

## Satisfaction of the Caregivers of the Patients with Spinal Cord Injury Regarding Homecare Guidelines: A Pilot Study

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### Abstract

*Spinal cord injury is a lifelong condition requiring ongoing efforts by multiple disciplines including family members/caregivers. In the current study, 'Homecare Guidelines' for the caregivers of the patients being discharged with spinal cord injury were developed. A pilot study was undertaken to assess the satisfaction level of the caregivers regarding homecare guidelines. Homecare guidelines for the caregivers of the patients with spinal cord injury were prepared by following all the steps of Delphi technique. These were validated by 11 experts in four Delphi rounds. The guidelines consisted of seven domains of care i.e. personal hygiene, bladder care, bowel care, bed sore prevention, changing position of patient, prevention of contractures and incentive spirometry. A checklist was prepared from the final draft of homecare guidelines to check the reliability of guidelines. It had total 125 items. The internal consistency reliability of the checklist was established with Cronbach's alpha. Its value was 0.91. The study was conducted in Neurosurgical outpatient department (OPD) at a tertiary hospital at Chandigarh, India. Thirty caregivers who were taught regarding the home care of their patients as per developed homecare guidelines at patients' discharge were purposively selected. A five point rating scale questionnaire was used to obtain responses from the caregivers. Parameters of satisfaction were related to benefits, systematizing their work, help in preventing errors, reading booklet at home, and satisfaction regarding content matter of the booklet/guidelines. Average score for satisfaction was 23.5 out of 25. The average score percentage for satisfaction regarding homecare guidelines was 94%. The results indicate that homecare guidelines are valid and reliable and can be applied in daily practice.*

**Keywords:** Caregivers, spinal cord injury, homecare guidelines, satisfaction

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### INTRODUCTION

The spinal cord plays a vital role in determining the ability of the body to function. Any kind of trauma that crushes and compresses the vertebrae may lead to irreversible damage. Depending on the level of the injury it may cause paraplegia and tetraplegia in patient. There is interruption of motor pathways in paraplegia and tetraplegia resulting in physical immobility. Total loss or partial inhibition of mobility interferes with self-care activities of the patient<sup>[1]</sup>. Outcome is

often a lifetime of frustration, hopelessness and despair for both the patient and family. They have to struggle to deal with related lifestyle alterations and health problems. These patients usually require long term care. After stabilizing their condition, patients are discharged from the hospital. However, the family/caregivers are not adequately prepared to give care at home<sup>[2]</sup>.

Inadequate knowledge of caregivers regarding care at home can further

deteriorate the patient's physical as well as mental health. Homecare guidelines are required to ensure that quality care is being provided to patients. Teaching has been identified as the responsibilities of all nurses. It is vital to ensure that teaching is not left to occur by chance. In order to have a meaningful patient education programme, it is important to ensure that guiding and teaching the patient and family is part of total nursing care plan. Nursing assessment and health education is required to meet the patient's needs and of the family as well. This may help them to return to their highest possible level of functioning by preventing complications amongst the suffers<sup>[3]</sup>.

It has been reported that patients, who received instructions and guidelines regarding skin care, bladder, bowel, and pain management before discharge, had a better quality of life to after discharge. Nurses in spinal cord injury rehabilitation should spend a significant amount of time in providing education and psychosocial support to patients and their families<sup>[4-5]</sup>.

In the current study, homecare guidelines were developed for the caregivers of the patients with spinal cord injury. These guidelines may assist the caregivers in providing best possible care to their patient after discharge. A pilot study has been undertaken to evaluate the satisfaction level of the caregivers regarding homecare guidelines.

## MATERIAL AND METHODS

Homecare guidelines for the caregivers of persons with spinal cord injury were prepared by following Delphi technique. These were validated by 11 experts in four Delphi rounds. The guidelines consisted of seven domains of care i.e. personal hygiene, bladder care, bowel care, bed sore prevention, changing position of patient, prevention of contractures and incentive spirometry. Checklist (name the

checklist) was prepared from the final draft of homecare guidelines to check the reliability of guidelines. It had total 125 items. The internal consistency reliability of the checklist was established with Cronbach's alpha (0.91).

Pilot study was conducted for assessment of satisfaction level of caregivers regarding homecare guidelines. Assessment of satisfaction level of the caregivers was done by administering the checklist to them during their first follow-up visit.

The study was conducted in Neurosurgery outpatient department (OPD) at a tertiary hospital, Chandigarh, India. Thirty caregivers who were taught regarding the home care of their patients as per developed homecare guidelines at patients' discharge were purposively selected. After obtaining informed consent, the identification data sheets of both patients and caregivers were filled. Information regarding injury was also obtained from patient and caregivers and as per hospital records separately. The caregivers were asked to fill in a questionnaire that was comprised of five questions. They were asked to give one response for each question. Tool constructed to assess the satisfaction level of the caregivers regarding homecare guidelines was a rating scale consisting of five questions related to benefits, systematizing their work, help in preventing errors, reading booklet at home and satisfaction regarding content matter of the booklet/guidelines. Each question had five responses: 5 = Always, 4 = Most of the time, 3 = Sometime, 2 = Rarely, 1 = Never. The content validity of tools was established with the help of the guide and the co-guides.

Ethical clearance from Institute Ethics committee was obtained.

**RESULTS**

**Socio-Demographic Data of the Patients**

Table 1 depicts socio-demographic data of the persons with spinal cord injury. The age of the patients was in the range of 17–63 years with mean of 37.60 ± 11.01. Majority (76.7%) was males and married (83.3%). Nearly one-third (33.3%) had attended school upto primary level and had per capita income from ` 600–1500. 40% of the patients were semi-skilled workers. Majority (66.7%) of them were from rural background.

**Table 1: Socio-Demographic Data of Patients (N = 30).**

Variables	N (%)
<b>Age (years)*</b>	
16–25	05(16.7)
26–35	10(33.3)
36–45	07(23.3)
> 46	08(26.6)
<b>Sex</b>	
Male	23(76.7)
Female	07(23.3)
<b>Marital status</b>	
Married	25(83.3)
Unmarried	05(16.7)
<b>Educational status</b>	
Illiterate	07(23.3)
Primary	10(33.3)
Matric	06(20.3)
Senior secondary	04(13.3)
Graduation and above	03(10.0)
<b>Occupation</b>	
Professional	01(3.3)
Skilled	03(10.0)
Semi-skilled	12(40.0)
Clerk/farmer/shopkeeper	07(23.3)
Unemployed	07(23.3)
<b>Per capita income ( `)**</b>	
600–1500	10(33.3)
1600–2500	07(23.3)
2600–3500	04(13.3)
>3600	09(30.0)
<b>Habitat</b>	
Rural	20(66.7)
Urban	10(33.3)

\*Mean ± SD = 37.60 ± 11.01, Range = 17–63 (years)

\*\*Median: 2350.

**Information Regarding Injury**

Table 2 depicts information regarding injury. The most common mode of injury was falls (76.7%) followed by road accidents (13.3%) and assaults (10.0%) and 66.7% had fall from height. After the accident, none of the patients (100%) neither received first aid at accidental site nor came to PGIMER, Chandigarh directly. Nearly half of them (46.7%) each attended local hospital between less than 1 hr and 2–3 hrs of injury respectively.

**Table 2: Information Regarding Injury (N = 30).**

Variables	N (%)
<b>Type of injury</b>	
Road accident	04(13.3)
Fall	23(76.7)
Assaults	03(10.0)
<b>If Road accident</b>	
Two wheeler	02(6.7)
Four wheeler	02(6.7)
<b>If two wheeler</b>	
Driver	01(3.3)
Pillion driver	01(3.3)
<b>If four wheeler</b>	
Driver	02(6.7)
<b>If fall</b>	
From height	20(66.7)
On same level	02(6.7)
Down stairs or steps	01(3.3)
<b>If assaults</b>	
With weapon	01(3.3)
By animal	02(6.7)
<b>After the accident First aid given at accidental site</b>	
No	30(100)
<b>Directly came to PGIMER, Chandigarh</b>	
No	30(100)
<b>Attended in local hospital</b>	
<1 hr	14(46.7)
2–3 hrs	14(46.7)
4 hrs or more	02(6.7)

### Information of the Patient's Injury as per Hospital Records

Table 3 depicts the information regarding the patient's injury as per hospital records. Nearly one-third (26.7%) of the patients had injury at lower dorsal level. More than half (53.3%) had complete injury when assessed as per ASIA (Expand) scale. 56.7% patients had total stay of 7–16 days in the hospital.

**Table 3: Information of the Patient's Injury as per Hospital Records (N = 30).**

Variables	N (%)
<b>Injury level</b>	
C spine sub axial	09(30.0)
Upper dorsal	03(10.0)
Mid dorsal	01(3.3)
Lower dorsal	14(26.7)
Lumbar supine	03(10.0)
<b>Severity of injury (ASIA)*</b>	
A complete	16(53.3)
B incomplete	10(33.3)
C incomplete	04(13.3)
<b>Total hospital stay (days)**</b>	
7–16	17(56.7)
17–26	05(16.7)
27–36	06(20.0)
>36	02(6.7)

\*ASIA is the American Spinal Injury Association

\*\*Mean  $\pm$  SD: 19.0  $\pm$  11.62, range: 7–46 (days)

### Socio-Demographic Data of the Caregivers

Table 4 highlights the Socio-demographic data of the caregivers. 43% of the caregivers were spouse of the patients. Age of the caregivers was in the range of 25–65 years with the mean of 37.60  $\pm$  11.01. Majority (66.7%) were males. All were married.

26.7% caregivers had educated upto primary level. 23.3% were Clerk, farmer, shopkeeper by occupation. 41.3% of the caregivers had lost their wages from ` 2500–3500 while they were with patient in the hospital. None of the caregivers had previous training for bed ridden Patient.

### Satisfaction Level of the Caregivers Regarding 'Homecare'

Table 5 depicts satisfaction level of the caregivers regarding 'Homecare'. Out of 30, majority of respondents (80%) were of the opinion that 'Homecare guidelines' always helped them in systematizing their work and was beneficial. Most of them (63.3%) responded that the guidelines always helped them in preventing errors, majority 22 (73%) said that they read the booklet always. The highest percentage of the caregivers 26 (86.7%) were always satisfied with content matter given in booklet.

**Table 4: Socio-Demographic Data of Caregivers (N = 30).**

Demographic parameters	N (%)
<b>Relationship with patient</b>	
Parents	06(20.0)
Sibling	03(10.0)
Spouse	13(43.0)
Children	03(10.0)
Others	05(16.0)
<b>Age (years)</b>	
26–35	09(30.0)
36–45	11(36.7)
46–55	06(20.0)
56–65	04(13.3)
<b>Sex</b>	
Male	20(66.7)
Female	10(33.3)
<b>Marital status</b>	
Married	30(100)
<b>Educational status</b>	
Illiterate	12(40.0)
Primary	08(26.7)
Matric	07(23.3)
Senior secondary	02(06.7)
Graduation and above	01(3.3)
<b>Occupation</b>	
Professional	01(3.3)
Skilled	01(3.3)
Semi-skilled	08(26.7)
Clerk/farmer/shopkeeper	07(23.3)
Unemployed	13(43.3)
<b>Wages lost (`) (N = 17)</b>	
2500–3500	07(41.3)
3600–4500	04(23.5)
4600–5500	03(17.6)
>5600	03(17.6)
<b>Has no previous training on care of bedridden patient</b>	30(100%)

**Table 5: Satisfaction Level of the Caregivers Regarding ‘Homecare Guidelines’ (N = 30).**

S.No	Items	Rating scale				
		5 Always	4 Most of the time	3 Sometimes	2 Rarely	1 Never
1.	Do you think ‘Homecare guidelines’ helps to systematize your work?	24 (80%)	6 (20%)	-	-	-
2.	Do you think it helps in preventing errors while caring your patient?	19 (63.3%)	7 (23.3%)	4 (13.3%)	-	-
3.	Do you think it is really beneficial?	24 (80%)	6 (20%)	-	-	-
4.	Do you read the given booklet at home?	22 (73.3%)	4 (13.3%)	2 (6.7%)	2 (6.7%)	-
5.	Are you satisfied with content matter given in booklet?	26 (86.7%)	4 (13.3%)	-	-	-

**Satisfaction Regarding ‘Homecare Guidelines’**

Table 6 depicts that out of the maximum score of 750 for satisfaction, the caregivers gave 705 scores with mean score of 23.5 out of 25. Thus, 94% was the score percentage for satisfaction level of the caregivers regarding homecare guidelines.

**Table 6: Total Scores and Score (%) given by the Subjects for their Satisfaction Regarding ‘Homecare Guidelines’.**

Maximum score	Total subjects	Total given score (%)	Mean given score
750	N = 30	705 (94%)	23.3

**DISCUSSION**

Spinal cord injury results in severe disability or death, with survivor facing myriad of health problems and multiple complications affecting their day to day living<sup>[5]</sup>. The interruption of motor pathways in paraplegia and tetraplegia results in physical immobility. As, there is no curative treatment of spinal cord injury, one can only prevent further damage to

spinal cord and secondary complications with proper management. Therefore spinal cord injury is a lifelong condition requiring ongoing efforts by multiple disciplines. Because of increase in medical expenses and with changing climate of health care delivery system, increasing number of clients is returning to their homes quicker but sicker. The patients are kept for shorter periods and discharged in shorter period of time from the hospital. When discharge planning does not occur or is inadequate, patients return to the hospital with serious complications. Hence, comprehensive discharge planning needs to be programmed to prevent patient re-admissions<sup>[6]</sup>.

To ensure the safest care for the patient at all times and to provide quality care at home, teaching and instructions should be given to caregivers regarding various care modalities and procedures<sup>[7]</sup>.

Satisfaction level of thirty caregivers who were taught regarding the home care of their patients as per developed homecare guidelines at patients’ discharge was

assessed by obtaining their responses on a rating scale. Average score for satisfaction was 23.5 out of 25 and average score percentage for satisfaction regarding homecare guidelines was 94%. Similar findings were reported by Kausal *et al.*<sup>[8]</sup> on development of nursing checklist to receive the patient in ICU. The average agreement percentage for effectiveness of the tool was evaluated to be 93.7%. In another study done in Chandigarh in 2012 on development of nursing checklist for cardiac catheterization the average mean score percentage for effectiveness of tool was evaluated to be 73%<sup>[9]</sup>.

To conclude, the results of homecare guidelines indicate that 'Homecare guidelines for the caregiver of the patients with spinal cord injury' are valid and reliable and can be applied in daily practice.

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