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REVIEW ARTICLE

A qualitative systematic review of burden among patients with hemodialysis

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Abstract

The study is to explore the burden experienced during dialysis care integration in a patient's life. A systematic search was employed and focused on qualitative studies. We searched some reference lists of eligible studies published in 2018-2022. We followed the PRISMA guidelines, and the analysis employed a meta-ethnography study. We identified that the dialysis care integration burden had been perceived since the initial decision to dialysis care integration. Patients felt powerless since they were provided with no choice of medical intervention. The perceived service affordability and barriers had added more burden experience of dialysis care integration. The dialysis care integration restricts various aspects of the patient's life: food and drink intake, mobilization, and activity. The strategy for integrated dialysis care required utilizing numerous resources to build positive coping strategies. The finding signified that dialysis patients demanded assistance from various resources to adjust to the current dialysis care.

Keywords: Health burden; dialysis care; kidney injury; chronic illness; quality of life

Introduction

End-stage renal disease (ESRD) is a health problem that currently has a high prevalence worldwide. Based on the United States Renal Data System (USRDS), data in 2018 shows that two million patients were diagnosed ESRD and 80% of them started dialysis. In addition, the prevalence of dialysis treatment is 1.685 in 2020 (Centers for Disease Control and Prevention, 2020). A recent report validates it states that nearly 786.000 people in the United States are currently living with ESRD, and the majority, 71%, are undergoing dialysis treatment (Centers for Disease Control and Prevention, 2021). Dialysis is a treatment that tends to be performed in the long term in patients with kidney failure. Patients dedicate their time to the dialysis unit twice to three times weekly for this treatment, even on weekends. Treatment sessions can last for several hours, ranging from three to four or more hours (Finnegan-John & Thomas, 2013; Zazzeroni et al., 2017). In addition, dialysis reduces patients' time for relaxation and social activities. Frequent visits to a hospital or dialysis unit have a cumulative effect of fatigue, interfering with ordinary life (Finnegan-John & Thomas, 2013).

Patients in the hemodialysis stage are susceptible to psychological stress, depression and anxiety that affect the clinical treatment effect. Previous studies reported that 29% were positively screened for depressive symptoms, 21% for concern, and 16% for both (Chen et al., 2022). Another study added that 20 and 40% of adults on dialysis were depressed compared to 4.4% of the general population. Depression among those with kidney disease is associated with poor quality of life (Schick-Makaroff et al., 2021). In addition, patients also express a sense of hopelessness. For some people, feelings of sadness and depression are constant struggles, and they imply that they feel "stuck" by their circumstances (Finnegan-John & Thomas, 2013). The symptoms of dialysis seem to have impact on decreasing patients' quality of life (Kim et al., 2021). The severity of the kidney problems and the variation in daily activities that the patient typically carries out is most often associated with complaints about their restricted life experience. The patients' restricted life was reported in the form of time restrictions, diet, loss of freedom, the burden of physical and mental symptoms, and psychological factors that affect each other in their lives (Balconi et al., 2019).

Suppose a comparison is made between patients' quality of life undergoing hemodialysis. In that case, there is a statistically significant difference between the quality of life of patients undergoing hemodialysis and peritoneal dialysis concerning the effects of kidney disease.

In contrast, peritoneal dialysis can be performed independently or with the help of a caregiver at home or work. Receiving dialysis modalities at home leads to a better quality of life and self-efficacy than traditional therapy at the hospital (Zazzeroni et al., 2017). Hemodialysis is considered to have a worse impact on the patient's psychological and social dimensions than other dialysis modalities. Nurses have an essential role in improving a holistic healthcare system, one of which is assessing aspects of the burden felt by hemodialysis patients, which can affect the overall quality of life. Hemodialysis patients have special conditions compared to other chronic patients. These special conditions, including dependence on dialysis machines, cause changes in the lives of patients and their families (Bellier-Teichmann et al., 2022). Hemodialysis patients need mental support to adapt to their current status, and nurses can help them become accustomed to their problems and fears of illness by reducing anxiety, increasing adaptability, supporting decision-making, and providing emotional and educational support. Therefore, nurses' awareness of the high quality of care can affect the care of these patients and increase patient satisfaction (Shahdadi & Rahnama, 2018).

In addition, it is related to the patient's experience in the hemodialysis unit and the psychological utility offered while the patient is undergoing dialysis in the hemodialysis department. It refers to relationships with health professionals who serve as a source of medical information and support needed to deal with the patient's dialysis condition. This relationship can also affect the experience of integration burden experienced by patients with ESRD conditions during dialysis therapy (Balconi et al., 2019). The care of patients with advanced CKD predominantly focuses on treating the patient's physical and biological problems. However, awareness among providers about the symptom burden of this integrated dialysis care process can affect patients holistically. Many patients report their ambivalence about dialysis treatment dependence, although crucially, they are disturbed by the burden of time, quality of life, and sense of control that result from their dialysis treatment (Finnegan-John & Thomas, 2013). This literature study aims at synthesizing the available evidence related to the perceived burden of patients with ESRD to integrate prolonged dialysis treatment into the life domain. The research questions discussed in this study review are as follows: how does integrated dialysis care experience in life result in patients with ESRD feelings of burden? It is expected that the results of this study will be used to make a model design recommendation that can help patients adjust or adapt to the burden of dialysis care.

Method

This study used a systematic review design integrating qualitative analysis. That design has been chosen according to the research question and the scope of the study. A systematic qualitative review reveals new understanding and help to explore along with build theory. Such thoughts can answer the question, 'What is it like to suffer from chronic pain such as hemodialysis?'. The PICOT framework developed eligibility criteria for study inclusion using participant, intervention, comparison, and outcome criteria (**Table 1**).

Table 1. PICOT criteria

Variables	Information
Population	The patients were at least 18 years old, diagnosed with stage 5 CKD or ESRD, and had been on dialysis therapy for two months.
Intervention	Dialysis therapy
Comparator	Not limited to comparative studies
Outcome	Qualitative data on the psychosocial burden experienced by patients during dialysis therapy
Study design	Primary study with qualitative study method written in English
Time	The study publication year is limited from 2018 to 2022

Studies excluded are guidelines, literature or discussions report, government reports, news, or academic studies from an institution, and studies not describing the topic being investigated. Studies published before 2018 were excluded to ensure the recentness of the findings included in this study to reflect the psychosocial burden

experienced by patients undergoing current dialysis therapy. Studies were also excluded if they focused on the effect of medication (such as anti-depressant treatment and others) or specific interventions (such as psychoeducational therapy, cognitive behavioral therapy, etc.). Patients with ESRD who underwent dialysis therapy after experiencing a kidney transplant procedure were excluded from the study because of the psychosocial difference experienced before and after transplantation. Studies that include health staff and caregivers are formed when the supporting data, such as the results of interviews and the themes obtained, can be explained differently between each sample group included.

We prepared structured questions before conducting the literature study. The literature search was done through some databases, Scopus, ProQuest, Science Direct, CINAHL Plus, and Web of Science. Research articles included in this literature review were collected using a combination of Medical Subject Headings (MeSH) to form keywords. The keywords used were “life experience”, “psychological”, “end-stage renal disease”, “end-stage kidney disease”, “hemodialysis”, “hospital hemodialysis”, “hemodialysis unit”, “home dialysis”, “peritoneal dialysis”, and combined with term “qualitative”. The keywords used were then limited by applying Boolean operators. Research articles included in the study are limited to between 2018 and 2022. The screening process and selection of study articles obtained can be seen in the figure (**Figure 1**).

We conducted a systematic review by following the PRISMA (Page et al., 2021). The quality assessment included in this study uses a quality-validated assessment tool following The Joanna Briggs Institute (JBI) Critical Appraisal Checklist for qualitative studies. We used the cut-off point value from the total score to classify the study quality into two categories, good and bad. When the study score is at least 50% of the critical appraisal criteria, it will be considered feasible and included in the excellent category. We excluded studies with low quality to avoid bias in the validity of the results. The data analysis and synthesis employed meta-ethnographic techniques. This process also ensures that the final examination has high explanatory power for all data (details of theme development can be seen in the appendix). We display the data synthesis as a tabulation table of the characteristics of research articles, quality, and theme results obtained from each research article so we can explore and combine each study's findings.

Results

The search from the databases resulted in 14.421 studies, including five studies by previously identified researchers. 3.121 duplicate studies were removed so that there were 11.351 studies left for screening. 11.279 studies were excluded because the title or abstract did not match the topic of the problem we wanted to know. A total of 72 studies were continued for a feasibility selection process related to the quality of the study based on the results of the JBI checklist assessment of qualitative studies and the suitability of the study with the problems studied through a full-text review process guided by the PICOT framework for the inclusion criteria of the studies to be selected. A total of 56 studies were excluded from this process for the reasons. From the 18 studies that had a full-text review, two studies were excluded after quality assessment. Thus, 16 studies were included in the final analysis for a systematic review of qualitative studies.

Most of the data in the study were collected through semi-structured interviews, group discussions, and open-text responses. In these studies, the smallest sample used was 10 participants, and the largest was 504 participants. The quality of the studies is all good categories, with the lowest score of 6 and the highest being 10. The studies that were obtained and met the criteria requirements were assessed for their similarities or differences in the results found based on the preliminary review of the resulting studies. The findings of this study are shown in Table 2 and appendix S1 Themes emerging from the data (primary search). The themes resulting from the synthesis process of all the included qualitative studies, along with the elaboration of the code, sub-themes, and related citations from the included studies to produce a summary of themes that can represent several sub-themes is provided in the appendix Themes emerging from the data (primary search). These findings are summarized in four overall pieces: The patient's experience in dialysis therapy starts from considering the decision to dialysis therapy to the perception of the affordability of services and the perceived barriers during dialysis. The limitation of life in various aspects creates negative views and impacts the patient. The distortion of life caused by ESRD and dialysis affects the patient's biopsychosocial well-being and strategies development for living with ESRD. In addition, lifelong dialysis treatment requires multiple sources of support.

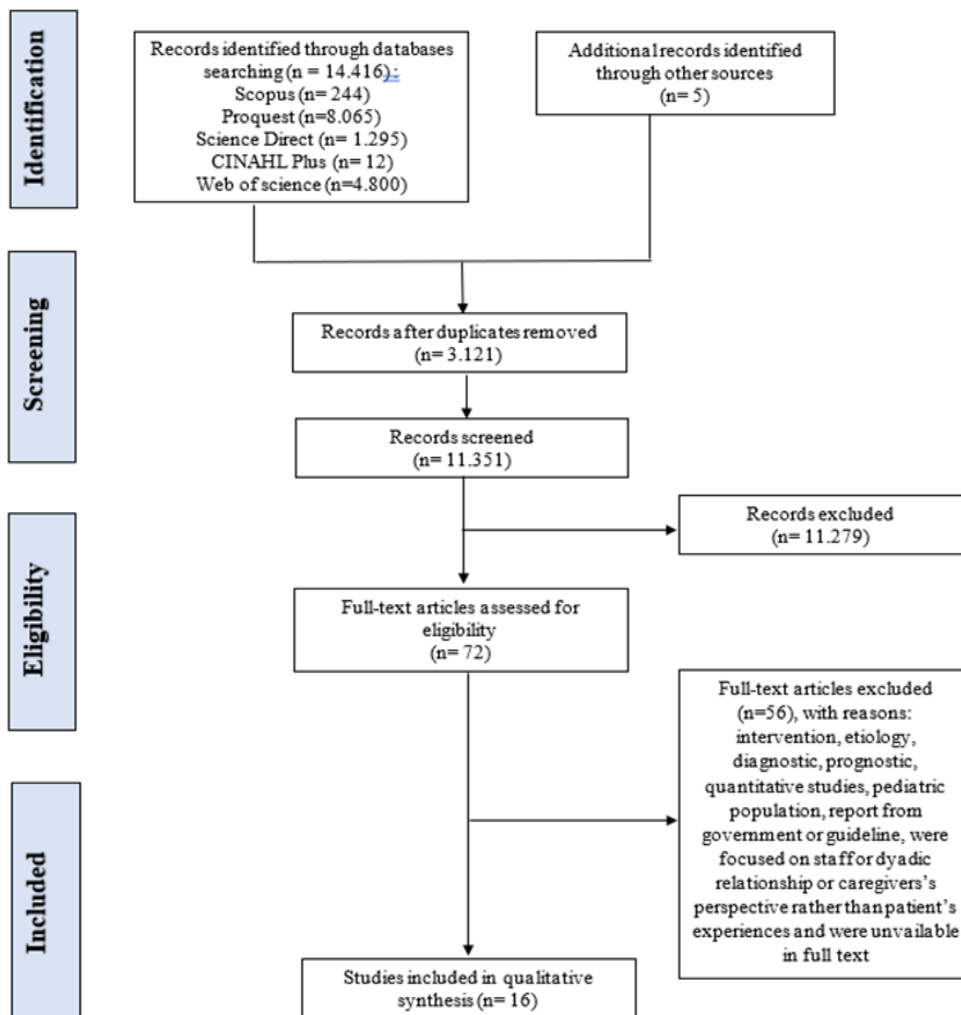


Figure 1. Article selection process

The four themes in the findings of this study produce a continuous line of argument. The results show that the experience of ESRD patients undergoing dialysis therapy has started since they decided to receive dialysis therapy to be integrated into their life. Various considerations that influence the patient's decision to undergo dialysis are the doctor's advice, family considerations, information obtained by the patient, and his life-threatening condition. However, they also have a particular view that they cannot refuse but be involved in deciding the therapy for their condition. It is because they have no other choice, exacerbated by the emergence of negative expectations in the future, that the situation will worsen. Although they hope that they can undergo a transplant one day to return to normal, they still feel uncertain. The difficulties in accessing services, the affordability of dialysis services, the quality of the dialysis machines used, and the dialysis care staff's skills and attitudes are some points that patients consider to develop a negative perception of dialysis treatment. They are going through many obstacles. The burden on the patient increases due to the limitations of the life that they must live. These limitations occur in various dimensions of life, including the need to adjust food and beverage intake, disease condition, mobility restrictions, feelings of wasting the remaining time and financial problems.

Table 1. Study finding

No	Authors	Study design	Sample size	Date	Country	Quality
1.	Tadesse <i>et al.</i>	Phenomenological study	12 participants	2021	Ethiopia	8
2.	Balogun <i>et al.</i>	Qualitative study	15 participants	2019	USA	7
3.	Sharma <i>et al.</i>	Qualitative study	24 participants	2019	England	9
4.	Avdal <i>et al.</i>	Phenomenological study	20 participants	2020	Turkey	7
5.	Andersen-Hollekim <i>et al.</i>	A qualitative study	11 participants	2020	Norway	9
6.	Jones <i>et al.</i>	Qualitative study	20 participants	2018	England	8
7.	Shahgholian & Yousefi	Qualitative study	17 participants	2018	Iran	10
8.	Han <i>et al.</i>	Interviews	16 participants	2019	Singapore	6
9.	Beng <i>et al.</i>	Qualitative study	19 participants	2019	Malaysia	6
10.	Flythe <i>et al.</i>	Qualitative study	42 patients	2018	USA	7
11.	Rezaei <i>et al.</i>	Qualitative study	12 participants	2018	Iran	9
12.	Rezaei <i>et al.</i>	Phenomenological study	12 participants	2020	Iran	10
13.	Stavropoulou <i>et al.</i>	Qualitative study	10 participants	2020	Greece	9
14.	Santana <i>et al.</i>	Qualitative study	12 participants	2020	Brazil	7
15.	Keskindag <i>et al.</i>	A qualitative study	14 participants	2020	Turkey	8
16.	Nataatmadja <i>et al.</i>	A qualitative study	233 participants	2020	USA	6

The limitation may trigger distortions or deviations from the order of life conceived by the patient. It results in changes in the order and plan of life due to fluctuations in the effects of dialysis treatment, affecting the patient's biopsychosocial well-being. It also resulted in patients' psychological and behavioral change and decreased roles and functional abilities, ultimately raising the thought that they become a burden in their family and social life. The feeling of getting negative views, being neglected from social and family associations, and the feeling that death is getting closer to their destiny because of the uncertainty of their condition makes the patients' acceptance of changes in life plans even more difficult. However, they also admit that dialysis allows them to experience a better life. Therefore, some claim to normalize dialysis if something terrible happens as destiny. Various strategies to deal with the condition and dialysis therapy that the patients undergo are developed both through cognitive development and patient behavior by utilizing patient support sources, including family support, social support, nursing staff, to spiritual support that can lead to the formation of positive strategies or vice versa in a negative direction. Most studies state that the coping strategy of accepting the condition is a form of adaptive coping carried out to get the condition to develop the patient's independence in care and lifestyle control.

Discussion

The findings in this study indicate that the patient's decision to dialysis lead to burden in their life. This condition due to the decision-making considerations are based on various opinions obtained by patients from doctors, families, other information, and life-threatening diseases. In addition, other study explained that patients' passiveness contributes to decision (Tadesse *et al.*, 2021). It supports the results that some patients feel they are not sufficiently informed about what they will receive during their treatment. These feelings primarily occur in those who feel they are not sufficiently involved in decisions about their care and the future they will face later (Sein *et al.*, 2020). However, based on the findings in this study, those who decided to undergo dialysis (Balogun *et al.*, 2019) could be based on their trust in the doctor's opinion. This situation can be motivated by patients' perception to position health care professionals' knowledge higher than their knowledge.

The readiness of the family support is the primary considerations for receiving dialysis (Muscat *et al.*, 2018). The family's enthusiasm to help the patient is also one of the primary considerations for receiving dialysis (Tone Andersen-Hollekim *et al.*, 2020; Balogun *et al.*, 2019; Pancras *et al.*, 2018). Cases of patients whose family members have abandoned and even their partners have been explored. It could be due to family problems or financial difficulties (Pancras *et al.*, 2018). Travel and medical expenses for hemodialysis and other supportive care are described as challenging (Tadesse *et al.*, 2021) because not all patients can get subsidies from medical social welfare or seek reimbursement from the Social Security Organization (SOCSO) (Sharma *et al.*, 2019). The psychological trauma of being diagnosed with life-threatening ESRD is exacerbated by thinking about how to raise money to pay for treatment (Boateng *et al.*, 2018). The lack of respect and empathy shown by some dialysis staff has offended some patients (Hughes *et al.*, 2019). The lack of time given by staff in busy renal units to discuss anything beyond substantial clinical issues creates a strong feeling. If staff members are well-trained in providing dialysis care and responding to

medical problems, they are usually less able to cope with the emotional side of the patients experiencing ESRD (Sein et al., 2020). They may be relatively lacking in recognizing signs of suffering in their patients, especially when patients try to normalize their feelings or try hard to 'retain the burden of suffering'(Damery et al., 2019).

As a result of ESRD and the dialysis they have to undergo, the patients experience life restrictions in some aspects. In the findings of this study, the limitations include restrictions related to food and beverage intake, mobility due to dependence on dialysis machines, time to spend time with family and social, as well as finances due to lack of time or difficulty integrating dialysis time with time to go to work. The life order that was initially planned deviated due to the burden of dialysis integration in the patient's life, either because of the effects of dialysis or the nature of dialysis therapy itself. Previous studies have found that many patients experience a decrease in their independence after starting their dialysis program (Hall et al., 2020). The patients' time that should be filled for work is limited; therefore, it impacts finances and decreases their work ethic assessment (Jones et al., 2018). In addition to physical problems such as fatigue and pain during or after dialysis, emotional issues such as worry, sadness, and depression are frequently reported by patients (Damery et al., 2019). Many patients comment on the stress caused by the various dialysis requirements, the time-consuming nature of dialysis (more than 14 hours per week), and the perpetuation of the treatment process with no definite endpoint (Jones et al., 2018).

The physical and psychological changes experienced by the patient cause negative feelings, including shame, frustration, sadness, and worry about being a burden on the family (Hall et al., 2020). Patients described the loss of identity since their ESRD diagnosis (Sein et al., 2020) and the failure of all ability to do things that could otherwise be done independently would "make life not worth living" (Hall et al., 2020). In addition, they noted much difficulty accepting significant changes in their lifestyle and abilities due to ESRD's physical and emotional burdens, including the impact of dietary and fluid restrictions (Damery et al., 2019). In overcoming this loss of independence, some people describe that "everything is going smoothly" and adjust their routines to what they can physically do, realizing that it takes longer to perform daily activities (Hall et al., 2020). Many patients reported mixed feelings about their ability to cope, fear that their condition might worsen, and anxiety about their future (Sein et al., 2020). The integration of dialysis in life forces the patient to develop strategies to deal with dialysis throughout their life. The study states that "dialysis helps one thing but takes other things away from you"(Hall et al., 2020). Specific transition points in the ESRD pathway may give rise to specific stressors, such as a diagnosis of ESRD or initiating dialysis treatment. However, adjustment to ESRD is a dynamic and constant process, and suffering can affect any patient at any time (Sein et al., 2020). This study's findings highlight that most coping strategies developed by patients are cognitive reframing with accepting their current condition (acceptance) strategies. A review of their current health and illness facilitates a shift in perceptions of disease management, the nature of health and illness, and self-experience concerning health and drugs (Nowakowski & Sumerau, 2019). Patients accept and adjust to the changes in their lives caused by ESRD. They utilize positive thinking and problem-solving to reduce the negative impact of illness and treatment on their quality of life (Han et al., 2019). Adjusting to dialysis often means thinking of dialysis as a "job" (Hall et al., 2020; Keskindag et al., 2021), which is illustrated by the fact that "it (dialysis) sets the schedule for our lives" (Hall et al., 2020). This acceptance triggers resilience and positive and adaptive coping strategies, such as proactive symptom reporting (Flythe et al., 2018).

The findings of this study also state that the existence of support from various sources will play an essential role in the patient's life. Some of these are influenced or mediated by experiences related to the renal unit/staff, whereas others are related to personal circumstances and individual coping resources (Damery et al., 2019). Most participants described the importance of having family, friends, and dialysis staff who provide emotional support (Hall et al., 2020). Another study reports that family, friends, and health professionals who patiently support and listen to patients ultimately help patients agree to integrate dialysis as one of the treatments (Min-Ling & Chu, 2022). The renal unit staff might support the patient who has a long and stable relationship with them and is proficient in paying attention to changes in their behavior or attitude that may indicate emotional problems (Sein et al., 2020). This study is the first time for the primary author to make synthesis data of systematic review based on qualitative research and have to take a demanding time to adapt to the technic of synthesis data. To minimize the risk of bias, the principal author has been supported by a co-author who still works in the dialysis unit to ensure the findings data suit the reality of the patient's experience. Another co-author as a lecturer has joined this study and they have many experiences arranging a systematic review study.

Conclusion

Our study showed that patients with hemodialysis experienced various psychological and social problems. Also, the burden of dialysis is varied and tends to be negative impact to the patients. Therefore, patients need assistance from

some sources to accommodate adjustments to their current integrated dialysis care. Further studies are needed to explore the intervention to reduce the burden among the group.

Author's declaration

The authors made substantial contributions to the conception and design of the study and took responsibility for data analysis, interpretation, and discussion of results. For manuscript preparation, all the authors read and approved the final version of the paper.

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Availability of data and materials

All data are available from the authors.

Competing interests

The authors have declared that no conflict of interest exists.

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