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A Study on the Effectiveness of a Self Instructional Module among Primary Care Givers to Paraplegic & Quadriplegic Patients

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Original Research Article

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Abstract: Care of paralysed patients & their associated needs, dependence, supporting care on the primary care givers as real challenges. 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 ***** & other associated complication. Our aim was to determine the socio-economic profile of the primary care givers of the paralytic patients and to assess the pretest knowledge of primary care givers regarding the care of paraplegic and quadriplegic patients. It is an evaluative cross sectional study with instructional approach. The study was conducted in the Deptt. of Orthopedics at VIMSAR, Burla period from 1st Jan 2014 to 31st Dec 2017. A total 30 primary care givers of the quadriplegic and paraplegic patients who were admitted in the orthopedic deptt 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 (which includes socio-demographic variables, knowledge, attitude and practice on care giving) to the paralysed patients. A self instructional guide cum module in Odia was prepared and implemented on the 5th day of admission. Out of 30 paralysed 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. The relationship of the primary care giver with the patients. 46.67% were the spouse of the patients. 53.33% were unemployed followed. Only 50% care giver providing care earlier 50% of the care giver & 7 had an exposure of care giving in the past of 1 – 2 months. Involve patient's family / care givers in assessment of post discharge needs and help them in decision making & to planning. Care giving training (multi disciplinary education about communicating strategies & patients in ****, proper handling, care and positioning of the patients and how to independently shoulder care based on patient strengths and limitations.
Keywords: Paraplegic & Quadriplegic, Pretest, Post test, Self instruction.

INTRODUCTION

Providing care for many patients with chronic disease at home in 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 [1]. 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 in growing [2, 3].

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 paralysed 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 [4].

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 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 is 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.

Objectives

- 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.
- To find the effectiveness of a self instructional module by comparing pretest and post test knowledge score.

METHODOLOGY

Type of study: Evaluative cross sectional study with instructional interventional approach.

Place of Study: The study was conducted in the Deptt. of Orthopedics at VIMSAR, Burla.

Period of Study: 1st Jan 2014 to 31st Dec 2017.

Study Participants: The primary care givers of the quadriplegic and paraplegic patients who were admitted in the Dept. of Orthopedics at VIMSAR, Burla.

Sampling Technique and Sample Size

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.

Study Instruments

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 paralyzed 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.

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

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

Characteristics	Frequency (n)	%
Sex		
• Male	11	36.67
• Female	19	63.33
Age (in years)		
• 20 – 30	2	6.67
• 41 – 50	15	50
• 51 – 60	8	26.67
• 61 – 70	1	3.33
Marital Status		
• Married	20	66.67
• Unmarried	10	33.33
Education Status		
• Illiterate	5	16.67
• Primary	6	20
• Secondary	13	43.33
• Higher Secondary	3	10
• Graduate & above	3	10
Socio Economic status (As per BG Prasad scale		
• 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.	%
Ever provided Care Earlier		
• Yes	15	50
• No	15	50
If Yes Duration		
• 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 Posttest 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 no. 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 no. 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 no. 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 no. 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 post test was 82.67% and that pre test was 32.61%. This it revealed that the SIM guide was an effective method of teaching in the care givers. Bhalla *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% [5].

CONCLUSION

- Involve patient's family members / 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 include cognitive impairments or urinary incontinence if any as it is commonly involved.
- Care giving training (multi disciplinary education about communicating strategies & patients in aphasia, proper handling, care and positioning of the patients and how to independently shoulder care based on patient strengths and limitations.

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