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COPING WITH MENTAL HEALTH STATUS: EXPERIENCES OF END-STAGE RENAL DISEASE PATIENTS UNDERGOING HEMODIALYSIS AT HOSPITAL PAKAR USM, MALAYSIA

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Abstract: *The prevalence of chronic kidney disease (CKD) in Malaysia has increased from 9% in 2011 to 15.5% in 2022. Approximately 28 Malaysians start dialysis treatment daily, and more than 55,000 CKD patients are currently undergoing dialysis nationwide, frequently experiencing mental health symptoms, including depression, anxiety, emotional stress, and cognitive dysfunction, which negatively affect their quality of life and daily functioning. These mental health symptoms are also exacerbated by the physical toll of the disease and the invasive nature of dialysis treatment. CKD impacts physiological and sociological well-being; consequently, coping strategies vary, with patients utilizing both problem-focused and emotion-focused approaches to manage the illness. This study employed a qualitative method which is a semi-structured interviews with five purposively selected participants to explore emotional challenges and coping strategies via thematic analysis. Qualitative themes revealed a heavy 'mental load' and life disruption, countered by resilience through spiritual coping and peer validation. Seven themes have emerged, including: (1) mental load and emotional distress, (2) life disruption and loss of freedom, (3) physical exhaustion and bodily suffering, (4) social isolation and altered relationships, (5) identity change and self-perception, (6) coping, adaptation, and resilience, and (7) gratitude and meaning-making. Qualitatively, findings revealed that "mental load" is characterized by life disruption, identity changes, and physical exhaustion. However, patients also demonstrated remarkable resilience through "meaning-*

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making," spiritual coping, and peer validation, which served as protective factors against total emotional collapse. This study underscores that while physical treatment is standardised, the psychological burden of hemodialysis is deeply personal and multifaceted. The persistence of high stress and anxiety levels in specific subgroups necessitates the integration of routine mental health screening and targeted psychosocial interventions. Future research should address socio-economic barriers as vital as clinical management in improving the quality of life for CKD patients.

Keywords: *chronic kidney disease, hemodialysis, depression, anxiety, stress*

Introduction

End stage renal disease (ESRD) is the final stage of chronic kidney disease (CKD) when kidneys are no longer able to function, and kidney replacement therapy is needed, either by haemodialysis, peritoneal dialysis or kidney transplant. As populations age and diabetes, hypertension, obesity, and other chronic diseases such as diabetes remain on the rise, the prevalence of ESRD has slowly grown worldwide (Centers for Disease Control and Prevention, 2017; Hooi, 2017). In Malaysia, the situation is similar, as there has been a rise in patients needing long-term dialysis (Kovesdy, 2022; Coresh, 2017; Ji & Kim, 2016; Mosleh et al., 2020). It places a significant burden on the health care system and has an impact on patients' physical, psychological and socioeconomic development (Saminathan et al., 2020; Loke Meng, 2017; Ministry of Health Malaysia, 2018).

Traditionally, the most frequently used treatment for ESRD in Malaysia is haemodialysis (Loke Meng, 2017; Ministry of Health Malaysia, 2018). While dialysis has progressed to better outcomes, patients need to be treated a few times per week and follow a strict diet, fluid and medication regimen (Hooi, 2017; National Kidney Foundation, 2021). These long-term needs affect work-life, family life, social life and independence, which in turn negatively impact quality of life (Jeon et al., 2020; Hooi, 2017). In addition to its physical effects, ESRD often brings with it depression, anxiety, stress, fear of death and an uncertain future. These psychological stresses have been associated with poor medication adherence, hospitalisation and poorer health outcomes (Dąbrowska-Bender et al., 2018).

Previous research has tended to quantify psychological symptoms, but not much has been explored to understand patients' experiences and coping strategies (Yu et al., 2021; Sameeha Alshelleh et al., 2023). The ability to adapt psychologically is affected by personal resilience, family support, spiritual beliefs, social and economic factors, and experiences with healthcare (Mosleh et al., 2020; Malik et al., 2022; Frandsen et al., 2023; Meuleman et al., 2023). It is important to be aware of these factors so that more comprehensive interventions can be developed that cater for both physical and psychological needs of patients receiving long-term haemodialysis. This research aims to explore the challenges experienced and coping strategies used by haemodialysis patients to manage their levels of depression, anxiety, and stress symptoms.

Literature Review

Existing literature on patients with ESRD undergoing haemodialysis highlights five interrelated dimensions of their experiences: psychological distress, disruptions to daily life, coping strategies, resilience, and spirituality.

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Psychological Distress - Haemodialysis.

Haemodialysis patients can be depressed, anxious and stressed due to a long-term illness, physical discomfort, uncertainty about the future and the time management of the treatment. According to Mosleh et al. (2020), anxiety and depression were significant psychological issues among patients undergoing haemodialysis. Likewise, Dąbrowska-Bender et al. (2018) associated the dialysis experience with problems related to quality of life. These issues can also be heightened if people rely on taking regular medication or worry about the disease getting worse. Emotional distress may then impact emotional health, functioning, and coping with illness. The importance of these experiences will be highlighted, as it is crucial to consider the psychological aspects of the patient's needs that can be treated with physical interventions.

Life Disruption

Haemodialysis can significantly impact patients' work, family life, social interactions and level of independence. Opportunities to work, travel and recreational activities may be limited due to regular attendance at the hospital, dietary restrictions, and fluid management. McKie et al. (2023) studied the qualitative experiences of those living with kidney failure who are receiving haemodialysis and found that there is importance in situating treatment within patients' lived experiences. Factors associated with depressive symptoms in working haemodialysis patients were also investigated by Jeon et al. (2020). The physical demands of treatment are not the only ones that may be required, as these findings show that the treatment demands can reach the fields of occupational participation, personal autonomy, and emotional adjustment.

Coping Strategies

Coping reactions can be cognitive, emotional and behavioral responses to stressful situations (Clarke et al., 2016). Emotion-focused strategies (such as accepting the reality of the situation, positive thinking, emotional support, etc.) can be used alongside problem-focused strategies (such as adapting daily routines and/or managing treatment needs). In the study by Malik et al. (2022), the illness perception of Pakistani patients on maintenance haemodialysis was explored, which showed that the patients' illness perception is extremely significant. The support of family, interaction with other patients and interaction with healthcare professionals can also be important in the management of distress. Coping reactions are different for different people, depending on their situation, supports and beliefs.

Resilience

Resilience is when patients are able to adjust to ongoing challenges and handle emotional issues. It is not necessarily a lack of distress, but rather that patients can feel anxious or sad, and work out ways to live their lives anyway. They conducted a study by Sameeha Alshelleh et al. (2023) to assess the psychological health of haemodialysis patients, focusing on depression, anxiety and quality of life, which showed the importance of considering psychological health along with treatment. Factors in resilience can be social support, coping positively and a slow adjustment. There can be continuing physical symptoms and social issues that contribute to the difficulty in adapting and require one-to-one psychosocial support.

Spirituality

Patients suffering from chronic disease may find comfort, hope, acceptance and meaning from spirituality and religious practices such as prayer (Salleh et al., 2015). Patients' spiritual beliefs can be used to help them understand their disease, cope with uncertainty and hope for progress in the treatment process. These practices can be used in addition to help from family, friends,

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and health care professionals. But spirituality must not be seen as a substitute for professional psychological treatment.
In general, the literature indicates that psychological stress among haemodialysis patients is a product of the inter-related physical, social and emotional difficulties. Discussing coping, resilience and spirituality along with the disruption from treatment can lead to a more holistic understanding of patients' experiences and a more comprehensive approach to nursing care.

Theoretical Framework

The coping approach of the patients with end-stage renal disease (ESRD) to the psychological issues of haemodialysis is analysed using the problem- and emotion-focused coping framework. Problem-focused coping includes strategies for meeting the demands of treatment and making lifestyle changes. On the other hand, emotion-focused coping is associated with coping with emotional reactions to illness, uncertainty and dependency. These dimensions contribute to an understanding of patients' experiences, including the use of family support, peer encouragement, positive meaning-making, and spirituality. This framework is in line with the coping literature that was reviewed by Clarke et al. (2016), which is associated with patients' coping response to their psychological distress and adaptation during long-term haemodialysis.

Methods

This study employs a qualitative research design.

Inclusion and Exclusion criteria

The inclusion criteria are adults (18 years or older), have a diagnosis of ESRD from a doctor, have been on hemodialysis for at least one year and have provided written informed consent. This study excludes those who have poor hearing or speaking skills, mental illness and lack of Malay or English language skills. There are no specific requirements for clinical stability, cognitive assessment and/or formal assessment of consent capacity in the study. Five participants were purposively selected based on their experiences and ability to provide rich information which closely related to the study phenomenon. A purposive sampling strategy was used to select participants whose experiences align with the research goals and whose information is rich in content, as confirmed by Goulding (2011).

Sample and Saturation

The data collection technique used was a semi-structured, individual face-to-face interview conducted in a private room lasting for 30-60 minutes. Participants consented to interviews, with their words captured on tape, transcribed verbatim and field notes taken and added. When no further themes, meanings, concepts, or important information emerge from the text, it is considered saturated. It doesn't, however, pinpoint when saturation was reached, indicate whether new codes and themes emerged during the fifth interview or whether analysis took place during data collection. Naeem et al. (2023) emphasise the importance of a systematic qualitative analysis and analytical process. Hence, a sample of 3-10 participants was considered sufficient to achieve thematic saturation (Saunders, 2018). The method proposed by Goulding (2011) was helpful to systematically understand the interpretation of qualitative data and obtain meaningful conceptual insights. Similarly, Naeem et al. (2023) highlight the importance of systematic qualitative data analysis of the collected data. Several probing techniques were used during the interview session. Firstly, clarification probes were used when the participants' responses were ambiguous or vague. The elaboration probes were used to encourage the participants to provide more details about what they had mentioned earlier. The comparison probe is commonly used to explore changes over time. The reflective probes are used by

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repeating the participant's words to encourage the participants to elaborate more on the information they had mentioned earlier (Robinson, 2023).

Participant Selection

Participants were chosen purposively based on inclusion and exclusion criteria as well as their availability for in-depth interviews. Data collection continued until a point of information saturation was reached, that is until further interviews did not provide any further concepts or themes.

Data Collection

Semi-structured face-to-face interviews were carried out to collect qualitative data, which was developed based on the literature review and study objectives using an interview guide. Open questions allowed participants to express their emotional feelings during hemodialysis, difficulties in everyday life and coping mechanisms that they used to deal with psychological distress. The interviews lasted about 30 - 60 minutes each, were conducted in a private room of the hospital to assure comfort and confidentiality of the participants, and were audio taped with the subject's consent. In addition to verbatim transcripts, field notes were taken immediately after each interview and included non-verbal observations and contextual information

Data Analysis

The recording of interviews was transcribed verbatim and analysed using the six-phase thematic analysis. The six stages of the thematic analysis developed by Braun & Clarke (2006) were utilised in this study. The researcher reread, transcribed and coded significant statements and compared and combined transcripts and codes into larger themes. A methodical trail was used to document the researcher's decisions regarding methodology, code and theme development. Confirmability was supported by the reflexive analysis and discussions in the research team. Transcripts were systematically coded for the purposes of identifying common themes concerning patients' emotional experiences and coping strategies. Codes were then categorised and considered as overarching themes that reflect the experiences of ESRD patients receiving haemodialysis. There was consistency and analytical rigour through continuous comparison of transcripts.

Trustworthiness

To enhance the credibility, the researcher engaged with the participants for an extended period of time, transcribed the interviews and re-read them throughout the analysis process. A detailed audit trail of the methodological decisions, the development of code and theme generation was maintained, which helped to increase dependability. The researcher bias in interpretation was minimised by reflexive analysis and frequent discussions within the research team for confirmability (Nowell et al., 2017). The provision of detailed descriptions of the study context, participant characteristics, and methodological procedures facilitated the transferability of the results and allowed others to assess the applicability of the results to other health care environment.

Ethical Considerations

The study has been carried out after getting ethical clearance from relevant institutional ethics committee. Ethical clearance obtained from the institutional ethics boards (IIUM/313/DDPRRI/13/12/8 and USM/JEPeM/KK/24080657). All participants signed informed consent and participation was voluntary. The study aims, confidentiality policy, and the right to withdraw from the study without impacting care were explained to the participants.

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To ensure anonymisation, any personal identifiers were eliminated during transcription and data analysis. All research material has been stored securely and accessed only by the research team in accordance with ethical requirements of the institution with regards to electronic/materials.

Results

Five participants were selected using purposive sampling technique and were subjected to semi-structured interviews. Most of the participants participate in the qualitative study are male (3), and then the ages of the participants ranging from 40 to 64 years. All participants were married. For the occupations of the participants, it's including for the clerk, housewife, lorry driver, and teacher. Then, for the duration of haemodialysis, it's ranges from 2 to 4 years. Qualitative findings for in-depth description of the emotional experiences of the patients when undertaking haemodialysis treatment. Seven major themes emerged from the thematic analysis.

Theme 1: Mental Load and Emotional Distress

Shock, sadness, fear and uncertainty were reported by participants as being overwhelming when they were diagnosed with ESRD. The recurrent need for haemodialysis and worries about the progression of the disease caused lifelong psychological suffering. Numerous symptoms were reported that seemed to be depression and anxiety; especially in the early treatment period as they experienced loss of independence and uncertainty about survival. It supported by participant quote such as:

"Sometimes I feel depressed all day, even though there are no external problems" (P2)

"I feel like I'm 'not alive', just existing but not enjoying the day" (P3)

"My life is no longer in my hands" (P5)

Theme 2: Life Disruption and Loss of Freedom

Haemodialysis significantly impeded participants in their daily life, specifically in their employment, family activities, travelling and social participation. Patients' freedom and autonomy were limited by their strict treatment regimens, dietary and fluid restrictions. Many people thought their lives were centered around dialysis, and there was frustration, changes in lifestyle and a diminished quality of life. It was supported by:

"I could no longer work full time" (P2).

"I can't work full-time like I used to" (P4).

"The routine HD treatment had caused me unable to work like before. It is significantly making me feel that I have lost part of my independence" (P3).

Theme 3: Physical Exhaustion and Bodily Suffering

After dialysis, the participants felt tired all the time, weak in their muscles, and experienced dizziness, headache, sleep problems, and poor physical endurance. Their symptoms restricted their work and daily life activities, causing emotional distress. The correlation between physical and psychological health was evident, as poor physical health often increased feelings of sadness, anxiety, and frustration and supported by:

"The arm of the needle inserted in the patient produces throbbing pain" (P1).

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"Sometimes I had experienced for muscle pain and the pain will continue for more than a day, with sometimes until the next HD session still pain" (P3).

"Sometimes I cry during dialysis due to the leg cramps can become so painful" (P2).

Theme 4: Social Isolation and Altered Relationships
Participants indicated that the impact of ESRD on family relationships and social participation was an issue. Family members were very supportive, but several found it difficult to not be dependent on family members. Withdrawal from community and family activities occurred due to dialysis schedules and physical limitations, and fear of stigma, embarrassment and fatigue and it was supported by:

"I felt isolated and lonely, even when surrounded by family" (P2)

"I have my spouse and children around me, but I still tend to feel lonely and isolated" (P4).

"Sometimes I feel alone due to the nobody able to understands and feels with me how difficult this HD treatment is" (P5).

Theme 5: Identity Change and Self-Perception
Participants' identity changed due to living with ESRD. The loss of work, strength and independence threatened the previous social roles and self-worth. Male participants specifically linked work to personal identity and family responsibilities, and more visible changes in their physical appearance and vascular access devices were negatively related to body image and confidence. It was said by participant such as:

"I began to see myself as a 'patient' rather than an 'independent individual" (P2)

"My illness has significantly changed how I think about myself." (P3)

"Sometimes I feel that being a patient has become my identity." (P4)

Theme 6: Coping, Adaptation and Resilience
With the many obstacles that were overcome, participants slowly came to terms with their new normal haemodialysis. The emotional distress was minimized by positive thinking, family support, peer interaction, trust in healthcare professionals, structured routines and increased knowledge of ESRD These coping tactics helped to build the resilience and thereby helped participants hold onto hope despite lifelong treatment. It supported by:

"all dialysis patients go through these feelings. It's normal, it's not your fault"(p1)

"a quick chat before or after a dialysis session becomes therapy without me realizing it"(p5)

"small hobbies help me feel like I am still myself, not just a patient"(p3)

Theme 7: Gratitude and Meaning-Making
A sense of spirituality and gratefulness gave meaning to the participants. They were helped by religious faith to accept their illness, diminish anxiety, and hope. Most considered haemodialysis to be life sustaining and were thankful of healthcare professionals, family

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members and other patients. A positive outlook fostered resilience, better relationships and long-term psychological adjustments. It supported by:

"gratitude to still be alive" (p1)

"this machine took over my kidney duties so I could stay alive"(p4)

"it gave me invaluable time waiting for a transplant opportunity" (p2)

Discussion

Results of this study showed that emotional, physical and social difficulties remained. The results indicate that the psychological adaptation cannot only be explained by the psychological symptom scores, but also by coping strategies, resilience and social support (Yu et al., 2021; Sameeha Alshelleh et al., 2023; Zegarow et al., 2022).

The qualitative themes emerged which known as the mental load and emotional distress, life disruption, and physical exhaustion had provided for the deeper insights regarding why some of the patients still continued to experience for moderate to severe of depression, anxiety and stress even though had received for the regular hemodialysis care. Also, the patients had expressed for the feelings of sadness, uncertainty, emotional exhaustion, and fears which related with their high dependence on the HD as the life-sustaining treatment, as revealed by Chongtham (2024) too. Then, the findings also suggested that the psychological distress among ESRD patients is not only can be measured through the structured and systematic psychological assessment tool, but it's also deeply being embedded within the patients' life experiences of managing for the lifelong illness.

Besides that, there were several socio-demographic factors that were linked to mental health outcomes. ESRD was more likely to cause psychological distress in younger patients than older patients, perhaps because ESRD was a disruption of employment, financial stability, and family responsibilities in economically productive years (Meuleman et al., 2023; Roy et al., 2024). Employment status also had an impact on emotional health: the unemployed participants reported more emotional distress related to diminished financial independence and self-esteem (Ponirah et al., 2026; Ahmad Othman et al., 2020). Moreover, long-term haemodialysis was associated with the accumulation of emotional fatigue, but those who had been on dialysis for a long period of time had gradually developed better coping mechanisms, suggesting better psychological adaptation ((Al-Jabi et al., 2021; Yu et al., 2021; Zegarow et al., 2022).

The diagnosis of ESRD was very traumatic for the participants and they reported feeling shocked, fearful, sad and uncertain. Living with haemodialysis, dietary and fluid restrictions, regular hospital trips and limited physical ability were all integral to a disrupted lifestyle and led to psychological distress as reiterated by Meulemen et al, (2024). Fatigue and muscle weakness also hampered participants' ability to work, along with unable to perform their normal activities of daily living.

Family support was a protective factor, however the participants felt poorly because they were depending on family and were concerns about being a burden. Emotional isolation and uncertainty about the future added to the emotional pain, and contributed to a reduction in community engagement as stated by by Mosleh et al. (2020), Frandsen et al. (2023), and Sameeha Alshelleh et al. (2023). Despite these challenges the participants were resilient in their

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coping strategies and were using positive ones including optimism, support from family, interaction with peers, reliance on healthcare professionals and having a daily routine ((Meuleman et al., 2023; Mohd Fadzli et al., 2021; Frandsen et al., 2023; Malik et al., 2022). Spirituality was also a key theme and helped participants to develop meaning, hope and to take up their illness.

In short, the data gathered gave a comprehensive picture of the psychological adjustment of the patients with ESRD. The results highlight the need to implement a psychological routine screening along with a comprehensive psychosocial evaluation and intervention to optimize patients' mental health and quality of life during long-term haemodialysis.

Limitations

The qualitative sample, although adequate for thematic saturation, was relatively small, which may not represent all haemodialysis patients' experiences.

Implications for Nursing Practice

The findings have a number of implications for nursing practice. There is need to incorporate the normal psychological screening of haemodialysis patients to enable prompt detection of depression, anxiety and stress. Nurses need to be familiar with the fact that distress may not always be apparent and should regularly seek to check for psychological issues during treatment.

Beyond physiological care, the nurse's care should be holistic and incorporate the psychosocial counselling, emotional support, patient education, and family involvement. Having peer support programmes in dialysis units can offer a feeling of neighbourhoods and exchange experiences to reduce isolation. As spiritual care emerged as an important aspect of care in this study, culturally sensitive spiritual care ought to be incorporated into the practice of nursing wherever appropriate.

It is recommended that more healthcare institutions should consider establishing multiprofessional psychosocial support services, including participation of nephrologists, nurses, psychologists, counsellors, social workers, religious advisors, etc. in a more integrated way to cover the complex needs of patients undergoing long-term haemodialysis.

Conclusion

Long-term haemodialysis and end-stage renal disease have a significant impact on the psychological, physical and social health of patients. Despite the successful psychological adaptation of many participants, concerning the nature of the treatment dependency, the disruption of their lifestyle, their physical restrictions and their uncertainty about the future. Supporting psychological resilience in addition to good medical care can help patients with ESRD adhere to treatment and enhance their quality of life and health.

Recommendation for future study

It is recommended for future studies to recruit larger samples from multiple HD centers across the different regions of Malaysia with the aim of improving the generalizability of the study findings. Also, longitudinal studies should be considered for future studies. This is because longitudinal study able to provide data regarding any changes in the psychological well-being, coping strategies employed, and the quality of life of the patient over time, especially following dialysis initiation. Besides, it’s highly recommended to involve the healthcare professionals and

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family caregivers in the future qualitative studies so that able to provide for the more comprehensive understanding regarding the psychosocial needs of the patients which receiving for the long-term HD.

Conflict of Interest

The authors declare that there are no conflicts of interest regarding the publication of this study.

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