

Experiences and Difficulties Faced by Family Caregivers of Hemodialysis Patients in Ranchi, Jharkhand

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Abstract: This paper presents the experiences and difficulties faced by family caregivers of hemodialysis patients in Ranchi, Jharkhand.

Keywords: chronic renal failure, exploratory and caregivers.

1. Introduction

Prevalence of chronic renal failure (CRF) is increasing not only in Western communities but also in developing countries. Overall, an average of 1/10 people suffers from renal diseases, with 110 billion dollars spent each year for the treatment of renal failure. In India, the prevalence of CRF has been estimated approximately 514 people and its incidence 70 people/1 million population. The patients under hemodialysis suffer from several complications due to the disease. Because of these tensions, incidence of negative reactions such as anger, depression, and even suicide, loss of self-esteem as well as family problems is very likely in these patients. In addition to dependency and the above-mentioned complications, undergoing hemodialysis three times a week can affect the daily lives of patients and their families. Furthermore, the complications and restrictions arising from hemodialysis influence all domains of life including physical, occupational, and economic and could be considered a negative dimension of quality of life (QoL), increasing the patients' dependency on other family members

Living with hemodialysis patients can be worrisome, restrictive, and stressful for both patients and caregivers; it is therefore highly important to understand the family caregivers' challenges and concerns and identify their needs to provide the high-quality care.] Compared with caregivers of patients with other chronic disease, hemodialysis patients' caregivers are faced with additional difficulties including repeated hospitalization and taking several drugs. The caregivers prefer the patients' needs over their own and therefore spend lower time practicing the behaviors of health promotion, which affects health and QoL negatively. Since family caregivers often assume heavy responsibilities of care without adequate preparation and training, many difficulties may happen to them. Although care and support of caregivers are very important, sufficient attention is not paid to them and they are not supported in Iran's health-care context. The need for clarifying

effective factors on caregivers and their needs should be investigated in future studies. In Given et al. review article, the need for research on promotion of knowledge and skill in the caregivers of chronic disease patients were noted. Meanwhile, it is critical to use relevant intervention. Besides that, if the caregivers' needs are not investigated and explained satisfactorily, the patients may not receive the optimal services the caregivers can offer to them, not to mention potential risks threatening their mental and physical health. Therefore, the needs of the caregivers, as hidden patients, should be investigated as with patients' needs and health-promoting and support programs should be developed for them. Therefore, the present study was conducted to investigate the family caregivers' experiences among the caregivers of the patients undergoing hemodialysis.

2. Methods

A. Study design

A descriptive-exploratory qualitative design, based on a thematic analysis approach, was used to reach the study aim. This design is an approach to qualitative research, particularly if there is inadequate data on the subject of study.

B. Setting and sample

This study was conducted in 2016 in Ranchi, Jharkhand, The participants were 25 family caregivers. The participants were selected by purposeful sampling. The inclusion criteria were being the main and family caregiver, having spent several months caring for hemodialysis patients, being consent to participate in the study, having ability to communicate in hindi, and no other patients needing care in the family. The participants were permitted to discontinue participation at any step of the study.

C. Ethical consideration

The ethical approval was obtained from the respective authorities'. The participants were informed about the aims and significance of the research, and then they provided written informed consent to participate in the study. In addition, the participants were ensured that participation in the study is voluntary and they can withdraw from the study at any step of

the study.

3. Data collection and procedure

The interviews were conducted in Hindi. First, the interviews were unstructured and started with the question “Would you please explain about your experiences of caring for your patient?” Probing questions such as “Could you say more about that?,” “What did you think then?,” and “Could you please give an example?” were asked depending on the participants' response, to enrich the data further. Eventually, after conducting 34 interviews (2–3 nonsuccessive sessions for each participant), the list of codes was merged into themes, with the analysis continuing until all the thematic categories were saturated. Any interviews, lasted for 45–60 min, were recorded by MP3 with the participants' consent. To supplement the data gathering, field note-taking was conducted as well.

A. Data analysis

A thematic analysis approach was used to figure out the patterns within the texts. Initially, the interviews were transcribed word for word and reviewed repeatedly and meticulously to ensure the data immersion. The first author gathered the data through face-to-face interviews, which were the main tools of data gathering. Throughout data collection, the researcher asked certain probing questions in the next interview. The analysis continued by reading the text several times to determine the differences and similarities. Finally, after 34 interviews, the list of codes was merged into themes, and the analysis continued until all thematic categories were saturated, that is, there was no new clear concept to detect and the categories were coherent or meaningful.

4. Results

Fifteen (60%) family caregivers were female and 10 (40%) male; the participants were 20–69 years old (mean \pm standard deviation = 47 ± 3.9 years). Twelve (48%) were married and the rest single. The relationship of the caregiver to the patient, most were the spouse ($n = 15$) or daughter ($n = 10$). Furthermore, the mean length of care per day was 10 h and the length of time of caring for their patients was 7 years. From the interviews, some codes and themes emerged, consisting of three main themes and nine subthemes. Then, the relevant themes were explained to the caregivers, and therefore, they could confirm them with further explanations.

A. Heavy care burden

A key theme generated from the experiences of the caregivers in the present study was heavy care burden, consisting of three subthemes:

B. Multifaceted and complex problems

The caregivers' experiences demonstrated that numerous physical and psychological difficulties and complex conditions of the disease brought about many challenges for them, and therefore, they had to tolerate the heavy burden of caretaking

the patient

C. Continuous and excruciating caretaking

Constantly talking of making efforts continuously, paying attention to the patient, and enduring hard circumstances, the caregivers perceived caretaking of a hemodialysis patient as continuous and excruciating

D. Changing nature of needs

A concern of the caregivers that led to a decline in their caring capacity was changing the nature of the patients' needs. These patients were always engaged in actual and potential problems because of chronic nature of the disease.

E. Tension in caretaking

The psychological pressure due to caretaking of the patients under hemodialysis brought about anxiety and concerns associated with anxiety and turbulence in the caregivers' mind. In fact, the atmosphere of caretaking of the patients was infused with tension and turbulence, consisting of four subthemes as follows

F. Variety of tasks and unspecialized caregivers

The caregivers constantly talked of the variety of tasks and lack of necessary expertise to do these tasks:

G. Disease interference with normal process of caregiver's life

The caregivers' experiences indicated as the disease progressed; the caregiver's life was further disturbed

H. Intensification of disease and adaptability

The caregivers argued that as the family member's disease intensified, coping with and adaptability to new conditions became more and more difficult. One of the caregivers said:

I. Caregiver's emotional exhaustion

Another concern of the caregivers was to tolerate hard and excruciating psychological conditions, which was due to the patients' constant suffering and discomfort. Emotional exhaustion was a concern of the caregivers and families as well as a challenge facing health system. This theme consisted of three subthemes as follows:

J. Fatigue and wearing out

An aspect of caregiver's emotional exhaustion was feeling fatigued and worn-out in encountering hard conditions of the disease.

K. Declined stamina of caregivers

The caregivers considered the complicated problems and their intensification as well as no recovery to be other factor contributing to declining their stamina.

L. Continuous suffering and hopelessness

Continuous suffering and turbulence of a caregiver due to encountering patient's problems leads him/her to hopelessness.

5. Conclusion

The present study sought to investigate the perspectives and experiences of the family caregivers of patients under hemodialysis. In this regard, the four general themes were generated. The first theme was heavy burden of care which was derived as a very significant problem among the caregivers. The heavy burden was a complicated, multifaceted problem derived from the care experiences. Relevantly, Suri et al. argue that the caregivers of hemodialysis patients may consider the care burden to be heavy because they have to contribute greatly to caring for hemodialysis patients. Besides that, they need further mental support to tolerate the heavy burden of disease-related difficulties, irrespective of what problem their patients are suffering from.

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