

# Effectiveness of a Self Instructional Module among Primary Care Givers of Persons with Spinal Cord Injury

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## ABSTRACT

**Background & Aim:** Care of spinal cord injury patients and their associated needs is a real challenge. So, the need of the hour is to provide comprehensive care to the survivors. Our aim was to determine the knowledge and socio-economic profile of the primary care givers of the spinal cord injury patients. **Methods:** The study was conducted in the Dept. of Orthopedics at VIMSAR, Burla period from 1st Jan 2017 to 31st Dec 2018. A total 30 primary care givers of the quadriplegic and paraplegic patients who were admitted in the orthopedic dept of VIMSAR, Burla were the study subjects to assess the purposive sampling technique. A Predesigned, pretested / post tested questionnaire was developed for the study purpose to the paralyzed patients. A self-instructional guide in Odia language was prepared and implemented on the 5th day of admission. **Results:** Out of 30 spinal cord injury patients 20 were paraplegics and 10 were quadriplegics. From 20 paraplegics, 75% were of Traumatic. Similarly out of 10 quadriplegic patients 76.67% were of traumatic. The socio demographic characteristics of participating primary care givers 63.33% were females and half of the participants belonged to 31 – 40 years age group, 66.67% were married and regarding educational status of care givers 43.33% having secondary education. The socio economic status was calculated as per capita income (modified BG Prasad scale) and 36.67% belonged to lower class. **Conclusion:** Care giving training including multi-disciplinary education about communicating strategies, proper handling, care and positioning of the patients plays vital role for proper care of patients.

**Keywords:** Spinal Cord Injury, Pretest, Posttest, Self-Instruction.

## INTRODUCTION

Persons with spinal cord injury (SCI) are typically cared for at home by family members who are responsible for providing a wide range of services, some of which were formerly delivered by traditional health care providers. Providing care for these patients with chronic disease at home is often done by a care giver who is essentially a family member and who assumes and / or coordinates the majority of care. Many a time it is seen that adults / children care to a family member or friend with a chronic, disabling or in terminal illness. Caregivers are a critical national health care resource. Family members care giving responsibilities for patient with chronic diseases have increased dramatically over the past decade and is now routinely adapted on an outpatient basis and hence patients lives for

longer periods.<sup>[1]</sup> With health care services being restructured and more patients residing outside the hospital, at home the reliance on family caregivers to support patients with chronic illness at home is growing.<sup>[2,3]</sup> Hence to inform the family caregivers about the disease we need to provide them a better understanding on the disease, the care, the needs of the disadvantaged group and how care giving affects them. The care for paralyzed patients involves multitasking as the condition itself is quite complex and challenging. The role of the health care team is to provide standards of patient care with a higher level of accountability & they may also devise and implement a plan of care after assessment.<sup>4</sup> Paralysis may be due to traumatic or non-traumatic in origin and the effect of paralysis will depend upon its severity. Paraplegia & Quadriplegia is a medical emergency which causes neurological damage and death if not appropriately, timely diagnosed and treated. It is one of the major causes of social & economic burden if its survivors have mental & physical disabilities. Care of paralysed patients & their associated needs, dependence, supporting care on the primary care

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givers as a real challenge. So, the need of the hour is to provide comprehensive care to the survivors. This can be achieved by a complete knowledge kit on physical therapy, speech therapy, occupational therapy, communication, nutrition, self-care & prevention of complication & early diagnosis & prompt treatment of comorbidities & other associated complication. It is the responsibility of the family members as primary care givers of these disable individuals to provide adequate care to those patients. The support of the near & dear ones are critical in achieving the best possible long term outcome for individual with disabilities. Keeping this in view the caregivers should be given the best possible instructional guide so that they can provide the best care to their patient & improve their quality of life. Keeping this perspective in mind this particular study was undertaken to study the effectiveness of the self-instructional module & guide among care givers in regard to the care of paraplegic and quadriplegic patients. Our aim was to determine the socio-economic profile of the primary care givers of the paralytic patients, to assess the pretest and posttest knowledge of primary care givers regarding the care of paraplegic and quadriplegic patients and to find the effectiveness of a self-instructional module by comparing pretest and posttest knowledge score.

## MATERIALS AND METHODS

This is an evaluative cross sectional study with instructional interventional approach which was conducted in the Dept. of Orthopedics at VIMSAR, Burla from 1st Jan 2017 to 31st Dec 2018. The primary care givers of the quadriplegic and paraplegic patients who were admitted in the Dept. of Orthopedics at VIMSAR, Burla. Purposive sampling technique. A total 30 primary care givers were included for study purpose after informed written consent in local language was taken from them after having undertaken prior permission of patients where possible. Predesigned, pretested questionnaire was developed for the study purpose which included the details of the socio-demographic variables of care givers as well as their knowledge, attitude and practice on care giving to the paralysed patients. Initially a pretest was conducted to assess the pre testing knowledge, attitude & practice on different aspects of care giving. A self-instructional guide cum module in Odia was prepared having consulted other faculty members of dept of Orthopedics and opinion of neurologist and physiotherapy was also taken. The validity of the module was established and implemented on the 5th day of admission. A post test was conducted by assessing the knowledge gained by the implementation of the same questionnaire.

**Table 2: Socio Demographic Characteristics of Participating Primary Care Givers**

### Different aspects of the Module:

- Definition of a primary care giver.
- Main objective of the SIMG (Self-instructional module & guide)
- Definition of paralysis. Different types and causes.
- Risk factors of paralysis
- Signs & symptoms
- Care of the paralyzed patients (Continence management, swallowing management, early mobilization)
- Physiotherapy (active & passive movement ,massage)
- Communication aids (difficulty, incoherent speech)
- Nutrition
- Co morbidities and its prevention (pressure area care, muscle spam, oedema, blood clots in lower limbs)
- Early diagnosis & prompt treatment of further complications. (bacterial infections, skin ragging , spasticity of limbs)

### Education to Care Givers:

- Personal care (bathing, eating, wound care, medication and symptomatic management)
- Family Care (support & communication)
- Disease Prevention (laboratory investigation)
- Health promotion (Exercise & nutrition)

### Other awareness:

- Home care nursing.
- Access to internet
- Knowledge about medical leave benefit.
- Hire help

### Guideline for Care givers:

- Are you willing to provide care.
- Are you staying with the patient.
- Willing to provide care
  - General health status (which include physical, mental, social, psychological & spiritual)
- Emotional stability (anxiety depression & sleep disorder)
- Cognitive skills (mental function)
- Attitude (empathy, responsible) affective skills.
- Psychomotor skills (practical)

## RESULTS

**Table 1: No. of caregivers based on Traumatic & non traumatic patients.**

Types of Paralysis	Traumatic		Non Traumatic		Total	
	No	%	No	%	No	%
Paraplegia	15	75	5	25	20	66.67
Quadriplegia	8	80	2	20	10	33.33
Total	23	76.67	7	23.33	30	100

Characteristics	Frequency (n)	%
<b>Sex</b>		
• Male	11	36.67
• Female	19	63.33
<b>Age (in years)</b>		
• 20 – 30	2	6.67
• 41 – 50	15	50
• 51 – 60	8	26.67
• 61 – 70	1	3.33
<b>Marital Status</b>		
• Married	20	66.67
• Unmarried	10	33.33
<b>Education Status</b>		
• Illiterate	5	16.67
• Primary	6	20
• Secondary	13	43.33
• Higher Secondary	3	10
• Graduate & above	3	10
<b>Socio Economic status (As per BG Prasad scale)</b>		
• Upper class	0	0
• Upper middle class	3	10
• Middle class	10	33.33
• Lower middles class	6	20
• Lower class	11	36.67

**Table 3: Relationship of the Primary Care giver or family care giver with the patients.**

Relationship	No.	%
Spouse	14	46.67
Children (son / daughter)	12	40
Near relative	4	13.33
Total	30	100

**Table 4: Employment of the Primary Care Givers**

Category of Service	No.	%
Retired	2	6.67
Employed in Govt./Pvt./Self	12	40
Unemployed	16	53.33
Total	30	100

**Table 5: Information of the Primary Care Giver**

Information	No.	%
<b>Ever provided Care Earlier</b>		
• Yes	15	50
• No	15	50
<b>If Yes Duration</b>		
• 1 – 2 months	7	46.67
• > 2 – 6 months	2	13.33
• 6 – 12 months	4	26.67
• > 1 Year	2	13.33

**Table 6: Comparative Analysis between the cognitive domain of the Pretest & Post test Score of respondents**

Different aspects of cognitive domain	Pre test		Post test		t - value	p - value
	Mean	SD	Mean	SD		
Definition of Paralysis	0.41	0.67	1.99	0.61	4.650	<0.001
Types & causes of Paralysis	0.67	0.91	1.79	0.72	2.721	<0.001
Risk Factors	2.10	1.61	3.81	1.21	3.241	<0.001
Signs & symptoms of Paralysis	1.70	1.67	3.46	0.61	5.987	<0.001
Nutritional therapy	1.80	1.17	3.61	1.91	5.899	<0.001
Physiotherapy	1.60	0.97	3.57	1.62	3.127	<0.001
Speech Therapy	1.80	1.26	2.67	1.82	2.949	<0.001
Self Care	1.70	1.66	3.69	1.73	5.921	<0.001
Associated Co morbidities	2.10	1.71	3.80	1.33	5.876	<0.001
Complications & their prevention	2.20	1.31	4.01	1.41	6.524	<0.001
Early Diagnosis & Prompt treatment	1.40	1.57	3.91	0.62	5.732	<0.001
Total	17.48	5.62	36.31	4.94	17.081	<0.001

**Table 7: Mean % Gain in Knowledge in Key areas between Pre and Post test on Care giving of Paralytic Patients**

Different Aspects of Knowledge Domain	Pre Test		Post Test		Mean %
	Mean core	Mean %	Mean Score	Mean %	
Definition of Paralysis	0.41	12	1.99	48.19	36.19
Types & causes of Paralysis	0.67	14	1.79	46.17	32.17
Risk Factors	2.10	39.27	3.81	89.17	49.90
Signs & symptoms of Paralysis	1.70	24.32	3.46	82.16	57.84
Nutritional therapy	1.80	26.14	3.61	85.96	59.82
Physiotherapy	1.60	21.16	3.57	83.14	61.98
Speech Therapy	1.80	26.14	2.67	85.26	59.12
Self Care	1.70	24.32	3.69	86.31	61.99
Associated Co morbidities	2.10	39.27	3.80	88.47	49.20
Complications & their prevention	2.20	42.61	4.01	97.76	55.15
Early Diagnosis & Prompt treatment	1.40	19.17	3.91	92.63	73.46
Total	17.48	32.61	36.31	82.67	50.06

## DISCUSSION

Table 1 provides information that out of 30 paralysed patients 20 were paraplegics and 10 were quadriplegics. Again out of 20 paraplegics, 15 (75%) were of Traumatic and 5 (25%) were non traumatic in etiology. Similarly out of 10 quadriplegic patients 8(76.67%) were of traumatic and 2 (23.33%) were of non-traumatic etiology. [Table 2] depicts the socio demographic characteristics of participating primary care givers. Out of 30 care givers 19 (63.33%) were females and half 15(50%) of the participants belonged to 31 – 40 years age group followed by 8 (26.67%) in the age group of 51 – 60 years. Out of 30 care givers 20 (66.67%) were married and regarding educational status of care givers 13(43.33%) were having secondary education followed by 6 (20%) having primary education. The socio economic status was calculated as per capita income (modified BG Prasad scale) and 11 (36.67%) belonged to lower class followed by 10(33.33%) to middle class.[Table 3] shows the relationship of the primary care giver with the patients. Out of 30 care givers nearly half i.e. 14(46.67%) were the spouse of the patients. [Table 4] depicts the employment of the care givers. Out of 30 care givers, 16(53.33%) were unemployed followed by 12 (40%) either self-employed /Govt employed / employed in private company.Regarding information on whether they ever provided care earlier 15(50%) of the care giver agreed to it. When enquired about the duration of the care giving in the past amongst care givers, out of 15 about 7(46.67%) had an exposure of 1 – 2 months. Table no 6 gives a comparative analysis between the cognitive domain of the pre test and post test score of the respondents. The finding reveal that all the different aspects of cognitive domain were found to be higher in the post test than in the pre test score on care of the paralytic patients. In the post test there was an increase in the level of knowledge in all aspects like in definition of paralysis (48.19%), types and causes of paralysis (46.17%), risk factors (89.17%), signs & symptoms (82.16%), Nutrition therapy (85.96%), physiotherapy (83.14%), self care(86.13%), complication and their prevention

(55.15%).However, the increase in the level of knowledge in all aspects was found to be statistically significant (as  $p < 0.05$ ) indicating that the effectiveness of self-instructional module & guide was an excellent interventional teaching mode to bring about a change in the level of knowledge amongst care givers. The overall mean % score of posttest was 82.67% and that pre test was 32.61%. This itself revealed that the SIM guide was an effective method of teaching in the care givers. Bhall et al in this study on involvement of the family members in caring of patients revealed that caregivers cleaned and dressed the patients in 94% and fed the patients in 90%, changed position and helped in back care in 65%.<sup>[5]</sup>Our results clearly show that caregivers of persons with SCI are in need of and can benefit from interventions that help them manage the medical and functional limitations of the care recipient, enhance support from formal and informal resources, reduce social isolation, and encourage them to monitor and improve their own health and well-being.<sup>[6-9]</sup> In as much as care giving is a highly interactive endeavor in which caregivers and care recipients mutually affect each other, it is critical that both members of the dyad be involved in clinical interventions. This study provides intervention strategies that can be useful in achieving this goal, but even these methods can be improved upon. Our recent work on the effects of suffering in the care giving context suggests that clinical interventions that provide the caregiver with tools for addressing care recipient suffering may be particularly effective in achieving positive outcomes for both caregivers and care recipients.<sup>[10-12]</sup>

## CONCLUSION

Involve patient's care givers in assessment of post discharge needs and help them in decision making and in planning. The family members and the treating team comprising of doctors & nurses should discuss about patients progress, rehabilitation, needs and issues after discharge, explained about next level of care, and how to provide support & care.The other areas to be discussed includes cognitive impairments or

urinary incontinence if any as it is commonly involved.

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