have focused on the differences caused by cultural and social circumstances. Therefore, the aim of the study was to identify which functional areas and psychosocial areas were considered as the most important recovery targets for people with SCI in Korea; furthermore, we aimed to compare this study's findings with those of similar studies from other countries.

Methods

Survey design

A survey questionnaire was designed to collect information on the domains of functional recovery and quality of life that were considered most important by SCI populations.

All respondents were asked to fill out the questionnaire personally. Because the survey details were complicated, well-trained physiatrists and clinical psychologist helped respondents to understand the contents properly. The survey questionnaire consisted of two sections; one section focused on functional recovery and the other assessed factors that affect quality of life. The first section contained questions about functional recovery-related priorities. Eight categories were developed based on previous survey studies on the recovery target; that is, arm and hand function, trunk balance, bladder and bowel function, elimination of autonomic dysreflexia, pain and spasticity control, locomotor function, sexual function, and normal sensation [6]. The second section included psychosocial questions about life-related factors to improve quality of life. Eight categories were chosen based on the top ranked areas in several previous studies [7]. The categories were stress management, support from friends and family, community participation, selfesteem, employment issues, financial problems, interpersonal relationships and communication, and leisure and recreation. The respondents were asked to place these factors in order of priority. In addition, all respondents were asked to answer some questions about quality of life and their satisfaction with their functions (Supplementary Table 1). The questionnaires asked what they considered to be the most important factor for restoring function, their expectation of restoring function, and their self-awareness regarding quality of life and health status.

The study procedures were reviewed and approved by the Pusan National University Yangsan Hospital Institutional Review Board for the human participants. The survey questionnaire included the purpose of the survey, privacy rights, and the intended and potential uses of the results.

Study sample

This cross-sectional study was conducted over a period of 3 months as a survey investigation. All visitors with SCI were asked to take the survey. The respondents were recruited from among those with SCI who visited the rehabilitation hospital and agreed to participate in the survey; they were individuals with SCIs, who were followed up at a university-affiliated rehabilitation hospital. The rehabilitation hospital is one of the major regional centers for the people with SCI in Korea. This regional disability health care center manages the entire population of people with SCI in the southern region of the South Korea; most of the individuals with SCI visited the hospital regularly for various reasons, including medical counseling, physical therapy, occupational therapy, and medication prescription. Our study was completed with cooperation from 100 individuals with SCI. The Institutional Review Board approved a waiver to document informed consent. Excluding individuals with cognitive problems and medically unstable conditions, all people with SCI were included in the survey investigation.

Data analysis

The respondents ranked the examples in both functional and psychosocial areas (Supplementary file). For this study, the target that was rated "first" most frequently in the survey was considered the primary target, while the target that was rated "second" most frequently was considered the secondary target. We descriptively analyzed the primary and secondary targets or factors in both functional and psychosocial areas among people with SCI. We analyzed the percentage of the answers recorded for each of the four questions in the quality of life and expectation of functional recovery section.

Results

Respondent characteristics

The overall response rate was 65%, and 100 respondents with SCI participated in the study. Fifty-five persons (55%) were living with tetraplegia and 45 (45%) were living with paraplegia. In addition, 74% were male and 26% were female. The age of the respondents ranged from 0 to 15 years (0%), 16 to 30 years (3%), 31 to 45 years (28%), 46 to 60 years (39%), 61 to 75 years (26%), and over 76 years (4%). The duration after injury was divided into two groups: <5 years (39%) and >5 years (61%) (Table 1).

Primary and secondary targets

Based on the level of injury, the collected data were sorted into two groups: people with tetraplegia and people with paraplegia. The primary and secondary targets are showed in Figs. 1 and 2. In the functional area, arm and hand function recovery was the primary target (31%) for those with tetraplegia; arm and hand function was also the secondary target (31%) for those with tetraplegia. In the case of primary targets, for those with tetraplegia, the restoration function targets were arm and hand function, pain and spasticity control, bladder and bowel function, trunk balance, locomotor function, autonomic dysreflexia elimination, normal sensation, and sexual function all in this order.

On the other hand, management of pain and spasticity (31%) was the highest priority target for those with

 Table 1 Characteristics of the respondents.

Variables	Categories	n (%)
Age (years)	20–29	5 (5%)
	30–39	15 (15%)
	40–49	18 (18%)
	50-59	26 (26%)
	≥60	36 (36%)
Gender	Male	74 (74%)
	Female	26 (26%)
Level of injury	Tetraplegia	55 (55%)
	Paraplegia	45 (45%)
Duration since injury (years)	<5	39 (39%)
	≥5	61 (61%)

paraplegia. The second-highest priority function that these people wished to achieve was pain and spasticity management (31%). The primary function targets for those with paraplegia were pain and spasticity control, locomotor function, bladder and bowel function, normal sensation, trunk balance, autonomic dysreflexia, arm and hand function, and sexual function all in this order. The comparison of this study's prioritized recovery targets with those of other studies is presented in Supplementary Table 2.

In the psychosocial sphere, stress management was the most important factor for improving quality of life for both those with tetraplegia (37%) and those with paraplegia (33%). Support from friends and family for individuals with tetraplegia (35%) and stress management for those with paraplegia (23%) were the second most important factors to improve their quality of life. The most important factors for those with tetraplegia were stress management, financial problems, friend and family support, employment issues, leisure and recreation, self-esteem, community participation, and interpersonal relationships and communication all in this order. For those with paraplegia, the most important factors were stress management, financial problems, friend and family support, interpersonal relationships and communication, employment issues, self-esteem, community participation, and leisure and recreation all in this order.

Quality of life and expectations regarding functional recovery

Most respondents reported that proper physical therapy (36%) and their relationship with clinicians (30%) were the two most important factors for restoring function. About half of the respondents said that they expected to restore their functions (47%), but others did not expect to restore functions (53%). Few were satisfied with their quality of life (16%), and others were unsatisfied (44%) or had no particular preference (40%). In addition, only a few (9%) were satisfied with their health status, and more than half of the respondents (65%) were unsatisfied (Fig. 3).

Discussion

Although some previous studies have examined the prioritization accorded to recovery targets after the onset of SCI, thus far, no study has examined this issue in Korea or Asia. As we mentioned previously, what is considered as the most important recovery target may differ depending on differences between various cultural backgrounds. This expectation could also apply to insurance policies. All citizens in Korea are covered by the National Health Insurance program, which provides coverage for a maximum period of 2 years after injury. Despite this social security system,

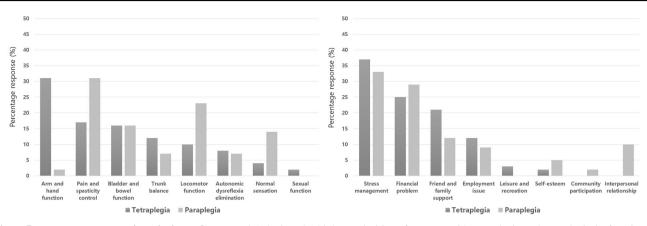


Fig. 1 Percentage responses in priority orders. Panel 1 depicts the highest priorities of persons with tetraplegia and paraplegia in functional domain. Panel 2 depicts the highest priorities of persons with tetraplegia and paraplegia in psychosocial domain.

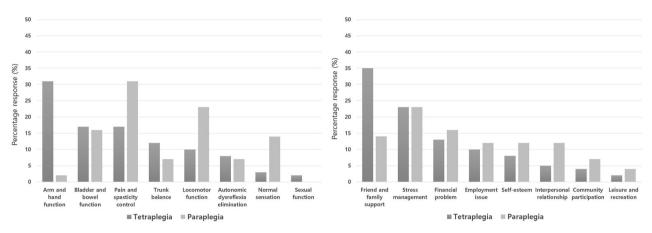


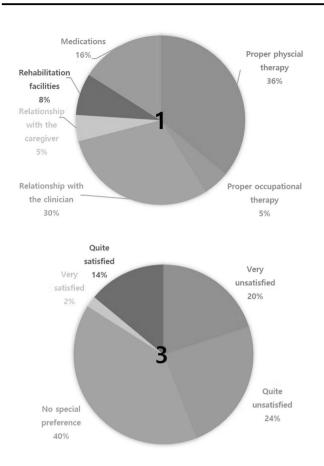
Fig. 2 Percentage responses in priority orders. Panel 1 depicts the secondary priorities of persons with tetraplegia and paraplegia in functional domain. Panel 2 depicts the secondary priorities of persons with tetraplegia and paraplegia in psychosocial domain.

engaging is still challenging for the people with SCI in Korea, and either the family or the caregiver must help the individuals with SCI. Only 13% of people with SCI are employed; thus, individuals with SCI suffer a huge economic burden [1].

The current study aimed to compare recovery goal priorities among people with SCI in Korea with the findings of studies dealing with this subject in other countries. The survey results are consistent with previous studies, but there are also several differences. In the group of people with tetraplegia, recovery of arm and hand function and stress management were the highest priority factors that these people wanted to achieve or resolve in their functional and psychosocial areas, respectively. Upper limb dysfunction may cause the most discomforting in the early stages after SCI onset, as impaired upper limb function is directly related to various daily activities. Previous research by Anderson regarding the recovery targets of those with SCI showed that arm and hand function was the first target to be achieved by those with tetraplegia, and restoration of sexual function was the primary goal of people with paraplegia. Recovery of bladder and bowel function and autonomic dysreflexia control were the second targets [6]. Management of pain and spasticity and stress management, however, were the primary goals of those with paraplegia. Compared with our study, those with tetraplegia showed the same results, but some differences were observed in those with paraplegia.

Recovery of sexual function was rated the lowest among both tetraplegia and paraplegia people in the current study. Although Lo et al. also reported sexual function as the lowest ordered priority, several other studies still identified sexual function as a high priority goal [6, 8, 11]. These results may be related to the Korean and Asian cultural backgrounds. In Korean culture, conversations about sex life are not very common, and the number of people who responded to sexual function in our study may have been underestimated. Furthermore, these results may be related to barriers to sexual satisfaction among Korean SCI sufferers. Choi et al. reported that 65% of men with SCI in Korea were having sexual relations with their partners, and only 9% were sexually satisfied. However, another study





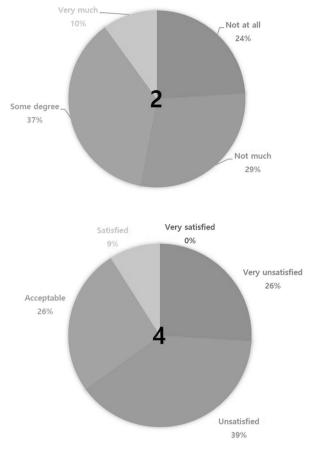


Fig. 3 Satisfaction and expectation regarding the aspects of function and quality of life. Question 1. What do you think is the most important factor for restoring function? Question 2. Are you expecting

functional recovery? Question 3. Evaluate your quality of life. Question 4. What do you think about your health status?

from Brazil reported that 48% of SCI sufferers were sexually satisfied [14, 15]. Lee et al. reported that the most common complaints regarding sexual function among those with SCI were erectile dysfunction and lack of libido, and 35% received no proper recommendations for improving their sexual life [5]. These results suggest that sexual satisfaction varies across different cultural and personal backgrounds, and this may have led to the differences in priorities.

Most SCI populations state that stress management is the primary factor that they want to resolve in their psychosocial sphere. Simpson et al., however, showed that the most frequent domains prioritized in other studies were leisure, relationships with family and friends and employment [7]; this significantly differs from our results. Stress management includes dealing with emotional lability, such as depression and anxiety. Shin et al. reported that 64% of people with SCI in Korea suffer from depression [16]. As depression is a serious health problem associated with mortality and morbidity, the questionnaire results indicate that clinicians should accord a high priority to dealing with the emotional lability of those with SCI [17]. Figure 3 shows how respondents think about functional restoration and quality of life. Half of the respondents expected their functions to be restored. Very few of those surveyed were satisfied with their quality of life and state of health. These results demonstrate the importance of having information about recovery goal-related priorities for those with SCI.

This study had several limitations. First, the small number of respondents does not represent the entire Korean population with SCI. We did conduct the study over a period of 3 months, and we recruited individuals with SCI in the outpatient and inpatient department who agreed to participate in the study. We asked all visiting and admitted persons with SCI to the hospital to avoid selection bias (response rate 65%). Previous reports regarding SCI in Korea showed that 73% of SCI sufferers were men, and 27% were women [1]; our study's results were consistent with these findings (74% men and 26% women). In addition, the rehabilitation hospital, where we recruited participants is one of the major national rehabilitation hospitals, which serves individuals with SCI from all over Korea; this could ensure the representativeness of the participants. Despite this condition, however, there may still have been

selection bias. Further studies with a larger number of participants are required for representativeness and further subgroup analyses. Second, the details of the questionnaire survey were quite complicated and time-consuming, and we did not consider participants' levels of education. There might be concerns as to whether respondents fully understood the questionnaire. Nevertheless, a well-trained physiatrist and clinical psychologist were on hand to help respondents understand the details of the survey, if needed. Finally, the survey questionnaire about SCI sufferers' functional and psychosocial spheres was designed based on a previous study of individuals with SCI [6, 18, 19]. However, the survey questionnaire could not obtain comprehensive details about the everyday thoughts of people with SCI. Some individuals with SCI may have wished to regain other functions or pursue other factors in order to improve their quality of life factors that were, however, not listed in the survey. From this point of view, it could be suggested that the results may not actually reflect the actual opinions of individuals with SCI.

Despite the several limitations mentioned above, the current study remains meaningful as no other comparable studies have investigated the recovery target of individuals with SCI in Korea, especially in comparison to studies from other countries. Furthermore, a multi-center survey of functional restoration in individuals with SCI may help to conduct subgroup analyses based on sex, time since injury, neurological level of injury, and injury completeness.

Data availability

The datasets generated and/or analyzed during the current study are available from the corresponding author on reasonable request.

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Author contributions SH had full access to all data in the current study and takes responsibility for the integrity of the data and the accuracy of the data analysis. The concept and design of the study were handled by SH and H-YK.

Compliance with ethical standards

Conflict of interest The authors declare that they have no conflict of interest.

Ethical approval The study procedures were reviewed and approved by the Pusan National University Yangsan Hospital Institutional Review Board for human participants (No. 05-2019-155). We certify that all applicable institutional and governmental regulations concerning the ethical use of human volunteers were followed during the course of this research. **Publisher's note** Springer Nature remains neutral with regard to jurisdictional claims in published maps and institutional affiliations.

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