

Original Research Article

Hemodialysis Patients' Lived Experience of Sleep Disturbances: A Qualitative Study

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ABSTRACT

Sleep disturbances are highly prevalent in patients undergoing Hemodialysis. The aim of the present study was to explore the lived experience of sleep disturbances among patients undergoing Hemodialysis. The study used an interpretive hermeneutic phenomenology based on Van Manen's method. The sample included seven patients undergoing Hemodialysis 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 accompanying discomforts (emotional and physical discomforts), abounding thoughts (ruined life thoughts and disturbing thoughts), ongoing coping with difficult hours (measures to sleep, passing the difficult hours and spouse support) and interrupted sleep. The findings illustrate the meaning of sleep disturbances as experienced by patients undergoing hemodialysis in an 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 sleep disturbances in Hemodialysis patients.

Key words: *Lived Experience, sleep disturbances, Hemodialysis*

INTRODUCTION

Hemodialysis (HD) is a life sustaining treatment for patients with End Stage Renal Disease (ESRD).^[1] The final stage of Chronic Kidney Disease (stage 5) marked by complete or nearly complete irreversible loss of renal function is ESRD. Based on the current Indian population of 1.2 billion, even a conservative estimate of ESRD burden in India would suggest that about 1,650,000 to 2,200,000 people develop ESRD every year.^[2] The only option for ESRD patient is lifelong dialysis or transplantation. HD continues to be the most common mode of therapy worldwide, evidenced by data showing that in over 70 per cent of reporting countries, at least 80 per cent of patients are on this mode of therapy.^[3]

Several studies carried out in the last 30 years have demonstrated a high percentage of sleep related disorders. According to previous studies, around 50 - 80% of dialysis patients have problems associated with sleep disorders, including difficulty in falling asleep, waking up early, daytime sleepiness, leg jerking and trembling.^[4] Compared with the general population, the prevalence of sleep disorders is significantly higher in ESRD patients treated by dialysis.^[5] The reported prevailing sleep disorders are insomnia (65.9%), Restless Leg Syndrome (RLS) (42%) and Obstructive Sleep Apnoea (OSA) (31.8%).^[6] High prevalence of sleep apnoea (65%) was reported in patients with ESRD,^[7] which is considerably higher than in the general population. Indian studies reported

the prevalence of sleep disorders ranging from 35.5% to 68.1% among patients undergoing HD. [1,8,9] Sleep quality is an important and determining factor that affects the QOL in dialysis patients. [10]

Although significant research has been conducted in HD patients to characterize sleep abnormalities in terms of prevalence, types, correlation and complications, little has been published related to the lived experience from a patient's perspective. Qualitative research methods have become increasingly important as ways of developing nursing knowledge for evidence based nursing practice. The research method of phenomenology has become more popular in the last ten years in the field of nursing, and, indeed, in other health disciplines. [11,12] Because professional nursing practice is enmeshed in people's life experiences, phenomenology as a research approach is well suited to the investigation of phenomena like sleep disturbances experienced by HD patients. [13]

A descriptive qualitative phenomenological study was conducted in 2010 among Peritoneal Dialysis (PD) patients examining the experience of sleep disturbances. The purpose of the study was to describe how patients on Peritoneal Dialysis treatment at home, experience tiredness linked to poor sleep in everyday life. The study was conducted among 14 patients in three hospitals from south east of Sweden. The results revealed one general structure "circling around in tiredness," that was visualized as a model and consisted of four constituent parts: the need for sleep and rest, consequences of tiredness in everyday life, abilities and strategies for adjustment and the sensation of being tired. [14] There were no other published studies that were identified by the researcher on the lived experience of sleep disturbances among patients' undergoing HD.

As poor sleep quality is found to predict morbidity, cardiovascular disease and QOL, it is essential to explore and understand the patient's lived experiences.

The insight gained by this qualitative finding can help health professionals, especially nurses to plan and implement interventions that can reduce or mitigate the sufferings related to sleep disturbances and thereby improve the QOL. The present investigation differs from other qualitative investigations because it tries to explore the lived experience of sleep disturbances that has not been researched so far in India in patients undergoing Hemodialysis. So the researcher chose to do a qualitative approach using Van Manen's approach to understand the lived experience of sleep disturbances among patients undergoing hemodialysis.

Objective

The objective of the study was to

1. explore the lived experience of sleep disturbances among patients undergoing Hemodialysis

MATERIALS AND METHODS

Research Design and Sampling

The study involved a qualitative approach that used an interpretive hermeneutic phenomenology based on Van Manen's method. [16] The sample was seven patients undergoing Hemodialysis, 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 were patients undergoing hemodialysis more than three months; undergoing dialysis twice a week; age above 18years; and who are willing to participate in the study.

Instrument

1. Personal information

It consist of a series of questions about the participant's age, gender, educational background, marital status, type of family,

occupation, duration since diagnosis of chronic renal failure, duration since undergoing hemodialysis, last hemoglobin 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 sleep disturbances while undergoing Hemodialysis? Subsequent questions that focused on spatiality, corporeality, temporality, and relationality were included. 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 cease the interview at any time. Pseudonyms were created to ensure confidentiality.

Data collection

The study was conducted from June 2014 - September 2014. Patients who were willing to participate in the study was assessed for eligibility as per to inclusion criteria. After obtaining permission from the hospital authorities, data were collected from seven patients undergoing hemodialysis, 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 hemodialysis. 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 analyzed 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 analyzing each interview separately or going from the parts (of the text) to whole. [15] 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 then 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. [15] In Hermeneutic reduction, researchers reflect on their pre-understanding, framework and biases. To achieve this 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

I. Description of the pertinent characteristics of the participants

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 Hemodialysis ranged from one year to six years. The Hb value ranged from 6.5 to 11.2gms/dL. Hypertension and diabetes mellitus were the major co-morbidities.

II. Themes derived from the lived experience of sleep disturbances among patients undergoing HD

The themes that emerged from the lived experience of sleep disturbances were accompanying discomforts (emotional and physical discomforts), abounding thoughts (ruined life thoughts and disturbing thoughts), ongoing coping with difficult hours (measures to sleep, passing the difficult hours and spouse support) and interrupted sleep.

1. Accompanying discomforts: The theme 'accompanying discomforts' comprised of the following subthemes: Emotional discomforts and Physical discomforts

1a. Emotional discomforts

The first theme that emerged in the lived experience of sleep disturbances among patients undergoing HD was accompanying discomforts. While experiencing sleeplessness, all study participants' experienced emotional disturbance. They were not at ease emotionally. Inability to sleep created a sort of emotional upset in terms of feeling angry, sad, irritated, tensed and even depressed. The fact that they were not able to sleep created all these emotions. A study participant, Saranya, recalled "I feel a sort of irritation when I don't sleep. I used to think, if I was able to sleep at least a little time..... If I am unable to sleep by one or two a.m., I feel highly upset..... When I don't get sleep, I feel angry.....I have to leave my son to school in the morning. My husband has to go to office. So

I have to prepare food at the right time. So when I am unable to sleep at night, I feel upset. Then I feel depressed".

A similar feeling was expressed by another participant, Paul, who said, "I used to feel sad and unhappy". Joseph also expressed his sadness during sleepless nights as, "I feel sad that I am unable to sleep". Anger was experienced by two study participants, when they experienced sleeplessness. Participant Suja said "I feel angry....I used to fight with my husband... When I feel sick, I used to feel angry and say like, I am unable to sleep and it's really terrible, etc."

1b. Physical Discomforts

The study participants also verbalized that they experienced physical discomforts during the long hours of sleeplessness. Their world of sleeplessness was surrounded by aches and cramps experienced during the silent night.

Participant, Sandhya, recalls, "I have great discomfort in my legs, hands and the body..... I have very little sleep". While Sandhya related the discomforts in legs, hand and body, Saranya expressed that the discomforts she experienced cannot be just put in words. In her words, "I have discomforts over the whole body..... I have pains when I don't sleep...when I experience sleeplessness, I have discomforts especially in the back. My eyes used to ache due to sleeplessness...still I don't get sleep...even though my eyes ache and pain, still I don't get sleep. I used to have severe cramps in my legs...I experience lot of discomforts, when I don't sleep...I cannot just tell in words the difficulties I face during sleeplessness....it's a horrible experience. I experience all sorts of discomforts during sleeplessness...a sort of retarded feeling I used to have headaches due to sleeplessness...I used to feel sad and drowsy due to this headache".

A similar experience was shared by Joseph as, "I don't get sleep till two a.m. especially on the day of dialysis. I used to experience aches in my hands and legs...watery eyes what to tell? I used to have cramping aches in my hands and legs".

2. Abounding thoughts

The following subthemes were included in the theme "abounding thoughts".

a. Ruined life thoughts and b. Disturbing thoughts

2a. Ruined life thoughts

Almost all participants expressed that, thoughts filled their sleepless nights. But the thoughts that sprung were neither fascinating nor pleasant. In contrary, their thoughts reminded them that their life was ruined and were disturbing.

Participant Sreejith expressed "Many thoughts used to come to my mind...but all those were not good thoughts. I used to have lot of tensions...I had no sleep since I was diagnosed with the disease. Thoughts like, my future is lost used to come to my mind....Since the disease came, all those small plans made for life came to nothing. Everything is lost".

These words were supported by Paul, who also expressed a nearly similar experience, "When I used to lie awake without sleeping, I used to think about lot of things during that time....Many thoughts do come to mind during that time. As various thoughts come to my mind, I used to think and doze into sleep...The thought that usually come to my mind is that, my life has ruined due to this disease."

Female participants also suffered thoughts of lost life during sleeplessness. In the words of Suja, "During sleepless nights, I used to think a lot about recent events...especially thoughts like...previously I was active and was able to go for a job...but now I am unable to do that...such thoughts disturb me and I used to suffer sleeplessness...I used to think a lot about my children and that we don't have an own land. ..If I never had this disease, I could have been active. I along with my husband would have worked to meet all necessities. But now neither he nor I are able to go for a job... I used to think all these things and feel sad. I keep lying down and just doze off early in the morning".

Nazia also expressed the same as "I used to think a lot and feel sad while lying

in the bed. ...During sleepless nights, I used to have thoughts like, I don't have money and am facing difficulties".

These ruined life thoughts highly conquered and ruled the mind of patients undergoing Hemodialysis and thus formed a part of the lived experience during their sleeplessness.

2b. Disturbing Thoughts

Next to ruined life thoughts, the second pressing concern was disturbing or troubling thoughts. Some participants verbalized that they suffered disturbing thoughts during sleeplessness. They had thoughts that sleeplessness would lead to complications or would affect the next day's daily chores.

Saranya said, "I have fear, that if I am unable to sleep, then my BP will rise". Similar to Saranya, Joseph also had troubling thoughts of fear, but expressed in a different way. He verbalized it as "I used to think a lot, as I lie down.I used to think about my children....about the absence of my children at home. Only me and my wife are there at home. So, if any serious problems do occur, my wife has to call my neighbours for help".

Suja was flooded with troubling thoughts that her condition has affected even the life of her spouse. She said, "My husband is unable to go for a job as he takes care of me and accompanies me for all dialysis and treatments. Weekly twice, we have to come here for dialysis. I have to go to Kottayam on Wednesdays for follow up visits and to buy medicines. Due to all these he doesn't get time to go for work. Thus he is taking care of me. I have all these troubling thoughts in my heart."

Thus, participants were not just experiencing physical and mental discomforts. Their minds were active taking them to a world of ruined and disturbing thoughts while experiencing sleepless nights.

3. Ongoing coping with difficult hours

This theme "ongoing coping with difficult hours" comprised of the following subthemes:

a. Measures to sleep b. Passing the difficult hours c. Spouse support

3a. Measures to sleep

During sleep disturbances, each participant had attempted their maximum by trying certain home measures to sleep. A study participant, Saranya, said that she used to take a cup of tea and antihypertensive medicines that sometimes helped her to sleep. In the words of Saranya "Then I would try to sleep, after taking medicines for BP and after having a cup of tea (pause)... Sometimes, I do sleep after that". Similarly some of them took sedatives to sleep. Two study participants Sreejith and Suja said the same. Sreejith verbalized "I had been taking tablets to sleep" and Suja said "I slept only after taking medicines". The words above reveal that the experience of sleep disturbances includes the attempts taken by the afflicted to promote sleep.

3b. Passing the difficult hours

The time of sleeplessness is not a very pleasant or a blossoming time of happiness. The participants felt the experience of sleep disturbances as daring to pass the difficult hours. Some were accustomed to the situation, where they tried certain divertional measures to pass the time, while others just lay awake while away the difficult hours. Paul said, "When I suffer sleep disturbance, I used to just keep lying down...eh...I used to watch TV till 11 or 12 midnight.....Sometimes, I used to prepare and take tea...that's how I spend time at night".

Saranya expressed her grief of passing the sleepless nights as follows "Without sleeping, I will wait for the break of the morning. I will keep sitting. Sitting like that, I will await the dawn". A similar phrase was added by Renjith who said "When I don't sleep, I used to wake up and sit. I used to get up around 12 midnight or one a.m."

Nazia said she used to lie down with eyes open and often used the time for her spiritual concerns. She verbalized it as "I don't sleep. I just lie down with my eyes open. ...Then I used to pray at night, even at

midnight.Then I used to chant all those which I have read in the Koran". Watching spiritual programs on TV was a method which Joseph tried to pass those helpless hours. He expressed his experience as "I don't get sleep. I used to turn this side and that side in the bed during sleeplessness, especially on the day of dialysis till 2 or 3 a.m. I used to sleep continuously for one to one and half hours, after which I awake. Then I used to watch TV or read for one to one and half hour. I used to watch Rosary – a spiritual programme that is telecast.....Then when I feel sleepy, I used to go and lie down".

3c. Spouse support

While coping with difficult hours was the key experience of sleepless nights, a few participants treasured the support that they received from their spouse. Suja's words welled with gratitude when she tried to express her husband's love and support during those sleep away hours. She said "my husband also will be awake from sleep...he used to press my legs when I have aches."

Similarly Joseph was sharing the support extended by his wife as, "I used to have cramping aches in my hands and legs...then my wife used to press and massage the extremities....sometimes I do sleep by that comfort...I never used to tell her to do so. Still she used to take care of me. She used to massage my back or legs...so I used to sleep for some time experiencing the comfort. But I don't get continuous sleep".

While receiving support from their spouse was the experience of sleep disturbances as narrated by two participants, Paul said he never used to wake up his spouse, until it was deemed necessary. In Paul's words, "I never use to wake her. I used to wake my wife, only when I experience any difficulties".

4. Interrupted sleep

A satisfied sleep is usually expressed in terms of deep uninterrupted sleep. The essence of freshness while awakening is usually equated to the number of hours of

continuous sleep experienced by a person. Participants undergoing hemodialysis experienced interrupted sleep.

Paul lamented, "I am not able to sleep continuously for eight hours. I used to wake up.... again I will sleep. Sleep pattern is like this..... It is not possible to sleep continuously for eight hours". Nazia expressed it as "I used to sleep at night 10 p.m. ...Then in between...around two or three am, I used to wake up".

Joseph with a touch of pain due to his lost blessed sleep added, "I don't get continuous sleep. Earlier I never used to feel satisfied even with six to eight hours of sleep. But now I don't get sleep continuously even for one and half hour. Even in daytime, I used to get only two hours of sleep ...I used to remain awake..." Thus the experience of sleep disturbances is like having to endure hours of interrupted sleep when all others in the world are in the lap of deep silent sleep.

DISCUSSION

Four themes emerged from the lived experience of sleep disturbances. They were accompanying discomforts, abounding thoughts, ongoing coping with difficult hours and interrupted sleep.

The first theme "accompanying discomforts" had two sub themes: emotional and physical discomforts. Literature supports the fact that many people on dialysis have trouble sleeping at night because of aching, uncomfortable, jittery, or restless legs. [16] This supports the present study finding.

The second theme extracted from the patient's lived experience was "abounding thoughts" with two sub themes: ruined life thoughts and disturbing thoughts. Almost all participants revealed that thoughts filled their sleepless nights. The ruined life thoughts that filled the experience of sleep disturbances included: future is lost; loss of job; loss of money and property and loss of an active life. Some participants verbalized the experience of disturbing thoughts which included sleeplessness will lead to complications; will affect the next day's

daily chores; fear of facing future and having affected the life of spouse.

A qualitative study was conducted in 2013 to explore the lived experience of critically ill patients in ICU with daily sedation interruption among 12 participants with an ICU stay ranging from three to 36 days recruited from a hospital in New South Wales, Australia. [17] Longing for sleep and being tormented by nightmares captured the experiences and concerns of some of the participants. This finding is slightly different from the present study findings, as participants expressed nightmares rather than abounding thoughts.

"Ongoing coping with difficult hours" was the third theme in the present study which had three sub themes: measures to sleep, passing the difficult hours and spouse support. Participants relied on certain measures to sleep when they experienced sleep disturbances. Some took a cup of tea or medications when they experienced sleep disturbances. The participants due to their helplessness were daring to pass the difficult hours of sleep disturbance. Some verbalized they were accustomed to the situation and they tried certain diversional measures like watching television, reading, chanting prayers etc. to pass the time, while others were just lying awake to while away the difficult hours. Few participants treasured the support that they received from their spouse, while they were coping with difficult hours of sleep disturbance.

A similar theme of "attempts at coping and sleep management" was observed in a qualitative study that was conducted in 2015 to explore the specific role of sleep in patients' experience of their illness among 11 participants with chronic fatigue syndrome in UK. [18] This theme correlates with the present study findings of coping with difficult hours.

In a study conducted in 2007 to explore the fatigue experience of HD patients in Taiwan, one of the participants verbalized a similar measure of passing the difficult hours during sleep disturbance. In

the words of the participant “Just can't fall asleep. Sometimes, I took a slight nap in the daytime. At night, I often sat in the living room, wide-awake and alone”.^[19]

In the present study, the fourth theme in the lived experience of sleep disturbance was “interrupted sleep”. Participants lamented over the loss of continuous sleep with which they were blessed before. Almost all patients experienced interrupted sleep.

The results of the current study were supported with the results of a study that was conducted to explore the fatigue experience of HD patients in Taiwan.^[19] In the compared study, most participants attributed their tiredness to sleeping problems. Some participants said that their sleep time could not to be continuous and they usually woke up every two or three hours. One of the participants had expressed “I just can't sleep well. Sometimes, I sit all night. But you can't sleep well that way. I usually woke up after an hour”. This is consistent with the present study findings.

CONCLUSION

There is no gainsaying that sleep is the sweet balm that soothes and restores us after a long day of work and play. But for patients undergoing HD for whom sleep is elusive or otherwise troubled, the issue is far more fraught. The findings of this research offer insight into the experience of sleep disturbances in patients undergoing Hemodialysis. Sleep disturbances in hemodialysis patients should be considered by healthcare providers, especially nurses and measures to treat them should be undertaken to help them lead a life with better QOL.

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