



# An Individualized Educational Package for Improving Knowledge and Practices of Caregivers of Patients with Spinal Cord Injury: A Quasiexperimental Study

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## Abstract

**Introduction** Globally, traumatic spinal cord injury occurs at a rate of 13 to 53 cases per million populations. These patients tend to get dependent on hospital staff as well as caregivers for their activities of daily living. There are insufficient data available on whether the caregivers have adequate knowledge and required skills to perform the same.

**Aim** Our aim was to evaluate the impact of an individualized educational package on the knowledge and practices of caregivers of patients with spinal cord injury.

**Methods** The caregivers ( $n = 30$ ) were recruited in the quasi-experimental study by using a nonequivalent, control group design using the TREND checklist. Study subjects were divided into two groups, that is, control and experimental. The intervention was delivered through an educational package in the experimental group, and no intervention was given to the control group. The educational package was delivered by dedicated registered nurse. Ethical approval was taken from the ethical committee, and informed consent was obtained from the study participants. Data were analyzed using STATA version 16 and SPSS version 20.

**Result** The mean age of patients was  $34.6 \pm 2.7$  years, and majority (90%) were males. The most common cause of spinal cord injury was fall from height in 53.3% patients followed by road traffic accidents in 36.6% patients. The mean posttest knowledge score ( $30.7 \pm 8.6$ ) of subjects in the experimental group was significantly higher than the control group ( $18.4 \pm 5.3$ ). Also, the mean posttest practice score ( $54.3 \pm 9$ ) of subjects in the experimental group was significantly higher than the control group ( $35.9 \pm 6.8$ ).

**Conclusion** Educating caregivers (relatives) can dramatically improve the quality of life of patients as well as prevent complications and rehospitalizations. A dedicated nurse educator should be posted in spinal cord injury wards to deliver such educational packages.

## Keywords

- ▶ spinal cord injury
- ▶ knowledge
- ▶ practices
- ▶ caregivers
- ▶ individualized educational package

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## Introduction

Spinal cord injury (SCI) is highly debilitating with severe consequences to the patients, family, and society.<sup>1</sup> Globally, SCI incidence is approximately 40 to 80 cases per million populations per year, implying that 2.5 lakh to 5 lakh people suffer with SCI every year from all causes. Among these all cases, 13 to 53 cases per million population suffer from traumatic SCI all over the world.<sup>2</sup>

SCI causes physiological and structural changes in the spinal cord resulting in loss of motor, sensory, and autonomic functions either temporary or permanent.<sup>3</sup> Moreover, people suffering with SCI incur lifelong risk of developing various complications, for instance, pain, urinary tract infections, bed sores, respiratory issues, and movement difficulties.<sup>4</sup> As a result, patients become dependent on hospital staff, private attendants, and caregivers for their activities of daily living.<sup>1</sup> Furthermore, the care provided by hospital staff is restricted to the hospital setting only. The paid care-giving services are highly expensive, and ultimately, the care is provided by family members who are sole caregivers for patients.<sup>5</sup> The early rehabilitation plays a vital role, and this should begin in the hospital to improve rehospitalization and to prevent comorbidities.<sup>6</sup> In this early rehabilitation phase, educational needs of patients and caregivers should be fulfilled on an individual basis so that they will be able to provide care at home efficiently. However, in India, due to high occupancy of bed, patients with SCI get discharged from hospitals early with discharge instructions only, which leave patients and their caregivers on their own.<sup>7</sup> Generally, family caregivers lack basic knowledge about SCI and skills required for caring the patient. Hence, they are unable to follow the instructions provided at the time of discharge.<sup>8</sup> Family members are the major supportive system in caring for their patients with SCI; their lack of knowledge and poor motivation cannot be ignored or blamed which ultimately may lead to secondary complications with which the patients often return to the hospital.

Studies have indicated that when the family has an adequate understanding of the patient's diagnosis and treatment, they can provide care efficiently which will help to decrease the comorbidities. A better level of care can be achieved by actively involving the family caregivers through a teaching program. Many other researchers have also found that caregivers with patients feel that they are untrained and unprepared.<sup>9-11</sup> Hence, this study was undertaken to assess the effectiveness of individualized educational training sessions on knowledge and practices of caregivers of patients with SCI during their hospital stay to facilitate caregiver's better understanding and augment their level of knowledge.<sup>8</sup>

## Methodology

A focused group discussion (FGD) with 20 caregivers of the SCI patients was performed which elicited those caregivers who needed explicit educational intervention for providing

home care to their patients. The questions and detailed responses are given below.

### Q1. What is the Impact of SCI on the Patient?

Participant A: "His arms and legs are not moving but they will work. We will take him to a specialist."

Participant B: "He will be unable to work now."

Participant C: "Sometimes he moves his legs like vibration then I feel like soon he will start moving legs."

### Q2. How do you help Patients in Activities of Daily Living?

Participant A: "I do every single work for him as he can't even move for now."

Participant D: "I am a bit hesitant to help him as his condition is severe, he has a pipe in neck to breath."

Participant B: "I don't know how to do suction; it seems difficult, but I will learn."

### Q3. What are the Different Complications of SCI?

Participant E: "He can develop bedsores."

Participant F: "He can develop breathing problems. My patient also re-hospitalized as his lungs are filled with water".

Participant E: "My patient is re-hospitalized as he developed deep bedsores."

### Q4. What are the Difficulties do you Face during the Care of Patients with SCI?

Participant G: "There is no end to difficulties."

Participant H: "I am hesitant to perform many cares as I don't have any medical background, but I am keen to learn."

### Q5. What do you do to Prevent the Patient from Complications of SCI?

Participant E: "I take lots of efforts but still he developed bedsores."

Participant I: "The care which he receives here is impossible to maintain at home."

### Q6. What are the Different Situations in Which you will Consult a Doctor when You are at Home?

Participant F: "Sometimes he develops a fever, then I take him to nearby physician. He develops it very often and I can't understand the reason."

Participant E: "When his bedsores increased in size, I consulted the doctor."

### Q7. How Do You Manage to Maintain Your and Patient's Mental Health?

Participant J: "It's very difficult we are running out of expense. There is no one to help us."

Participant K: "I have to quit my school to take care of my sister."

By this FGD, the researcher decided of framing an educational package related to the general impact of SCI, its complication, and prevention.

## Research Design

Thus, a quasiexperimental study using nonequivalent, control group was conducted using the TREND checklist on 30 caregivers selected conveniently for SCI patients in a tertiary care hospital of Delhi, India.

Group	Pretest on day 1	Day 1 (educational package)	Posttest on day 7
Nonequivalent control group	O1		O2
Experimental group	O1	X	O2

The hospital has its own trauma center having 30 beds in a particular ward in which 10 beds are dedicated for SCI patients (flow of participants in ►Fig. 1).

### Inclusion and Exclusion Criteria

The patients were recruited if they sustained SCI in the last 12 months, were admitted to the hospital with a tracheostomy tube, and were not on ventilator support.

The caregivers were enrolled if they were near to the patient for around 6 hours a day, were able to understand and speak Hindi, willing to participate in the study, and were not suffering from any major illness. Paid caregivers/paid attendants were excluded from the study. Ethical clearance was obtained from the ethical committee.

### Intervention: Educational Package

The educational package was designed based on the knowledge deficit, and practice needs of caregivers of patients with SCI. The educational package refers to a structured information package including individualized face-to-face teaching to caregivers regarding SCI, complications and prevention of complications (along with information booklet for future reference for the participants), and one-to-one demonstration of skills including skin care to prevent bedsore, tracheostomy care, and tracheostomy suction. The duration of the intervention was 1 hour 10 minutes. The intervention was given by the first author who was doing her master's thesis as a partial fulfilment of her study. The detail of the individualized educational package is given in ►Tables 1 and 2.

The researcher hypothesized that the caregivers of SCI patient who receive a structured educational package will

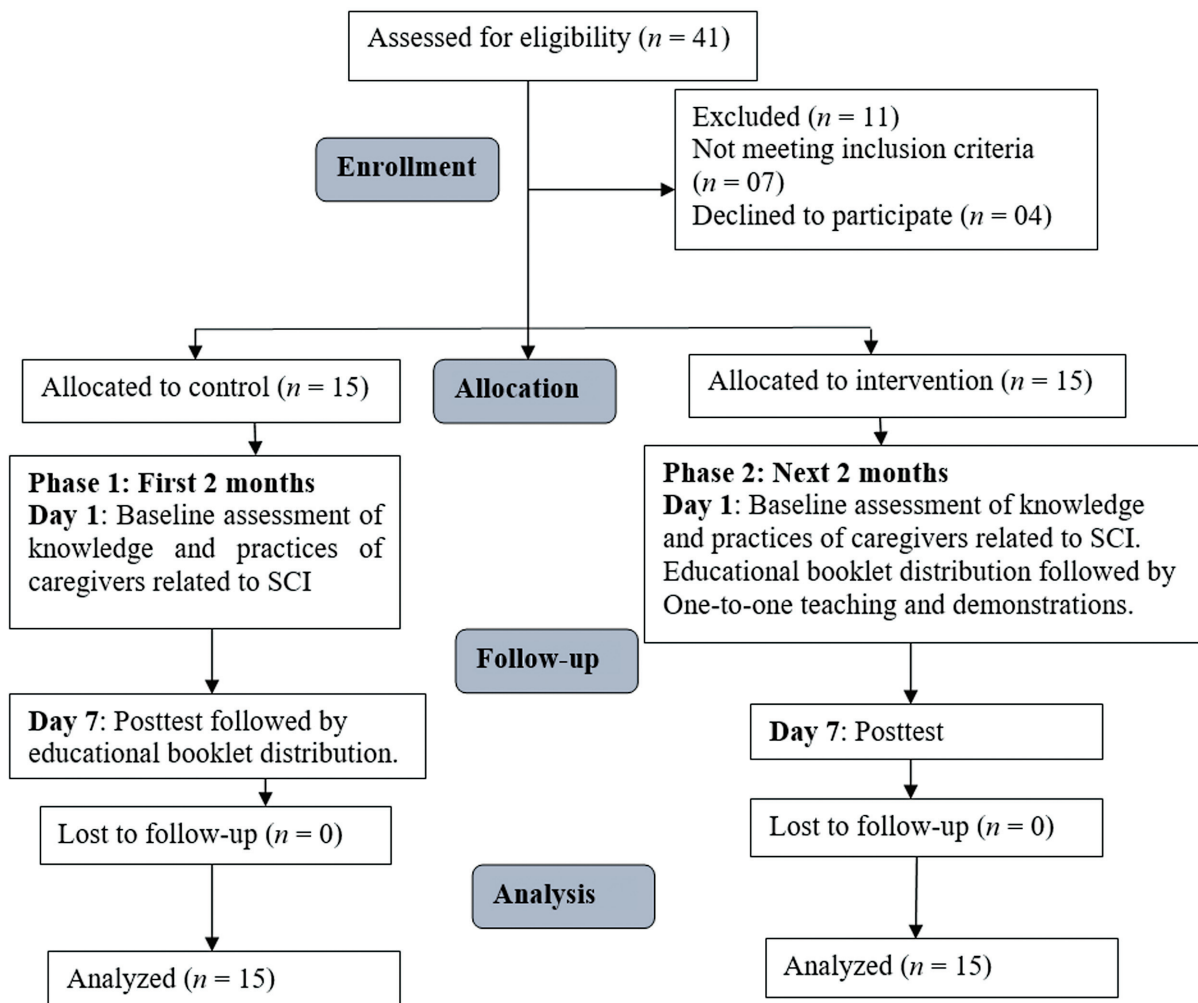


Fig. 1 Flow of participants.

**Table 1** Individualized educational package

Session	Content
Theory session	Following areas were covered in the individualized educational package: <ul style="list-style-type: none"> <li>• Overview of SCI, its complications, prevention of complications.</li> <li>• Complications of SCI including respiratory, integumentary, musculoskeletal, bowel and bladder complications.</li> <li>• How to prevent these complications.</li> </ul>
Demonstration	Individualized face to face demonstration was given on: <ul style="list-style-type: none"> <li>• Skin care to prevent bed sore,</li> <li>• tracheostomy care, and</li> <li>• tracheostomy suctioning.</li> </ul>

Abbreviations: SCI, spinal cord injury.

have improved knowledge as compared to a caregiver who receives routine education as assessed by a knowledge questionnaire at a *p*-value of < 0.05.

### The Objectives of the Study

The objectives of this study were as follows.

1. To assess the effect of the educational package on the knowledge and practices of SCI patient caregivers.
2. To find out the association of select variables with the knowledge and practices of the caregivers.
3. To find out the perception of the caregivers about the usefulness and acceptance of the educational intervention.

Primary outcomes were the knowledge and practices of caregivers of SCI patients.

Secondary outcomes were the perception of the caregivers.

### Tools and Techniques

The demographic data included age, gender, education, occupation, duration of injury, bread earner of the family, mode of injury, and type of injury. A self-developed

structured questionnaire was used to assess the knowledge of caregivers on SCI, its complications, and prevention of complications. The correct response was given one mark, and the incorrect response was given zero. The minimum and maximum scores were 0 and 35, respectively. The test-retest reliability coefficient value was 0.86. A self-developed structured observational checklist (score: 0–80) was used to assess the practices of caregivers for providing care to patients. The checklist included three practice areas, viz, tracheostomy care, suctioning, and skin care to prevent bedsores. Interrater reliability of the checklist was 95% with individual interobserver agreements 96% (skin care measures to prevent bed sore), 93% (tracheostomy care), and 97% (suctioning tracheostomy). The feedback form was used to assess the satisfaction and acceptance of caregivers of patients with SCI. The content validity of the tools was established by experts in the field of nursing and neurosurgery.

### Sample Size

Since no reference study was available, the sample size was calculated based on the pilot study; the mean posttest score of patients on 7th day in the intervention group was  $51 \pm 3.24$  and in the control group was  $39.2 \pm 10.2$ . Using 90% power and an alpha error 5%, a minimum of 13 subjects per group were required. Considering the attrition rate of 20%, a total of 30 (15 subjects in each group) were included in the study.

### Pilot Study

A pilot study was conducted on 10 participants to assess the feasibility of the study. The possibility of interaction of confounders was identified during the pilot study; hence, the study was conducted in two phases. In phase one, the control group was enrolled in the study, and data were collected. In phase two, the intervention group was enrolled in the study, intervention delivered, and data were collected.

**Table 2** Individualized educational package

Phase	Groups	Day 1	Day 7
Phase 1 (first 2 mo)	Control group	<ul style="list-style-type: none"> <li>• Baseline assessment of knowledge and practice of caregivers for home care.</li> <li>• Routine care was given to the patients.</li> <li>• No Education package intervention was provided to caregivers.</li> </ul>	<ul style="list-style-type: none"> <li>• Postintervention assessment of knowledge and practice of caregivers for home care.</li> <li>• Educational booklets were distributed among caregivers for future reference.</li> </ul>
Phase 2 (next 2 mo)	Experimental group	<ul style="list-style-type: none"> <li>• Baseline assessment of knowledge and practice of caregivers for home care.</li> <li>• Individualized education package was provided to caregivers.</li> </ul>	<ul style="list-style-type: none"> <li>• Individualized face to face teaching by nursing student to the subjects via power point presentation.</li> <li>• Individualized face to face demonstration by nursing student to the subjects by researcher on tracheostomy care, tracheostomy suction and skin care to prevent bed sore.</li> <li>• Postintervention assessment of knowledge and practice for home care.</li> <li>• A discussion round was kept for clarifying the doubts of caregivers related to the educational package.</li> <li>• Educational booklets were distributed among caregivers for future reference.</li> </ul>

## Data Analysis

Data were analyzed using STATA software version 16 and SPSS version 20. Descriptive statistics (frequency, mean, median, and standard deviation, range) was used for describing the demographic variables. The tests used for inferential statistics were Fisher's exact test, one-way analysis of variance, independent t-test, and paired t-test. The level of significance was  $p < 0.05$ .

## Results

The data were collected from August 2019 to December 2019. The mean age group of patients in the control group was  $34.6 \pm 2.64$  years and in the experimental group was  $34.73 \pm 3.37$  years. Most patients in both groups (93.3% in the control group and 80% in experimental group) had an SCI in last 6 months. Most of the patients, that is, 80% in the control group and 60% in the experimental group were bread earners in the family. Both the groups were comparable in relation to age, gender, period of injury, bread earner of family, educational level, employment status, mode of injury, site of injury, and American Spinal Injury Association (ASIA) scoring ( $p$ -value  $> 0/05$ ). However, most of the patients (46.6%) in the experimental group had complete tetraplegia compared to a very few (1.1%) in the control group with a  $p$ -value of 0.024. (► **Table 3**). Regarding caregivers' characteristics, the mean age of caregivers in the experimental group was 34.7 years and 34.6 years in the control group. The caregivers were comparable in both the groups ( $p > 0.05$ ) (► **Table 4**).

### Effectiveness of Individualized Educational Package on the Knowledge and Practices of the Caregivers of Spinal Cord Injury Patients

► **Table 5** shows a statistically significant increase in the mean total knowledge score ( $15.86 \pm 6.87$  vs.  $30.71 \pm 8.62$ ;  $p < 0.001$ ) in the experimental group before and after the intervention as compared to the control group with no significant increase in the mean total knowledge score ( $17.33 \pm 5.3$  vs.  $18.4 \pm 5.9$ ;  $p = 0.16$ ). Likewise, the posttest knowledge score was improved significantly in all six subdomains in the experimental group compared to the control group. Similarly, the mean total posttest practice score ( $54.3 \pm 9$ ) significantly improved from the mean total pretest practice score ( $41.1 \pm 9.6$ ) in the experimental group, ( $p < 0.001$ ). Caregivers' practices improved significantly in skin care to prevent bed sore ( $p < 0.001$ ), performing tracheostomy care ( $p < 0.001$ ), and suctioning ( $p < 0.001$ ) after an individualized educational package compared to the caregivers in the control group (► **Table 6**).

### The Association of Caregivers' Knowledge and Practices with Selected Variables

Caregivers with patients having ASIA grade A spinal injury (complete injury with no motor or sensory functions preserved in the sacral segments) had significantly better knowledge ( $18.38 \pm 6.69$ ) than the caregivers with patients having ASIA grade B spinal injury (sensory functions preserved but not motor functions in the sacral segments)

with knowledge score of  $14.58 \pm 4.33$  ( $p = 0.046$ ). Post-hoc test revealed that caregivers who work on daily wages or not employed had a significantly higher knowledge score ( $21.14 \pm 4.53$ ) as compared to caregivers who had private job/businesses ( $14.21 \pm 4.73$ ) with a  $p$ -value of 0.037. However, caregivers' knowledge was not related to their gender, marital status, educational level, relation to patients, and duration of patients' injury.

The caregivers whose patients' SCI period was up to 12 months scored significantly higher in the practice score ( $46.5 \pm 6.55$ ) than caregivers whose patients' SCI period was up to 6 months ( $36.34 \pm 9.51$ ) with a  $p$ -value of 0.043. Furthermore, caregivers of patients with ASIA grade A scored significantly higher in practice ( $41.11 \pm 9.6$ ) than caregivers of patients with ASIA grade B in practice ( $32.58 \pm 7.73$ ) with a  $p$ -value of 0.016.

Caregivers' employment played a significant role in their practices while caring for their patients ( $p = 0.004$ ). A post-hoc test revealed that caregivers who worked on daily wages or not working had significantly higher practice scores ( $47.42 \pm 6.47$ ) as compared to caregivers who had private job/businesses ( $33.28 \pm 8.25$ ) with  $p$ -value of 0.003 or caregivers who were government employee ( $37 \pm 9.2$ ) with a  $p$ -value of 0.045. Furthermore, the practice score of caregivers ( $43.25 \pm 9.24$ ) whose patient had complete tetraplegia was significantly higher in comparison to caregivers whose patient had complete paraplegia ( $31.9 \pm 6.12$ ) with  $p$ -value of 0.03.

Regarding the perception of caregivers about the usefulness and effectiveness of the educational package, the majority of the caregivers (80%) found the educational package knowledgeable and relevant. All the participants (100%) reported that the educational package was beneficial for patients and improved the caregivers' practices as well as for providing care to patients.

## Discussion

This study was undertaken to assess the effectiveness of an individualized educational package on the knowledge and practices of caregivers of patients with SCI. Significant improvement was seen in the knowledge of caregivers before and after one-to-one training ( $15.86 \pm 6.87$  vs.  $30.71 \pm 8.62$ ,  $p < 0.001$ ). These results are in concordance with Madhanraj et al (2019)<sup>12</sup> who reported that caregivers who received one-to-one teaching had significant knowledge enhancement ( $p < 0.05$ ). Similarly, Kanmani et al, (2019),<sup>13</sup> Weheida (2018),<sup>14</sup> and Khanal (2014)<sup>15</sup> reported that the knowledge of caregivers of SCI patients was significantly increased after educational interventions.

In the present study, the knowledge score for the bed sore prevention was enhanced after the intervention. Shrestha and Khatiwada (2018)<sup>16</sup> also reported that the majority of the respondents (82.9%) had adequate knowledge after administering intervention on the prevention of pressure ulcers. Similarly, Schubart (2014)<sup>17</sup> reported that postprogram knowledge score was higher than the pre-program score related to the prevention of bedsores.



**Table 3** Demographic and clinical profile of the patients in experimental and control group  $n=30$ 

Variables		Control group ( $n_1 = 15$ )	Experimental group ( $n_2 = 15$ )	$p$ -Value
		Mean $\pm$ SD		
Age		34.6 $\pm$ 2.64	34.7 $\pm$ 3.37	0.51 <sup>f</sup>
		Frequency (%)		
Gender	a) Male	14 (93.3)	12 (80.0)	0.28
	b) Female	1 (6.67)	3 (20)	
Duration of injury	a) Up to 6 mo	14 (93.3)	12 (80)	0.28
	b) Up to 1 y	1 (6.6)	3 (20)	
Bread earner of family	a) Yes	12 (80)	9 (60)	0.23
	b) No	3 (20)	6 (40)	
Educational level	a) Primary education	6 (40)	7 (46.7)	1.00
	b) High school	5 (33.3)	5 (33.3)	
	c) Graduation and higher degree	4 (26.7)	3 (20)	
Employment status	a) Government employee	3 (20)	1 (6.7)	0.21
	b) Private work	1 (6.7)	6 (40)	
	c) Work on daily wages	6 (40)	4 (26.7)	
	d) No work	5 (33.3)	4 (26.7)	
Mode of injury	a) Road traffic accident	6 (40)	5 (33.3)	0.9
	b) Fall from height	8 (53.3)	8 (53.3)	
	c) Sports injury	1 (6.6)	1 (6.6)	
	d) Other	0	1 (6.6)	
Site of injury	a) Cervical	14 (93.3)	15 (100)	0.9
	b) Thoracic	0	0	
	c) Lumbar	0	0	
	d) All	1 (6.6)	0	
Type of injury	a) Complete tetraplegia	1 (6.6)	7 (46.6)	0.024 <sup>a</sup>
	b) Incomplete tetraplegia	9 (60)	3 (40)	
	c) Complete paraplegia	5 (33.3)	5 (33.3)	
	d) Incomplete Paraplegia	0	0	
ASIA score	a) A	6 (40)	12 (80)	0.30
	b) B	9 (60)	3 (20)	
	c) C	0	0	
	d) D	0	0	
	e) E	0	0	

Abbreviations: ASIA, American Spinal Injury Association; SD, standard deviation;  $t$ , two sample  $t$ -test.

Fisher's exact test.

<sup>a</sup> $p$ -Value < 0.05.

Kanmani et al (2019)<sup>13</sup> also reported that after the intervention, subjects achieved a good grade in areas of skincare practices.

The mean posttest practice score was 54.3  $\pm$  9.0 compared to the mean pretest practice score of 41.1  $\pm$  9.6, with a  $p$ -value < 0.001. These findings are in line with Kanmani et al (2019)<sup>13</sup> in which significant higher posttest practice scores were noted ( $p = 0.001$ ). In the posttest, 90% of subjects showed greater skill improvement in certain procedures.

Around 93.3% of subjects demonstrated enhanced skills in catheter care. These scores were significantly enhanced in practices such as tracheostomy care (12.86  $\pm$  3.23 vs. 17.21  $\pm$  3.04;  $p < 0.001$ ), tracheostomy tube suction (13.0  $\pm$  3.62 vs. 17.64  $\pm$  2.34;  $p < 0.001$ ), and skin care for bed sore prevention (14.71  $\pm$  3.83 vs. 18.71  $\pm$  4.45;  $p < 0.001$ ) after the intervention. Similarly, Karaca et al (2019)<sup>18</sup> reported that in posttests, the mean score of the tracheostomy care skill was 9.13  $\pm$  3.46 for the

**Table 4** Demographic characteristics of the caregivers of SCI patients in control and experimental group  $n=30$ 

Variables		Control group ( $n_1 = 15$ )	Experimental group ( $n_2 = 15$ )	p-Value
		Mean $\pm$ SD		
Age		30.1 $\pm$ 9.66	32.8 $\pm$ 13.02	0.74 <sup>t</sup>
		Frequency (%)		
Gender	Male	10 (66.7)	10 (66.7)	1.00
	Female	5 (33.3)	5 (33.3)	
Religion	a) Hindu	13 (86.7)	11 (73.3)	0.51
	b) Muslim	2 (13.3)	3 (20)	
	c) Sikh	0	0	
	d) Christian	0	1 (6.7)	
	e) Other	0	0	
Marital status	a) Married	12 (80)	7 (46.7)	0.16
	b) Unmarried	3 (20)	6 (40)	
	c) Other	0	2 (13.3)	
Educational level	a) Elementary and 10th	8 (53.3)	8 (53.3)	1.00
	b) Graduation	4 (26.7)	4 (26.7)	
	c) Other/Postgraduation	3 (20)	3 (20)	
Employment status	a) Government employee	5 (33.3)	4 (26.6)	0.52
	b) Private job/business	8 (53.3)	6 (40)	
	c) Work on daily wage and no work	2 (13.3)	5 (33.3)	
Relation to patient	a) Partner	6 (40)	2 (13.3)	0.32
	b) Child	2 (13.3)	4 (26.6)	
	c) Parent	1 (6.6)	3 (20)	
	d) Other	6 (40)	6 (40)	

Abbreviations: SCI, spinal cord injury; SD, standard deviation; *t*, independent *t*-test.

Note: Fisher exact test.

**Table 5** Comparison of pretest and posttest scores of overall and subdomains of knowledge between two groups  $n = 30$ 

S. no.	Subdomain score of knowledge questionnaire (range score)	Control group ( $n_1 = 15$ ) mean $\pm$ SD		p-Value	Experimental group ( $n_2 = 15$ ) mean $\pm$ SD		p-Value
		Pretest	Posttest		Pretest	Posttest	
1	General facts about SCI (0–5)	2.33 $\pm$ 1.59	3.20 $\pm$ 1.21	0.02 <sup>a</sup>	2.79 $\pm$ 0.89	4.64 $\pm$ 0.63	< 0.001 <sup>a</sup>
2	Respiratory system <sup>b</sup> (0–3)	1.27 $\pm$ 0.59	1.07 $\pm$ 0.70	0.19	1.07 $\pm$ 0.83	2.43 $\pm$ 0.65	< 0.001 <sup>a</sup>
3	Cardiovascular system <sup>b</sup> (0–6)	3.13 $\pm$ 0.743	3.67 $\pm$ 0.98	0.04 <sup>a</sup>	2.93 $\pm$ 1.21	4.36 $\pm$ 1.01	< 0.001 <sup>a</sup>
4	Gastrointestinal system <sup>b</sup> (0–10)	3.87 $\pm$ 1.77	4.13 $\pm$ 2.10	0.49	3.43 $\pm$ 2.28	6.93 $\pm$ 1.44	< 0.001 <sup>a</sup>
5	Integumentary system <sup>b</sup> (0–6)	3.47 $\pm$ 1.51	3.53 $\pm$ 1.59	0.86	3.50 $\pm$ 1.51	4.71 $\pm$ 0.99	0.02 <sup>a</sup>
6	Musculoskeletal system <sup>b</sup> (0–5)	3.13 $\pm$ 1.30	2.73 $\pm$ 1.53	0.21	2.43 $\pm$ 1.87	4.00 $\pm$ 1.24	< 0.001 <sup>a</sup>
	Total knowledge score (0–35)	17.33 $\pm$ 5.3	18.4 $\pm$ 5.9	0.16	15.86 $\pm$ 6.87	30.71 $\pm$ 8.62	< 0.001 <sup>a</sup>

Abbreviations: SCI, spinal cord injury; SD, standard deviation.

Note: Paired *t*-test

<sup>a</sup>p-Value < 0.05 significant

<sup>b</sup>Knowledge related to complications and prevention of respective system complications.

**Table 6** Comparison of pretest and posttest practice score between two groups  $n = 30$ 

S. no.	Variables (range score)	Control group ( $n = 15$ )		$p$ -Value	Intervention group ( $n = 15$ )		$p$ -Value
		Mean $\pm$ SD			Mean $\pm$ SD		
		Pretest	Posttest		Pretest	Posttest	
1	Practices for skin care to prevent bed sore (0–30)	12.07 $\pm$ 3.83	13.07 $\pm$ 3.37	0.10	14.71 $\pm$ 3.83	18.71 $\pm$ 4.45	< 0.001 <sup>a</sup>
2	Practices related to tracheostomy care (0–26)	10.47 $\pm$ 2.53	11.27 $\pm$ 2.25	0.12	12.86 $\pm$ 3.23	17.21 $\pm$ 3.04	< 0.001 <sup>a</sup>
3	Practices related to tracheostomy suctioning (0–24)	11.73 $\pm$ 3.99	11.53 $\pm$ 3.07	0.81	13.0 $\pm$ 3.62	17.64 $\pm$ 2.34	< 0.001 <sup>a</sup>
	Total practice score (0–80)	34.3 $\pm$ 8.7	35.9 $\pm$ 6.8	0.22	41.1 $\pm$ 9.6	54.3 $\pm$ 9.0	< 0.001 <sup>a</sup>

Abbreviation: SD, standard deviation.

Note: Paired  $t$ -test

<sup>a</sup> $p$ -Value < 0.05 significant.

experimental group and  $4.96 \pm 2.35$  for the control group with a  $p$ -value < 0.05, indicating tracheostomy care skills improvement after intervention. Likewise, Nagi (2012)<sup>19</sup> suggested the role of one-to-one skill demonstration of tracheostomy suction and significant improvement of caregivers' practices ( $p < 0.05$ ). Similarly, Madhanraj et al (2019),<sup>12</sup> Khanal (2014),<sup>15</sup> and Weheida et al (2018)<sup>14</sup> reported similar findings and concluded that training programs were effective in improving the practices of caregivers of SCI patients. Approximately 80% of caregivers reported that the educational package was knowledgeable and relevant. Furthermore, 100% of caregivers reported that the educational package was beneficial for patients and improved the caregivers' practices. In concordance with these findings, Carvalho et al (2013)<sup>20</sup> reported that the learning opportunities and patient care activities taught during the hospitalization period helped the caregivers understand patient care at home.

### Strengths

The major strength of the study included having FGDs to make it more caregiver oriented. Furthermore, the inclusion of the control group helped in comparing and validating the findings of the study. Efforts were taken to minimize the contamination by enrolling the study participants in two phases. Individualized teaching sessions were delivered to the study to cater to their learning needs. Furthermore, the feedback sessions were included at the end of the educational intervention for their clarifications to have sustained effects. The subjects in the control group were provided with the information booklet for their future reference after the data collection.

### Limitations

The study had certain limitations. First, the sample size was inadequate which limits the generalizability of the findings. The participants were chosen on a convenience basis, which adds to the sampling bias in the study. Some major important procedures such as catheter care which are also required for SCI patients could not be included in the demonstration part

of the study due to gender differences as most of the patients were male and the nurse researcher was a young female student. Long-term effects of the intervention were not studied.

### Recommendations

This study recommends exploring different methods of caregivers' education to yield the best results for both patients and caregivers and can be established in different settings. The burden of caregivers of patients with SCI could be assessed, and psychological intervention for the caregivers can be introduced and tested since many of the participants verbalized their stress during the study. Similar studies can be conducted in different settings and with a large sample size to generalize the findings. More interventions can be introduced and tested to reduce the complication rate. Similar studies could be conducted in home settings and community settings. Patient caregiver dyad could be included in further studies. Interventions can be chalked out uniquely according to each patient and caregiver's needs.

### Conclusion

A structured individualized educational package is effective in improving the knowledge of the caregivers of SCI patients regarding SCI, its complication, and prevention. This is also effective in improving the practices of caregivers of SCI patients related to the procedures including bed sore prevention, tracheostomy care, and suctioning tracheostomy. A dedicated SCI nurse who had administered the educational package helped in providing home care efficiently to caregivers who had poor knowledge and practices. Hence, it is recommended that a dedicated SCI nurse should be appointed in SCI wards to deliver such an educational package which would be phenomenal in improving home-based care and would augment the quality of life of SCI patients. Caregivers with better knowledge and practices may prevent secondary complications among SCI patients. This study infers that planned educational



intervention given on a one-to-one basis on home care management is effective in improving the skills of caregivers of patients with SCI.

#### Contribution Details

I.P., M.A.K.R., D.C.K., and D.A. contributed to conceptualization, design, definition of intellectual content, methodology, validation, investigation, supervision, data analysis, writing (review and editing), and manuscript review. I.P. contributed to data acquisition. I.P. and M.A.K.R. contributed to literature search, statistical analysis, and writing the original draft. D.C.K. also contributed to writing the original draft.

#### Ethical Approval

The study received ethical approval from the Institutional Ethics Committee, with ref. no. IECPG- 131/28.02.2019 dated 05.03.2019.

#### Funding

None.

#### Conflict of Interest

None declared.

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**Appendix** TREND statement checklist

Paper section/Topic	Item No.	Descriptor	Reported?	
				Pg #
<b>TITLE and ABSTRACT</b>			✓	
Title and abstract	1	• Information on how units were allocated to interventions	✓	1
		• Structured abstract recommended	✓	1
		• Information on target population or study sample	✓	1
<b>INTRODUCTION</b>				
Background	2	• Scientific background and explanation of rationale	✓	2–3
		• Theories used in designing behavioral interventions		N/A
<b>METHODS</b>				
Participants	3	• Eligibility criteria for participants, including criteria at different levels in recruitment/sampling plan (e.g., cities, clinics, subjects)	✓	3–4
		• Method of recruitment (e.g., referral, self-selection), including the sampling method if a systematic sampling plan was implemented	✓	4
		• Recruitment setting	✓	4
		• Settings and locations where the data were collected	✓	4
Interventions	4	• Details of the interventions intended for each study condition and how and when they were actually administered, specifically including:		
		◦ Content: what was given?	✓	4–5,12
		◦ Delivery method: how was the content given?	✓	4–5,12
		◦ Unit of delivery: how were subjects grouped during delivery?	✓	4–5,12
		◦ Deliverer: who delivered the intervention?	✓	4–5,12
		◦ Setting: where was the intervention delivered?	✓	4–5,12
		◦ Exposure quantity and duration: how many sessions or episodes or events were intended to be delivered? How long were they intended to last?	✓	4–5,12
		◦ Time span: how long was it intended to take to deliver the intervention to each unit?	✓	4–5,12
		◦ Activities to increase compliance or adherence (e.g., incentives)		N/A
Objectives	5	• Specific objectives and hypotheses	✓	5
Outcomes	6	• Clearly defined primary and secondary outcome measures	✓	5
		• Methods used to collect data and any methods used to enhance the quality of measurements	✓	5

## Appendix (Continued)

Paper section/Topic	Item No.	Descriptor	Reported?	
				Pg #
		<ul style="list-style-type: none"> <li>Information on validated instruments such as psychometric and biometric properties</li> </ul>	✓	5
Sample size	7	<ul style="list-style-type: none"> <li>How sample size was determined and, when applicable, explanation of any interim analyses and stopping rules</li> </ul>	✓	5–6
Assignment method	8	<ul style="list-style-type: none"> <li>Unit of assignment (the unit being assigned to study condition, e.g., individual, group, community)</li> </ul>		N/A
		<ul style="list-style-type: none"> <li>Method used to assign units to study conditions, including details of any restriction (e.g., blocking, stratification, minimization)</li> </ul>		N/A
		<ul style="list-style-type: none"> <li>Inclusion of aspects employed to help minimize potential bias induced due to non-randomization (e.g., matching)</li> </ul>	✓	6
Blinding (masking)	9	<ul style="list-style-type: none"> <li>Whether or not participants, those administering the interventions, and those assessing the outcomes were blinded to study condition assignment; if so, statement regarding how the blinding was accomplished and how it was assessed</li> </ul>		N/A
Unit of analysis	10	<ul style="list-style-type: none"> <li>Description of the smallest unit that is being analysed to assess intervention effects (e.g., individual, group, or community)</li> </ul>	✓	6
		<ul style="list-style-type: none"> <li>If the unit of analysis differs from the unit of assignment, the analytical method used to account for this (e.g., adjusting the standard error estimates by the design effect or using multilevel analysis)</li> </ul>		N/A
Statistical methods	11	<ul style="list-style-type: none"> <li>Statistical methods used to compare study groups for primary methods outcome(s), including complex methods for correlated data</li> </ul>	✓	6
		<ul style="list-style-type: none"> <li>Statistical methods used for additional analyses, such as subgroup analyses and adjusted analysis</li> </ul>		N/A
		<ul style="list-style-type: none"> <li>Methods for imputing missing data, if used</li> </ul>		N/A
		<ul style="list-style-type: none"> <li>Statistical software or programs used</li> </ul>	✓	6
<b>RESULTS</b>				
Participant flow	12	<ul style="list-style-type: none"> <li>Flow of participants through each stage of the study: enrollment, assignment, allocation and intervention exposure, follow-up, analysis (a diagram is strongly recommended)</li> </ul>		
		<ul style="list-style-type: none"> <li>Enrollment: the numbers of participants screened for eligibility, found to be eligible or not eligible, declined to be enrolled, and enrolled in the study</li> </ul>	✓	12 + Figure 1
			✓	12 + Figure 1

(Continued)

## Appendix (Continued)

Paper section/Topic	Item No.	Descriptor	Reported?	
				Pg #
		◦ Assignment: the numbers of participants assigned to a study condition		
		◦ Allocation and intervention exposure: the number of participants assigned to each study condition and the number of participants who received each intervention	✓	12 + Figure 1
		◦ Follow-up: the number of participants who completed the follow-up or did not complete the follow-up (i.e., lost to follow-up), by study condition	✓	12 + Figure 1
		◦ Analysis: the number of participants included in or excluded from the main analysis, by study condition	✓	12 + Figure 1
		• Description of protocol deviations from study as planned, along with reasons		N/A
Recruitment	13	• Dates defining the periods of recruitment and follow-up	✓	6
Baseline data	14	• Baseline demographic and clinical characteristics of participants in each study condition	✓	6,14–15+ Table 2A, 2B
		• Baseline characteristics for each study condition relevant to specific disease prevention research		N/A
		• Baseline comparisons of those lost to follow-up and those retained, overall and by study condition		N/A
		• Comparison between study population at baseline and target population of interest	✓	Table 2A, 2B
Baseline equivalence	15	• Data on study group equivalence at baseline and statistical methods used to control for baseline differences		N/A
Numbers analyzed	16	• Number of participants (denominator) included in each analysis for each study condition, particularly when the denominators change for different outcomes; statement of the results in absolute numbers when feasible	✓	Table 2A, 2B
		• Indication of whether the analysis strategy was “intention to treat” or, if not, description of how non-compliers were treated in the analyses		N/A
Outcomes and estimation	17	• For each primary and secondary outcome, a summary of results for each estimation study condition, and the estimated effect size and a confidence interval to indicate the precision		N/A
		• Inclusion of null and negative findings	✓	6-7, Table 3,4
		• Inclusion of results from testing pre-specified causal pathways through which the intervention was intended to operate, if any		N/A

## Appendix (Continued)

Paper section/Topic	Item No.	Descriptor	Reported?	
				Pg #
Ancillary analyses	18	<ul style="list-style-type: none"> <li>Summary of other analyses performed, including subgroup or restricted analyses, indicating which are pre-specified or exploratory</li> </ul>		N/A
Adverse events	19	<ul style="list-style-type: none"> <li>Summary of all important adverse events or unintended effects in each study condition (including summary measures, effect size estimates, and confidence intervals)</li> </ul>		N/A
<b>DISCUSSION</b>				
Interpretation	20	<ul style="list-style-type: none"> <li>Interpretation of the results, taking into account study hypotheses, sources of potential bias, imprecision of measures, multiplicative analyses, and other limitations or weaknesses of the study</li> </ul>	✓	6–10
		<ul style="list-style-type: none"> <li>Discussion of results taking into account the mechanism by which the intervention was intended to work (causal pathways) or alternative mechanisms or explanations</li> </ul>	✓	6–10
		<ul style="list-style-type: none"> <li>Discussion of the success of and barriers to implementing the intervention, fidelity of implementation</li> </ul>	✓	6–10
		<ul style="list-style-type: none"> <li>Discussion of research, programmatic, or policy implications</li> </ul>	✓	6–10
Generalizability	21	<ul style="list-style-type: none"> <li>Generalizability (external validity) of the trial findings, taking into account the study population, the characteristics of the intervention, length of follow-up, incentives, compliance rates, specific sites/settings involved in the study, and other contextual issues</li> </ul>	✓	9–10
Overall evidence	22	<ul style="list-style-type: none"> <li>General interpretation of the results in the context of current evidence and current theory</li> </ul>	✓	9–10

Source: Des Jarlais DC, Lyles C, Crepaz N, and the Trend Group. Improving the reporting quality of nonrandomized evaluations of behavioral and public health interventions: The TREND statement. *American Journal of Public Health* 2004;94:361–366. For more information, visit: <http://www.cdc.gov/trendstatement/>