

Lived Experience of Patients Undergoing Hemodialysis: Quality of Life Perspective

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ABSTRACT

There is growing recognition of Health-Related Quality of Life (HRQOL) issues in End Stage Renal Disease (ESRD) patients undergoing Hemodialysis (HD). The aim of the present study was to explore the lived experience of Quality of Life (QOL) among patients undergoing Hemodialysis. The study involved a qualitative approach that 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 six steps delineated by Max Van Manen and four themes emerged. They were crestfallen life (3 sub themes; hard pressed life, deserted life and abounding losses); support and comfort; accompanying death and unfulfilled wishes. The findings shed light on the lived experience of QOL that has not yet been researched in an Indian scenario. The generated knowledge can be used by health professionals including nurses to help patients undergoing HD lead a life with better quality of life.

Keywords: *Lived Experience, Quality of life, End Stage Renal Disease, Hemodialysis.*

Chronic kidney disease (CKD) is a common on-communicable disease that is becoming a worldwide health problem. CKD is a gradual and permanent loss of kidney function. Generally, renal diseases progress to a final stage as End Stage Renal Disease and the function is substituted by Renal Replacement Therapy (RRT), Hemodialysis, Peritoneal Dialysis or transplantation (Jamison et al, 2006). Hemodialysis continues to be the most common mode of therapy worldwide, evidenced by data showing that, in over 70 percent of reporting countries, at least 80 percent of patients are on this mode of therapy (Zhang & Rothenbacher 2008).

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Health-related QOL is an important measure of how a disease affects the lives of patients. Patients who are treated with dialysis experience many threats to Health Related Quality of Life, both from the myriad symptoms of ESRD itself and from the physical and mental burden of dialysis treatment (Jaar, Chang, & Plantinga, 2013). World Health Organization (WHO) has defined Quality of Life as ‘an individual's perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns (Jaar, Chang, & Plantinga, 2013).

There is increasing awareness in the literature that patients undergoing HD live a poor QOL. Many studies report that ESRD patients on HD have poor HRQOL when compared with the general population (Jaar, Chang, & Plantinga, 2013; Yusop, Mun, Shariff, & Huat, 2013; Feroze, Noori, Kovesdy, Molnar & Martin, 2011). Though there are quite a large number of studies describing the frequency, percentage and the mean QOL score which translate patients' subjective experiences into objectively quantifiable data, there are only few qualitative studies that have examined the experiences of these patients' life situation.

A systematic review and thematic synthesis was conducted to synthesize published qualitative studies of patients' experiences, beliefs, and attitudes about Peritoneal Dialysis by using Databases (MEDLINE, Embase, PsycINFO, and CINAHL), theses, and reference lists searched up to November 2011 (Tong, Lesmana, Johnson, Campbell & Craig, 2013). The results revealed 7 themes: resilience and confidence, support structures, overwhelming responsibility, control, freedom, sick identity and disablement.

There was only one Indian study that used a phenomenological research design (using Husserl's Method) to explore the lived experience among 10 persons undergoing haemodialysis from the dialysis unit of Kasturba Hospital, India (Valsaraj, Bhat, Prabhu & Dinesh, 2014). The themes emerged at the end of the study were mental agony, physical limitations, coping, financial burden, lack of support, feelings towards the machine and dialysis, search for hope and betterment, spiritual coping, marital relationship and sexuality and uncertainty and fear of tomorrow.

There is no published qualitative study found by the researcher that has examined the lived experience of QOL among patients undergoing HD. But it is important to develop a deeper understanding of this phenomenon, because from a better understanding of the experience among people living on dialysis, health professionals can more adequately support them. So the researcher chose to do a qualitative approach using Van Manen's approach to understand their lived experiences which will provide a valuable insight about the patient's world related to QOL.

The present investigation differs from other qualitative investigations because it tries to explore the lived experience of quality of life that has not researched so far especially in India. This research will add to the body of research on and may generate ideas for intervention research.

OBJECTIVE

The objective of the study was to

1. explore the lived experience of QOL among patients undergoing Hemodialysis

METHODS

Research Design and Sampling

The study involved a qualitative approach that used an interpretive hermeneutic phenomenology based on Van Manen's method. 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 who were undergoing hemodialysis more than 3 months; undergoing dialysis twice a week; age above 18years;and who were without active medical or psychiatric conditions.

Instrument

1. Personal information

The first section involved a series of questions obtaining information about the participant's age, gender, educational background, marital status, type of family, 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 Quality of life 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. Informed consent was obtained from the participants. Confidentiality and anonymity was assured. As the information sought was of a personal nature, there was a possible risk of participant distress, in recalling an unpleasant event, for example. 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. As a health professional the investigator was skilled in monitoring and assessing patient responses and therefore was competent to recognise and respond to any distress that may have been exhibited by a participant. No such situation arose during data collection. Pseudonyms were created to ensure confidentiality.

Data collection

The study was conducted from June 2014 – September 2014. Subjects 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. All 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.

Statistical Analysis

The data were analyzed manually using interpretive phenomenology. The thematic analysis followed the six steps delineated by Max Van Manen. In order to attribute meaning to the data, van Manen suggests three methods (the detailed reading approach, the selective or highlighting approach and the holistic reading approach) for isolating thematic statements. All three approaches were employed during the data analysis of this research. The early analysis involved analyzing 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 (Manen, 1990). 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 (Manen, 1990). In Hermeneutic reduction (Adams and Manen 2008), researchers reflect on their pre-understanding, framework and biases. They also search for genuine openness to engage in a conversational relation with phenomena. 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 that has been of value in interpretation and discussion of participant's data.

RESULTS

I. Description of the pertinent characteristics of the participants

The participant's age ranged from 39 to 62 yrs. 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 3 to 7 years. The years since undergoing

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Hemodialysis ranged from 1 year to 6 yrs. 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 QOL among patients undergoing HD

The themes that emerged were crestfallen life (hard pressed life, deserted life and abounding losses), support and comfort, accompanying death and unfulfilled yearning wishes.

1. Crestfallen life

The meaning of the word Crestfallen is feeling dejected, dispirited and discouraged. All these meanings turn true for a person undergoing dialysis, as they lead a life enduring experiences of abounding loss, hard pressed and deserted life.

a) *Hard pressed life*

All study participants echoed that their experience was hard pressed, which is transparent in the following words. The harsh effects of disease and treatment, financial drain, feelings of uncertainty about future, adhering to food and fluid restrictions and living with co-morbidities were the subcomponents included in hard pressed life. (*Names mentioned here are pseudonyms*) Sreejith expressed “*This disease is a big trouble. As I told you, I used to pray everyday morning; let not even my enemies suffer this disease. I used to feel, that even cancer may not be such a deadly disease..... This disease is difficult.....I used to feel, let any other disease come, but not this disease....*” He also added “*Life is a tragedy for all those who are undergoing dialysis*”. He added “*weekly twice, I have to come and lie down like this for dialysis...to lie down like this.....Then when I come here, I have to lie down like a dead corpse, for nearly 4 hours. I am unable to turn or position myself during dialysis. I have to lie still these 4 hours*”.

Joseph also felt a nearly similar experience that he said “*I always pray, let not even my enemies suffer this disease, because it is like having bitten by a non- poisonous snake. You neither live nor die. There is an immediate cure for the rest of the diseases. But it is not so for this one. It just gets prolonged in spite of spending money or taking treatment. If we adhere and live as per to the physician’s instructions, our life may still prolong*”.

The helpless situation of financial drain made all participants to feel that they are undergoing a hard pressed experience while on hemodialysis. They felt that life was squeezed into a hard pressed experience. Saranya verbalized that the financial crisis she experienced made her life difficult to meet ends. She says “*When life was getting settled in a good way, I started to suffer this disease. With that, life started to shatter. I ended up with a great financial crisis. Now itself, within 6 years, I have spent nearly 10 to 11 lakh rupees for this disease*”.

Few participants shared that, the feelings of uncertainty about the future and their kids made them feel terrible and their experience as hard pressed. Saranya was apprehensive that the

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disease and treatment had an unexpected future, *“Because, this disease is unpredictable, as this is a killing disease. Though no symptoms are obvious outside, the effect of this disease is inside”*.

All the participants expressed a deep grief over the inability to take water and food as per to the heart’s desire and felt it really disgusting. Thus the compelling force to adhere to fluid and diet restrictions was another aspect which made the participants to perceive their lived experience as hard pressed.

Paul said *“The most pressing desire for me is to drink water. During summer, I experience severe thirst. Hmm..I wish to drink water. I don’t have much desire towards food. But to drink water...anyone will feel greedy to drink water. but if I drink, I get admitted straight in ICU. I can drink water provided I have ten to fifteen thousand rupees in my hand”* [Hmm...smiling].

b) Abounding losses

Life while undergoing hemodialysis is an experience of abundant losses. Loss as said by participants varied from loss of physical strength to loss of job and prosperity. The loss experienced made them to narrate that, life is filled with change and can never be compared to the life lived before.

Most of the participants shared their experience of suffering a job loss. Saranya said, *“When I had a job, there was lot of benefits like financial status, relationship with people, social contacts and can mingle with others. But now all these are not there”*.

Few of them felt they were experiencing a loss of comfort and prosperity. Nazia verbalized *“Earlier I used to have servants in my home. They were there for nearly twelve years. When I fell sick, all that went off...I was living with all comforts as I was taken care of. ... I also had a job....so I used to pay and keep people for work”*.

c) Deserted life

Patients undergoing hemodialysis experience a life of solitude especially when they feel abandoned by the relatives and friends. The deserted life experience was spelled by Saranya, *“Genuinely speaking, I feel like I don’t have any relations.....Now meeting people happens only if there is utter necessity. More relationship (smiling) for me is only with hospital. I don’t have relationship with anyone else, even with my family members, because I am unable to go and meet them.”*

Suja said *“People used to come and visit me. They will visit. But it’s not a helping relationship. When I was admitted in the hospital, there was none to visit me”*.

2. Support and comfort

Though experience of participants undergoing hemodialysis was narrated as a crestfallen life, still a ray of support was evident in their journey of dialysis. Subjects expressed the support from their spouse; few had a handful of support from relatives; and few entrusted their support to the Almighty God.

Suja was full of praise when she expressed the steadfast support given by her husband. In her words, *“My husband only takes care of me...even now. Only my husband will take care of me. The love of my husband is outstanding. Really I am alive today because of his love towards me.... He only brings and takes for dialysis. I live because of his support. If not, I would have died earlier”*.

Paul’s support was from his in-laws and an aunt. He said, *“I have only my wife’s parents.... As we don’t have anybody else to take care of us, they are helping us... There is nobody else to help us. Only one aunty helps us”*.

3. Accompanying death

The curtain of death always seem to wave before the eyes of patients undergoing Hemodialysis, reminding them about the uncertain future that life holds for them. Most of the participants verbalized that the thoughts of death always accompanied them. Saranya expressed, *“because, this disease is unpredictable....as this is a killing disease.Death may occur at any time....I don’t have any thoughts about my future”*. A similar experience was revealed in expressions of Joseph, *“I can’t tell about myself sister...just a breathlessness may be enough to...I am learning by watching two three incidents....My life may get over with just breathlessness. Hmm..[tears in eyes]....I myself am seeing a lot of patients who undergoing dialysis are becoming worse every day and then expire.”*

4. Unfulfilled wishes

Patients undergoing Hemodialysis have numerous yearning wishes which due to their disease and treatment turn unfulfilled.

Joseph’s wishes were to attend a social or family gathering like functions. He said, *“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”*.

Nazia exclaimed her desire towards food and rest as, *“But sometimes when I see certain foods that I was eating previously, I used to have a desire to eat that.... Sometimes I used to think, if I was just able to take rest...to do nothing”*.

DISCUSSION

Four themes emerged from the lived experience of QOL among patients undergoing HD; crestfallen life, support and comfort, accompanying death and unfulfilled wishes.

A similar study finding of strict diet, fluid and strict schedule was reported in a study that was conducted to explore the lived experience of patients with ESRD in Oklahoma (Clarkson & Robinson, 2010). Some patients have described it as “strict renal diet and limitations on intake of fluid”. In the compared study, a theme on limitations with the subtheme limited social contact was similar to the deserted life in the present study.

A similar concept of the theme accompanying death is evident in an Indian study that explored the lived experience among 10 persons undergoing haemodialysis in the dialysis unit of Kasturba Hospital (2014). The study concluded that the individual's life is centred on negatively oriented cognitions that can be modified with theoretically oriented interventions like cognitive behaviour therapy. This is consistent with the present study findings.

RECOMMENDATIONS

Psycho therapeutic interventional studies can be carried out to improve the QOL of HD patients, targeting the concepts of hard pressed, deserted life and to help them cope up with thoughts of abounding losses and accompanying death.

CONCLUSION

The findings shed light on the inner world of lived experiences regarding QOL by patients undergoing HD. More research studies are warranted to illuminate and intensify the knowledge in this area. The generated knowledge would be helpful to test new non-pharmacological interventions that may help patients undergoing HD to lead a life with better QOL and dignity.

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