

Level of mental burden among caregivers of spinal cord injured patients

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ABSTRACT

Objectives. Spinal cord injury (SCI) is defined as damage to spinal cord that result in loss of sensory, motor and autonomic function. With advancement in medical profession, it is reported that the death rate of SCI patients decreases, and patients survive after initial injury therefore, problem extends beyond patients to their family members. Caregiver is responsible to provide emotional, physical and functional support. As a result, burden on caregivers increases, which not only affected them physically but mentally as well. In this study we aimed to find out the mental burden among caregivers of spinal cord injured patients.

Methods. Census was conducted among caregivers of SCI patients in paraplegic centre, Peshawar. Data was collected from 80 participants/caregivers, included both male and female. Zarit burden interview scale was used to gather data regarding mental burden from caregivers of SCI patients. SPSS version 25 was used for data analysis.

Outcomes. In this study the number of participants who responded to this survey was 80 out of 86 participants. Among these 80 participants, 59 (73.75%) were male while 21 (26.25%) were female with mean age of 31.83 ± 12.050 . Participants experienced different intensities of mental burden (11.3% no or little burden, 31.3% mild to moderate, 45% moderate to severe and 12.5% had severe burden. Response to question 3, 4, 20 and 21 was quite different from other questions in questionnaire. Significant difference between means of male and female caregivers regarding mental burden was calculated ($p = 0.030$). No significant difference between age and total score obtained was found ($p = 0.116$).

Conclusions. Caregivers of SCI patients had moderate to severe level of burden. Response to certain questions in questionnaire was quite different from others. There was significant difference between means of male and female caregivers regarding mental burden and no significant difference between age and total score obtained was found in caregivers of SCI patients.

Keywords: caregivers, caregiver burden, level of mental burden, spinal cord injury, Zarit burden interview scale

INTRODUCTION

Spinal cord injury (SCI) is a life changing condition that significantly affects the person affected and it suddenly changes their daily life and role within their family and in society(1). The spinal cord injured (SCI) patients approximately worldwide are more than three million (2) and the incidence is 29.5 per million (3). With the advancement

in the medical profession, it is reported that the death rate of SCI patients decrease and 65% patients survive after initial injury (4) and therefore, problem extends beyond patients to their family members (5-7). SCI is defined as an injury to the spinal cord which results in loss of body movements and feeling (7) or SCI is a serious disabling condition which causes disability and as a result patient una-

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ble to take care of his/herself (2). Most cases of SCI is traumatic ones which can be due to a road traffic accident, fall and lack of safety programs in working areas (8).

SCI patients require support as twice as aged persons in the general population and require support in personal assistance 7 times more (9). Numerous patients having SCI face challenges in their psychological, physical and social functioning and SCI patients require support in these regions for the rest of their lives (10). SCI not only affect patients but also people who deliver care to them (caregivers) (11). However, being a caregiver of someone with SCI is not unproblematic (10). Caregivers are people who take care of deceased individuals (SCI patients) (12). There are three categories of caregivers, one is “Formal caregivers” who are employs of the health care system and who need to be paid. The second category we have is “Informal caregivers” they are the people who live in a community with patients, and they usually are friends and relative. The third one is “Family caregivers”, we can also call them “primary caregivers” (13). A primary caregiver is a family member who is responsible for providing care to the patients and usually lives with them (7,13). The primary caregivers become the primary source to provide support in daily life activities (13) like in dressing, feeding and in bowel and bladder care (3). Moreover, caregivers also have to deal with possible negative psychological after comes of SCI like depression and aggressive behavior of SCI patients (10). Most of time family caregivers are unready and not mentally set to cope with this complex caregiving activities due to lack of skills and proper training and as a result caregivers face heavy burden (14). The behavior of patients is one of the factors which increase stress or burden on caregivers (11). Caregiver burden (CB) is a term which describe the weight or load carried by caregivers because of caregiver role (8,15). Or When caregivers recognize that caregiving has hurt their mental health, physical health, social life, and financial status then we called it caregiver burden. As a consequence of increasing burden on caregivers the quality of life (QOL) of caregivers and care of patients affected (16) therefore, care of patients and QOL of caregivers, these are interrelated thing (17), one can alter other like feedback mechanism (18). One of study showed that increased level of emotional and physical strain, anger, depression, and resentment in caregivers can effect QOL of caregivers (7,19). Even one study revealed that caregivers have lower QOL score compared to injured patient (20). Quality of life (QOL) is defined as change in individual physical, emotional, financial, and social well-being (21).

Furthermore, caregivers could undergo financial deprivation due to cost of illness and decreas-

ing hours of work to take care of their loved one (8). Caregivers devote a mean of 11.3 hours per day for caring (14). There is a strong relation between the amount of stress or burden experienced by caregivers and hours of day devoted for caring (22). As we know that, care providing to SCI patients is a difficult job and especially for those who don't have the skill and not trained (primary caregivers). Caregiving not only affects the life of caregivers but also of patients because caregivers won't be able to provide support and care as needed. Furthermore, caregiving for a long period can affect the financial status of the family by reducing hours of work. As we studied in different articles from different countries the level of mental burden among caregivers of SCI patients were high and none of them had little burden. So, it's necessary to work on this topic further in order to find ways to reduce mental burden among them, which won't only improve the QOL of caregivers but of patients too. Despite the fact that mental burden among caregivers of SCI patients is one of most common problem but according to investigator no such study has been conducted so far in Peshawar, Pakistan. The finding of our study will report the level of mental burden among caregivers of SCI patients in the paraplegic centre, Peshawar, Pakistan, which in turn will increase awareness in society and in health care professional and ultimately will promote health of SCI patients and their caregivers.

MATERIAL AND METHODS

After our research proposal was approved by the Graduate Committee of Institute of Physical Medicine and Rehabilitation (Khyber Medical University) and Paraplegic Centre Peshawar, Pakistan and all participants agreed to participate in the study and signed the approved consent form, we have started to collect data. We collected data from the caregivers of SCI at Paraplegic Centre Peshawar between March and May 2019. As we were conducting census therefore, we recruited all caregivers of SCI patients (n = 80).

At paraplegic center, census was conducted, out of 88 participants, 82 were screened on the basis of inclusion and exclusion criteria. Three of them which were rejected were not fulfilling the age criteria while the remaining 3 were not willing to give consent. Participants were selected according to inclusion criteria i.e. age must be between 18 to 60 years, both male and female caregivers, at least one month spent with SCI patients and the most important is he/she is willing to participate. Participants (caregivers) who had systematic diseases, trauma, psychological disease and those who didn't fit into our inclusion criteria were rejected.

Demographic data, including age, gender was recorded. Zarit burden interview scale was used to assess level of mental burden among caregivers of SCI patients (reliability, $r = 0.81$ and validity, $r = 0.91$).

SPSS version 25 was used in analysis of data. Means, standard deviation, minimum and maximum range of age and total score obtained was found via descriptive statistics. Furthermore, frequency and percentage of male and female population was obtained by frequency table. Similarly, categories of mental burden were also measured by frequency table. For association between means of male and female caregivers with total score obtained we have used independent t test while for correlation of age and total score obtained, we used Pearson correlation. We expressed data as mean \pm standard deviation with p value of 0.05 considered statistically significant.

RESULTS

The number of beds for SCI patients were round about eighty and according to their administration each patient had one caregiver but some of them

TABLE 1. Frequency and percentage of male and female participants

	Frequency	Percentage
Male	59	73.8
Female	21	26.3
Total	80	100.0

TABLE 2. Descriptive statistic

	N	Minimum	Maximum	Mean	Std. deviation
Age	80	18	59	31.83	12.050
Total	80	9	73	41.52	14.760

TABLE 3. Categories of mental burden

	Frequency	Percentage
Little or no burden	9	11.3
Mild to moderate burden	25	31.3
Moderate to severe burden	36	45.0
Severe burden	10	12.5
Total	80	100.0

TABLE 4. Response of some questions in questionnaire

Questions:	Never	Rarely	Sometimes	quite frequently	nearly always
Q3. Do you feel embarrassed about your relative's behaviour?	70.0%	11.3%	8.8%	7.5%	2.5%
Q4. Do you feel angry when you are around your relative?	62.5%	12.5%	18.8%	3.8%	2.5%
Q20. Do you feel you should be doing more for your relative?	10.0%	3.8%	5.0%	33.8%	47.5%
Q21. Do you feel you could do a better job in caring for your relative?	13.8%	2.5%	1.3%	30.0%	52.5%

had two, depend on dependency level of the patient. Data collected from eighty (80) caregivers of SCI patients. Among these eighty caregivers, 59 (73.75%) were male while 21 (26.25%) were female (Table 1). The mean age of these eighty participants was (31.83 ± 12.050) . They ranged from minimum of 18-year-old and maximum of 59-year-old (Table 2). Data collected from eighty participants and each participant gets total marks on the questionnaire. Zarit burden interview scale was used. In this scale, we have total of 22 questions and each question has marks from 0 up to 4. Scoring key of this questionnaire is available and has total marks range from 0 up to 88. This range has already been distributed into categories or level according to its scoring key, like 0 to 20 = no or little burden, 21 to 40 = mild to moderate burden, 41 to 60 = moderate to severe burden, 61 to 88 = severe burden. The mean of total marks was (41.52 ± 14.560) . They ranged from minimum of 9 total marks to maximum of 73 total marks (Table 2). When data was analysed, 9 (11.3%) of 80 patients had no or little burden, 25 (31.3%) had mild to moderate level of burden, 36 (45%) caregivers had moderate to severe burden while 10 (12.5%) had severe burden (Table 3). In Zarit burden interview scale each question has four options and each option has its own value or marks, like "never has 0 marks", rarely = 1, sometimes = 2, quite frequently = 3, nearly always = 4. During the analysis, answers to some questions were quite different from others. In these questions, question number 3 in questionnaire, about 70% participants response to "never" option while only 2.5% response to "nearly always" option. The response of question number 4 was also nearly same as question 3. In this question 50 participants out of 80 (62.5%) response to "never" and 2 (2.5%) participants response to "nearly always". While the results of some questions were quite opposite from above two questions. In these questions, one was question number 20, in which 47% of participants responded to "nearly always" while only 10% responded to "never". The response to question number 21 was same as to question 20. In this question, 52.2% participants replied to "nearly always" while 13.8% answered to "never" (Table 4). As our data was normally distributed so we used independent sample t-test to find the significant dif-

TABLE 5. Correlation of age and total score obtained

		Age	Total
Age	Pearson correlation	1	.177
	Sig. (2-tailed)		.116
	N	80	80
Total	Pearson correlation	.177	1
	Sig. (2-tailed)	.116	
	N	80	80

ference between means of two groups (male and female). The p value of independent sample t-test is ($p = 0.030$) which is less than our chosen significant level ($p < 0.05$). Hence, it shows that there is significant difference between means of male and female caregivers regarding mental burden. Beside it, correlation was found between age and total marks obtained by caregivers in questionnaire. In correlation, the value of significant difference for age and total marks obtained is 0.116 which shows that there is no significant difference between age and total marks regarding mental burden. The magnitude and strength of association is approximately weak ($.1 < |r| < 0.3$) (Table 5) (Figure 1).

DISCUSSION

Mental burden is a major health problem among the caregivers of SCI patients. This study was conducted in a paraplegic centre from Peshawar to find out level of mental burden among caregivers of SCI patients. The study includes both male and female

those who were willing to participate and spent at least one month with patient in the paraplegic centre. In our study, we have found that the mean of total score obtained by each caregiver is 41.52 ± 14.560 ranged from 9 to 73 which is closely related to study done in Spain with mean of total marks is 42.39 ± 12.23 and range of 22 to 77 (14). We also have measured that 31.3% of participants had mild to moderate level of burden and 45% of participants had moderate to severe level of burden, which is closely related to one of study in which they found moderate to severe burden in 43% of participant and mild to moderate burden in 52% of participants (14). Similarly, Post et al. reported moderate to severe burden in 50% of caregivers of SCI patients (10).

Beside it, a study conducted in Iran concluded moderate to severe level of burden in 33.1% of participants and mild to moderate burden in 43.6% of participants (12). Their results showed slight deviation from our findings which might be because they have recruited caregivers with outpatients while in our study, we have collected data from caregivers of inpatients. A study conducted in China reported moderate to severe level of burden in 88% of participants (2). This result shows quite deviation from our study. As we were studying their article, we have found that they had 80% of female participants with education level in 88.7% were at or below junior high school. Beside it, we also have found that only 10.7% of their participants were associated with organized religion while 89.3% participants

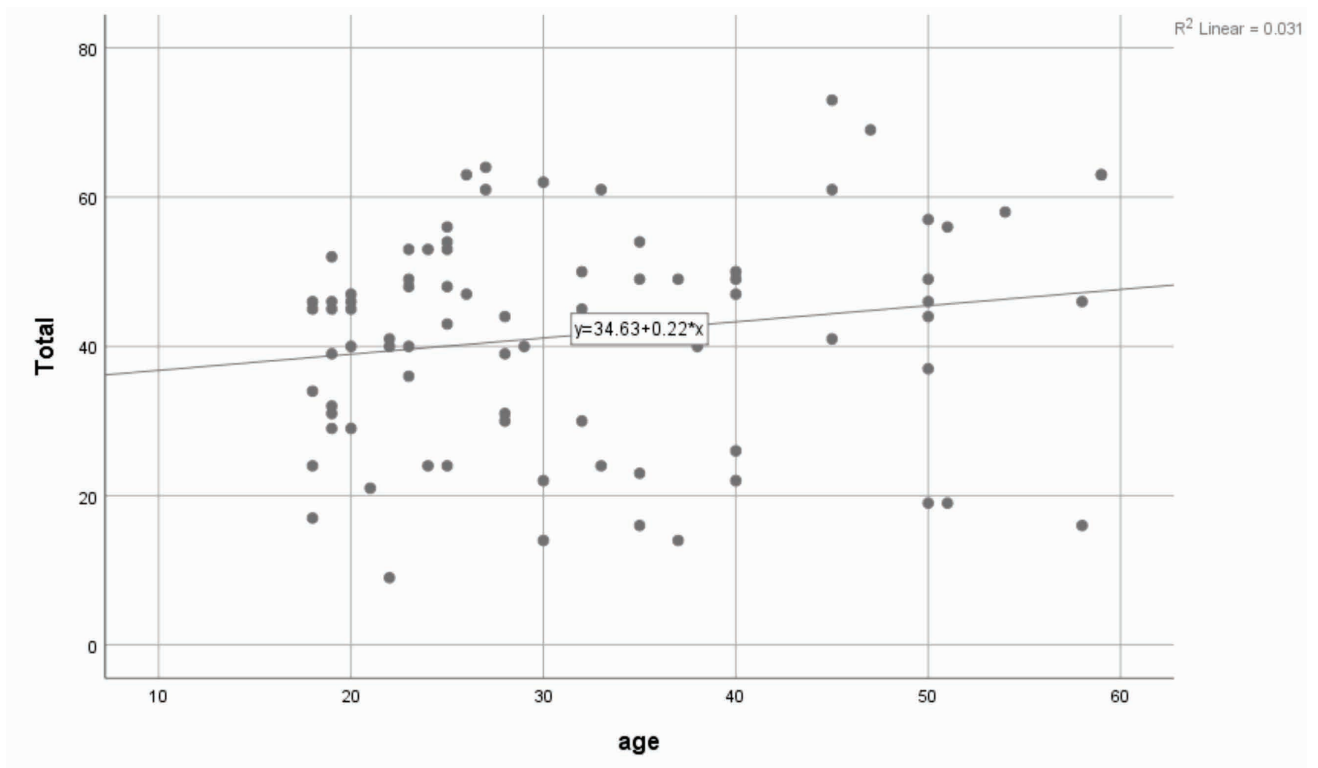


FIGURE 1. Non-linear correlation of age and total score obtained

indicating no religion. So, being female and with such education level might be cause behind this deviation. A study done in India calculated moderate to severe burden in 10% of participants (16). Result deviation of this study might be because of following reasons: education level of caregivers, in this study 64% of caregivers had completed high school; age of caregivers, 28% participants were in third and fourth decade of lives; caregiver relation, 34% participants were spouses and 28% were children. These might be reasons which cause deviation from our finding. In present study, response of some questions was found quite different from other questions in the questionnaire. In our finding's participants response to question no. 3 is 70.0% and response to question 4 is 62.5% in favour of never option. These findings of our study are somehow similar to findings of Rajabi-Mashhadi et al. in Iran. They have measured ceiling and floor effect of question 4, which is 63.9% and 8.3% respectively (11). Such response to question number 3 and 4 might be because of our religious, cultural, ethical and moral values. It's our religion and culture which compel us to support and care our loved one, and this is ethically not good to be angry on patients and to be embarrassed over your relative (SCI patient) behaviour. Furthermore, we also have calculated the response to question 20 and 21. In questions 20, 10% participants response to never option while 47.5% response to nearly always option. Similarly, response to question 21 is 13.8% in favour of never option while 52.5% to nearly always option. Previous study shows that the ceiling and floor effect for question 20 is 27.8% and 38.9% while for question 21 is 47.2% and 23.6% respectively (11). The reason behind response to these questions is again our religious and cultural value which force us to support and provide care to affected individual. It's considered good deeds in our religion to help, support and care our loved one. Moreover, treatment or rehabilitation in paraplegic centre Peshawar is free of cost. It is funded by Red Cross (ICRC) and health department of Khyber Pakhtunkhwa. This free of cost treatment is one of the reasons which keeps patients and their caregivers optimistic. In addition, paraplegic centre also provides psychological counselling and recreational activities for patients and caregivers. Such type of activities keeps patients and their caregivers confident and optimistic.

Moreover, we also have calculated that there is significant difference between means of male and female caregivers regarding mental burden. The finding of our research is similar to the study of Ma et al.; they calculated that male caregivers have more burden as compared to female caregivers. The mean and standard deviation for male and female caregivers is 15.7 ± 3.95 and 13.8 ± 4.16 respec-

tively (2). In our data, 73.8% participants were male while 26.3% were female participants, which is because of limited beds available for female patients and caregivers. This difference in percentage of male and female caregivers might be the reason behind difference in means of male and female caregivers. Moreover, male caregivers also have to support the family along with caring for SCI patients, which could create difference in means of male and female caregivers regarding mental burden. Additionally, we also calculated that there is a no statistically significant difference between age and total score obtained by caregivers via Pearson correlation. A study was done in China found that age didn't affect burden level in caregivers of SCI patients (2). Beside it, a study done in Spain revealed that there is significant difference between age and total score obtained via Zarit burden interview scale (14).

As strengths of our study, we can mention that data was collected from all caregivers of SCI patients in the paraplegic centre Peshawar, the interview was taken from participants by our self and clearly explained each and every question to participants, the correlation between age and total score was obtained and significant difference between gender and total score obtained was found. There are some weaknesses in our study such as regarding level of injury of SCI patient's data was not collected, data was not collected regarding educational level of caregivers, data was not assembled regarding marital status, employment status, socioeconomic status of caregivers and also haven't found the relationship between patients and caregivers.

As limitations of this study, we only have taken data from caregivers of SCI patients in a paraplegic centre from Peshawar. The paraplegic centre has limited number of beds for patients and each patient ought to have one caregiver while some have two depend on dependency level. Furthermore, we have collected data from some caregivers who spent more than three months in the paraplegic centre, which could have affected the result of our study. Moreover, the paraplegic centre, Peshawar is providing a lot of facilities and support free of cost to the patients and caregivers which might have affected the result of our study.

The findings of this research will increase awareness in health care professionals, especially in physiotherapists and in psychiatrists. Psychiatrists can reduce burden of caregivers of SCI patients by counselling while physiotherapist can also reduce burden via counselling and teaching physiotherapy techniques to caregivers. Once caregivers of SCI patients learned, how to roll over, transfer and mobilize patients, the burden on caregivers will be reduced. Moreover, this study will also motivate

community-based rehabilitation which in turn will decrease psychological and economic burden in caregivers of SCI patients.

CONCLUSIONS

Caregivers of SCI patients had significant level of mental burden. moderate to severe level of mental burden was found in most of caregivers. Among these caregivers, most of caregivers were male and few of them were female. Moreover, response to

certain questions were quite different from other questions in questionnaire. Furthermore, significant difference between gender and total score obtained by caregivers was also found. Beside it, no significant difference between age and total score was obtained.

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