

Lived Experience of Haemodialysis-Related Fatigue: A Phenomenological Study

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Abstract

Fatigue is a widely documented symptom among patients undergoing haemodialysis. The aim of the present study was to explore the lived experience of fatigue among patients undergoing haemodialysis. The study involved a qualitative approach that used an interpretive hermeneutic phenomenology based on Van Manen's method. The sample included seven patients undergoing haemodialysis in two selected hospitals at Ernakulam district in Kerala. They were recruited by purposive sampling. Data were collected using semi-structured interviews. The thematic analysis followed the methods as suggested by Max Van Manen for isolating themes, and four themes emerged. They were overwhelming physical toll (two sub themes; unable to do even insignificant activities and aches and discomforts); cornered to home; demanding rest and dynamic fatigue. The findings illuminate the meaning of fatigue as experienced by patients undergoing hemodialysis in Indian context, and highlight the need for its management. The generated knowledge can be used by health professionals to develop and test psychosocial interventions to mitigate fatigue in haemodialysis patients.

Chronic kidney disease (CKD) is a major and growing public health problem worldwide, with a 9 percent annual increase in numbers of patients. CKD is a gradual and permanent loss of kidney function (Jha et al, 2013). The final stage of CKD is End Stage Renal Disease (ESRD). Haemodialysis (HD) is a life sustaining treatment for patients with ESRD. While HD is a lifesaving procedure, it cannot substitute a healthy kidney, it taxes the patient and those on maintenance dialysis often lead lives of compromised quality due to the burden of illness, which usually includes managing multiple concurrent symptoms, comorbidities and the demands of dialysis (Buemi et al, 2008). Research suggests fatigue as one of the most common symptoms experienced by patients receiving dialysis. The prevalence of fatigue ranges from 60 percent to as high as 97 percent in ESRD patients on long-term dialysis therapy.

Literature Review

A systematic review was conducted in 2007 to describe the prevalence of all symptoms and to understand the total symptom burden in ESRD. The weighted mean prevalence (and range) of fatigue/tiredness was 71

percent (12% to 97%). Although there are numerous studies describing the prevalence and severity of fatigue experienced by patients undergoing HD, only few studies that had explored the experience of fatigue among these patients in developed countries were found (Letchmi et al, 2011). A qualitative descriptive study was conducted in 2013 to describe the experience and self-management of fatigue among 14 adult patients on HD from a dialysis centre in a rural area in the mid-Atlantic US.

The results revealed four themes. Participants described fatigue as having physical and mental components, being difficult to manage and as having consequences and associated factors (Horigan AE, Schneider SM, Docherty S, and Barroso J, 2013). A similar qualitative study was conducted using Colaizzi's methods to explore the fatigue experience of 14 HD patients from a hospital in South Taiwan. Ten themes were delineated and were classified into three domains. The first domain 'physical fatigue' consisted of four themes: (1) habitual fatigue (2) experiencing the uraemic symptoms (3) suffering from sleep disturbance and (4) insufficient physical energy. The second domain 'affective fatigue' contained three themes: (a) detesting long-term treatment (b) perceiving depression (c) and feeling exhausted. The third domain 'cognitive fatigue' included three themes: (a) regretting lost cognition (b) intentional isolation and (c) coping with fatigue (Lee et al, 2007).

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There were no published Indian studies identified by the researcher that explored the experience of fatigue among patients undergoing HD. Fatigue in patients on HD has been associated with lower Quality of Life (QOL) and lower survival rates (Jhamb et al, 2009).

As fatigue can have negative effect on HD patients, it is important to develop a deeper understanding of this phenomena and its meaning for the HD patients. This will help health professionals, especially nurses to understand, support and thereby develop strategies to help alleviate the consequences of fatigue in these patients. So the researcher chose to do a qualitative approach using Van Manen's approach to understand the lived experience of fatigue among patients undergoing haemodialysis. The present investigation differs from other qualitative investigations because it tries to explore the lived experience of fatigue that has not been researched so far in India.

Objectives

The objective of the study was to explore the lived experience of fatigue among patients undergoing haemodialysis

Methodology

Research Design and Sampling: The study involved a qualitative approach that used an interpretive hermeneutic phenomenology based on Van Manen's method (Van, 1990). The sample was seven patients undergoing haemodialysis, selected purposively from two selected hospitals (Regional Dialysis Centre, Aluva and Lourdes Hospital of Ernakulam district) in Kerala. Sample size was seven, as this was the number at which 'saturation' of the data was reached. As the purposive sampling was conducted for the purpose of diversifying the participants, it was called a maximum variation sampling technique.

Criteria of sample selection: Patients undergoing haemodialysis for more than three months; undergoing dialysis twice a week; age above 18 years; and willingness to participate in the study.

Instrument

1. *Personal information:* It consisted of a series of questions about the participants' age, gender, educational background, marital status, type of family, occupation, duration since diagnosis of chronic renal failure, duration since undergoing haemodialysis, last haemoglobin value, and co morbidities.

2. *Interview guide:* A semi-structured interview guide was developed based on the literature review and; was

sent to experts and modifications were done as per to the expert opinions. It had the main question as: Tell me about your thoughts and feelings about your fatigue while undergoing haemodialysis. Subsequent questions focused on spatiality, corporeality, temporality, and relationality. Probes were offered as a means to clarify participant descriptions.

Ethical consideration: Ethical clearance was obtained from the institutional ethics committee. Written informed consent was obtained from the participants. Confidentiality and anonymity were maintained. Every effort was made to ensure that the participants were not put at risk of emotional harm and they were assured that they could withdraw from the interview at any time. Pseudonyms were created to ensure confidentiality.

Data Collection : The data was collected from June 2014 - September 2014. Patients who were willing to participate in the study were assessed for eligibility as per inclusion criteria. After obtaining permission from the hospital authorities, data were collected from seven patients undergoing haemodialysis, using a semi structured interview guide. The place for interview was decided based on the comfort expressed by the study participants. The interviews were conducted while the patients were undergoing haemodialysis. The researcher gathered experiential description through face-to-face interviews. Participants were encouraged to elaborate on their responses to some questions and to further expand and clarify these responses.

The researcher listened and observed the participants closely, noted their body language and tone of voice. The researcher was respectful of silences as it would allow the participant to generate meaning and new understanding. The average time taken for each interview was approximately 15-20 minutes. Each interview was audio taped and later transcribed for data analysis. Information about demographics was collected at the end of the interview. Data collection was stopped when data saturation occurred with seven study participants, i.e., data was collected until no new information emerged. During the period of analysis, the researcher checked the credibility of the findings by returning to the participants. Thus the researcher had two sessions of contact with the participants.

Statistical Analysis

The data were analysed manually using interpretive phenomenology. The thematic analysis followed the three methods as suggested by Van Manen viz. detailed reading approach, the selective or highlighting approach and the holistic reading approach for isolating thematic statements. The early analysis involved analysing each interview separately or going from the parts (of the text) to whole (Manen, 1990). Highlighting of keywords, phrases and ideas were done. Keywords became concepts through intuitive ideas and reading and re-reading the data, dwelling with the data and dialoguing with the text. During the final analysis, the concepts from the preliminary analysis were grouped in an additional column of the table, pooled with similar concepts after much thought on which ideas belonged together, to form the subthemes and finally the development of major themes. Hermeneutic phenomenological reduction was used for qualitative analysis (Manen, 1990). In hermeneutic reduction (Adams & Manen 2008), researchers reflect on their pre-understanding, framework and biases. To achieve reduction and critical self-awareness, a journal of personal reflections on the interview as well as researcher's thoughts throughout the study period was kept.

Results

The participant's age ranged from 39 to 62 years. Four were males. Majority had secondary education. All participants were married and were unemployed. Five of them belonged to nuclear family. The years since diagnosis of ESRD ranged from three to seven years. The years since undergoing haemodialysis ranged from one year to six years. The Hb value ranged from 6.5 to 11.2 gm/dL. Hypertension and diabetes mellitus were the major co-morbidities.

The themes that emerged from the lived experience of fatigue were overwhelming physical toll (unable to do even insignificant activities, aches and discomforts), cornered to home, demanding rest and dynamic fatigue.

Overwhelming Physical Toll

Physical discomforts may be experienced when a person experiences fatigue. But patients undergoing haemodialysis expressed that their experience of fatigue was not just tiredness but beyond it. The two subthemes were inability to do even insignificant activities, and aches and discomforts.

Inability to do even insignificant activities: Participants expressed that their body felt reluctant to do even insignificant daily chores when they experience fatigue (*Names mentioned here are pseudonyms*).

Saranya said, "I have leg pain and tiredness to such an extent, that I will not be able to wear even slippers. I have difficulty in walking... I can't climb steps... I have severe difficulty in speaking while experiencing fatigue. When I speak using cell phone, and when the duration of conversation is prolonged, I experience severe fatigue. Then I will not be able to speak at all. But I can't say so to the caller".

Similarly, Saranya, Sreejith said, "I feel extremely tired, to such an extent that I cannot eat my lunch or go to kitchen or even just step out of my house. I used to lie down in the room... I never used to step down even to the courtyard".

Renjith lamented that his activities and strength are completely low, compared to past due to fatigue. He said "I experience fatigue as completely drained... I don't feel like doing anything. I don't feel even to walk... I just lie down... Compared to past, I feel sad that I am not able to do things as before".

Aches and discomforts: Almost all study participants stated that they experienced pain and bodily discomforts during fatigue. Saranya expressed it as "When I experience fatigue, there is body discomfort. I used to have arm and leg pains in between. Then sometimes, I do have mild chest pain. I have headache. I really give importance to fatigue, especially when I do experience all such body pains". Paul also supported the above statements in his experience, "I have body pains... When I have fatigue, I experience severe back pain. The pain is intolerable".

Suja's experience of fatigue was a bit terrific, as she felt the discomfort she experienced was beyond verbal description. Suja said, "I cannot open my eyes when I feel that fatigue. My eyes just start to close and I feel drowsy. Then I used to feel as though I am losing my consciousness. I feel drained when that fatigue comes... I cannot tell what sort of an experience it is during severe fatigue... I cannot just describe it in words". Suja shared that her experiences of fatigue were bodily and mental discomforts "I feel mood off... severe discomfort". In contrast, Nazia's experience was that she felt drowsy and light-headed. Joseph like Nazia said that he had light headedness, "I feel light headed... a sort like very weak... loss of strength... eh... what to tell?"

Cornered to Home

Fatigue among dialysis patients was not just limited to experiencing body aches and discomforts, but it moved a step beyond by confining them to lead a restricted life. Their experience of tiredness was so intense that it chained their lives, cornered to home. Though their spirit yearned to participate in the leisure moments, their experience of fatigue cornered their life to a world in home.

Sreejith said sadly, “Weekly twice I have to come here for dialysis. I will be unable to go anywhere, due to fatigue that I experience on the day of dialysis... I don’t go anywhere for the rest two days... I just keep lying down in the bed. I don’t go anywhere outside my home... I used to watch TV... I used to lie down in the room... I never used to step down even to the courtyard”. Paul in anguish said, “I will go and lie down at home. That’s it... When I experience fatigue I never used to go out of my home. Only, if there is any necessity, I will go outside, on the next day of dialysis. Thus always, I used to be at home”.

The lessons taught by experience prompted Joseph to utter the words “I don’t even go for walking. By walking, I used to become breathless or my BP used to go down. So I stay cornered to home watching TV... If not, I used to walk only inside the house... I used to feel, if I could have gone for a function, it would have been good to go and meet all of relatives and friends... I have not gone for any function after I was started on dialysis. I don’t go anywhere even when my friends call me. When I go and come back I used to feel severe fatigue”. The experience of fatigue was so harsh that Joseph went out only for a relative’s or a friend’s funeral. In the words of Joseph, “I used to go out only when any of my significant people dies...to see them at last. I go so that I can see them once more for the last time.”

Renjith also shared a similar experience of being cornered to home. He said, “I just lie down... I don’t go out of my home. I will just be inside my home. I don’t have relations with anybody... I used to do work inside my home... take care of my children... eat 3 dots only bathe... and be just a support for my wife. That’s all.” He added, “The problem is I feel thirsty when I go outside due to hot climate. That’s why I don’t go outside. If I go out I will drink more water due to hot weather. Then my weight will increase. It will cause problems... breathlessness. Due to that when I come here, sometimes there will be no machines available for dialysis, as it may be occupied. So I stay at home to control all these.”

Demanding Rest

Fatigue, when experienced compelled the patients undergoing dialysis to seek rest, irrespective of place or situations. The physical symptoms they experienced forced them to lie down and rest. It was a kind of demanding rest for Paul who said that when he experienced fatigue, he even has lain down in public places, because of the severe aches he felt. “It may be in the bus stop. I had lain down in the bus stop. I had even lain on the roadside... sometimes, these problems occur. I used to lie down near the bus stop or near any building. Suddenly I used to sweat profusely and experience severe tiredness. I just would like to lie down somewhere for just ten minutes. Then I will become alright... Mostly I experience fatigue”

Saranya also expressed, “When I have fatigue, I want to lie down. I will be unable to walk. I can’t walk even a bit. I just want to lie down somewhere”.

Dynamic Fatigue

Fatigue among patients undergoing dialysis was found to have its up and downs. Participants expressed that they felt extremely tired during certain days while they felt better on the other days. This was evident in Paul’s words, “I experience severe fatigue after dialysis. I experience fatigue on the day and the following day after the dialysis session. As the dialysis gets over, I experience severe fatigue. Some days, I used to experience severe fatigue. On other days, fatigue is not very severe”. This was experienced irrespective of gender. Suja said, “Some days I used to experience severe fatigue. Some days when I feel ok, I used to do some small works. I would do some small household works”.

Renjith felt near normal during certain days, when fatigue level was minimal or nil. In his words, “Sometimes my fatigue level is very low, that I feel I don’t suffer this disease... then I used to feel that I can do anything. But I feel so only at some time”.

Nazia felt fatigued during some days, especially in the morning. She felt it was really challenging to get up from the bed in the morning due to fatigue. In Nazia’s words, “I used to have fatigue in the morning. Some days... I have difficulty in getting up especially on the next day of dialysis... I experience fatigue especially to get up from the bed in the morning.”

Discussion

Four themes that emerged from the lived experience of fatigue were overwhelming physical toll, cornered to home, demanding rest and dynamic fatigue.

A similar finding of physical fatigue was found in a study conducted in 2013 to describe the experience and self-management of fatigue among 14 adult patients in the mid-Atlantic US. The participants described a lack of physical strength and energy that made them feel lifeless, washed out, weak, and drained. They described how they could not do things that they wanted to do, such as going out, exercising, climbing stairs, doing household chores and reading (Horigan et al, 2012).

Similar experience of restricted life had been shared by participants, in a study conducted among HD patients in Taiwan, where they reported a feeling of intentional isolation due to the decreased interest, motivation and apathy to the surroundings (Lee et al, 2007). These are consistent with the present study findings.

Nursing Implications

Nursing practice: To provide holistic care, nurses should first try to understand the patients' unique experience and try to assist them in developing strategies to address their problems. The study reminds the practicing nurses that "if we understand what the patient understands, we can develop interventions that are not only medically sound but also that are accepted by patients". Knowledge gained from the qualitative aspect of this research offers insight into the experiences of patients' fatigue that help nurses to deliver a better patient care. Hence, the staff nurses who are tempted to label the patients as non-compliant must consider the impact of dialysis on the patient.

Nursing education: This study illuminates the lived experience of fatigue which can help students to understand the daily turmoil faced by patients undergoing HD.

Nursing administration: Nurse administrators can organise and make plans for various programmes to provide support for patients undergoing HD.

Nursing research: There are numerous problems faced by patients undergoing HD due to the encountered fatigue. This study can be used as a framework by budding nurse researchers to understand and manage selected problems

Recommendations

Based on the findings of this study, nurse researcher can develop and test the effect of various non-pharmacological strategies for fatigue reduction in patients undergoing HD. Further phenomenological studies on lived experience of nurses and care givers

working with patients undergoing HD can be carried out.

Conclusion

This study offers insights into the experience of fatigue in patients undergoing haemodialysis. As nurses are on the front line, encountering the patients, they can facilitate support by developing and implementing strategies of non-pharmacological interventions like counselling to help patients cope up with the fatigue. Measures to treat fatigue must be actively addressed so that patients can have a better quality of life.

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