

Research Article

Impact of an Educational Intervention on Care Burden among the Caregivers of Patients Undergoing Hemodialysis

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ABSTRACT

Background: Chronic kidney disease (CKD) is a major disease burden, which is affecting the population across the globe, CKD patients depends on hemodialysis to sustain life. These patients are cared by an informal support system comprises spouse, father, mother, daughter, son, or any other caregiver who are related or not related to patient. Providing continuous care for such type of patients whose prognosis, an irreversible outcome is an overwhelming experience for caregivers due to physical and psychological distress, limitations to their personal and social activities, and impending financial burden. **Objective:** The objective of this study was to assess the burden among the caregivers of patients undergoing hemodialysis before and after the educational intervention. **Methods:** A quasi-experimental one-group pre- and post-test design was used. Sixty participants were selected through non-probability convenient sampling. Care burden was assessed through standardized tool (Zarit Care Burden Interview) with r -value of 0.98. **Results:** Statistical analysis shows that the pre-test mean score was 45.63 with standard deviation (SD) of 10.42, whereas post-test mean score was 27.13 with SD of 8.69. Wilcoxon signed-rank test; a non-parametric test was applied, and P -value was found to be < 0.001 at 95% of the confidence interval ($P < 0.05$). Therefore, the educational intervention on home care management was found to be effective in reducing the care burden among the caregivers of hemodialysis patients. **Conclusion:** Hence, educational intervention on home care management was an effective reinforcement strategy to reduce the care burden among the care providers of hemodialysis patients.

Keywords: Care burden, Caregivers, Chronic kidney disease, Hemodialysis

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Introduction

Goodman and Punoos called family caregivers who care for a patient for a long period a “second victim” and the family of a person with a chronic disease “potential patient.” Issues around the presence of disability within a family are not only

limited to person with disability but they also concern the whole family as the mental and financial burden are shared and care is provided as per the level of severity. However, when care is provided for a long time, he/she may experience burden. This, in turn, may return in a more negative impact on emotional and social aspects of caregiver’s life.^[1]

The patients of chronic kidney disease (CKD) are rising worldwide strikingly, it affects 8–16% of the world population including India.^[2] The rising incidence of the disease is likely to pose major problems for both health care and the economy in future years.^[3]

Singh *et al.* (2013) conducted a cross-sectional survey using a tool Screening and Early Evaluation of Kidney Disease on 6120 Indian subjects from 13 academic and private medical centers all over India, the purpose of the study was to know the epidemiology and risk factor of CKD. Result of the study shows that prevalence of CKD (Chronic Kidney Disease) was 17.2% out of which ~6% had CKD stage 3 or worse state.^[4]

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CKD is much more common than people realize and often goes undetected until the disease is well advanced and kidney failure is imminent. It is possible to slow or stop the progression of the disease through renal replacement therapies. One of the treatment modalities is hemodialysis, it is the procedure for removing wastes and excess water from the body using artificial filter.^[5]

According to Hall *et al.*, once a person commences to hemodialysis, significant numbers of dietary, fluid, activity, and medication restrictions are imposed traditionally and uniformly on maintenance dialysis patients. Most of these patients and their family members suffer from depression.^[6] The most frequently reported physiological and psychological concerns of people undergoing hemodialysis are food and fluid restrictions, changes in marital and social role, financial concerns, frequent hospitalization, limitation in leisure activities, sleep disturbances, increased dependency on artificial kidney machine, changes in body appearance, and uncertainty about the future.^[7]

Hedayati *et al.* (2009) stated in his study that most chronically ill patients are cared by an informal support system comprised family members. Moreover, caring for patients with chronic and disabling disease is associated with the caregiver experiencing physical and psychological distress, limitation to their personal and social activities, and financial burden. Especially, the experience of a wife caregiver has been described as a mixture of anger, helplessness, guilt, and isolation and was deemed to lost freedom because they had relinquished recreational and social activities.^[8]

Kim (2017) stated in his recent study that some family members find caregiving to be burden and stressful, while others derive self-satisfaction in giving care to their loved one. To reduce caregiving stress and depression in the family caregivers and to improve their self-esteem, continuous support and help from specialists are necessary. In addition, a variety of intervention programs needs to be designed to motivate them to participate regularly at the community level.^[1]

A cross-sectional analytical descriptive study was conducted in 2014 on the caregivers of hemodialysis patients. About 72.5% of caregivers reported moderate-to-severe levels of caregiver burden. A significant relationship was observed between gender of the patient with caregiver burden score of $P = 0.031$ and type of the income with caregiver burden score of $P = 0.000$. Caregivers of male patients and patients with inadequate income had a higher caregiver burden score.^[9]

A study was conducted in 2011, to evaluate the burden on caregivers as perceived by hemodialysis patients in the Frequent Hemodialysis Network (FHN) trials. According to this study, most hemodialysis patients in FHN trials perceived substantial burden on their unpaid caregivers, and self-perceived burden was associated with worse depression and quality of life.^[10]

Purpose of the study

The aim of this study was to reduce care burden among the caregivers of patients undergoing hemodialysis through a

structured teaching program on various aspects of coping strategies and assessing their burden before and after the structured teaching program through standardized ZBI.

Methods

Design and participants

The selection of the research design depends on the purpose of the study and the conditions under which the study is conducted. For the present study, a descriptive evaluative approach was chosen and quasi-experimental one-group pretest-posttest design was used.

This study was conducted at the dialysis units of selected hospitals of Navi Mumbai, India. These institutions were included for the study based on ease in availability of the sample, researcher's accessibility, and familiarity with the institutions.

A total of 60 study participants were selected through non-probability convenient sampling based on the inclusion and exclusion criteria. Participants were the caregivers of patients undergoing hemodialysis in selected dialysis units.

Measures

For the assessment of the burden, standardized Zarit Care Burden Interview (ZCBI) was used, which was validated by 17 experts of varied field of nursing, medical, and paramedical sciences. Reliability of the tool was assessed through inter-rater reliability method and calculated by intraclass consistency reliability value ($r = 0.98$), and the tool was found to be highly reliable in assessing caregiver's burden. Translated version (Hindi) of the tool was used.

Procedure

Ethical consideration

1. Ethical approval was obtained from the Institutional Ethical Review Committee
2. Permission was also obtained from the guide and authorities of the selected hospitals for data collection
3. Before the data collection, informed consent was obtained from each participant involved in the study
4. Permission was obtained from Mapi Research trust for using the standardized ZBI tool.

Data collection process

Written permission was taken from the medical superintendents of various hospitals. Data collection was done for a period of 4 weeks. The samples were introduced to the study; informed consent was obtained from each of them. On the 1st day, the pre-test was conducted to assess burden through standardized ZBI and 45 min of teaching session was taken on various aspects of home care management. Then, post-test was conducted after 7 days.

Demographic information

Majority of the caregivers (56.6%) were in the age group of 40–59 years, 56.7% were female, 40% were wives, and they reported no previous training on home care management [Figure 1]; 44% were graduate and only a few (13%) were illiterate [Figure 2]. Majority of the treatment expenses (for dialysis) 71.7% were covered under government health scheme and 26.7% were self-financed [Figure 3].

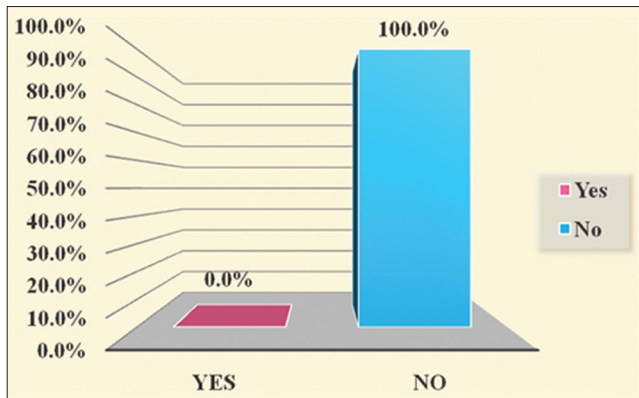


Figure 1: Distribution of caregivers based on previous training on home care management ($n = 60$)

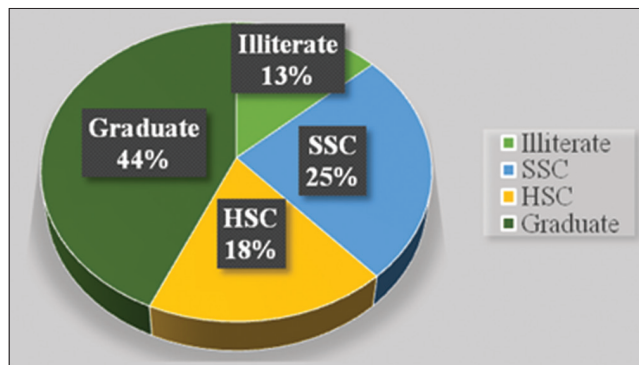


Figure 2: Distribution of caregivers based on educational qualification

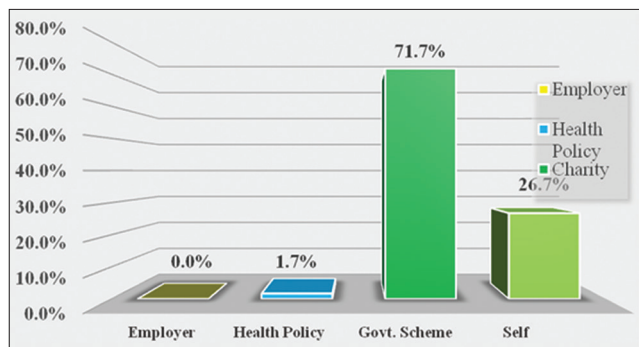


Figure 3: Distribution of caregivers based on expenses covered for the hemodialysis patients

Figure 1 depicts that none of the caregivers underwent any previous training on home care management. Figure 2 shows that most of the caregivers (44%) were graduate and only a few (13%) were illiterate ($n = 60$). Figure 3 shows majority of the treatment expenses (for dialysis) 71.7% were covered under the government health scheme and 26.7% were self-financed ($n = 60$).

Results

Distribution of sample based on care burden among caregivers of patients undergoing hemodialysis before and after the structured teaching program

The burden interview is scored by summing the responses of the individual items. Higher scores indicate greater caregiver distress. The level of subjective burden was determined according to the following standardized scoring:

- 0–20 – Little to no burden
- 21–40 – Mild to moderate
- 41–60 – Moderate-to-severe burden and
- 61–88 – Severe burden.

Table 1 shows that in pre-test, 63.33% of samples reported moderate burden, 6.66% reported severe burden, whereas in post-test, none reported severe burden and only 6.66% reported moderate burden.

Table 2 shows that mean pre-test burden was 45.63 with a standard deviation (SD) of 10.42, whereas the post-test mean was 27.13 with SD of 8.69. Since the data do not follow normal distribution and there was no random selection of the study participants, so a non-parametric test equivalent of Student's t -test and Wilcoxon signed-rank test (Z) were applied to find whether there is any significant difference between pre- and post-burden score. $P = 0.001$ (<0.05) indicates that there is a statistically significant difference between pre-test and post-test score of care burden. Hence, null hypothesis (H_0) is rejected. The educational intervention was found to be effective in reducing the care burden of the study participants.

Table 3 shows that there is a significant difference in the overall median score of pre-test (2) and post-test (1). In pre-test, majority of the sample reported that they sometime feel burden, whereas in post-test, it was reported as rarely. Hence, the structured teaching program is effective as there is a significant reduction in all the aspect of burden except financial burden.

Table 1: Distribution of sample based on overall burden score ($n=60$)

Care burden	Pre-test $f(\%)$	Post-test $f(\%)$
Little (0–20)	2 (3.33)	11 (18.33)
Mild (21–40)	16 (26.66)	45 (75)
Moderate (41–60)	38 (63.33)	4 (6.66)
Severe (61–80)	4 (6.66)	0 (0)

Table 2: Distribution of caregivers based on significant difference in pre-test and post-test mean burden score

Care burden	Mean	Standard deviation	Difference mean	Wilcoxon signed-rank test (Z)	P-value	Level of significant
Pre-test	45.63	10.42	1.73	6.791	<0.001	S
Post-test	27.13	8.69				(P<0.05)

*S – Significant

Table 3: Comparison of overall item-wise median score regarding care burden (n=60)

Item-wise total median score for burden	Pre-test	Post-test
	Median score	Median score
Burden in relationship	2	1
Emotional well-being	2	1
Social and family	2	1
Loss of control over one's life	3	2
Financial burden	4	4
Overall score	2	1

*0 – Never, 1 – Rarely, 2 – Sometime, 3 – Quite frequently, 4 – Nearly always

Discussion

The scoring range criteria in Zarit Burden Interview (ZBI) were little to no burden, mild to moderate, moderate-to-severe burden, and severe burden. Results of the study show that using standardized ZBI tool, 63.33% of caregivers reported moderate burden, 26.6% reported mild burden, 6.66% had severe burden, and only 3.33% reported little burden in pre-test assessment of burden, whereas in post-test, 75% reported mild, 18.3% had little burden, 6.66% had moderate burden, and none of the caregiver had reported severe burden during post-test [Table 1]. The present study reveals that there is a significant reduction in the overall burden mean score (27.13) among the caregivers of patients undergoing hemodialysis during post-test (pre-test mean score was 45.63), after the educational intervention on home care management [Table 2].

Findings of the study conclude that change in certain aspects of burden such as burden in relationship, emotional well-being, social and family life, and loss of control over one's life [Table 3] was evident after the administration of educational intervention. After the intervention, their perception toward burden has been changed and developed a positive outlook in taking care of hemodialysis patients [Table 3]. Therefore, the study proved that the educational intervention was an effective reinforcer for the caregivers to reduce their care burden and provide appropriate and prompt home care to the client undergoing hemodialysis. Although the caregivers had an appropriate knowledge regarding patient care, they required some form of training or counseling to change their perception toward certain aspects of burden. There was no reduction in the financial burden before and after the educational intervention because this variable cannot be manipulated by an educational intervention.

The present study is consistent with the study conducted by Ozmen and Yurttas.^[11] They carried out a descriptive study in Turkey with 92 caregivers, the aim of this study was to determine the care burden of caregivers of patients with multiple sclerosis. Data were collected by standardized Zarit Burden Scale completed by caregivers. Most of the caregivers (65.2%) were female and 71.7% of them were married. The average age of caregivers was 38 and above. The mean ZCBI score of caregivers was 25.44 ± 9.50 . ZCBI score was significantly higher in caregivers providing care for more than 6 years (28.09 ± 10.16). In addition, ZCBI score was significantly higher in caregivers providing care 3–4 h/day (32.23 ± 8.37) and providing physical care (29.28 ± 5.18).

Conclusion

Findings of the study conclude that reduction in the care burden was evident after the administration of educational intervention on home care management. This study will help the nurses to arrange a teaching session in hemodialysis departments on home care management of hemodialysis patients and coping mechanism for caregivers to relieve their burden and develop a positive thinking within self and others.

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