Quality of Life among Persons with Paraplegic Spinal Cord Injury

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ABSTRACT

Purpose: *This study aimed to examine quality of life (QoL) among persons with paraplegic spinal cord injury (SCI), to determine their socio-demographic details, and to measure the different levels of performance in correlation with the International Classification of Functioning, Disability and Health (ICF).*

Method: *A descriptive cross–sectional study was conducted with a structured questionnaire to collect information from 45 persons with paraplegic SCI. Data was collected by purposive sampling technique and face-to-face interviews.*

Results: *Most of the participants (47%, n=21) were in the age group of 20-30 years, with a mean age of 33.53 (± 11.14) years. There were more men (89%, n=40) than women (11%, n=5) and the ratio was 8:1. The most common occupation was farming (27%, n=12), followed by daily labour (22%, n=10). Fall from a height (58%, n=26) was the most common cause of injury. A high percentage of participants (36%, n=16) rated their quality of life as poor. Depression was felt very often (44%, n=20), whereas happiness lasted for only a little while (38%, n=17). Older participants faced problems at work more often than younger persons. Males and those who worked in public places faced problems in dressing or bathing independently. Married participants were more dissatisfied regarding income and the amount of work they were able to do. Those who had met with road accidents had more emotional problems than others. Association analysis showed that by increasing happiness and decreasing depression participants' quality of life could improve.*

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Conclusion: *The study demonstrated that spinal cord injury greatly affects quality of life and gives rise to more problems, especially in the areas of physical and mental health. It is necessary to take steps to improve the physical and emotional status of persons with paraplegic spinal cord injury, as this will eventually lead to improvement in their quality of life.*

Key words: *Quality of life, spinal cord injury, paraplegic.*

INTRODUCTION

Spinal cord injury (SCI) is a devastating disorder that can cause impairment in physical, psychological, and social functioning (Gurcay et al, 2010; New et al, 2013; Smith et al, 2013). It is a frequent cause of mortality, and is reflected in radical changes in lifestyle and quality of life (QoL) for both the persons with SCI and their family members (Oyinbo, 2011; Ali and Tawfiq, 2013; Kawanishi and Greguol, 2013). In a developing country like Bangladesh, life expectancy of spinal cord injured persons is much lower than in a developed country (Razzak et al, 2011). Deficits in motor control function that occurs after SCI causes disturbances in daily activities (Rahman et al, 2012). In Asia, the incidence rates of SCI range from 12.06 - 61.6 per million, while the average age range of affected persons is 26.8 - 56.6 years (Ning et al, 2012). In the United States, the annual incidence of traumatic SCI is 40 cases per million or 12000 new cases each year (Rabadi et al, 2013). The worldwide incidence of SCI is 10.4 and 83 per million per year and the mean age is 33 years (Wyndaele and Wyndaele, 2006). The causes of SCI may differ from person to person due to different age, sex, race and socio-cultural activities (Hoque et al, 2012). The most frequent cause of traumatic spinal cord injury is motor vehicle accidents, followed by falls in America and Nigeria (Chen et al, 2013; Mothe & Tator, 2013; Nwankwo & Uche, 2013). The third most common cause of SCI in America is violence (Putzke et al, 2001).

'Quality of life' refers to an individual's satisfaction with health, relationships, emotional, social, and physical function, and also happiness and satisfaction with living situation and finances (Manns and Chad, 1999). According to the World Health Organisation (WHO), quality of life can be defined as "individuals' 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" (Kawanishi and Greguol, 2013). Specific health status and health related quality of life (HRQoL) are both important because they can vary from person to person due to different disease conditions (Andresen et al, 1999). Quality of

life (QoL) measurement can give information about the health status beyond diagnosis, impact of the disease and its management on different domains of life (Geyh et al, 2010). Spinal cord injured (SCI) persons experience poor and lower health-related quality of life (HRQoL) than the general population (Gurcay et al, 2010; Saadat et al, 2010). In Canada, QoL is significantly decreased in persons with SCI as compared to other people, and it was found that younger age, employment and lack of hospitalisation played an important role for a better quality of life (Leduc and Lepage, 2002). Chronic illnesses such as diabetes, renal disease, chronic pulmonary diseases and pressure ulcers have an effect on quality of life of persons with SCI (Saadat et al, 2010). Since long-term rehabilitation programmes can improve quality of life, the aim of this study was to determine the level of quality of life of persons with SCI, and make recommendations so that treatment can be tailored to their needs.

METHOD

Study Design: A descriptive cross-sectional study design was chosen to fulfil the study objectives.

Study Area: This study was conducted at the Spinal Cord Injury Unit of the Centre for the Rehabilitation of the Paralysed (CRP), Savar, in Dhaka, Bangladesh.

Sampling Technique: Purposive sampling technique was employed. This involves sample collection based on predefined criteria pertaining to the purpose of the study.

Inclusion criteria: Paraplegic SCI clients at the rehabilitation stage in CRP.

Exclusion criteria: Those who were tetraplegic and below 18 years of age.

Data Collection Method and Tools: A questionnaire was designed with the information from SF-36 and WHOQOL - BREF scale. Data was collected during face-to-face interviews.

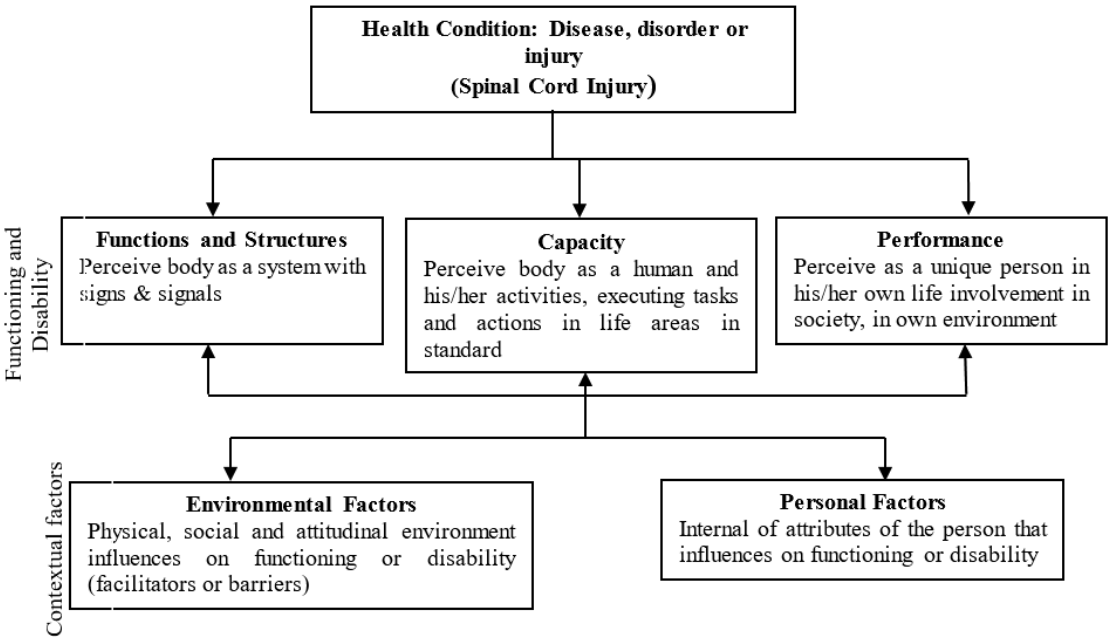
Ethical Consideration: The study was permitted by the dissertation committee of Bangladesh Health Professions Institute (BHPI). Permission for data collection was also taken from the SCI unit of CRP.

Informed Consent: Participants were informed verbally about the aim and objectives of the study. They were also told that they could refuse to answer any question during the interview. A written consent form was given to help them understand, and their signatures were obtained. They were informed about the

interview timing and assured that their information would be kept confidential. It was also explained that they had the right to withdraw consent at any time during the interview.

Conceptual Framework of ICF: The International Classification of Functioning, Disability and Health (ICF) is organised into components of body structure, body functions, activity and participation, personal and environmental contextual factors that are described in Figure 1(WHO, 2001;Tucker et al, 2014). All questions were grouped according to the ICF and statistical analysis was done according to these groups.

Figure1: Conceptual Framework of International Classification of Functioning, Disability and Health (ICF)



Data analysis

Information was analysed by SPSS v.16 software. Several variables were included such as socio-demographic, injury-related variables and quality of life related variables. For every quality of life variable, there is a possibility of association with each demographic variable. Chi–square test was performed to determine whether there is association between a demographic variable and a quality of

life variable. The null hypothesis was that either there are no associations or they are independent, against the alternative that there are some sorts of associations or they are not independent. Quality of life variables that are associated with demographic variables are reported here with p-values. P-values less than or equal to 0.05 are reported and considered as the pair have significant association. The higher the p-values, the less was the association.

RESULTS

Demographic Characteristics

Majority of the participants (76%, n=34) were below 40 years of age. More men were affected (approximately 89%, n=40) than women (about 11%, n=5). Most of the participants were married (around 73%, n=33). Most of them (80%, n=36) were from the rural area and the most common occupation was farming (27%, n=12). 31% (n=14) of the participants were illiterate.

Clinical Characteristics

Fall from a height was the most common cause of SCI for approximately 58% (n=26) of the participants, while the second most common cause was road traffic accident for about 29% (n=13). According to ASIA Impairment Scale (AIS), 80% (n=36) of the respondents were Complete – A, while the rest or about 20% (n=9) were Incomplete (Table 1).

Table1: Demographic and Clinical Characteristics

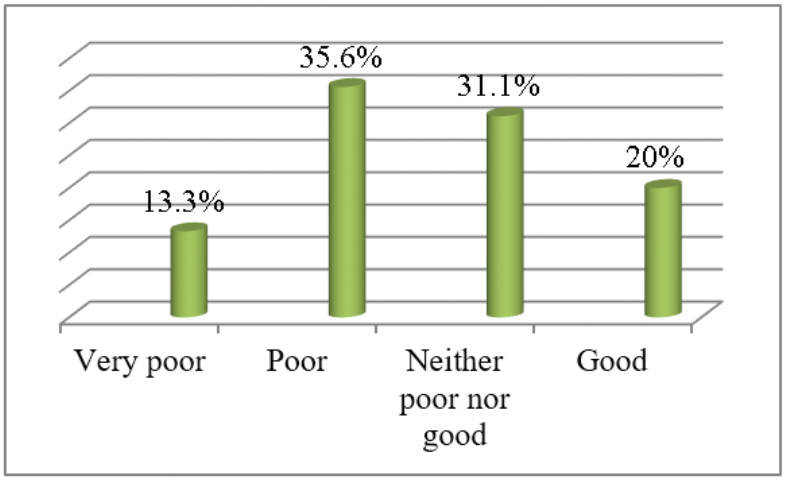
Demographic	% (n)	Demographic	% (n)	Clinical	% (n)
Age		**Educational Status**		**Cause of injury**	
<40 years	75.6% (34)	Illiterate	31.1% (14)	Road traffic accident	28.9% (13)
≥40 years	24.4% (11)	Primary	17.8% (8)	Fall from height	57.8% (26)
Sex		Secondary	46.7% (21)	Fall with heavy object on back	8.9% (4)
Male	88.9% (40)			Transverse Myelitis	4.4% (2)
Female	11.1% (5)	**Occupation**		**Type of injury**	
Marital status		Business	11.1% (5)	Complete -A	80% (36)
Married	73.3% (33)	Daily Labourers	22.2% (10)	Incomplete	20% (9)
Unmarried	24.4% (11)	Farmers	26.7% (12)		

Divorced	2.2% (1)	Service Holders	17.8% (8)		
Bachelor	4.4% (2)	Garment Workers	4.4% (2)		
Residential Area					
Rural	80% (36)	Housewives	8.9% (4)		
Urban	20% (9)	Rickshaw Pullers	4.4% (2)		
		Students	4.4% (2)		

Quality of Life

Of the 45 participants, about 13% (n=6) reported that they had very poor QoL, 36% (n=16) had poor QoL, 31% (n=14) had neither poor nor good QoL, and around 20% (n=9) had good QoL (Figure 2).

Figure 2: Client rating of their Quality of Life



Functions, Capacity and Performance

About 47% (n=21) of the participants said that they suffered slightly or did not suffer from pain. More than half of them (55.6%, n=25) reported that pain did not interfere in their work. However, 71% (n=32) felt that physical health interfered in normal work, either greatly or moderately. 42% (n=19) said that they experienced much limitation in bathing or dressing independently. About 69% (n=31) expressed dissatisfaction that all the time or most of the time they were able to accomplish less work than they wanted. The majority of the participants, about 89% (n=40), had little or moderate amounts of energy, while only 11% (n=5)

had sufficient energy. On the whole, 53% (n=24) of the respondents mentioned that they felt tired (Table 2).

Table 2: Function, Capacity and Performance of the Participants

Function, Capacity and Performance			
% (n)		**% (n)**	
Severity of pain		**Limitation in bathing or dressing independently**	
Extremely	17.8% (8)	Very much	42.2% (19)
Quite a bit	20% (9)	A moderate amount	20 (9)
Moderately	15.6% (7)	A little	20 (9)
Slightly	20% (9)	Not at all	17.8 (8)
Not at all	26.7% (12)	**Accomplish less work than the participants want**	
Pain interferes in the work		All of the time	28.9% (13)
Extremely	2.2% (1)	Most of the time	40% (18)
Quite a bit	26.7% (12)	Some of the time	26.7% (12)
Moderately	15.6% (7)	A little of the time	4.4% (2)
Slightly	8.9% (4)	**Energy for doing work**	
Not at all	46.7% (21)	A little	44.4% (20)
Physical health interferes in normal work		Moderately	44.4% (20)
Extremely	8.9% (4)	Mostly	11.1% (5)
Mostly	33.3% (15)	Feel tired	
Moderately	37.8% (17)	Mostly	20% (9)
Slightly	13.3% (6)	Moderately	33.3% (15)
Not at all	6.7% (3)	A little	37.8% (17)
		Not at all	8.9% (4)

Chi–square test on physical status with demographic and clinical characteristics showed significant associations with:

'Physical health interferes in work' and age;

'Limitation in bathing or dressing independently' and gender, marital status, occupation;

'Accomplish less work than the participants want' and marital status, education; and,

'Energy for doing work' and marital status ($p<0.05$).

Considering p-value, insignificant association was found with:

'Physical health interferes in work' and quality of life;

'Limitation in bathing or dressing independently' and quality of life;

'Accomplish less work than the participants want' and quality of life (p>0.05) (Table 3).

Table3: P-values of Chi–square test

Function, Capacity and Performance	Age	Sex	Marital Status	Education	Occupation	QoL
Physical health interferes in work	0.01	-	-	-	-	0.09
Limitation in bathing or dressing independently	-	0.03	0.02	-	0.01	0.10
Accomplish less work than the participants want	-	-	0.02	0.04	-	0.06
Energy for doing work	-	-	0.01	-	-	-

Environmental Factors

Of the 45 participants, about 58% (n=26) felt moderately safe in their daily life. Around 56% (n=25) said that the surrounding environment was moderately clean. About 58% (n=26) said that they were satisfied or very satisfied with their treatment facilities. Approximately 38% (n=17) reported that they had received most or complete support from the staff, while 47% (n=21) stated they had received moderate support. Almost 98% (n=44) of the participants said that they have had opportunity for recreational activities. However, most of the participants (84%, n=38) mentioned that they did not have enough money to meet their needs (Table 4).

Table 4: Environmental Factors of the Participants

Environmental Factors			
	% (n)		**% (n)**
Feel safe		**Support from the staff**	
A little	20% (9)	A little	15.6% (7)
A moderate amount	57.8% (26)	Moderate	46.7% (21)
Very much	22.2% (10)	Mostly	33.3% (15)
Level of clean environment		Completely	4.4% (2)

Not at all	4.4% (2)	**Opportunity for recreational activities**	
A little	6.7% (3)	A little	2.2% (1)
A moderate amount	55.6% (25)	Moderate	64.4% (29)
Very much	33.3% (15)	Mostly	33.3% (15)
Satisfied with treatment		**At present enough money to meet participant's needs**	
Very dissatisfied	2.2% (1)	Not at all	40% (18)
Dissatisfied	6.7% (3)	A little	44.4% (20)
Neither satisfied nor dissatisfied	33.3% (15)	Moderately	13.3% (6)
Satisfied	53.3% (24)	Mostly	2.2% (1)
Very satisfied	4.4% (2)		

Chi–square test on environmental status with demographic and clinical characteristics found significant associations with:

'Level of clean environment' and age and marital status;

'Satisfied with treatment' and marital status; and,

'At present enough money to meet participant's needs' and marital status and education ($p<0.05$).

Considering p-value, insignificant association was found between 'Support from the staff' and marital status and residential area (Table 5).

Table 5: P-values of Chi–square test

Environmental Factors	Age	Marital Status	Residential Area	Education
Level of clean environment	0.03	0.01	-	-
Satisfied with treatment	-	0.01	-	-
Support from the staff	-	0.09	0. 06	-
At present enough money to meet participant's needs	-	0.03	-	0.05

Personal Factors

56% (n=25) of the participants claimed that emotional problems interfered in activities of daily living (ADL), either very much or moderately. Most of them (60%, n=27) felt very sad. 60% (n=27) reported that they felt extremely or very

depressed. About 82% (n=37) of the participants thought that they had a little or a moderate ability to concentrate on work. Around 78% (n=35) mentioned that they felt happy for a little while or for some of the time. However, 62% (n=28) reported that their personal relationships were satisfactory or very satisfactory (Table 6).

Table 6: Personal Factors of the Participants

Personal Factors			
	% (n)		**% (n)**
Emotional problems interfere in ADL		**Ability to concentrate on work**	
Very much	22.2% (10)	A little	40% (18)
Moderately	33.3% (15)	A moderate amount	42.2% (19)
A little	17.8% (8)	Very much	17.8% (8)
Not at all	26.7% (12)	**Happiness**	
Sadness		None of the time	11.1% (5)
An extreme amount	2.2% (1)	A little of the time	37.8% (17)
Very much	60% (27)	Some of the time	40% (18)
A moderate amount	20% (9)	Most of the time	4.4% (2)
A little	17.8% (8)	All of the time	6.7% (3)
Depression		**Personal relationships**	
Extremely	15.6% (7)	Very dissatisfied	4.4% (2)
Very much	44.4% (20)	Dissatisfied	8.9% (4)
Moderately	22.2% (10)	Neither satisfied nor dissatisfied	24.4% (11)
A little	13.3% (6)	Satisfied	51.1% (23)
Not at all	4.4% (2)	Very satisfied	11.1% (5)

Chi–square test on emotional status with demographic and clinical characteristics found significant associations with:

'Emotional problems interfere in activities of daily living (ADL)'and causes of injury.

'Depression' and quality of life;

'Happiness' and quality of life ($p<0.05$).

Considering p-value, insignificant association was found with:

'Ability to concentrate on work' and age and occupation;

'Blue or sadness' and type of injury;

'Depression' and age ($p>0.05$) (Table 7).

Table 7: P-values of Chi–square test

Personal Factors	Age	Occupation	Cause of injury	Type of injury	QoL
Ability to concentrate on work	0.07	0.08	-	-	-
Emotional problems interfere in ADL	-	-	0.05	-	-
Blue or sadness	-	-	-	0.09	-
Depression	0.08	-	-	-	0.05
Happiness	-	-	-	-	0.00

DISCUSSION

About 75% of the participants were below 40 years of age, and nearly half of them were in the age group of 20–30 years. This indicates that spinal cord injury generally affects people during their earning life. There were more men than women, with a ratio of 8:1. An epidemiological in Southeast Nigeria found that the male and female ratio was 4.3:1 and the 31-45 year age group was more frequently affected (Nwankwo and Uche, 2013). In North America the main cause of traumatic spinal cord injury (TSCI) was motor vehicles accident rather than fall from height (Mothe and Tator, 2013). But in the current study, the most common cause of injury was fall from height followed by road traffic accidents. This could be due to the fact that a greater percentage of people live in the villages in Bangladesh, similar to neighbouring countries like India (Singh et al, 2003).

Around 27% of the participants were farmers, while daily labourers, service holders, business, garment workers, housewives, rickshaw pullers and students were 22%, 18%, 11%, 4%, 9%, 4%, and 4% respectively. This differs from the Nigerian study, where it was found that farmers were the fifth most common occupation group who suffered from SCI (Nwankwo and Uche, 2013).

The current study found that about 73% of the participants were married, about 24% were unmarried, and about 2% were divorced. This pattern of distribution is similar with the study conducted by Tasiemski et al (2013).

Most of the participants in the current study mentioned that, in general, their quality of life was poor. About half of them felt their quality of life was below the standard of poor. Only 20% of the participants said that in general their quality of life was good.

Function, Capacity and Performance

This study showed that the 'severity of pain' and 'pain interferes in the work' did not hamper physical status. However the maximum number of participants felt 'physical health interferes in the normal work', 'limitations in bathing or dressing independently', 'accomplish less work than the participants want', as well as decline in energy and feeling tired most of the time. Hence, it was found that there was a reduced level of physical functioning in paraplegic SCI clients. The same results were noted in a study in Australia which reported that the limitation was more in physical functioning (Kreuter et al, 2005).

Physical health interference and age were found to be are strongly associated ($p=0.01$). Older participants experienced more interference in work due to physical health. A significant association between 'limitation in bathing or dressing independently' and demographic variables of gender, marital status and occupation were found with $p<0.03$. Men faced severe limitations in bathing or dressing independently, and so did most of the married participants. Participants who worked in public places also faced the same problem. This is not significantly associated with quality of life ($p=0.1$). Married participants were dissatisfied with the amount of work they could accomplish. Education was also found to have a strong association with 'accomplish less work than the participants want'. This is strongly not associated with quality of life ($p=0.06$). Besides, a strong and significant association between 'energy for doing work' and marital status was observed.

Environmental Factors

Most of the study respondents felt that the environment was moderately clean, and most of them felt moderately safe. The maximum number was satisfied with treatment facilities, getting support from the staff, and opportunities for recreational activities. However most of the participants did not have enough money to meet their needs.

Age and marital status have significant association with level of 'clean environment' ($p<0.05$). There is also strong association between marital status

and satisfaction of participants with treatment facilities (p=0.01). 'Support from staff' showed insignificant association with marital status and residential area, with p-value >0.05. There was significant association between 'at present enough money to meet participant's needs' and marital status and education. The data revealed that most of the married participants did not have sufficient money to meet their needs.

Personal Factors

The study showed that emotional problems interfered in the activities of daily living (ADL). In most of the cases, the participants were sad and depressed, which interfered in their ability to concentrate on work. They mentioned that they were happy for a little while and for some of the time; most of the participants said that they were satisfied with their personal relationships. Overall it was found that the emotional status level was poor among the participants, which affects quality of life greatly. This supports the finding of Munce et al (2013) and Kreuter et al (2005), that for SCI clients' health status, physical and psychological factors have great impact on quality of life.

With a 5% level of significance, there were no associations between 'ability to concentrate on work' and age and occupation. Participants who had met with road traffic accidents were suffering from more emotional problems than those with other causes of injury (p=0.05). Also, there was insignificant association (p>0.05) between 'blue or sadness' and type of injury and 'depression' with age. Depression and happiness have strong associations with quality of life ($p \leq 0.05$). By examining cross-frequencies, it was found that most of the extremely depressed participants mentioned their very poor quality of life and vice-versa. Findings were similar for feelings of happiness.

CONCLUSION

There are many events that affect a person's lifestyle and quality of life; spinal cord injury is one of these. The study revealed that men were more vulnerable than women, and, in general, people in the younger age group were affected during their earning life. It could be concluded that SCI results in many physical and mental problems, such as limitations in doing work, problems in bathing or dressing, more anxiety or depression, and varying perceptions of happiness. Though most of the participants were satisfied with treatment and environment, their physical and mental health status hampered their quality of life. Along with

greater awareness and proper counselling, necessary steps should be taken to improve the physical and mental health of persons with paraplegic spinal cord injury, in order to improve their quality of life.

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