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Mukesh Kumar Mr
College of Nursing, Sikar (Rajasthan)

Rajesh Kumar Sharma Mr
Himalayan College of Nursing, Swami Rama Himalayan University, Dehradun,
rajeshsharma.hcn@gmail.com

Mahalingam

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Cover Page Footnote

I would like to express my deep appreciation to Dr Ratna Prakash, Former Principal, Himalayan College of Nursing and Dr Sanchita Pugazhendi, Principal, Himalayan College of Nursing for granting necessary permission and constantly encouraging throughout the research project. In addition, I would like to express my gratitude to the caregivers of CRF patients for their full cooperation to make this study possible.

Need based instructional program on care competency of informal care givers for chronic renal failure patients at home

Mukesh Kumar¹, Rajesh Kumar Sharma², Mahalingam²

1) Lecturer, College of Nursing, Sikar (Rajasthan), India

2) Assistant Professor, Department of Medical Surgical Nursing, Himalayan College of Nursing, Swami Rama Himalayan University, Dehradun, Uttarakhand, India

Abstract

Introduction: Majority of patients with Chronic Renal Failure (CRF), Chronic Kidney Disease (CKD) and End Stage Renal Disease (ESRD) depends on their family and friends, to manage their chronic illness throughout the course of illness. Appropriate home care of CKD can help to prevent or delay the progression of illness. **Methods:** A pre-experimental study with quantitative approach was undertaken on 45 care givers of CKD patients with the objective to study the improvement in competency regarding home care through administration of an instructional programme and information booklet. The program and the booklet consisted information on nutritional management, rest and exercises, psychological support and communication, fistula care, maintaining skin integrity and maintaining fluid and electrolyte balances in CKD patients. Subsequently knowledge and skills of care givers regarding care at home was assessed. **Results:** The mean difference of knowledge score was statistically significant ($t = 19.156$), at 0.05 level of significance. The mean difference in practice score was statistically significant at 0.05 level of significance. The results suggested that instructional programme regarding home care was effective in terms of enhancing knowledge and practice score among care givers of CRF patients. **Conclusion:** Educating the caregivers of CKD patients about importance of specialized care will help in providing optimum care in patients of CKD.

Key words: Chronic Renal Failure, Care givers, Home care, Instructional programme.

INTRODUCTION

Chronic kidney disease (CKD) is a global public health problem affecting 5–10% of world population in general (Eknayan G., *et al.*, 2004). Chronic kidney diseases are evolving as a most important health threat (Remuzzi & Weening, 2005). The people suffering from kidney diseases eventually require a form of renal replacement therapy which is expensive and life-long therapy. Even though haemodialysis, peritoneal dialysis and kidney transplantation save lives, they are expensive and unaffordable for poor people. In India, nearly 90 per cent of patients cannot afford this cost (Dash & Agarwal, 2006).

CKD is associated with decreased quality of life, increased health care expenditure and premature death. There is an urgent need for developing

approaches for early identification of CKD and to take actions to prevent further advancement to end stage renal disease (ESRD) (Remuzzi & Weening, 2005). In India, nearly 1,00,000 patients develop ESRD each year (Kher, 2002). Very few patients consult the nephrologists. Others may initiate treatment and likely to lost to follow up within three months. These patients may drop out because they realize that dialysis is not a cure and has to be performed over the long-term period (Perico & Remuzzi, 2012).

Maximum number of patients with CRF are receiving care at home and they require support from family members and friends to manage CRF. The quality of life of caregivers of haemodialysis patients may be affected adversely and they may also experience a momentous burden. Health care professionals

Rajesh Kumar Sharma

Assistant Professor, Department of Medical Surgical Nursing, Himalayan College of Nursing, Swami Rama Himalayan University, Swami Ram Nagar, Dehradun (Uttarakhand) – 248140, India. E-mail: rajeshsharma.hcn@gmail.com

should provide social support and psychological interventions to improve caregiver's quality of life and in turn better patient outcome (Belasco & Sesso, 2002). In the management of CRF patients, caregivers' needs are often unrecognized or neglected. The caregivers can experience stress, and poor quality of life and the needs of caregivers are often neglected (Tong, Peter, & Craig, 2008).

The CKD patients have to be taken care at home for a longer time before kidney transplantation and they depend on intermittent dialysis and drugs to maintain optimum health. Hence the investigator intended to undertake the present study to assess the improvement in competency regarding home care among caregivers of patients with CRF.

METHODS AND MATERIALS

A quantitative approach with pre-experimental design was adopted to assess the effectiveness of a need based instructional programme regarding home care of patients with CRF on care competency of informal care givers.

The study was conducted at Himalayan Hospital, Dehradun, where family members and caregivers at home of CRF patients were accompanying their patients during haemodialysis. The study was approved by the Research and Ethics Committee of Himalayan Institute of Hospital Trust and permission was obtained from Principal Himalayan College of Nursing. Administrative permission was obtained from authorities of Himalayan Hospital. Forty five caregivers of CRF patients were selected by non-probability convenient sampling technique. The study tools, (1) Structured Knowledge Questionnaire (SKQ) and (2) Self-Reported Practice Checklists were given to nine experts from various disciplines of nursing and medicine for establishing content validity. Reliability of SKQ was calculated by Split half method ($r=0.91$) and indicated a high reliability of tool. Reliability of self-reported practice check list was calculated by test retest method ($r=1$) and it was found highly reliable.

After obtaining a written informed consent, on the day one of the study, the demographic data of care givers and data related to illness profile of their

patients were collected. On the same day a pre-test SKQ and Self-Reported Practice Checklists were administered to the care givers to assess knowledge and practice. Later, intervention was administered. On 8th day post-test was conducted.

RESULTS

Demographic Characteristics of care givers of CRF patients

The demographic characteristics of the participants is presented in table 1

Table 1: Frequency distribution of care givers according to their selected demographic variables. (n=45)

Demographic Characteristics	Frequency	Percentage
Gender		
Male	28	62
Female	17	38
Relationship with patient		
Parents	10	22
Life partner	24	53
Siblings	9	20
Others	2	5
Marital status		
Married	38	85
Unmarried	7	15
Occupation		
Employed	36	80
Unemployed	12	20
Area of Residence		
Rural	27	60
Urban	18	40
Educational status		
Primary Education	6	13
Secondary education	22	49
Graduation	12	27
Post-Graduation	5	11

Majority 28 (62%) of the caregivers of CRF patients were males and more than half of the care givers [24 (53%)] were life partners of the CRF patients. Most of the caregivers [38 (85%)] were married and 36 (80%) of the caregivers were employed. More than half [27 (60%)] of the care givers were residing in rural area and only half of the caregivers [22 (49%)] had secondary level of education.

Illness profile of CRF patients:

The information such as duration of illness, duration and number of haemodialysis, diet and food restrictions are presented in table 2.

Table 2: Distribution of illness profile of chronic renal failure patients (n=45)

Clinical profile	Frequency	Percentage
Duration of illness		
< 1year	16	36
1-2 year	9	20
2-3 year	6	13
> 3years	14	31
Duration of undergoing Haemodialysis		
< 1year	23	51
1-2 year	9	20
2-3 year	5	11
> 3years	8	18
Number of haemodialysis per week		
1	2	4
2	35	78
3	8	18
Total number of haemodialysis visits		
<50	9	20
51-100	14	31
101-150	5	11
>150	17	38
Restriction of food and fluid		
Yes	40	89
No	5	11
Presence of other chronic diseases		
Hypertension	14	31
Diabetes	9	20
Others	7	16

Data presented in table 2 shows that only 16 (36%) of CRF patients were diagnosed one year ago and 23 (51%) of the CRF patients were undergoing haemodialysis for the past one year. Most of [35 (78%)] the CRF patients were undergoing haemodialysis process twice a week. Only 17 (38%) of the CRF patients had undergone haemodialysis more than 150 times in their course of illness. Majority [40 (89%)] of the CRF patients were advised to take less food and fluid. About two thirds [30 (67%)] of the CRF patients had been diagnosed to have other chronic disease such as hypertension and diabetes.

Comparison of pre-test and post-test knowledge scores of care givers

Paired 't' test was used to assess the significant difference between pre and post-test knowledge scores of caregivers regarding homecare of CRF patients. The data are presented in Table 3.

The mean pre-test knowledge score was 15.8 (± 2.97) whereas, the mean post-test knowledge score was

21.2 (± 2.47) which reveals the effectiveness of need based instructional program regarding homecare of chronic kidney disease patients. The findings showed a statistically significant difference between pre and post-test knowledge scores ($p=0.0001$) and interpreted that intervention was effective in improving the knowledge of caregivers of CKD patients.

Table 3: Comparison of pre and post-test knowledge score of caregivers regarding homecare of chronic renal failure patients (n=45)

Knowledge scores	Mean \pm Standard Deviation	Mean difference	't' value	'p' value
Pre-test	15.8 \pm 2.97	5.54	19.15	0.0001
Post-test	21.2 \pm 2.47			

Comparison of pre-test and post-test practice scores

Paired 't' test was used to assess the significant difference between pre and post-test practice scores regarding homecare of chronic kidney disease patients.

Table 4: Comparison of pre and post-test practice scores of caregivers regarding homecare of chronic renal failure patients. (n=45)

Practice scores	Mean \pm Standard Deviation	Mean difference	't' value	'p' value
Pre-test	10.6 \pm 1.91	3.35	16.45	0.0001
Post-test	13.39 \pm 1.52			

Data presented in Table 4 shows that the pre-test mean practice score was 10.6 (± 1.91) whereas, in the post-test the mean practice score was 21.2 (± 2.47) which reveals the effectiveness of need based instructional program regarding homecare of CRF patients in improving the practice of caregivers of CRF patients. The paired 't' test findings showed a statistically significant difference between pre and post-test practice scores ($p = 0.0001$).

Table 5: Correlation between post-test knowledge score and post-test practice score of care givers (n=45)

Variables	r	p-value
Post-test knowledge and Post-test practice score	0.30	0.05

Table 5 shows a positive correlation between post-test knowledge score and post - test practice score which was statistically significant ($p<0.05$). It also shows that if knowledge increases then the practice also improves.

DISCUSSION

In this present study it was found that the need based instructional program administered to caregivers of CRF patients was useful in increasing awareness to follow healthy practice to prevent complications and to maintain healthy living of their patients within the imposed limitations. These findings were similar to study findings of Babamohammadi & Khalili, (2006), who reported that home-care programme helped the patients receiving haemodialysis in weight gain and decreasing associated symptoms. Most of the caregivers were interested in the instructional programme. They responded well by clarifying their doubts regarding home care especially dietary practices. The acceptability of teaching depends on many factors such as motivation of subject to learn, benefits, emotions of learner towards life of patient, availability of facilities, financial capacity and availability of supportive system at the site of home care.

This study used small convenience sample and did not include comparison groups. In addition, samples were limited to caregivers of patients with a single setting. Randomized trials can be undertaken to demonstrate the role of teaching programmes in enhancing caregiver's knowledge and skill. Researchers had given limited attention to the nature of the personality factors or dispositions of caregivers. The validity and reliability of the questionnaire was approved but the lack of specific questionnaires on knowledge of caregivers is another limitation of the study. Therefore, results of the study cannot be generalized.

Further research can focus on a broader range of caregiver interventions such as psychological therapy, counselling and practical support. This could stimulate recommendations for improving caregiver support. Providing care and treatment for CKD patients and support for family care provider should be a critical component of care of CRF patients.

CONCLUSION

Improvement in caregivers understanding about home care management of CKD patients is needed to advance awareness and practices so that they

promote the health and improve the quality of life of patients with CKD.

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