

ARTICLE



# An assessment of disability and quality of life in people with spinal cord injury upon discharge from a Bangladesh rehabilitation unit

Ehsanur Rahman<sup>1</sup>✉, Nirupom Bardhan<sup>2</sup>, Michael Curtin<sup>3</sup>, Md. Shofiqul Islam<sup>1</sup>, Md. Fazlul Karim Patwary<sup>4</sup> and Shazal Kumar Das<sup>1</sup>

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**DESIGN:** Cross-sectional.

**OBJECTIVES:** The purpose of the study was to determine the level of disability and quality of life of people with spinal cord injury at the end of their inpatient rehabilitation at a rehabilitation center in Bangladesh. These outcomes were considered indicators of successful rehabilitation and a basis for comparing the success of reintegration into community.

**SETTING:** Center for the Rehabilitation of the Paralyzed, Bangladesh.

**METHODS:** Two standard structured questionnaires, the WHODAS 2.0 and WHOQOL-BREF, was used to collect data to assess level of disability and quality of life (QOL). Data were analyzed using Mann–Whitney–U test and Kruskal–Wallis test.

**RESULTS:** One hundred participants (91 men and 9 women) with SCI were recruited. Just prior to discharge from in-patient rehabilitation at CRP people with SCI perceived themselves overall as having on average a mild level of disability, and good QOL in physical, psychological, and environmental health domains. They indicated poor QOL in the social health domain. There were some specific differences in various WHODAS 2.0 Domains and overall scores when comparing age, gender, type and level of injury, occupation, and income. Between-group comparisons indicated that male participants had a significantly higher quality of life in the Environmental Health Domain and those with a paraplegic injury had a significantly higher quality of life in the Physical Health Domain.

**CONCLUSION:** By the end of their rehabilitation people with SCI had a relatively positive perception of level of disability and QOL. However, the results of other research has found that post-discharge their disability level increase and QOL decrease across all domains. Hence, it is recommended that more monitoring of level of disability and QOL is conducted post-discharge, along with a greater focus on community-based rehabilitation strategies and procedures to contribute to long-term reduction in level of disability and improved QOL.

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## INTRODUCTION

Spinal cord injuries (SCI), and/or secondary complications from a spinal cord injuries, can impact on each individual's level of cognition, mobility, self-care, relationships, life activities, overall participation, and quality of life [1–3]. This can lead to people with SCI experiencing different degrees of disability, that can be further impacted by the level and type of injury and many other demographic, social and environmental factors. For example, Kader et al. [4, p. 239] found that having tetraplegia “was the strongest significant contributing factor, followed by rural residence, and complete injury” to increased activity limitations and participation restrictions, and more severe disability.

The World Health Organization [5, p. 3] defines quality of life (QOL)

As an individual's perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns. It is a wide-ranging perception incorporating, in a multipart way, a person's physical health and psychological state, level of independence, social relationships, personal beliefs, and relationship to salient features of the environment.

Several studies of QOL following a SCI, highlight that it is affected by physical factors, age, and gender [6–8]. Gupta et al. [9] found that individuals with neurological illnesses, including SCI, reported compromised QOL in all domains of life. Lidal et al. [10] suggest that QOL decreased for people who have lived with

<sup>1</sup>Department of Physiotherapy, Bangladesh Health Professions Institute (BHPI), CRP, Savar, Dhaka, Bangladesh. <sup>2</sup>Department of Physiotherapy, Centre for the Rehabilitation of the Paralyzed (CRP), Savar, Dhaka, Bangladesh. <sup>3</sup>School of Allied Health, Exercise and Sports Sciences, Charles Sturt University, Bathurst, NSW, Australia. <sup>4</sup>Institute of Information Technology, Jahangirnagar University, Savar, Dhaka, Bangladesh. ✉email: ehsanurrahman.bhpi@gmail.com

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SCI for a long period due to an increase in the number of comorbidities they experienced. However, Barker et al. [11] found that QOL was more impacted by functional impairment, secondary complications, and level of participation, rather than time since injury. Decreases in QOL can have a negative impact on “social and physical well-being, and treatment outcomes” of people with SCI [12, p. 469]. Vural et al. [13, p. 193] stated that,

Given the likelihood of surviving the initial injury and having a prolonged life expectancy among patients with SCI, an improved quality of life (QOL) has become an increasingly important target in post-SCI rehabilitation practice.

Bangladesh is a developing country with a population of 166 million. The incidence of SCI is unknown. The Center for the Rehabilitation of the Paralyzed (CRP), the only specialized hospital for people with a SCI in Bangladesh, admits approximately 350 people with SCI a year [14]. It is acknowledged that the number of people admitted to CRP would be a small proportion of the overall number of people in Bangladesh who experience SCI. Of the people admitted to CRP there is a predominance men and people from the low-socioeconomic group [15].

Hossain et al. [7] found that following discharge from CRP, as many as one in five people with SCI die within two years of discharge. The most common cause of death was sepsis due to pressure ulcers. Furthermore, Hossain et al. [7, 16]. found that for many people living with SCI in the community three to six years post-discharge from CRP were house-bound, unemployed, living in poverty, and had pressure ulcers. It was also noted that many of these people reported experiencing moderate rates of depression and poor quality of life. Hence, in-patient rehabilitation for people with SCI may not have a long-term positive impact on their level of disability and quality of life post-discharge.

Although CRP has been working with people with SCI since the 1970s there has been little research conducted that has investigated the level of disability and the QOL of these people at the end of their inpatient rehabilitation to provide a basis for comparison post-discharge. This study was conducted to determine the level of disability and QOL of people with SCI at the end of their inpatient rehabilitation at CRP as these outcomes are considered essential indicators of successful rehabilitation and provide a basis for comparing the success of integration back into community post-discharge.

### Research question

What are the levels of disability and quality of life of people with SCI on completion of their inpatient rehabilitation at the CRP as measured by WHODAS 2.0 and WHOQOL-BREF?

### METHOD

Ethics approval for the study was provided by Institutional Review Board (IRB) of Bangladesh Health Professions Institute (BHPI).

### Study design

A cross-sectional survey was used to investigate the levels of disability and quality of life of people with SCI on completion of their inpatient rehabilitation at CRP in Dhaka, Bangladesh.

### Sample size and data collection procedure

One hundred men and women, 18 years and older, who had a SCI were recruited for the study at the completion of their inpatient rehabilitation at CRP. At the end of inpatient rehabilitation each person was invited to voluntarily participate in this study. Recruitment continued until 100 people who met the inclusion criteria completed the survey. It took approximately four-months to recruit this number of participants. To assist with the completion of the survey and to ensure that each person understood the questions, all surveys were conducted in person, and completed by a researcher who filled in the survey based on the responses of the participant. Each interview took between 20 and 30 min to complete.

### Measurement tools

A survey consisting of three sections was developed.

Section 1: This section gathered demographic information on each person completing the survey. The collected data included: age, gender, religion, educational status, occupation, cause of injury, type of injury, ASIA scale, and monthly income.

Section 2: Thirty-six questions grouped into six domains from the World Health Organization Disability Assessment Schedule 2.0 (WHODAS 2.0) [17] were included to provide a measure of disability:

- (i) Cognition: understanding and communication (6 questions, range of score 6–30);
- (ii) Mobility: moving and getting around (5 questions, range of score 5–25);
- (iii) Self-care: attending to hygiene, dressing, eating and staying alone (4 questions, range of score 4–20);
- (iv) Getting along: interacting with other people (5 questions, range of score 5–25);
- (v) Life activities: domestic responsibilities, leisure, work, and school (8 questions, range of score 8–40); and
- (vi) Participation: joining in community activities, participating in society (8 questions, range of score 8–40).

For each of the questions in each domain, participants indicate their perceived level of disability using the scale of 1–5, where 1 = no limitation, 2 = mild limitation, 3 = moderate limitation, 4 = severe limitation, and 5 = extreme limitation or cannot do. The overall score for the WHODAS 2.0, when all domain scores are summated, can range from 36 to 180. The higher the score the more severe the disability in that domain and overall (Table 1).

**Table 1.** WHODAS 2.0 level of disability scores for each domain and overall.

	No disability	Mild disability	Moderate disability	Severe disability	Extreme disability
<b>Cognition:</b> understanding and communication	6	12	18	24	30
<b>Mobility:</b> moving and getting around	5	10	15	20	25
<b>Self-care:</b> attending to hygiene, dressing, eating and staying alone	4	8	12	16	20
<b>Getting along:</b> interacting with other people	5	10	15	20	25
<b>Life activities:</b> domestic responsibilities, leisure, work and school	8	16	24	32	40
<b>Social participation:</b> joining in community activities, participating in society	8	16	24	32	40
Overall score	36	72	108	144	180

WHODAS World Health Organization Disability Assessment Schedule 2.0.

**Table 2.** Demographic and clinical characteristics.

Demographic	% (n)	Demographic	%(n)	Clinical characteristics	% (n)
Age		Educational status		Cause of injury	
Median (IQR) = 28		Illiterate	17% (17)	Traumatic	97% (97)
18–30 year	55% (55)	Primary	42% (42)	Non-traumatic	3% (3)
31–50 year	36% (36)	Secondary	17% (17)	Type of Injury	
51–65 year	9% (9)	Higher Secondary	16% (16)	Paraplegic	60% (60)
Gender		Bachelor or above	8% (8)	Tetraplegic	40% (40)
Male	91% (91)	Occupation		ASIA Scale	
Female	9% (9)	Service holder	23% (23)	Complete A	74% (74)
Religion		Businessman	15% (15)	Incomplete B	16% (16)
Muslim	94% (94)	Housewife	7% (7)	Incomplete C	7% (7)
Hindu	5% (5)	Others	55% (55)	Incomplete D	3% (3)
Buddhist	1% (1)	Monthly income (BDT)			
Marital status		56% (56)			
	<10,000				
Married	57% (57)	10,001–20,000	39% (39)		
Single	43% (43)	>20,000	5% (5)		

ASIA American Spinal Injury Association, BDT Bangladeshi Taka, IQR interquartile range, n number.

Section 3: Twenty-six questions grouped into four domains of the World Health Organization Quality of Life – BREF (WHOQOL-BREF) [5] were included in the survey to provide an indication of overall QOL:

- (i) Physical health (8 questions);
- (ii) Psychological health (6 questions);
- (iii) Social health (6 questions); and
- (iv) Environmental health (8 questions).

For each question participants indicated their perceived level of satisfaction using the scale of 1–5, where 1 = very dissatisfied, 2 = dissatisfied, 3 = neither dissatisfied nor satisfied, 4 = satisfied, and 5 = very satisfied. To calculate an overall score for each domain the formula provided with the WHOQOL-BREF was used:

$$\text{Domain Score} = \left\{ \frac{(\text{Actual Raw Score} - \text{lowest possible raw score})}{\text{Possible raw score range}} \right\} \times 100$$

### Data analysis and statistical test

Data were organized and analyzed using Windows version of Statistical Package for Social Sciences (SPSS), ver. 22 software (IBM, Armonk, NY, USA) and crosschecked twice.

Descriptive analysis, using frequency and percentage, was completed for different sociodemographic factors: age, gender, education, marital status, occupation, and type of injury.

As Likert scales were used to record the responses for different items in each domain of the WHODAS 2.0 and WHOQOL-BREF these results were treated as ordinal data. Scores for each domain of the WHODAS 2.0 and WHOQOL-BREF were calculated. For the WHODAS 2.0, the higher the score in each domain and overall, the more severe the level of disability. For the WHOQOL-BREF domain scores lower than 45 indicate low QOL, from 45 to 65 indicate a normal QOL, and above 65 suggest a high QOL.

For ordinal data, mean, median and interquartile range were calculated to express the distribution of data. As the scores of each of the six domains of the WHODAS 2.0 and the four domains in the WHOQOL-BREF were calculated, the IQR were used to observe the variability for each domain. The Kolmogorov–Smirnov test was used to determine whether the distributions of the WHODAS 2.0 and the WHOQOL-BREF data approximated normal distributions. The results of this test indicated that the data for both tests were not normally distributed and hence non-parametric statistics were used for the analysis of data.

The Mann–Whitney–U test was used to test the homogeneity between two independent categories (i.e. gender and type of injury) [18] and the Kruskal–Wallis test was used to test the homogeneity between more than

two independent categories (i.e. age, education, ASIA scale, occupation and monthly income) [19].

## RESULTS

### Participant demographics

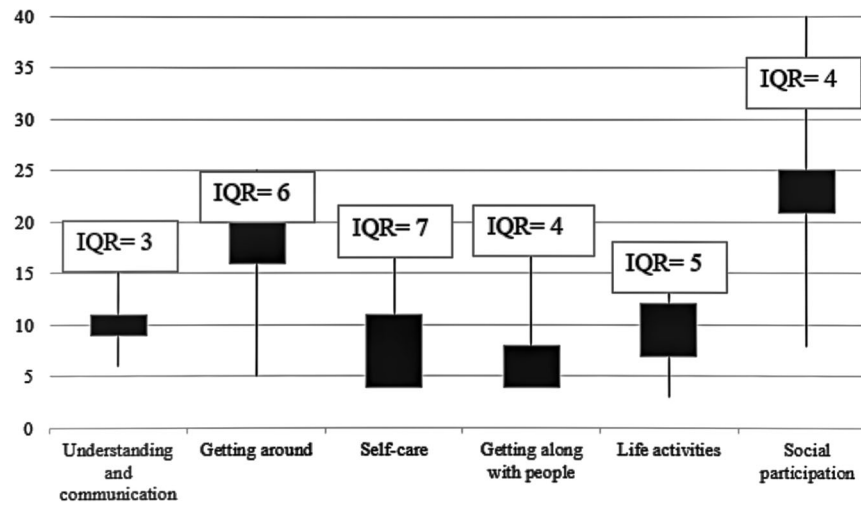
One hundred people with SCI completed the survey. The demographic information and clinical characteristics of the participants are summarized in Table 2. The age range of the participants was 18–65 years. The median age was 28 years and IQR was 19.50 (20.50–40) years. There were 91 men and 9 women respondents. Ninety-four participants identified as Muslim, five identified as Hindu, and one as Buddhist. Twenty-three participants were service holders, 15 were businessman, seven were housewives, and the remaining 55 indicated they had other employment/occupations such as student, day laborer, and rickshaw puller.

Eight participants had bachelor or higher degree, 17 completed secondary education, 16 had some level of higher secondary education, 42 only had primary education, and the remaining 17 never attended school. A little more than half the participants were married ( $n = 57$ ). There was a traumatic cause of SCI for 97, and non-traumatic for three, participants. Sixty participants had a paraplegic injury and 40 had a tetraplegic injury. According to the American Spinal Injury Association (ASIA) Impairment Scale [26], 74 participants had a Complete A SCI, 16 had an Incomplete B SCI, 7 had an Incomplete C SCI, and 3 had an Incomplete D SCI.

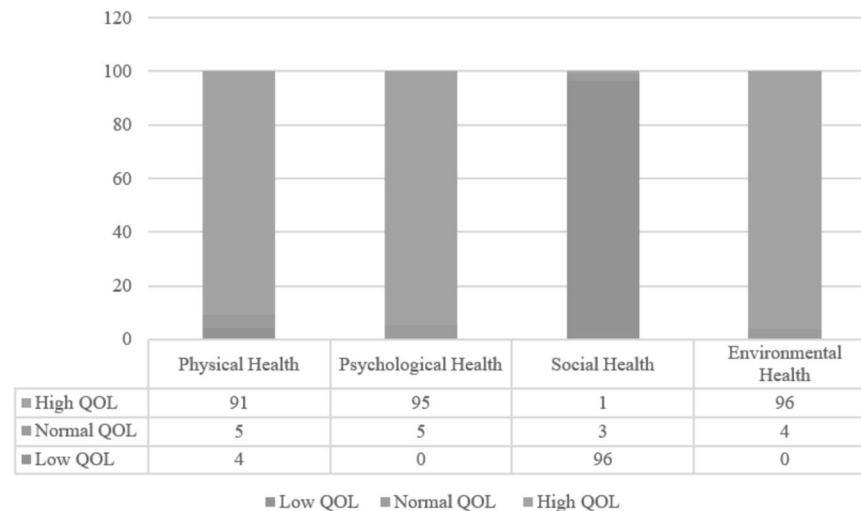
### WHODAS 2.0 results

The mean and median scores and  $p$  values for each domain of the WHODAS 2.0 associated with each socio-demographic factor are presented (see Supplementary file 1) and the full range and interquartile ranges for these scores are illustrated in Fig. 1. The overall mean and median scores for each domain suggests that participants perceived themselves to have a mild level of disability. Generally, participants indicated they had no (or very minimal) disability in the domains of understanding and communication, getting along with people, and life activities. They indicated overall they had a moderate level of disability with the social participation domain, and a severe level of disability with the getting around domain.

Although participants indicated that they had no to a minimal level of disability in the Understanding and Communication



**Fig. 1 Full range and interquartile range score of domains of WHODAS 2.0.** WHODAS World Health Organization Disability Assessment Schedule 2.0, IQR interquartile range.



**Fig. 2 The quality of life of the participants according to four domains of WHOQOL-BREF.** WHOQOL-BREF, abbreviated World Health Organization Quality of Life; QOL quality of life.

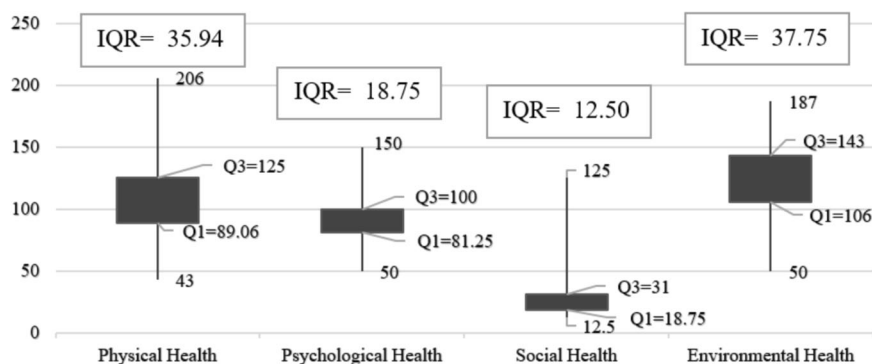
Domain, there was an indication ( $p = 0.01$ ) that the older the participant the greater the potential for disability with this domain. Female participants indicated more disability compared with male participants in the Getting Along with People ( $p = 0.01$ ) and Life Activities ( $p = 0.03$ ) Domains. Participants with tetraplegia had a higher level of disability compared to those with paraplegia ( $p < 0.05$ ) in the Self-care ( $p = 0.01$ ), Getting Along with People ( $p = 0.01$ ), and Life Activities ( $p = 0.01$ ) Domains, and the total WHODAS 2.0 score ( $p = 0.01$ ). Participants with an incomplete-C ASIA classification had a significantly higher level of disability than those with another ASIA classification in the Self-care Domain ( $p = 0.04$ ) and total WHODAS 2.0 score ( $p = 0.03$ ). Businessmen had more a higher level of disability in all, except Social Participation, Domains ( $p < 0.05$ ) compared to participants in the other employment categories. In addition, both businessmen and housewives had a significantly higher level of disability ( $p = 0.01$ ) compared to the participants in the other employment categories according to their total WHODAS 2.0 score. Participants who had a monthly income of more than 20,000 taka had a significantly higher level of disability compared to those who earned less in the domains of Understanding and Communication ( $p = 0.01$ ), Self-

care ( $p = 0.01$ ), and Participation in Society ( $p = 0.01$ ), and according to their total WHODAS 2.0 score ( $p = 0.01$ ). No other socio-demographic factors were found significantly associated with total or individual domain scores on the WHODAS 2.0.

#### WHOQOL-BREF results

The mean and median scores and  $p$  value for each domain of the WHOQOL-BREF associated with each category of the socio-demographic factors are presented (See Supplementary file 2) and the ranges and interquartile ranges for these scores are illustrated in Figs. 2 and 3. Overall, the respondents indicated a high quality of life in the physical, psychological, and environmental health domains. They indicated low quality of life in the social health domain.

Male participants had a significantly ( $p = 0.02$ ) higher quality of life than female participants in the Environmental Health Domain. Participants who had a paraplegic injury had a significantly higher quality of life compared to those with a tetraplegic injury in the Physical Health Domain ( $p = 0.04$ ). No other socio-demographic factors were significantly associated with scores on the WHOQOL-BREF domains.



**Fig. 3 Full range and interquartile range domain scores of WHOQOL-BREF.** WHOQOL-BREF, abbreviated World Health Organization Quality of Life, IQR interquartile range.

## DISCUSSION

The aim of this study was to determine the level of disability and the QOL of people with SCI on completion of their in-patient rehabilitation at the CRP as measured by WHODAS 2.0 and WHOQOL-BREF. The findings suggest that just prior to discharge from inpatient rehabilitation people with SCI perceived themselves as overall having on a mild level of disability, and a good QOL in all except the social health, domains.

The WHODAS 2.0 outcomes were different to those of Hossain et al. [7–9] who followed up people with SCI post-discharge from CRP and found that there were negative changes in their level of disability. Hossain et al. [16] found that 6 years' post discharge many people with SCI were house-bound, unemployed, lived in poverty, and had pressure ulcers. Many of these people reported experiencing moderate rates of depression and poor QOL. The authors indicated that these factors had a significant impact on people with a SCI, and their families, as most people who had a SCI were young married men who were the main income source for the family prior to injury.

Barker et al. [11] suggest that QOL was influenced by the presence of secondary complications, and degree of participation. When participants were discharged from the protective, enabling environment of CRP where their medical and rehabilitation needs were catered for, they had to learn to live with SCI in their community. This may lead to a decrease in functional abilities and their QOL [12]. Gupta et al. [9] found that at post-discharge the QOL of people with SCI was compromised in all domains. This finding was supported by Kadar et al. [4] who found that people with tetraplegia, who had a complete injury, and who lived rurally experienced greater levels of disability and poorer QOL. The proposed reason for this was that people with tetraplegia experienced greater physical challenges compared with those with paraplegia. In addition, those with a complete injury were more impacted by secondary complications and health issues, and those living more rurally were impacted by limited availability of, and access to, health care and rehabilitation services.

The findings from the current study provide an indication that at the point of discharge from inpatient rehabilitation there are early signs of differences in the perceived level of disability and QOL depending on a person's age, gender, type of injury, education level and occupation. The higher level of perceived disability among businessmen and those with a higher income was an unexpected finding. The reason for this is unclear and requires further investigation. It may relate to these people having a more sedentary lifestyle and a perception of their disability impacting their standing. The impact of these sociodemographic factors on people may increase as people with SCI return to live in their community, as suggested by the research findings of Kadar et al. [4] and Hossain et al. [7, 8, 16].

In the current study participants indicated they only had low QOL in the domain of social health. This may reflect the disconnection participants experienced from their family and

friends while in inpatient rehabilitation. Although family members and friends could visit, the distance between CRP and many communities can make this difficult, and hence impact the social health QOL of people with SCI. In addition, at the time of completing the survey, all participants were in the integration phase of their rehabilitation preparing to return to their communities. It is possible that as they near the end of their inpatient rehabilitation they become more aware of the impact having SCI may have when they return to their community, and this may negatively affect their social health QOL.

The difference between the current study and the findings from studies focusing on people with SCI who lived in the community in Bangladesh [4, 16] may be explained by participants in the current study being inpatients, with no or very limited experience of learning to live with SCI within their communities. The supportive nature of the rehabilitation setting and the availability of medical, nursing, and allied health staff, along with the accessible environment, may have contributed to participants' experiencing little disability in the domains overall. It may also be the case that as Vural et al. [13] found secondary complications from SCI, such as spasticity and pressure ulcers, have a greater negative impact on the level of disability and quality of life following discharge. This is likely to be due to the decreased medical interventions available when people with a SCI return to live in their communities compared with the in-patient rehabilitation at CRP.

Kumar et al. [20] found that a supportive and accessible environment had a positive impact on people with SCI. These researchers proposed that this was because the participants residing in rehabilitation facilities were encouraged to perform various activities that support their well-being and were able to move about easily. When participants were discharged from the protective, enabling environment of CRP, where their medical and rehabilitation needs were catered for, they had to learn to live with a SCI in their community. This may lead to an increase in their level of disability and QOL [12]. Tzanos et al. [21] found that easy and well-organized access to health services and follow-up post-discharge were key to ensuring the level of disability remained low and perception of QOL high.

A strength of this study was that the 100 participants were representative of the people with SCI admitted to CRP. Hence, the findings provide a snapshot of level of function and QOL of participants at the end of their inpatient rehabilitation at CRP that may be indicative of other people with a SCI at CRP. One main limitation of the study was that it only investigated functional limitation and QOL at the point of discharge from rehabilitation. Although this provides a baseline for these outcome measures, it would be important to follow up this cohort of participants at regular intervals post-discharged. This would allow the monitoring, and an understanding, of the factors that impact on level of disability and QOL to inform community-based rehabilitation strategies and procedures.

## CONCLUSION

The 100 participants included in this study appear to be relatively representative of the people with SCI admitted to CRP. Hence, the findings provide a snapshot of level of disability and QOL of participants at the end of their inpatient rehabilitation at CRP. As the overall findings indicate that at the point of discharge the participants perceived that they had a mild level of disability and good QOL in all domains apart from social health, it could be stated that the inpatient rehabilitation offered at CRP led to successful outcomes. This is most likely because of the positive impact a supportive rehabilitation setting and the availability of medical, nursing, and allied health staff, along with the accessible environment, had on participants. There were some specific differences in various WHODAS 2.0 Domains and overall scores when comparing age, gender, type and level of injury, occupation, and income. Between group comparisons indicated that male participants, compared with female participants, had a significantly higher quality of life in the Environmental Health Domain and those with a paraplegic injury, compared with those with a tetraplegic injury, had a significantly higher quality of life in the Physical Health Domain. It is possible that these between group differences may become more significant, as other research indicates that both level of disability and QOL can be negatively impacted by several demographic attributes, primary and secondary complications, and geographic factors post-discharge. Hence, there may need to be greater focus on community-based rehabilitation strategies and procedures to contribute to long-term reduced levels of disability and improved QOL. The outcomes of this study may be used to identify areas of inpatient rehabilitation that need to be improved, but perhaps more importantly, provide a baseline for comparing and monitoring the level of disability and QOL for people with SCI once they returned to their communities.

## DATA AVAILABILITY

Any reasonable request for individual participant data will be considered by the authors.

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## AUTHOR CONTRIBUTIONS

ER and NB designed the study. ER, MC, MSI, and MFKP conducted the statistical analysis and interpreted the results. ER, NB, MC, MSI, MFKP, and SKD wrote and reviewed the paper.

## FUNDING

The study is solely a self-funded and academic work.

## COMPETING INTERESTS

The authors declare no competing interests.

## ETHICAL APPROVAL

This study conducted with the ethical clearance of the Institutional Review Board (IRB) of Bangladesh Health Professions Institute (CRP/BHPI/IRB/11/2021/537). Also written consent was taken from all the participants.

## ADDITIONAL INFORMATION

**Supplementary information** The online version contains supplementary material available at <https://doi.org/10.1038/s41393-022-00852-4>.

**Correspondence** and requests for materials should be addressed to Ehsanur Rahman.

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