

LIVED EXPERIENCE OF HEMODIALYSIS PATIENTS IN THE MIDDLE EAST COUNTRIES: A THEMATIC SYNTHESIS

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ABSTRACT

The number of haemodialysis patients globally is increasing. Patients on hemodialysis experience considerable psychological and physical stress due to the changes brought on by chronic kidney disease. This study examined the lived experience of hemodialysis patients in the Middle East countries through thematic synthesis. Twelve qualitative studies were found on this topic. Having insights about the feelings and experiences of the hemodialysis patients is important for future interventions and development of theories. Understandings gained in this study can help health providers and patients set care goals and match them with treatment choices. Better understanding of factors contributing to patient lived experiences can provide vital insight to health care providers, advance medical knowledge, assist in developing social policy, and contribute to public and private decision-making. Health complications can occur during dialysis. Complications and challenges appeared in the different studies presented through the emergence of several themes such as emotional challenges, financial burden, challenges, and psycho-social restrictions. However, spiritual sources and faith likewise emerged in the reviews. Patients also emphasized the importance of family, carers, and social support towards the hemodialysis patients.

Keyword: Hemodialysis, Feelings, Experiences, Complications, Challenges

1. INTRODUCTION

Majority of the patients with chronic kidney disease (CKD) are undergoing maintenance hemodialysis. Hemodialysis-dependent patients with chronic renal failure must cope with severe restrictions such as strict adherence to dialysis and medication regimens, dietary and fluid limitations, and minimal physical activities. They often experience chronic fatigue, sexual dysfunction, sleep disturbances, altered body image, and uncertainty concerning the future. The way an illness is experienced is highly subjective and reflects the meaning attached to it by the person concerned [1].

For patients, with end-stage renal disease (ESRD), who are in poor physical state, they minimize their chance of transplantation and dialysis has become a life-saving but regressive treatment with an extended course. Cohen et al think that dialysis is a both a life-prolonging therapy and a death prolonging treatment since patients who are receiving dialysis treatment have to deal with several physical disabilities that affect their quality of life including peripheral vascular disease requiring amputation. Being dependent on dialysis implies several changes in lifestyle and it is not uncommon for patients to become depressed and anxious about their well-being. A significant proportion of patients who need dialysis are unlikely to comply with the treatment [2].

Several studies also dealt on the depressive symptoms experienced by hemodialysis patients. Depression could be linked to the hemodialysis treatment requiring continuous connection with the hemodialysis machine and the patients experiencing serious restrictions on their level of independence. Moreover, HD patients also faced

psychosocial problems including interactions with carers and other health providers plus the fact that the treatment itself would require frequent hospital visits and prolonged waiting time in the hemodialysis unit [3].

The experiences encountered by patients with chronic kidney disease (CKD) undergoing maintenance haemodialysis have been studied in many quantitative studies, which translate patients' subjective experiences into objectively quantifiable data. However, there are no qualitative synthesis yet which examined the experiences of these patients and their life situations based on their own perspective. Hence, the investigator felt the need to explore the lives of patients undergoing hemodialysis in end-stage renal disease in the Middle East countries through a thematic synthesis.

2. OBJECTIVE

To undertake a thematic synthesis review on the lived experience of hemodialysis patients in the Middle East countries

3. METHODS

Meta-Synthesis method was utilized in this study wherein interpretive analytical technique was used from the qualitative findings reported in previous studies as building blocks for gaining a deeper understanding of the experiences encountered by the hemodialysis patients.

Framing involved the identification of the research question from the general to the very specific in order to reduce the scope over the course of undertaking the synthesis.

Three potential database search strategies using Thesaurus terms such as hemodialysis, using free-text terms such as patients, using broad terms such as qualitative, meta-synthesis, interviews. Other methods in locating papers included reference list checking, citation searching, hand searching through back issues of selected journals, and author searching.

A scoring system was created to facilitate the use of the categories using a rating scale of 0 through 3 for each of the thirteen inclusion criteria. The scoring scale is as follows: 3 - Good (75% to 100% of the criteria were met); 2 - Fair (50% to 74% of the criteria were met); 1 - Poor (25% to 49% of the criteria were met); and 0 - Less than 25% of the criteria were met. A quality of evidence rating for each qualitative study is then assigned using the legend: QI – total score of 22.5 to 30 (75% to 100% of the total criteria were met), QII – total score of 15 to 22.4 (50% to 74% of the total criteria were met), and QIII – total score of less than 15 (less than 50% of the total criteria were met). The result of this quality assessment showed that the quality of the articles in this meta-synthesis was good with an achieved grade of QI, indicating these articles met 75% to 100% of the five criteria [4].

As a result of this assessment, no articles were excluded from the meta-synthesis. The inclusion criteria included: study is qualitative, research questions are clearly stated, approach is appropriate for the research question, qualitative approach is justified, study context is described, sampling method is described, sampling method is appropriate to the research question, data collection method is described, data collection method is appropriate to the research question, method of analysis is clearly described, analysis is appropriate for the research question, and claims are supported by sufficient evidence.

Synthesizing was also used specifically, thematic synthesis for this review. Thematic synthesis included the free coding of the original findings, the grouping of similar free codes into descriptive themes, or the generating of analytical themes that emerge from and step beyond the descriptive themes [5]. A clear audit trail should be observed so that key study information can be reported in the synthesis write-up. The report included search strategy, number of studies at each stage of the search process, and the summary of studies selected for synthesis.

4. RESULTS

The search strategy located only eight studies meeting the inclusion criteria. Eight of the studies met the quality criteria, and were therefore included in the systematic review of findings. Integrating findings across the ten studies enabled a set of recurrent and dominant experiences to be identified. These experiences related both to the constraints operating on the hemodialysis treatment and other challenges they faced as HD patients.

4.1 Physical Manifestations

Fatigue is one of the most frequent complaints of haemodialysis patients and is associated with impaired health related quality of life. Fatigue is documented as a negative symptom experienced by a large number of patients with end stage renal disease undergoing hemodialysis. Research indicates that patients on hemodialysis in

the Middle East felt the most fatigue immediately after hemodialysis, were not able to carry out daily activities, and experienced role limitations and a decrease in strength and physical ability due to their fatigue [6]. Further, they had trouble remembering and concentrating due to fatigue.

Fatigue is a distressing symptom, and the consequences of fatigue can be overwhelming. The person with fatigue needs more efforts to perform activities, physical and cognitive, compared with the effort required before the onset of fatigue. Kazemi et al [7] also found out in their study the four major themes that were constructed from the analysis of the transcripts which were arranged and analyzed thematically and these were: living with fatigue; changes in self-image; patients' dependency on the device, place, and time of hemodialysis; and hiding the disease. The results from this study showed that the patients who were living with hemodialysis in Iran experienced altered social interactions with others. The culture of Iran resulted in the participants trying to hide their disease from others, which led to social avoidance, thus reducing the participants' social interactions with others. It is recommended that nurses include a comprehensive assessment of the social interactions of persons who are receiving hemodialysis in their overall nursing assessment and that this is reviewed on a regular basis.

A similar research was conducted to investigate the factors affecting fatigue in patients under hemodialysis treatment. In this descriptive study, 59 patients with chronic renal failure treated with hemodialysis at Qena University Hospitals in Upper Egypt. Data collection tool was a personal information questionnaire based on demographic characteristics and also information regarding the duration of illness, history of hemodialysis, psychedelic drugs, levels of hemoglobin, urea, creatinine, systolic blood pressure and dry weight. The second data collecting tool was the fatigue severity scale. Inclusion criteria were the medical diagnosis of chronic renal failure according to patients' medical records, continuous and regular visit for treatment, having some degree of fatigue based on the fatigue severity index questionnaire, willingness to participate in the study, age of 19 years and older, auditory and speech ability and an having enough consciousness for answering the questions. Findings revealed that there was no significant difference in terms of fatigue, between different age groups and the most fatigue was observed in the age group of 19-28 and above 69 years. In this study fatigue showed an increase with the increase of dialysis history but this was significant only in terms of disease history. The frequency of fatigue is high in hemodialysis patients. Overall, men are more fatigued than women when treated with hemodialysis [8].

Any chronic illness puts a person and family at risk of long term suffering, financial depletion and burden on the caregiver. When it comes to chronic kidney disease (CKD), the sufferers have to be dependent on maintenance dialysis weekly twice or thrice that demands a lot of time and finances. Apart from that, they face physical symptoms of fatigue, anaemia, nausea, muscle cramps, fluctuating blood pressure and many other symptoms. They are asked to maintain a strict dietary, fluid and medication regimen in order to support the kidneys.

The experience of haemodialysis patients in South Karnataka, India was studied where ten HD patients were interviewed and the data were analyzed using Husserl's method. 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 [9].

4.2 Psychological Challenges

Of particular interest with regards to depression which is considered as the most common and probably the most important psychopathological complication of end stage renal disease (ESRD). Depression has the potential to alter adversely the medical outcome of ESRD patients and the psychological stress can affect patient's adherence to medication regimen. In Iraq as well as many other Arab countries, the true prevalence of depression among ESRD patients is unknown. Seventy-five patients were recruited for a study on the maintenance HD. Using the Arabic version of diagnostic and statistical manual of mental disorders fourth edition (DSM-IV) was used to diagnose depression. Beck's Depression Inventory was used to grade its severity; it was found out that the prevalence of depression among this cohort of HD patients was 80%. The prevalence of severe, moderate and mild depression was 25%, 50% and 25% respectively. The mean depression score was 17.1. Female gender, unemployment, and marital status had statistically significant associations with depression [10].

A study was carried out to assess the frequency of psychiatric disorders in 50 patients with ESRD on haemodialysis therapy in Turkey. The findings highlighted that depression was the most common diagnosis occurring in 24% of the participants. Depression was assessed using the Hamilton Rating Scale for Depression. After six months, 14 participants were followed up and the level of depression remained unchanged [11].

Similarly, a study used Hamilton Rating Scale to assess the level of depression in dialysis patients in Turkey. The sample included 52 patients on haemodialysis and 26 patients on peritoneal dialysis. The findings indicated that the majority of patients in the haemodialysis group were diagnosed as having depression in various degrees. For instance, major depression was identified in 11 patients, moderate depression was identified in 10

patients, mild depression was identified in 21 patients, and no depression was identified in 10 patients. In contrast, fifty percent of the peritoneal dialysis group had depression. For example, major depression was identified in 2 patients, moderate depression was identified in 3 patients, mild depression was identified in 8 patients, and no depression was identified in 13 patients. However, as the sample of patients on peritoneal dialysis was half the size of the haemodialysis patient group, it may be difficult to make accurate comparisons [12].

4.3 Social Relationships

On the other hand, a similar study was done by Sathvik, Prathasarathi, Narahari, & Gurudev (2008) among 75 patients who had completed their 3 months maintenance hemodialysis with the use of WHOQoL-BREF. Results revealed that the QoL of Hemodialysis patients was significantly impaired ($p < 0.05$) in comparison to healthy individual particularly in respect to physical, psychological and social relationship domains. In comparison to the QoL of renal transplant patients, the QoL of hemodialysis patients was significantly lower in all the four domains. Only in environmental domain was the QoL of hemodialysis patients found significantly lower ($p < 0.05$) than asthma patients. Female patients on hemodialysis showed significantly lower QoL than male patients in psychological and environmental dimensions. There was a positive association between higher education and psychological functioning and environmental dimensions.

4.4 Family, Carers, and Social Support

Two qualitative studies were conducted to determine the life of the patients undergoing hemodialysis. Rohini and Ezhilarasu [13] studied the lived experience of Quality of Life (QoL) among patients undergoing Hemodialysis where seven patients were involved and data were collected through semi-structured interviews and themes were analyzed using Van Manen's method. An evaluation on the individual quality of life among hemodialysis patients using themes was conducted [14]. A multiple approach design and convenience sampling were applied to recruit 53 patients from a hemodialysis unit in Iran. Data were collected through structured interviews and then analyzed using conventional content analysis. They found that patients experienced the feelings of crestfallen life (hard pressed life, deserted life and abounding losses); support and comfort; accompanying death and unfulfilled wishes [15]. However, it was found out that the most important aspects of life for the HD patients were health, family, financial status, living conditions, leisure activities, relationships and socializing, religious and spiritual issues, medical knowledge, and therapies or treatments. Moreover, the relationships between the QoL scores and education, job and marital status were not statistically significant.

Hemodialysis treatment prolongs the life of chronic renal failure disease patients who must tolerate many physical, emotional, social and economic difficulties. Therefore, social support is considered as a vital area of investigation for such patients. Social support is very evident in a study which focused on the experiences of the hemodialysis patients. Social support was explored based on the implications of five general themes including: perceived threats caused by disease complications, searching for social support, accessible social support, beliefs and values, and perceived social support. The acceptance of the reality of the conditions caused by the disease is very vital to the patients. The findings suggest that individual aspects of patient experiences must be considered if social support is to be given and Healthcare Providers have to facilitate positive health services [16].

A study utilizing typical sampling method was used to select the sample, which consisted of 16 hemodialysis patients. Thematic analysis of patient interviews followed established conventions so as to ground the analysis in the data, rather than pre-existing ideas. Results show that qualitative analysis identified different ways in which the patients evaluated their lives. The patients described the effects of ESRF on their lives primarily in terms of attitudes towards limitations, mixed feelings about caregivers, and changes in their own character. Caregivers were frequently described as supportive, but patients also perceived them as sources of distress and difficulty. ESRF and its treatment were reported to have worsened not only the patients' emotional states, but also aspects of their character; however, the effect of ESRF also involved the experience of positive changes in character. Conclusion: The present study provides a detailed systematic account of how hemodialysis patients evaluated their lives. Some of the findings provide details about how the psychological processes that have been previously reported operate in practice, which clinicians and researchers need to understand; however, some findings cannot readily be explained according to existing ideas. The findings, therefore, identify potential targets for educational intervention to improve patient adjustment [17].

4.5 Faith

Moreover, religion and faith also play important roles in the lives of HD patients. Two similar studies were conducted on religion involvement, spiritual coping and religiosity in the lives of HD patients. Patients on hemodialysis experience considerable psychological and physical stress due to the changes brought on by chronic

kidney disease. Religion is often turned to in order to cope with illness and may buffer some of these stresses associated with illness. This study used Muslim Religiosity Scale, Structured Clinical Interview for Depression, Hamilton Depression Rating Scale, Global Assessment of Functioning scale, and other established measures of psychosocial and physical health. Findings revealed that religious involvement was more common among those who were older, better educated, had higher incomes, and were married. Overall psychological functioning was better and social support higher among those who were more religious. The religious also had better physical functioning, better cognitive functioning, and were less likely to smoke, despite having more severe overall illness and being on dialysis for longer than less religious patients. Religious involvement is correlated with better overall psychological functioning, greater social support, better physical and cognitive functioning, better health behavior, and longer duration of dialysis [18].

A study examined the relationships between spiritual/religious, demographic and clinical variables and quality of life among Iranian Muslims undergoing haemodialysis. Using a cross-sectional design, 362 haemodialysis patients were surveyed from three general hospitals located in Tehran, Iran. Spiritual coping strategies, Duke University Religion Index, EQ-5D 3L and a demographic questionnaire were administered. The distribution of reported problems across dimensions of quality of life was: mobility (59.4%), usual activities (30.4%), self-care (21.3%), pain/ discomfort (47.8%) and anxiety/depression (29.3%). Univariate analysis showed that factors such as age, sex, marital status, location, number of children, body mass index, serum albumin, having diabetes mellitus or other co-morbidity, as well as spiritual/religious factors that were related to quality of life, health status or both. Regression models revealed that demographics, clinical variables and especially spiritual/religious factors explained about 40% of variance of quality of life and nearly 25% of the variance in health status [19].

5. DISCUSSION

Across medical, health and welfare policy, there is an increasing appreciation that patients' views are important for developing effective policies. In fact, involving the patients and other stakeholders including local government units in research processes is considered as a key component of successful interventions. There is always the need to encourage the active involvement and participation of those affected by hemodialysis treatment in developing policy and services which are effective and meet their needs.

Over the last ten years, there has been a rapid increase in research concerning hemodialysis and the perspective of the patients regarding the treatment. This is dominated by research carried out in the USA, UK and other Western Countries, where the majority of studies are quantitative or qualitative in nature.

Acceptance of the reality of the conditions caused by the disease is vital for the patient. The synthesis shows that patients indeed encounter so many challenges and barriers in their lives due to hemodialysis treatment. Various themes emerged from the synthesis such as social and emotional distance and the feeling of being vulnerable. This means that the hemodialysis patients experienced emotional instability and psychological distress, financial burdens, inadequate disease knowledge and less social support which influenced their quality of life.

Other themes emerged at the end of the review 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.

Patients living with end-stage renal disease experience different levels of physical and psychological disability that can impact on the type and level of social interaction in which they engage with others. Moreover, depression is common in this group of Iraqi HD patients and its prevalence is comparable to the results of similar studies in other societies.

This synthesis indicated that, in the lives of patients on haemodialysis, the main areas of suffering were related to loss of freedom expressed as dependence on the haemodialysis machine as a lifeline and the caregivers. This time-consuming and tiring dependence affected marital, family and social life.

Religious involvement is correlated with better overall psychological functioning, greater social support, better physical and cognitive functioning, better health behavior, and longer duration of dialysis. Whether religion leads to or is a result of better mental and physical health will need to be determined by future longitudinal studies and clinical trials. Spiritual resources may contribute to better quality of life and health status among haemodialysis patients but further longitudinal studies are needed to determine whether these associations are causal and the direction of effect.

The patients' views of the aspects of life could be used by health policy makers, clinicians, and caregivers as a reliable guide to the most important priorities for treatment and medical interventions.

5. CONCLUSIONS

The findings shed light on the lived experience of QOL that has not yet been fully researched in all the Middle East countries. The generated knowledge can be used by health professionals including nurses to help patients undergoing HD lead a life with better quality of life. By comparison, there is very little qualitative research on the experiences of hemodialysis patients in the Middle East.

Theme which emerged from the several studies presented in this paper such as psycho-emotional challenges which includes depression, mental agony, and the dependency on the hemodialysis machine; financial burden for the patients and their families; physical challenges which comprise of decrease in strength and physical ability as well as physical limitations. Hemodialysis patients also experienced poor social relationships since they spent longer time in their weekly hemodialysis sessions and resting than going out with friends and relatives.

Spiritual resources may contribute to better quality of life and health status among haemodialysis patients but further longitudinal studies are needed to determine whether these associations are causal and the direction of effect.

However, amidst all these challenges the patients encounter daily, they consider the following very vital in their existence: family, leisure activities, relationship and socializing, and their faith or religion. In addition, the studies also emphasized the importance of family, carers, and social support towards the hemodialysis patients.

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