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What are the qualitative experiences of people affected by kidney failure receiving haemodialysis?

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REVIEW ARTICLE

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What are the qualitative experiences of people affected by kidney failure receiving haemodialysis?

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Abstract

Background: People affected by kidney failure receiving haemodialysis experience complexity within their health condition unlike any other chronic illness or condition. Kidney failure impacts the individual in all areas of their life including relationships and activities of daily living.

Objective: To conduct a meta-aggregation of studies about the lived experiences of people with kidney failure receiving haemodialysis.

Design: Using PRISMA Guidelines, six databases (CINAHL, ClinicalTrials.gov, Cochrane Library, MEDLINE, PsycINFO, and Scopus) were comprehensively searched using keywords and subject headings from January 1990 to October 2021. Articles were assessed according to prespecified eligibility criteria. Data extraction and quality appraisal was conducted. A meta-aggregation of qualitative findings was conducted using the Joanna Briggs Institute methodology for meta-aggregation.

Results: Of the 9409 articles screened, 55 studies were included. This represented a total of 188 findings across 45 categories representing a range of unmet supportive care needs. The meta-aggregation identified 11 synthesised findings broadly related to psychological/emotional needs, physical needs, social needs, interpersonal/intimacy needs, patient-clinician communication needs, family related needs, health system/information needs, spiritual needs, daily living needs, practical needs and daily living needs.

Conclusions: This meta-aggregation has identified that people affected by kidney failure can experience a range of unmet supportive care needs. It was evident that living with kidney failure and receiving haemodialysis impacted a person's sense of self, introduced practical needs and other complex needs which were not being addressed in existing services. This review has highlighted important implications for clinical practice and future research directions.

KEYWORDS
experiences, haemodialysis, kidney failure, meta-aggregation

INTRODUCTION

It is estimated that globally 1.2 million people died from kidney failure in 2017 (Bikbov et al., 2020) underscoring the burden of this condition. Kidney failure is a prevalent condition and commonly caused by hypertension and diabetes (Graciolli et al., 2017). When the disease progresses and kidney function decreases to stage five, kidney replacement therapy (KRT) needs to be considered. KRT includes either peritoneal dialysis, haemodialysis (HD) or kidney transplantation (KT), and the choice of treatment may include a shared decision making model between the patient and health professionals, and dependent on medical and surgical contraindications as well as resources available. For individuals requiring HD, quality of life can be reduced, and the disease burden is significant when compared with age-matched general populations (Kraus et al., 2016; Ware et al., 2019). These issues have recently underscored by a strong call for health care professionals to move away from a 'one-size-fits-all' approach to HD to providing a person-centred model of care that incorporates patient goals and preferences for care while still incorporating best practices to ensure safe therapy administration (Chan et al., 2019). Kidney failure is an increasing global burden and complicated health issue projected to double from 2.5 million to 5.4 million by 2030 for those who will require KRT (Liyanage et al., 2015). This means many more people will require a person-centred approach to address the persistent unmet supportive care needs for those living with this complex disease (Freidin et al., 2019; Sellars et al., 2019).

Renal supportive care is a nephrology multidisciplinary approach to maintain quality of life, optimise family and emotional support, manage distressing symptoms, and facilitate advanced care planning for patients living with kidney failure (Davison et al., 2015; Murtagh et al., 2016). People affected by kidney failure and receiving HD treatment can experience a significant amount of physical and psychological burden (Almutary et al., 2016; Yapa et al., 2020). Evidence has identified that as the disease progresses and individuals require HD the self-management of symptoms experienced can become intense and distressing (Ju et al., 2018; Yapa et al., 2020).

People who are receiving HD experience complexity in their health condition that includes managing the illness and adopting lifestyle alterations which are emotionally challenging for the individual and their family members (Keskin et al., 2019). People affected by kidney failure and requiring HD have reported a range of unmet supportive care needs (Culp et al., 2016; Hashemi et al., 2018). According to Davison et al. (2015) renal supportive care needs include therapies intended to prolong life expectancy including HD and providing patient centred conservative nursing care that aims to relieve symptoms burden.

Currently, there is only one meta-aggregation of the lived experiences of people receiving HD that included 10 studies, the results were grouped into four themes and this review is not current (Hatthakit, 2012). Many other reviews focus on an area of need as Ling et al. (2021) performed a systematic review of coping strategies of people receiving HD, but this review did not provide a holistic view of the complex needs of people receiving HD. Cantor-Cruz et al. (2021) performed a qualitative systematic review of health needs of people with kidney failure however this review has a strong global perspective that includes dominants of health and includes people receiving PD and HD, both in centre and home setting. Therefore, there is a clinical need to synthesis the qualitative experiences of patients affected by kidney failure who require HD treatment, to understand their experiences as articulated by them. The aim of this systematic review was to understand qualitative experiences of people affected by kidney failure treated by HD within a centre health care facility.

METHODS

Design

A meta-aggregation of qualitative studies was conducted. The presentation of findings conforms to the Enhancing Transparency in Reporting of the Synthesis of Qualitative Research (ENTREQ) statement (Tong et al., 2012), see (Supporting Information: Table 1 for completed checklist). This systematic review was conducted according to a priori protocol available from PROSPERO [CRD42020148231]. and has been reported according to the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRIMSA) guidelines.

Pre-eligibility screening criteria

Types of studies

Inclusion criteria

- All qualitative studies irrespective of research design.
- English language studies in peer-reviewed journals.

Exclusion criteria

- All quantitative publications and case reports, conference abstracts, commentaries, editorials or studies without data to address the research question.

Types of participants

- All participants (≥aged 18 years) diagnosed with kidney failure and treated by HD.

Search strategy

The CINAHL, ClinicalTrials.gov, Cochrane Library, MEDLINE, PsycINFO and Scopus, databases were searched for all relevant publications (data cut-off January 1990–October 2021, English language studies only). Relevant systematic reviews were scrutinised for potentially relevant studies for screening. The search architecture was designed by an expert systematic review librarian and the management of citations was conducted using Endnote software. The search used a wide range of keywords and subject headings to increase the sensitivity and inclusiveness of the searches, see Supporting Information: Table 2 for exemplar of a database search.

Study selection

Following the search, all identified citations were imported into Covidence software for de-duplication and screening according to the inclusion and exclusion criteria. Titles and abstracts were screened by two reviewers, with any conflicts resolved by discussion. Full-texts of selected studies were retrieved and assessed in detail against the inclusion criteria by two reviewers. Full-text studies that did not meet the inclusion criteria were excluded, and exclusion reasons provided. The study selection process is described using the PRISMA flow diagram (Page et al., 2021).

Assessment of methodological quality

All studies meeting the inclusion criteria were assessed using the Joanna Briggs Institute (JBI) Critical Appraisal Checklist for Qualitative Research (Lockwood et al., 2015). This is a 10-item checklist which assesses congruity between the philosophical/theoretical position adopted in the study, study methodology, study methods, the research question, the representation of the data, and the interpretation of the findings of each of the selected studies (Lockwood et al., 2015). The item ratings of each appraisal were consolidated and represented in a final quality appraisal table. The included studies were assigned a score based on each question within the appraisal tool, with an adopted quality assessment of yes quality criteria met, no the criteria not met, and unclear whether the quality assessment has been met s–0.

Data extraction

The data extracted included specific details about the population, context, geographical location, study methods and the phenomena of interest relevant to the review research question. In this meta-aggregation, the units of extractions are specific findings highlighted by the authors which constitute textual conclusions, and these were presented as key themes/subthemes. The findings were extracted directly from the original studies by the reviewers, referring to specific quotations which justify the generation of each finding. The focus therefore was to extract the findings generated by the researchers of each study, without interpreting the actual data from the individual studies. Themes of the individual qualitative studies were classified and categorised using the supportive care framework as findings in this review which were supported by illustrative direct participant quotes. This afforded an accurate and reliable presentation of results and eliminated the risk of reinterpreting the included studies.

Analytical approach

The JBI method of meta-aggregation was used to extract, synthesis and categorise the data. Findings and supporting illustrations were assessed for congruence and given a ConQual ranking of either ‘unequivocal’ (clear association between the finding and illustration), ‘equivocal’ (unclear association between the finding and illustration, leaving it open to challenge) or ‘not supported’ (findings not supported by data). Unsupported findings were not included in the final synthesis. Following careful and repeated assessment of the compiled data, two or more findings were grouped into categories accompanied by an explanatory statement. Further synthesis of these categories produced a single comprehensive description of the findings to represent each category.

Findings

Of 9409 publications retrieved from the search 9308 were excluded following the application of the inclusion/exclusion criteria, see Figure 1. A total of 101 full-text articles were assessed in full and 46 articles were excluded with reasons because they did not meet the inclusion criteria. In total 55 studies were included in this meta-aggregation. The studies were conducted in various countries including Iran ($n = 8$), Jordon ($n = 1$), Turkey ($n = 1$), Brazil ($n = 1$), Canada ($n = 3$), Ireland ($n = 1$), USA ($n = 12$), Sweden ($n = 4$), Korea ($n = 2$), Taiwan ($n = 2$), Australia ($n = 6$), New Zealand ($n = 1$), UK ($n = 6$), Norway ($n = 1$), Denmark ($n = 1$), Ethiopia ($n = 1$), Portugal ($n = 3$) and Japan ($n = 1$). The sample size across the included studies ranged from five to 189, with a total number of 1059 participants treated by HD across all studies. See Table 1 for overview of included studies. The methodological quality assessment results of the individual studies are presented in Table 2.

Across the included studies there were a total of 188 findings and 45 categories (see Supporting Information: Table 3). The categories were then synthesised into individual supportive care needs domains (see Table 3). This meta-aggregation identified 11 synthesised findings namely: ‘The individual’, ‘Practical needs’, ‘Spiritual and existential needs’, ‘Physical needs’, ‘Intimacy and sexual needs’, Relationship with health care professionals’, ‘Supported self-management’, ‘Service improvements’, ‘Social restrictions’, ‘Impacts on family caregivers’ and ‘Coping emotionally’.

The individual

The effect of HD on a person's sense of self was identified in 17 studies. Participants expressed that they felt bound to the medical

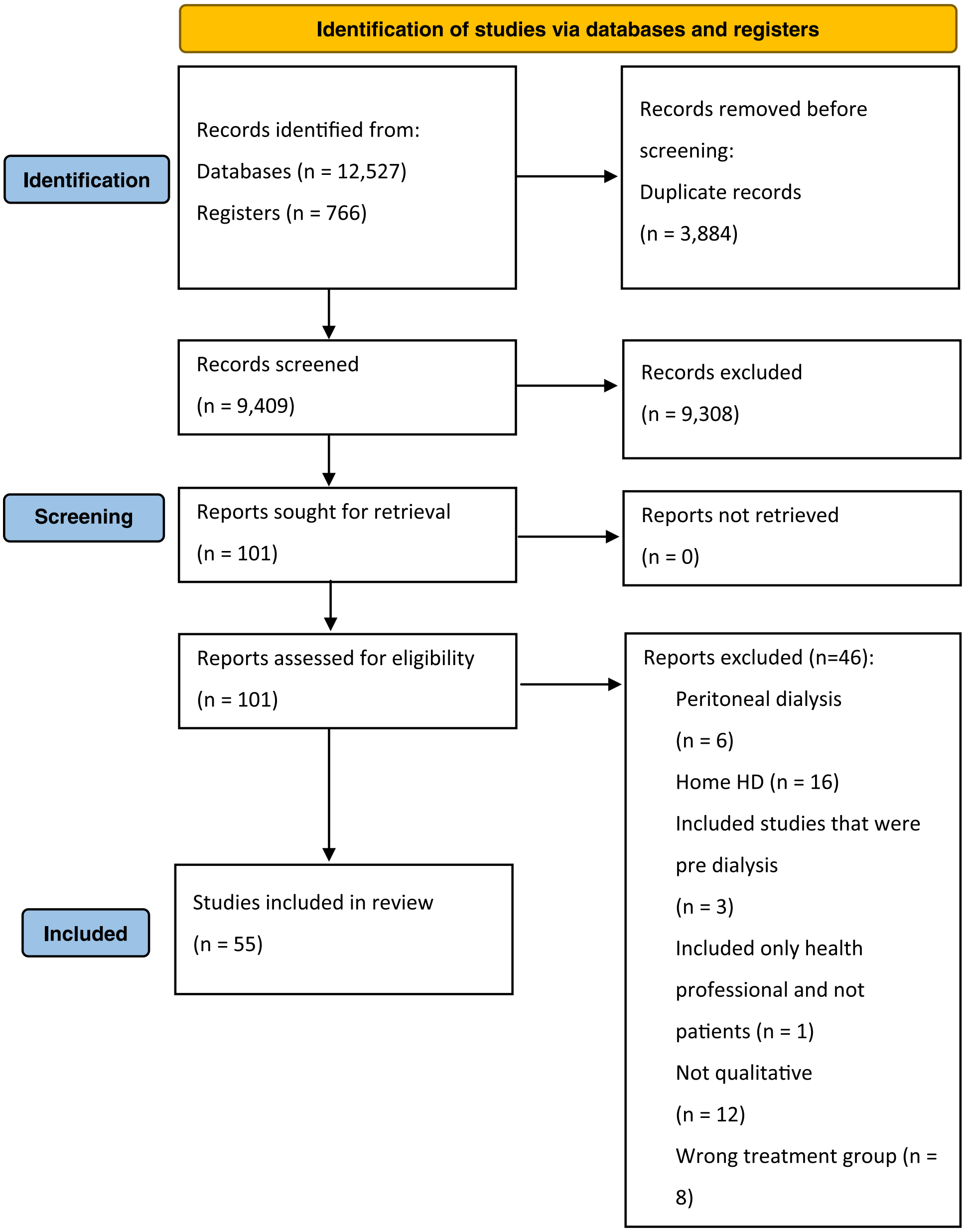

FIGURE 1 PRISMA 2020 flow diagram (Page et al. 2021)

apparatus and sole dependence on HD. This experience was commonly reported and led to negative feelings and resentment towards receiving treatment (Barbosa & Valadares, 2009; Chenitz et al., 2014; Ekelund & Andersson, 2010; Frandsen et al., 2020; Hagren et al., 2005; Frontini et al., 2021). The feeling of dependence upon their fistula graft and the HD machine for treatment was difficult for some people to accept as they felt they had no alternative but to continue with HD treatment (Frontini et al., 2021; Moore et al., 2020; Sousa et al., 2021). Some people felt living with kidney failure and receiving HD was worse than other diseases and some forms cancers as they felt they were on borrowed time with no chance of living a individual normal life (Sousa, Ribeiro, Costa et al., 2021; Sousa, Ribeiro, Figueiredo, 2021; Tadesse et al., 2021).

The loss of independence and autonomy combined with the amount of time that HD consumed in one's life meant many people felt that they were wasting their life away, with no meaningful direction any longer (Barbosa & Valadares, 2009; Hagren et al., 2001, 2005). The experience of the sense of self impacted employment and their sense of positional role within the family unit (Aghakhani et al., 2014; Liu et al., 2022). While some people affected by kidney failure receiving HD gradually adjusted over time with acceptance (Wongboonsin et al., 2021), some continued to grapple with HD and used avoidance coping strategies.

Practical needs

The practicality of receiving HD treatment can affect all areas of a person's life including their finances, employment and transport to and from hospital. The practical needs of those undergoing HD were

TABLE 1 Overview of characteristics of the included studies

Lead Author/Year	Methods for data collection and analysis	Country	Phenomena of interest	Participant characteristics and sample size	Major findings domain of need
Aghakhani et al. (2014)	Methodology: grounded theory data collection: face to face interviews	Iran	To understand the participants' concerns and needs during their experience of receiving HD	22 participants receiving HD, 3 nurses, 4 GP, 1 specialist doctor, 2 family members	Five themes emerged that included: perceived threats caused by disease, seeking social support, accessible resources for social support, beliefs and values and perceived social support
Al-Ghabeesh and Suleiman (2014)	Methodology: phenomenology data collection: face to face semi-structured interviews	Jordan	To identify the lived experience of a person receiving HD	10 participants receiving HD	Four themes were identified including stressors of HD, goodness and badness, still alive, and quality of care
Andersen-Hollekim et al. (2020)	Methodology: Narrative design Data collection: face to face interviews using open ended questions	Norway	To explore how working-age adults experience patient participation within hospital-based haemodialysis	12 participants receiving HD	Three themes emerged that included: informed, but not involved in treatment choices, duality of care and control, and frail trust reflecting collaborative deficiencies
Arslan and Ege (2009)	Methodology: one-on-one interview Data collection: in-depth, semi-structured interviews	Turkey	Exploring the sexual difficulties in women receiving HD	10 participants receiving HD	Two themes emerged that included sexual dysfunction relating to HD and the inability to fall pregnant
Barbosa and Valadares (2009)	Methodology: Grounded theory data collection: face to face semi-structured interviews	Brazil	To describe how people receiving HD cope with their disease	10 participants receiving HD	High levels of denial and negative thoughts while receiving HD and trying to adjust to their disease. Acceptance of the disease and treatment within the period of adjustment
Barnieh et al. (2014)	Methodology: descriptive Data collection: open ended questions using surveys	Canada	To understand the views of people receiving HD and their carer's	A total of 189 participants that included 123 receiving HD, 24 receiving peritoneal dialysis, 6 people about to start HD and 36 care providers	Four themes were identified which included gaining knowledge, maintaining quality of life, sustaining psychological well-being and ensuring appropriate care
Biniaz et al. (2018)	Methodology: phenomenology Data collection: semi-structured face to interview	Iran	To gain a deeper understanding of the experiences in people receiving HD	19 participants receiving HD, 2 carers, 2 HD nurses and 2 nephrologists	Five themes included inner wholeness, well-being, positive social interaction, effective self-empowerment and improvement of economic conditions
Bristol et al. (2021)	Methodology: descriptive Data collection: semi-structured interview using open ended questions	USA	To identify the palliative care needs of people with CKD receiving HD	8 participants receiving HD and 3 caregivers	Two themes that included communication addressing the emotional and physical aspects of disease and filling the gaps in care

TABLE 1 (Continued)

Lead Author/Year	Methods for data collection and analysis	Country	Phenomena of interest	Participant characteristics and sample size	Major findings domain of need
Calvey and Mee (2011)	Methodology: phenomenology data collection: semi-structure interviews	Ireland	To understand the life of the person receiving HD beyond the outpatient renal centre	7 participants receiving HD	Two themes emerged that included the living and future self, and the mortal/fragile self
Cassidy et al. (2018)	Methodology: descriptive Data collection: semi-structured interviews	Canada	To understand treatment decision making in people receiving HD	12 participants receiving HD	Three themes emerged that were related to patient, education factors and support systems (including social and family support)
Cervantes et al. (2017)	Methodology: one-on-one interview Data collection: semi-structed interviews	USA	To understand the experience of illness in people who are immigrants receiving HD	20 participants receiving HD	Four themes emerged including the distressing symptom burden related to the need for emergency dialysis. Anxiety related to impending death, family and social consequences related to HD and the perception of the health care system
Chenitz et al. (2014)	Methodology: focus groups Data collection: semi-structured interviews	USA	To understand the types of barriers some people experience with attending their scheduled HD session	30 participants receiving HD	Three themes were identified that included, access to reliable transport, motivation to attend HD and feeling and attitudes about HD
Clark-Cutaia et al. (2020)	Methodology: exploratory Data collection: semi-structured interviews	USA	To explore the factors that contribute to the high rates of hospitalisation in people receiving HD	21 participants receiving HD and 10 family caregivers	Three themes from the patient's perspective were identified. They include graft/site/catheter/access issues, my resistance is low and I could not breathe
De Silva et al. (2021).	Methodology: descriptive Data collection: focus groups	Australia	To describe patient and caregivers' perspectives of sleep in HD to inform strategies to manage sleep disorders and disturbances	7 participants receiving HD and 1 caregiver	Five themes emerged that included constraints of daily living, roadblocks in relationships, burden on caregivers, losing enjoyment and undermining mental resilience
Ekelund and Andersson (2010)	Methodology: one-on-one interview Data collection: questionnaire based semi-structured telephone interviews	Sweden	To understand the patient and their partners accounts of living with ESKD and receiving treatment	2 participants receiving HD and 17 PD with 21 partners	Five themes emerged that identified the importance of individualised treatment, dependence, consequences of disease treatment, hopes for the future and concerns about death
Frandsen et al. (2020)	Methodology: phenomenology Data collection: Open-ended questions and in-depth interviews	Denmark	To investigate the experiences and perspectives of everyday life in people who receive HD treatment	5 participants receiving HD and 5 partners	Four themes emerged that included changes in everyday life, the importance of knowledge and participation in illness and treatment, thoughts about the future and the importance of relationships.

(Continues)

TABLE 1 (Continued)

Lead Author/Year	Methods for data collection and analysis	Country	Phenomena of interest	Participant characteristics and sample size	Major findings domain of need
Frontini et al. (2021)	Methodology: exploratory Data collection: semi-structured, individual and in-depth interviews were conducted	Portugal	To explore the main fears and concerns of people receiving HD and their family members	20 people receiving HD and 14 family members	Four themes were identified that included fear of death, fear of problems during HD, and concerns related to the disease
Ghaffari et al. (2019)	Methodology: one-on-one interviews Data collection: deep, semi-structured interviews	Iran	To explain the coping styles in HD patients in relation to stress	22 people receiving HD	Three themes emerged that include coping effort, meaning based coping and moderators
Hagren et al. (2001)	Methodology: onterpretive Data collection: face to face semi-structured interviews	Sweden	To describe the experiences of suffering from ESKD	15 participants receiving HD	Two main themes were identified which included the HD machine as a lifeline and the alleviation of suffering
Hagren et al. (2005)	Methodology: interpretive data collection: Face to face semi-structured interviews	Sweden	To identify how people receiving HD express their life situation	41 participants receiving HD	Three main themes related to not finding space for living, feelings evoked in the care situation and attempting to manage restricted life
R. K. Hall, Cary et al. (2020); R. Hall, Rutledge et al. (2020)	Methodology: observational Data collection: semi-structure interviews and focus groups	USA	To identify unmet needs of people receiving HD treatment	14 people receiving HD, 24 health care professionals (includes nurses, nephrologists, social workers and technicians)	Four themes emerged that include mobility, medications, social support and communication
R. K. Hall, Cary et al. (2020); R. Hall, Rutledge et al. (2020)	Methodology: phenomenology Data collection: semi-structured interviews	USA	To identify quality of life themes in older adults receiving HD	12 participants receiving HD	Two themes emerged that include having physical well-being and having social support
Hashemi et al. (2018)	Methodology: investigative Data collection: semi-structure face to face interviews	Iran	To identify how care plans can be changed and improved to meet the persons needs when receiving HD	35 participants that included 9 patients, 6 family members, 9 nurses, 4 nephrologist, 4 psychologist, 2 social workers and 2 dieticians	Four main themes were identified that included modification of physical stressors, improving support systems, improving quality of health care services and improving the patient's comfort while receiving HD
Hughes et al. (2019)	Methodology: phenomenology Data collection: in-depth interviews	Australia	To describe the experiences and satisfaction of health care users of a large government kidney health service provider	13 people receiving HD, 1 person receiving PD and 2 kidney transplant recipients	Themes such as knowledge gaps, health care provider quality, service environment, carer needs, impacts of relocation and client recommendation to enhance the health care service experience were identified

TABLE 1 (Continued)

Lead Author/Year	Methods for data collection and analysis	Country	Phenomena of interest	Participant characteristics and sample size	Major findings domain of need
Jhamb et al. (2016)	Methodology: grounded theory Data collection: in-depth interviews	USA	To identify the barriers to exercise and physical activity in people receiving HD	36 participants (16 patients, 14 staff members, 6 nephrologists)	Several themes were identified that included knowledge and perceived benefits of exercise, barriers to exercise during and after HD, motivators and facilitators to exercise
Kim et al. (2018)	Methodology: ethnography Data collection: participant observations and interviews	Korea	To identify the social behaviours and interactions of people within the waiting areas of HD units	4 patients and 14 family members	Three themes were identified that include sharing information and consoling, ease and discomfort, and unsure stillness
Lambert et al. (2018)	Methodology: sensemaking theory Data collection: semi-structured interviews	Australia	To describe the experiences of interpreting and implementing a renal diet in people receiving HD and PD	8 people receiving HD, 4 receiving PD, 3 transplant recipient, 11 CKD (not on RRT) and 10 carers	Six themes emerged that include (1) overwhelming, frustrating, and emotional journey (2) complex and challenging diet (3) dietician input is highly valued (4) carer support is important (5) developing problem solving strategies and (6) desire for additional resources and/support
E. J. Lee, Chang et al. (2021)	Methodology: descriptive Data collection: focus groups and in-depth interviews	Korea	To explore the barriers and facilitators affecting fluid restriction adherence among Korean HD patients	27 people receiving HD	Three themes emerged that include (1) Intrapersonal (2) Interpersonal and (3) organisational levels
B. O. Lee et al. (2007)	Methodology: phenomenology Data collection: In-depth face to face interviews	Taiwan	To identify the meaning of fatigue in people who receive HD	14 participants receiving HD	Three domains were identified that included physical, affective and cognitive fatigue
Lin et al. (2005)	Methodology: phenomenology Data collection: In-depth, open ended semi-interviews	Taiwan	To identify the experience of decision making in people with HD	12 participants receiving HD	Three broad themes were identified that included confronting the HD treatment, seeking further information, and living with HD
Liu et al. (2022)	Methodology: Phenomenology Data collection: semi-structured interviews	USA	To identify important personal factors impacting the mobility of older adults receiving HD	31 participants receiving HD and 12 caregivers	Five major themes were extracted that include (1) mobility represents independence (2) mobility is precarious (3) limitations in mobility cause distress (4) sources of encouragement and motivation are critical, and (5) adaptability is key
McLean et al. (2021)	Methodology: exploratory Data collection: semi-structured interviews	New Zealand	To describe the perspective and experiences of dietary management among patients on HD in New Zealand	40 people receiving HD	Three themes that include (1) major disruption (2) independence, adherence, and control and (3) importance of appropriate professional support

(Continues)

TABLE 1 (Continued)

Lead Author/Year	Methods for data collection and analysis	Country	Phenomena of interest	Participant characteristics and sample size	Major findings domain of need
Miller et al. (2017)	Methodology: exploratory Data collection: face to face workshops using a question guide	Australia	To identify other important topics to include into current guidelines	8 patients and 3 caregivers	Five major themes were identified related to shock and vulnerability, burden of isolation, fear of infection, privacy and confidentiality and confusion over procedural inconsistencies
Mitchell et al. (2009)	Methodology: positive psychology Data collection: semi-structured interviews	UK	To identify factors that enable people to transition in HD successfully	10 participants receiving HD	Three main themes were identified that included preparation, cognitive style and social support
Monaro et al. (2014)	Methodology: phenomenology Data collection: semi-structured face to face interviews	Australia	To explore the lived experiences of people with ESKD commencing HD	11 patients receiving HD and 5 family caregivers	One theme from patients emerged that included the concept of lost life. From caregivers the theme of intense vigilance was identified
Moore et al. (2020)	Methodology: grounded theory Data collection: semi-structure interviews	UK	To explore the impact of dialysis on dyadic relationship	20 people receiving HD and their respective partners	Four themes emerged that include prioritising the patient, carrying the burden, changing identities, and managing the relationship
Nilsson (2019)	Methodology: phenomenology Data collection: individual semi-structured interviews	Sweden	To understand the experiences in people with ESKD when HD is unplanned	5 participants who commenced HD in an unplanned manner	Themes that emerged included awareness, undesirable and unexpected, acceptance and support
Onbe et al. (2013)	Methodology: ethnography Data collection: microethnography	Japan	To understand attitudes towards renal dietary management in people receiving HD treatment	9 participants receiving HD treatment	Three themes identified that included propensity of behaviour, affect and cognition, and culture and cognition
Parker et al. (2017)	Methodology: exploratory Data collection: face to face semi-structured interviews	USA	To understand experience of managing medications in people with ESKD receiving HD	13 participants receiving HD	Three main themes that included complex health and health care needs that disrupt their everyday lives, medication management requires individualised strategies and strong social networks, medication management services should be offered for others, but not for me
Rezaei et al. (2018)	Methodology: phenomenology Data collection: face to face semi-structured interviews	Iran	To explore the experience of fatigue in people receiving HD	12 patients receiving HD, 1 spouse, 1 doctor, 1 nurse	Two main themes were identified that included psychological effects and, needs and restrictions

TABLE 1 (Continued)

Lead Author/Year	Methods for data collection and analysis	Country	Phenomena of interest	Participant characteristics and sample size	Major findings domain of need
Salter et al. (2015)	Methodology: exploratory Data collection: focus groups	USA	To explore perceptions of HD and KT among African American adults receiving HD	36 people receiving HD	Four main themes that include (1) current health perceptions (2) support while undergoing HD (3) interactions with medical professionals, and (4) concerns about KT
Sass et al. (2020)	Methodology: descriptive Data Collection: Focus groups and semi-structured interviews	Canada	To describe the patient, caregiver, and health professional perspectives regarding challenges and solutions to individualisation of care in people receiving HD	64 people receiving HD, 18 caregivers, and 31 health care providers	Four main themes were identified that included (1) session set-up (2) transportation and parking (3) socioeconomic and emotional well-being, and (4) HD treatment location and scheduling
Sciberras and Scerri (2017)	Methodology: Data Collection: Phenomenology Semi-structured interviews	UK	Explored the perceived barriers and facilitators experienced in receiving HD	7 participants receiving HD	Three themes were identified that included social network outside the renal unit, the renal setting as a context and qualities relating to staff
Sein et al. (2020)	Methodology: Exploratory Data Collection: In depth, semi-structured interviews	UK	To explore patients' experience of mild to moderate distress in ESKD	24 people receiving HD, 8 people pre-HD, and 14 kidney transplant recipients	Two main themes were identified that included the patients' experience of distress and the kidney unit support
Senteio and Ackerman (2022)	Methodology: Uncertainty management theory Data Collection: Semi-structured interviews	USA	What are the perceptions of transplantation of black ESRD patients' who are on HD but not on a KT waitlist	24 people receiving HD	Two main themes that included (1) uncertainty for these patients is prevalent and multi-layer, and (2) social support can both dissuade an individual from pursuing a KT
Shahgholian and Yousefi (2015)	Methodology: Phenomenology Data Collection: Face to face unstructured interviews	Iran	To understand the concept of support in people receiving HD	17 participants receiving HD	Four themes emerged that included psychological support, accompaniment, social and spiritual support
Shahgholian and Yousefi (2018)	Methodology: Phenomenology Data Collection: Face to face, in depth and semi-structured interviews	Iran	To understand the concept of care in people receiving HD	17 participants receiving HD	Four themes included empathy, companionship in everyday needs, social support and concerns, and good quality HD
Sharma et al. (2019)	Methodology: Focus groups Data Collection: Face to face focus groups	UK	To understand the thoughts, feelings, and experiences of receiving HD treatment	24 participants receiving HD	Four themes were identified that included (1) treatment imposition, (2) the patient clinician relationship, (3) coping strategies and (4) pursuit of transplantation

(Continues)

TABLE 1 (Continued)

Lead Author/Year	Methods for data collection and analysis	Country	Phenomena of interest	Participant characteristics and sample size	Major findings domain of need
Sousa, Ribeiro, Costa et al. (2021)	Methodology: Exploratory Data Collection: In depth, semi-structured interviews	Portugal	To explore the impacts of coronavirus in non-COVID-19 people receiving HD	20 people receiving HD	Four major themes were identified that included (1) psychosocial negative impacts, (2) impacts on disease and treatment related behaviours (3) positive impacts, and (4) coping strategies
Sousa, Ribeiro, Figueiredo (2021)	Methodology: Exploratory Data Collection: Semi-structured interviews	Portugal	To examine the experiences of couples living with ESRD and receiving HD	12 people receiving HD and their spouses (12)	Two themes merged that included negative impacts and unmet needs
Sutherland et al. (2021)	Methodology: Exploratory Data Collection: Semi-structured interviews	UK	To explore the experience of death among people receiving HD and to determine if it changes patients' understanding of their own mortality	10 people receiving HD	Four main themes emerged that included (1) patients' relationship with HD (2) how patients define the HD community (3) patients' views on death and bereavement, and (4) patients' expectations around death in the dialysis community
Tadesse et al. (2021)	Methodology: Phenomenology Data Collection: Semi-structured, in-depth interviews	Ethiopia	To explore the lived experience of CKD patients receiving HD in Ethiopia	12 people receiving HD	Six major themes were identified that included (1) the seriousness of the disease (2) challenges to get HD (3) financial constraints (4) restricted life (5) feeling of dependency (6) psychological impacts
Taylor et al. (2016)	Methodology: Descriptive Data Collection: face to face, semi-structured interviews	Australia	To describe the patient's experience of management their own vascular access for HD	26 participants receiving HD	Five major themes included developing mental fortitude for cannulation, device intrusiveness, imposing burdens, inhibiting pain and exposure to dire health outcomes
Vafaei and Nobahar (2017)	Methodology: Exploratory Data Collection: semi-structured interviews	Iran	To examine the care preferences of people receiving HD	20 participants receiving HD	Three themes emerged that included preserving life, dependence on HD and self-care
Wongboonsin et al. (2021)	Methodology: Descriptive Data Collection: Semi-structure interviews	USA	To explore the difficulties in arranging travel for people receiving HD	16 people receiving HD and 8 renal social workers	Three themes emerged from the interviews that included travel process, travel-related barriers, and travel-related facilitators

Abbreviations: CKD, Chronic kidney disease; ESKD, End stage kidney disease; GP, General practitioner; KT, Kidney transplant; HD, Haemodialysis; RRT, Renal replacement therapy; UK, United Kingdom; USA, United States America.

TABLE 2 Results of quality assessment

Study	1	2	3	4	5	6	7	8	9	10
Aghakhani et al. (2014)	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
Al-Ghabeesh and Suleiman (2014)	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
Andersen-Hollekim et al. (2020)	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
Arslan and Ege (2009)	U	U	Y	Y	Y	Y	Y	Y	U	Y
Barbosa and Valadares (2009)	Y	N	Y	Y	Y	Y	Y	Y	Y	Y
Barnieh et al. (2014)	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
Biniaz et al. (2018)	U	Y	Y	Y	Y	Y	Y	Y	Y	Y
Bristol et al (2021)	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
Calvey and Mee (2011)	Y	Y	Y	Y	Y	Y	Y	Y	U	Y
Cassidy et al. (2018)	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
Cervantes et al. (2017)	Y	Y	Y	Y	Y	Y	Y	Y	Y	y
Chenitz et al. (2014)	U	Y	Y	Y	Y	Y	Y	Y	U	Y
Clark-Cutaia et al. (2020)	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
De Silva et al. (2021)	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
Ekelund and Andersson (2010)	Y	Y	Y	Y	Y	U	Y	Y	U	Y
Frandsen et al. (2020)	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
Frontini et al. (2021)	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
Ghaffari et al. (2019)	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
Hagren et al. (2001)	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
Hagren et al. (2005)	Y	Y	Y	Y	Y	Y	Y	Y	U	Y
R. K. Hall, Cary et al. (2020); R. Hall, Rutledge et al. (2020)	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
R. K. Hall, Cary et al. (2020); R. Hall, Rutledge et al. (2020)	Y	Y	Y	Y	U	Y	Y	Y	Y	Y
Hashemi et al. (2018)	Y	U	Y	Y	Y	Y	Y	Y	U	Y
Hughes et al. (2019)	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
Jhamb et al. (2016)	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
Kim et al. (2018)	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
Lambert et al. (2018)	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
E. J. Lee, Chang et al. (2021)	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
B. O. Lee et al. (2007)	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
Lin et al. (2005)	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
Liu et al. (2022)	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
McLean et al. (2021)	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
Miller et al. (2017)	Y	Y	Y	Y	Y	Y	Y	Y	U	Y
Mitchell et al. (2009)	U	Y	Y	Y	Y	Y	Y	Y	Y	Y
Monaro et al. (2014)	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
Moore et al. (2020)	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
Nilsson (2019)	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
Onbe et al. (2013)	U	Y	Y	Y	Y	Y	Y	Y	Y	Y
Parker et al. (2017)	Y	U	Y	Y	Y	Y	Y	Y	U	Y
Rezaei et al. (2018)	Y	Y	Y	Y	Y	Y	U	Y	Y	Y
Salter et al. (2015)	U	U	U	Y	Y	Y	Y	Y	Y	Y
Sass et al. (2020)	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
Sciberras and Scerri (2017)	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
Sein et al. (2020)	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
Senteio and Ackerman (2022)	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
Shahgholian and Yousefi (2015)	Y	U	Y	Y	Y	Y	Y	Y	Y	Y
Shahgholian and Yousefi (2018)	Y	U	Y	Y	Y	Y	Y	Y	Y	Y
Sharma et al. (2019)	U	Y	Y	Y	Y	Y	Y	Y	U	Y
Sousa, Ribeiro, Costa et al. (2021)	Y	U	Y	Y	Y	Y	Y	Y	Y	Y
Sousa, Ribeiro, Figueiredo (2021)	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
Sutherland et al. (2021)	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
Tadesse et al. (2021)	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
Taylor et al. (2016)	Y	U	Y	Y	Y	Y	Y	Y	Y	Y
Vafaei and Nobahar (2017)	Y	U	Y	Y	Y	Y	Y	Y	Y	Y
Wongboonsin et al. (2021)	Y	U	Y	Y	Y	Y	Y	Y	Y	Y

Note: Item number checklist key: (1) Is there congruity between the stated philosophical perspective and the research methodology? (2) Is there congruity between the research methodology and the research question or objectives? (3) Is there congruity between the research methodology and the methods used to collect data? (4) Is there congruity between the research methodology and the representation and analysis of data? (5) Is there congruity between the research methodology and the interpretation of results? (6) Is there a statement locating the researcher culturally or theoretically? (7) Is the influence of the researcher on the research, and vice-versa, addressed? (8) Are participants, and their voices, adequately represented? (9) Is the research ethical according to current criteria for recent studies, and is there evidence of ethical approval by an appropriate body? (10) Do the conclusions drawn in the research report flow from the analysis, or interpretation, of the data?

identified in 15 studies. The financial burden of HD was evident in relation to the cost of medications and the inability to maintain regular employment secondary to HD treatment schedules, which were difficult to manage (Aghakhani et al., 2014; Barnieh et al., 2014; Sass et al., 2020). This was in contrast, to a minority who were able to continue their employed positions and expressed that they worked more efficiently because HD had improved their overall health and well-being (Biniaz et al., 2018). Practical issues with management of diet, food, fluid, and weight control were identified as some people struggle to understand and apply a renal diet to their lifestyle as many people indicated they did not have the strategies to manage this competently (Lambert et al., 2018; B. O. Lee et al., 2007; E. J. Lee, Chang et al., 2021)

Medication management was a common theme as some participants found it hard to manage their complex medications regimes. Others invented alternate self-management reminders to organise their medications so that they did not forget to take them (Frontini et al., 2021; Parker et al., 2017; Salter et al., 2015). The dependence on HD for life encompassed the inflexible nature of treatment schedules and dietary routines, which meant that patients were unable to be spontaneous any longer. The continual dependence on treatment also meant that it was difficult for people receiving HD to take holidays (Senteio & Ackerman, 2022; Wongboonsin et al., 2021). Some were dependent on renal centre transport to and from the hospital to receive HD. This often-caused stress and anxiety in when transportation was late, which had an impact on their scheduling of care (Chenitz et al., 2014; Rezaei et al., 2018;). Many participants voiced a lack of knowledge about accessing and using support care organisations and additional community services to help them with meals, transport and practical needs such as carrying groceries. Many participants acknowledged they needed help but did not know how to arrange and access support when they needed it most (Aghakhani et al., 2014; Shahgholian & Yousefi, 2018; Taylor et al., 2016).

Spiritual and existential needs

Several studies identified that spirituality was important among people receiving HD. Some patients shared a strong sense of faith in God that provided them with comfort and support in managing HD and in alleviating distressing symptoms associated with kidney failure (Aghakhani et al., 2014; Al-Ghabeesh & Suleiman, 2014; Biniaz et al., 2018; Shahgholian & Yousefi, 2015). Faith helped people in the process of acceptance of HD and their disease (Biniaz et al., 2018; Sousa, Ribeiro, Costa et al., 2021) as well as their families happiness (Aghakhani et al., 2014; Ghaffari et al., 2019). Some patients felt strongly that God was in control of their future and their acceptance of HD was centred around this in some way (Aghakhani et al., 2014; Biniaz et al., 2018).

Nine studies within the review identified existential needs that were unmet within their care. Many people living with HD openly discussed feelings about their current and future existence, and caregivers expressed concerns about how long one can live for when receiving HD treatment (Bristol et al., 2021; Cervantes et al., 2017; Frontini et al., 2021; Hagren et al., 2001; R. K. Hall, Cary et al. 2020; R. Hall, Rutledge et al. 2020; Kim et al., 2018; Lin et al., 2005). A range of emotions were expressed such as sadness and suffering (R. K. Hall, Cary et al., 2020; R. Hall, Rutledge et al. 2020; Sutherland et al., 2021; Vafaei & Nobahar, 2017) that was associated with the fear of dying and seeing people they know receiving HD, pass away and not being informed by staff members. Other individuals experienced distressing side-effects of HD that included hypotensive events which reminded people of their mortality and that they were facing a terminal illness (Calvey & Mee, 2011; Cervantes et al., 2017). Others found witnessing blood movement in HD lines made them question their existence and the ability to return to a 'normal life' similar to the life they had before HD (Calvey & Mee, 2011; Cervantes et al., 2017).

The existential impact of HD affected how people perceived themselves. Some articulated that it made them feel unclean and dirty, while others feared that their illness may accompany them to the 'next life' if they did not accept and come to terms with their illness (Calvey & Mee, 2011; Lin et al., 2005). A minority of the participants perceived kidney failure was a punishment for evil in their past lives, and that the physical suffering of HD treatment needed to be endured to make right again (Liu et al., 2022; Lin et al., 2005; Vafaei & Nobahar, 2017).

It was common for patients receiving HD to express concern about the health and well-being of others undergoing HD. Many health professionals did not discuss the death of other patients with them despite knowing that this person was part of their peer support network in hospital. Consequently, this left many patients feeling lonely and created negative anticipation towards their own death (Cervantes et al., 2017; Kim et al., 2018; Mitchell et al., 2009). In some studies, health professionals did not openly discuss the KT or HD treatment with patients, and this resulted in people feeling unsure about the future (Sharma et al., 2019). However, when health professionals did explain HD treatment and management thoroughly with patients, it left the patient feeling confident, optimistic about the management of their treatment (Mitchell et al., 2009).

Physical needs

The impact of HD on a person's physical well-being was noted across many studies. Feelings of tiredness, fatigue, drowsiness and apathy after HD treatment was commonly experienced, and for some lead to prolonged episodes of sleep (Al-Ghabeesh & Suleiman, 2014; Frandsen et al., 2020; Lee et al., 2007; Parker et al., 2017; Salter et al., 2015). The issue of sleep disturbances and tiredness was identified as patients reported poor sleep quality and restlessness from ongoing HD treatment and this impaired how they felt the following day (De Silva et al; 2021; Lee et al., 2007; Liu et al., 2022). These symptoms prevented people from attending appointments with members of the clinical team and negatively impacted their social and family relationships (R. K. Hall, Cary et al. 2020; R. Hall, Rutledge et al. 2020; Hashemi et al., 2018). Participants reported physical discomfort in their arms, legs and other areas after HD treatment, which lasted until the next day. This prolonged discomfort resulted in fear of tripping and falling due to tiredness and fatigue (Al-Ghabeesh & Suleiman, 2014; B. O. Lee et al., 2007).

The physical demands of having multiple blood tests and having lines, catheters and needles inserted affected their ability to feel physically well (Clark-Cutaia et al., 2020; Moore et al., 2020; Nilsson, 2019; Onbe et al., 2013). Conversely, some people receiving HD wanted to improve their health and engage in regular exercise to counteract the side-effects of HD. However, patients expressed that their ability to exercise would only be possible on the non-HD treatment days due to fatigue and tiredness (Jhamb et al., 2016; Liu

TABLE 3 Synthesised findings

Findings	Categories	Synthesised finding
25 findings: F1, F14, F15, F37, F38, F48, F53, F54, F57, F62, F64, F66, F81, F83, F104, F107, F122, F136, F165, F170, 171, F173, F175, F180, F191	Sense of self Loss of independence Impact of disease Routine	The individual The loss on the individual's sense of self, impacted all areas including independence, spontaneity, personal time, employment, individual bodily functions, and their sense of position within the family unit. Patients became solely dependent on HD machines. Patients gradually accepted the impact on their sense of self over a period of adjustment, but for some, they continued to avoid HD on every occasion if they could due to the impact of this long-term disease.
22 findings: F2, F3, F19, F24, F36, F58, F72, F89, F90, F95, F105, F134, F135, F137, F141, F142, F144, F151, F158, F178, F182, F190	Financial Transport Medications Diet	Practical Needs The impact of HD resulted in a range of practical needs related to financial toxicity, issues and access to patient transport, the requirement for additional support resources and help in meal preparations. Some patients learned to develop their own practical self-management solutions in their daily lives, while others continued to have difficulties with the practical self-management needs of daily living.
25 findings: F4, F7, F20, F21, F26, F28, F33, F51, F56, F60, F63, F69, F71, F86, F102, F103, F108, F118, F149, F156, F164, F168, F174, F179, F186	Importance of prayer Spiritual coping Transplantation Fear of death and dying	Spiritual and existential needs Patients shared a strong sense of faith in God and divine intervention to alleviate distressing symptoms. Religious beliefs provided individuals with an active coping strategy and a sense that they were not alone. Patients feared death and dying and both patients and family caregivers articulated uncertainty in how long they would live for on HD. Some accepted that they would never meet the criteria for a transplant.
23 findings: F5, F6, F32, F39, F40, F41, F42, F45, F46, F52, F67, F73, F84, F98, F106, F124, F127, F130, F136, F138, F181, F184, F187	Physical stressors Distress Adjustment Quality of life	Physical needs The physical needs of people receiving HD and the consequences of the condition was distressing. Patients experienced chest pain, painful limbs, breathlessness, fatigue, reduced mobility, dizziness, falls, cramps, hypotension, drowsiness and sleep disturbances. Patient and their family caregivers adjusted to the physical appearance of the fistula over time.
22 findings: F8, F10, F11, F16, F22, F25, F35, F47, F55, F65, F70, F78, F82, F117, F140, F148, F150, F153, F157, F160, F162, F189	Patient-nurse relationship Psychological support Lack of empathy	Relationship with health care professionals Patients valued the psychological support provided to them by nurses, continuity of care and many patients had positive perceptions of the service provided to them. However, some articulated a lack of person-centred care, individualised HD treatment plans, complex terminology, and no empathy from medical professionals.
5 findings: F12, F13, F17, F49, F169,	Sexuality and fertility Psychological impact Lack of support	Intimacy and sexual needs Patient articulated unmet sexual needs which were poorly, if at all, discussed with health care professionals. Little advice was provided in the practicality of having intercourse with lines or catheters related to their HD. Others experienced on-going difficulties with fertility issues which were not addressed despite regular follow-up with health care professionals.
19 findings: F9, F23, F30, F31, F76, F77, F91, F93, F94, F97, F101, F111, F114, F126, F166	Education and information Decision making Lack of information	Supported self-management Patients valued clear, easy to understand information to support their self-management. Timely patient education was essential in treatment making-decisions. Some experienced inconsistencies in the information provided, a lack of education related to risk factors, the consequences of

(Continues)

TABLE 3 (Continued)

Findings	Categories	Synthesised finding
		treatment, infection control procedures and the longevity of therapy. Family caregivers also experienced a lack of education and informational support.
10 findings: F75, F79, F85, F88, F115, F116, F143, F145, F147, F176	Health systems Hygiene practice Physical activity support Confidentially and privacy	Service improvements Some patients perceived poor infection control practices among health care professionals and a lack of medical attention when emergencies occurred on the ward. Maintaining patient confidentially and privacy was regarded as important. Promoting physical activity while being hooked up to HD was regarded as important for future models of service delivery.
15 findings: F43, F96, F100, F113, F119, F120, F128, F129, F139, F152, F155, F159, F161, F172,	Social needs Isolation Inevitable consequence Peer support	Social restrictions Due to HD and the side-effects of treatment some patients experienced reduced social networks, social activities with family members, including their inability to plan holidays. Individuals found it difficult to ask for help from their social networks at times, but when support was provided, some patients perceived it as pity which was upsetting to them. The importance of peer support and connection reduced the sense of isolation.
20 findings: F18, F27, F34, F44, F50, F61, F68, F80, F92, F121, F123, F132, F146, F154, F163, F177	Family and relationships Marital problems Caregiver burden	Impact on family carers The importance of family support was essential. However, some patients experienced martial breakdowns due to the burden of the disease. Patients also felt disappointed in close blood relatives who did not offer them a kidney transplant. Family members felt an obligation to care for their loved one in all aspects of daily living which had a profound psychological impact.
14 findings: F29, F59, F74, F87, F99, F109, F110, F112, F125, F131, F167, F183, F185, F188	Psychological Anxious preoccupation Daily impact Vulnerability	Coping emotionally Patients experienced a range of emotions such as anger, sadness, shock, anxiety, sense of dread and stress. Many experienced the psychological burden most days. For others it was important to take a positive approach to coping with HD and to assist them in the acceptance of living with this long-term condition.

et al., 2022; Parker et al., 2017). The physical consequences of the disease and HD treatment included the following bothersome side-effects: tiredness, fatigue, drowsiness, chest pain, painful limbs, breathlessness, fatigue, reduced mobility due to dizziness and cramps, hypotension and all these negatively impacted their quality of life.

Relationship with health care professionals

Patients valued having a positive relationship with their specialist nephrology nurse who provided them with psychological (Shahgholian & Yousefi, 2015, 2018) and educational support during dialysis (Al-Ghabeesh & Suleiman, 2014; Biniaz et al., 2018; Bristol et al., 2021; Cervantes et al., 2017). Patients expressed that they viewed their relationship with health care professionals as a safety net and mostly described health care professionals as empathetic and with whom they developed close friendships (Andersen-Hollekim et al., 2020; Cervantes et al., 2017; Sein et al., 2020). However, some patients experienced a lack of person-centred care, inadequate education to support their self-management, with no information provided to them about the results of their tests/investigations or care interventions (Barnieh et al., 2014; Cassidy et al., 2018; R. K. Hall, Cary et al., 2020; R. Hall, Rutledge et al., 2020; Hashemi et al., 2018; Miller et al., 2017; Nilsson, 2019). A lack of information about their condition and how to self-manage (i.e., cooking meals at home, fistula care) and the use of complex terminology during interactions with health care professions was a concern to both patients and their family caregivers (Barnieh et al., 2014; Cassidy et al., 2018; Hashemi et al., 2018; Nilsson, 2019). When a therapeutic and positive relationship was established between patient and health professional, the patient reported feeling well cared for and involved in the decision-making about their treatment (Calvey & Mee, 2011). Other patients felt rushed during consultations with their medical team with little time to consider the information shared with them (Salter et al., 2015; Wongboonsin et al., 2021) and this was viewed as suboptimal dialysis care (Andersen-Hollekim et al., 2020; Shahgholian & Yousefi, 2018).

For some participants across several studies, the patient-doctor relationship lacked empathy and person-centred care (Barnieh et al., 2014; Sharma et al., 2019). Patients felt they needed to ask questions and push for essential information because the doctor was not forthcoming to communicate this to them either verbally or in writing (Hagren et al., 2005; Mitchell et al., 2009). Patients and caregivers expressed the need for continuity and personalised care with their doctor as important because it was challenging seeing many different doctors at their hospital visits (Ekelund & Andersson, 2010; Hagren et al., 2005; Hughes et al., 2019) who lacked understanding of the burden of regular HD treatment (Salter et al., 2015).

Intimacy and sexual needs

Concerns with intimacy, sexuality and sexual dysfunction were commonly experienced among both men and women (Barnieh et al., 2014; Ekelund & Andersson, 2010). Patients found that the position of lines and permcaths was difficult and how to self-manage during sexual activity was distressing (Arslan & Ege, 2009; Barnieh et al., 2014; Sousa, Ribeiro, Figueiredo, 2021). Participants expressed that fatigue, lack of sexual desire, erectile dysfunction and vaginal dryness were not acknowledged, discussed or treated by health professionals during their consultations (Barnieh et al., 2014; Ekelund & Andersson, 2010). People living with HD found their questions and concerns about fertility and reproduction were not addressed and that they received little or no information from their care team (Arslan & Ege, 2009; Barnieh et al., 2014). Among younger participants the desire to have a family was important but men and women were unsure if this was possible due to their chronic illness and HD treatment (Arslan & Ege, 2009; Barnieh et al., 2014).

Supported self-management

A lack of information and education about kidney failure and disease management was identified in 14 studies. Patients and caregivers struggled to understand the reasons behind their illness and why symptoms occurred because of a lack of information (E. J. Lee, Chang et al., 2021; Miller et al., 2017; Sousa, Ribeiro, Costa et al., 2021). There was considerable confusion surrounding symptoms and infection control self-care. Many patients and caregivers had many unanswered questions and consequently patients expressed that they struggled to maintain a clean environment (Miller et al., 2017).

Patients and caregivers felt anxious and frustrated in having to make decisions hastily and feeling poorly informed about the different treatment modalities available (Andersen-Hollekim et al., 2020; Cassidy et al., 2018; Nilsson, 2019). Others experienced a barrage of complicated information from health professionals, this also was not helpful to ensure informed decision-making about dialysis treatment choices (Cassidy et al., 2018).

Some people were proactive in researching, clarifying, and confirming information about their disease using the internet, family members and asking other health professionals to be more informed about kidney failure and dietary restrictions (Biniaz et al., 2018; Cassidy et al., 2018; Hughes et al., 2019; Lin et al., 2005). Patients and caregivers experienced difficulties and confusion in managing their dietary and fluid restrictions associated with HD (Hashemi et al., 2018; Lambert et ail., 2018; McLean et al., 2021). It was common for participants to report that they received no information about substituting foods and cooking requirements, which usually meant they could not enjoy their meals. The complexities of dietary and fluid restrictions are not new in people with kidney failure and receiving HD, the challenges lie in giving adequate and timely information provided in a manner that ensures understanding and support.

Service improvements

Issues with privacy, infection control, and coordination of care within HD treatment centres were identified in six studies. The structure of HD units and parking availability for patients and relatives was identified as a problem as people struggled to access the HD unit for treatment and visiting (Sass et al., 2020). Many privacy concerns were evident as people receiving HD treatment regularly observed that health professionals openly discussed private details about patients in front of other patients and family members (Miller et al., 2017; Sciberras & Scerri, 2017). According to Hashemi et al. (2018), poor infection control procedures and a lack of medical attention were perceived to be the cause of their chronic illness and the reason as to why patients viewed their health as poor (Kim et al., 2018). Carers and family members felt obligated to remain with their loved one when receiving HD as they did not feel they were being properly looked after by health professionals (Kim et al., 2018). Interestingly, only one study found the delivery of care was adequate, supportive, and organised and that health professionals were considered motivating and encouraging regarding their health (Jhamb et al., 2016).

Social restriction

The restrictions of HD had a profound social impact on many people receiving HD, resulting in isolation and loneliness in 10 studies. According to Sharma et al. (2019) there was an inability to plan social events and holidays, which made it difficult for people to remain socially connected as the demands of HD treatments dominated their schedules (B. O. Lee et al., 2007). However, the HD renal centre provided an opportunity for positive social interactions between peers receiving HD, families, and staff members, which helped to reduce the negative social impact (Mitchell et al., 2009; Nilsson, 2019; Salter et al., 2015; Senteio & Ackerman, 2022). Social and family interactions enhanced a person's well-being and helped them cope with HD treatments within the family unit (Salter et al., 2015).

Importantly, people living with HD felt alone and not well supported by health professionals when they experienced difficulties in asking for help and assistance (Miller et al., 2017; Monaro et al., 2014; Shahgholian & Yousefi, 2015; Shahgholian & Yousefi, 2018; Sutherland et al., 2021). For some, when help and assistance was provided from friends and family, people receiving HD perceived this as pity for them, which caused further negative feelings and unrest (Monaro et al., 2014; Shahgholian & Yousefi, 2015, 2018). Due to the consequences of HD many people deliberately withdrew from their family and social network due to the physical effects, which included fatigue and the fear of people seeing them unwell (De Silva et al., 2021; B. O. Lee et al., 2007; E. J. Lee, Chang et al., 2021; Nilsson, 2019).

Impacts on family carers

The impact of HD on personal and family relationships was evident in many studies. Marital breakdowns and detached family relationships occurred due to the burden of receiving HD and the changing of roles within the family unit because of the disease and treatment (Barnieh et al., 2014; Calvey & Mee, 2011). Often people living with HD felt they were a burden to their family members, which made them feel like an inconvenience to others (Cervantes et al., 2017; R. K. Hall, Cary et al., 2020; R. Hall, Rutledge et al., 2020; Monaro et al., 2014; Shahgholian & Yousefi, 2015;). Conversely, some people valued the support they received and considered themselves lucky to have a family that provided care and encouragement in managing HD treatment so that they did not feel alone (Lambert et al., 2018; Onbe et al., 2013; Sharma et al., 2019).

Interestingly, resentment was common in people receiving HD because they had to sacrifice valuable family time to comply with HD treatment and schedules (Calvey & Mee, 2011; Sciberras & Scerri, 2017). Feelings of disappointment and hurt were noted as family members had not offered them a donor kidney and patients had to continue to wait in vain for a KT, which caused stress and anxiety, because the KT was perceived as a pathway to improved quality of life (Ekelund & Andersson, 2010).

For the family members, caring for those receiving HD made them feel overwhelmed, anxious and stressed. They articulated that this placed a significant strain on their own levels of health and well-being (De Silva et al., 2021). Many people receiving HD realised the pressure that caring for them entails and felt deep empathy for the sacrifice their carer had made in caring for them (Moore et al., 2020; Tadesse et al., 2021). However, some families embraced the challenge of providing care to their family member and accepted their caregiver role with pride and courage, and as an essential part of being in a marital/family network with those who they loved (Ghaffari et al., 2019; Monaro et al., 2014; Onbe et al., 2013).

Coping emotionally

Coping emotionally with the psychological burden of living and managing HD was challenging. The presence of stress and anxiety related to HD treatments was identified as people were engulfed daily by negative feelings that impacted their ability to feel happy and fall asleep (Hashemi et al., 2018; B. O. Lee et al., 2007). Some people felt unprepared for HD treatment and lacked knowledge of their current health status, making the psychological transition to HD even more emotionally challenging (Cassidy et al., 2018; McLean et al., 2021; Miller et al., 2017). Feelings of shock and dread were common and the constant fear of living in anticipation that 'something was going to go wrong' was regularly experienced before, during and after HD (Kim et al., 2018; Taylor et al., 2016).

According to Cassidy et al. (2018), the long-term continuation of HD treatment caused intense psychological distress including prolonged episodes of crying and the sense of feeling trapped and this was perceived to be worse than cancer (Rezaei et al., 2018). For others, it was important to accept their illness and the prospect of long-term HD to embrace independence and positive feelings towards treatment as it was their means to stay alive (Ghaffari et al., 2019; Onbe et al., 2013; Parker et al., 2017; Vafaei & Nobahar, 2017). Only one study focused on coping mechanism during the COVID-19 pandaemic, as people receiving HD viewed this a a learning experience in how to manage their illness while identifying that family and social intereacts are important in learning how to cope with HD (Sousa, Ribeiro, Costa et al., 2021).

DISCUSSION

This systematic review set out to identify the lived experiences of people affected by kidney failure receiving HD and has identified several important recommendations for practice and research. The impact of HD is significant and debilitating, which affects multiple and concurrent aspects of quality of life. The experiences reported highlight that despite continued care, frequent and regular contacts with health care professionals, many individuals continued to report a range of unmet supportive care needs. This review has made an important contribution by informing health care professionals about the complex unmet supportive care needs of those affected by this long-term condition.

Patients lacked informational support and practical advice from their health care professionals in how they could effectively self-manage their long-term condition. Given its complex nature, individuals living with this condition are required to have active involvement in their health to further slow the progression of the disease and prevent further complications (Schrauben et al., 2020). Globally, enablement of self-management among people living with kidney failure is now recognised as effective care management (Shah et al., 2021). Self-management is defined as an individual's ability to manage symptoms, treatment, psychological and physical consequences of the disease and lifestyle changes associated living with a long-term condition (Barlow et al., 2002). With ever increasing numbers of people diagnosed with this life-limiting condition, many more people will require the necessary support from health care professionals to enable them to effectively self-manage. However, this review has identified that people affected by kidney failure receiving HD experienced a lack of support, information, and available resources, with a lack of educational support from their health care providers and shared informed decision-making. Despite an increasing number of self-management interventions tested through research (Donald et al., 2021; Jenkins et al., 2021; M. C. Lee, Wu, et al., 2021; Morris & Lycett, 2021) patients are still experiencing unmet needs in practice.

An important aspect rarely discussed in clinical consultation with health care professionals was the impact on sexuality and intimacy. In keeping with the broader literature sexual dysfunction is prevalent in people living with kidney failure (Pizzol et al., 2021). There are a range of sexual well-being interventions available, including both pharmaceutical and nonpharmaceutical (Frühauf et al., 2013) however, quite often the opportunity to discuss these with patients is limited (Mckie et al., 2021).

STRENGTHS AND LIMITATIONS

This review followed a clear, rigorous and transparent review process, however there are various limitations to highlight. Only studies published in the English language were included and therefore important information from studies in other languages may have been omitted. This review included qualitative studies to elicit how unmet needs were expressed by the participants without being necessarily assessed as a primary objective in the included studies, which may have introduced bias. A supportive care framework was used (Culp et al., 2016) to inform this review across international literature as strength to understand the experience of unmet supportive care needs of people affected by kidney failure receiving HD.

IMPLICATION FOR CLINICAL PRACTICE

This review has highlighted important implications for clinical practice and future research directions. For the moment, all members of the multidisciplinary team caring for people receiving HD are encouraged to use the findings of this review to inform them of the person-centred needs of their patients. Guidelines, protocols and specific services can be introduced early with kidney failure diagnosis as this study has clearly identified many areas needing attention when a person commences HD.

CONCLUSION

This systematic review has identified that people affected by kidney failure can experience a range of unmet supportive care needs. It was evident that living with kidney failure and receiving HD impacted a person's sense of self, introduced practical needs and other complex unmet supportive care which were not being addressed in existing services. Despite the advancements within medical management of chronic diseases, it is evident that services are lacking as people with kidney failure and receiving HD struggle to manage their condition affectively.

AUTHOR CONTRIBUTIONS

Amanda Mckie: Literature search, formal analysis, interpretation, writing original draft, writing–reviewing and editing. **Catherine Paterson**: Conceptualisation, methodology, validation, formal analysis, interpretation, writing original draft, writing–reviewing and editing, supervision. **Murray Turner**: Literature searches, interpretation, writing original draft, writing–reviewing and editing.

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CONFLICT OF INTEREST

The authors declare no conflict of interest.

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REFERENCES

Aghakhani, N, Sharif, F, Molazem, Z & Habibzadeh, H (2014) Content analysis and qualitative study of hemodialysis patients, family experience and perceived social support. *Iranian Red Crescent Medical Journal*, 16, 3.

Al-Ghabeesh, S. & Suleiman, K. (2014) The lived experience of patients' with end stage renal disease on hemodialysis: a phenomenological study. *International Journal of Medicine and Medical Sciences*, 47(1), 1423–1429.

Almutar, H., Bonner, A. & Douglas, C. (2016) Which patients with chronic kidney disease have the greatest symptom burden? A comparative study of advanced CKD stage and dialysis modality. *Journal of Renal Care*, 42(2), 73–82.

Andersen-Hollekim, T., Solbjør, M., Kvangarsnes, M., Hole, T. & Landstad, B.J. (2020) Narratives of patient participation in haemodialysis. *Journal of Clinical Nursing*, 29(13–14), 2293–2305.

Arslan, S.Y. & Ege, E. (2009) Sexual experiences of women exposed to hemodialysis treatment. *Sexuality and Disability*, 27(4), 215–221.

Barbosa, G.D.S. & Valadares, G.V. (2009) Hemodialysis: patient's adaptation and life style. *Acta Paulista de Enfermagem*, 22, 524–527.

Barlow, J.C., Wright, J., Sheasby, A., Turner, S. & Hainsworth, J. (2002) Self-management approaches for people with chronic conditions: a review. *Patient Education and Counselling*, 48(2), 177–187.

Barnieh, L., King-Shier, K., Hemmelgarn, B., Laupacis, A., Manns, L. & Manns, B. (2014) Views of Canadian patients on or nearing dialysis and their caregivers: a thematic analysis. *Canadian Journal of Kidney Health and Disease*, 1, 4.

Bikbov, B.C.A., Purcell, A.S., Levey, M., Smith, A., Abdoli, M., Abebe, O.M. et al. (2020) "Global, regional, and national burden of chronic kidney disease, 1990–2017: a systematic analysis for the global burden of disease study 2017". *The Lancet*, 395(10225), 709–733.

Biniaz, V., Moonaghi, H.K., Froutan, R. & Ebadi, A. (2018) Subjective adequacy of dialysis: a neglected concept in hemodialysis adequacy. *Journal of Renal Injury Prevention*, 7(3), 164–170.

Bristol, A.A., Chaudhry, S., Assis, D., Wright, R., Moriyama, D., Harwood, K. et al. (2021) "An exploratory qualitative study of patient and caregiver perspectives of ambulatory kidney palliative care". *American Journal of Hospice and Palliative Medicine*, 38(10), 1242–1249.

Calvey, D. & Mee, L. (2011) "The lived experience of the person dependent on haemodialysis". *Journal of Renal Care*, 37(4), 201–207.

Cantor-Cruz, F., Cruz-Benavides, J., Henao-Castano, A.M. & Gomez-Ramirez, O.J. (2021) Health needs in chronic kidney disease on dialysis: a qualitative systematic review. *Spring Nature Comprehensive Clinical Medicine*, 2, 117–135.

Cassidy, B.P., Harwood, L., Getchell, L.E., Smith, M., Sibbald, S.L. & Moist, L.M. (2018) "Educational support around dialysis modality decision making in patients with chronic kidney disease: qualitative study". *Canadian Journal of Kidney Health and Disease*, 5, 2054358118803323.

Cervantes, L., Fischer, S., Berlinger, N., Zabalaga, M., Camacho, C., Linas, S. et al. (2017) "The illness experience of undocumented immigrants with end-stage renal disease". *JAMA Internal Medicine*, 177(4), 529–535.

Chan, C.T., Blankestijn, P.J., Dember, L.M., Gallieni, M., Harris, D.C., Lok, C.E. et al. (2019) "Dialysis initiation, modality choice, access, and prescription: conclusions from a kidney disease: improving global outcomes (KDIGO) controversies conference". *Kidney International*, 96(1), 37–47.

Chenitz, K.B., Fernando, M. & Shea, J.A. (2014) "In-center hemodialysis attendance: patient perceptions of risks, barriers, and recommendations". *Hemodialysis International*, 18(2), 364–373.

Clark-Cutaia, M.N., Jarrín, O.F., Thomas-Hawkins, C. & Hirschman, K.B. (2020) The perfect storm: stakeholder perspectives on factors contributing to hospital admissions for patients undergoing maintenance hemodialysis. *Nephrology Nursing Journal*, 47(1), 11–20.

Culp, S., Lupu, D., Arenella, C., Armistead, N. & Moss, A.H. (2016) Unmet supportive care needs in US dialysis centers and lack of knowledge of available resources to address them. *Journal of Pain and Symptom Management*, 51(4), 756–761.e752.

Davison, S.N., Levin, A., Moss, A.H., Jha, V., Brown, E.A. & Brennan, F. et al. (2015) "Executive summary of the KDIGO Controversies Conference on Supportive Care in Chronic Kidney Disease: developing a roadmap to improving quality care". *Kidney International*, 88(3), 447–459.

Donald, M., Beanlands, H., Straus, S.E., Smekal, M., Gil, S., Elliott, M.J. et al. (2021) A web-based self-management support prototype for adults with chronic kidney disease (my kidneys my health): co-design and usability testing. *JMIR Formative Rresearch*, 5(2), e22220.

Ekelund, M.-L. & Andersson, S.I. (2010) "I need to lead my own life in any case"—a study of patients in dialysis with or without a partner. *Patient Education and Counseling*, 81(1), 30–36.

Frandsen, C.E., Pedersen, E.B. & Agerskov, H. (2020) When kidney transplantation is not an option: haemodialysis patients' and partners' experiences—a qualitative study. *Nursing Open*, 7(4), 1110–1117.

Freidin, N., O'Hare, A.M. & Wong, S.P. (2019) "Person-centered care for older adults with kidney disease: core curriculum 2019". *American Journal of Kidney Diseases*, 74(3), 407–416.

Frontini, R., Sousa, H., Ribeiro, Ó. & Figueiredo, D. (2021) "What do we fear the most?": exploring fears and concerns of patients, family members and dyads in end-stage renal disease". *Scandinavian Journal of Caring Sciences*, 35(4), 1216–1225.

Frühauf, S., Gerger, H., Schmidt, H.M., Munder, T. & Barth, J. (2013) "Efficacy of psychological interventions for sexual dysfunction: a systematic review and meta-analysis". *Archives of Sexual Behavior*, 42(6), 915–933.

Ghaffari, M., Morowatisharifabad, M.A., Mehrabi, Y., Zare, S., Askari, J. & Alizadeh, S. (2019) "What are the hemodialysis patients' style in coping with stress? A directed content analysis". *International Journal of Community Based Nursing and Midwifery*, 7(4), 309–318.

Graciolli, F.G., Neves, K.R., Barreto, F., Barreto, D.V., Dos Reis, L.M., Canziani, M.E. et al. (2017) "The complexity of chronic kidney disease–mineral and bone disorder across stages of chronic kidney disease". *Kidney International*, 91(6), 1436–1446.

Hagren, B., Pettersen, I.M., Severinsson, E., Lützén, K. & Clyne, N. (2001) "The haemodialysis machine as a lifeline: experiences of suffering from end-stage renal disease". *Journal of Advanced Nursing*, 34(2), 196–202.

Hagren, B., Pettersen, I.M., Severinsson, E., Lützén, K. & Clyne, N. (2005) Maintenance haemodialysis: patient's experiences of their life situation. *Journal of Clinical Nursing*, 14(294), 300.

Hall, R., Rutledge, J., Colón-Emeric, C. & Fish, L.J. (2020) "Unmet needs of older adults receiving in-center hemodialysis: a qualitative needs assessment". *Kidney Medicine*, 2(5), 543–551. e541.

Hall, R.K., Cary, M.P., Washington, T.R. & Colón-Emeric, C.S. (2020) "Quality of life in older adults receiving hemodialysis: a qualitative study". *Quality of Life Research*, 29(3), 655–663.

Hashemi, M.S., Irajpour, A. & Abazari, P. (2018) "Improving quality of care in hemodialysis: a content analysis". *Journal of Caring Sciences*, 7(3), 149–155.

Hatthakit, U. (2012) Lived experiences of patients on hemodilaysis: a meta-synthesis. *Nephrology Nursing Journal*, 39(4), 295–304.

Hughes, J.T., Freeman, N., Beaton, B., Puruntatemeri, A.-M., Hausin, M. & Tipiloura, G. et al. (2019) My experiences with kidney care: a qualitative study of adults in the Northern Territory of Australia living with chronic kidney disease, dialysis and transplantation. *PloS one*, 14(12), e0225722.

Jenkins, Z.M., Tan, E.J., O'Flaherty, E., Knowles, S., Thompson, D.R., Ski, C.F. et al. (2021) A psychosocial intervention for individuals with advanced chronic kidney disease: a feasibility randomized controlled trial. *Nephrology*, 26(5), 442–453.

Jhamb, M., McNulty, M.L., Ingalsbe, G., Childers, J.W., Schell, J., Conroy, M.B. et al. (2016) Knowledge, barriers and facilitators of exercise in dialysis patients: a qualitative study of patients, staff and nephrologists. *BMC Nephrology*, 17(1), 1–14.

Ju, A., Unruh, M.L., Davison, S.N., Dapueto, J., Dew, M.A., Fluck, R. et al. (2018) "Patient-reported outcome measures for fatigue in patients on hemodialysis: a systematic review". *American Journal of Kidney Diseases*, 71(3), 327–343.

Keskin, G., Babacan Gümüş, A. & Taşdemir Yiğitoğlu, G. (2019) Sexual dysfunctions and related variables with sexual function in patients who undergo dialysis for chronic renal failure. *Journal of Clinical Nursing*, 28(1-2), 257–269.

Kim, Y., Kim, M., Bhandari, P. & Choi, S. (2018) Experience of the waiting area as perceived by haemodialysis patients and family carers. *Journal of Advanced Nursing*, 74(2), 364–372.

Kraus, M.A., Fluck, R.J., Weinhandl, E.D., Kansal, S., Copland, M., Komenda, P. et al. (2016) Intensive hemodialysis and health-related quality of life. *American Journal of Kidney Diseases*, 68(5), S33–S42.

Lambert, K., Mansfield, K. & Mullan, J. (2018) How do patients and carers make sense of renal dietary advice? A qualitative exploration. *Journal of renal care*, 44(4), 238–250.

Lee, B.O., Lin, C.C., Chaboyer, W., Chiang, C.L. & Hung, C.C. (2007) The fatigue experience of haemodialysis patients in Taiwan. *Journal of Clinical Nursing*, 16(2), 407–413.

Lee, E.J., Chang, A.K. & Chung, Y.C. (2021) Socioecological factors affecting fluid restriction adherence among Korean patients receiving hemodialysis: a qualitative study. *Journal of Transcultural Nursing*, 32(3), 239–247.

Lee, M.C., Wu, S.F.V., Lu, K.C., Liu, C.Y., Liang, S.Y. & Chuang, Y.H. (2021) Effectiveness of a self-management program in enhancing quality of life, self-care, and self-efficacy in patients with hemodialysis: a quasi-experimental design. *Seminars in Dialysis*, *Wiley Online Library*. 34, 292–299.

Lin, C.-C., Lee, B.-O. & Hicks, F.D. (2005) The phenomenology of deciding about hemodialysis among Taiwanese. *Western Journal of Nursing Research*, 27(7), 915–929.

Ling, W.T., Khuan, L., Baharom, A. & Arshad, M.M. (2021) Coping strategies of patients with end stage kidney disease on hemodialysis: a systematic review. *Nephrology Nursing Journal*, 48(1), 31–48.

Liu, C.K., Seo, J., Lee, D., Wright, K., Tamura, M.K., Moye, J.A. et al. (2022) Mobility in older adults receiving maintenance hemodialysis: A qualitative study. *American Journal of Kidney Diseases*, 79(4), 539–548.e531.

Liyanage, T., Ninomiya, T., Jha, V., Neal, B., Patrice, H.M., Okpechi, I. et al. (2015) Worldwide access to treatment for end-stage kidney disease: a systematic review. *The Lancet*, 385(9981), 1975–1982.

Lockwood, C., Munn, Z. & Porritt, K. (2015) Qualitative research synthesis: methodological guidance for systematic reviewers utilizing meta-aggregation. *JBI Evidence Implementation*, 13(3), 179–187.

Mckie, A.L., Green, T. & Bonner, A. (2021) Nurse's practices and attitudes toward sexual health, wellbeing, and function in people receiving haemodialysis: a scoping review. *Journal of renal care*, 47(3), 184–192.

McLean, R.M., Xie, Z., Nelson, V., Nosa, V., Thein, H., Po'e-Tofaeono, A. et al. (2021) Experiences of New Zealand haemodialysis patients in relation to food and nutrition management: a qualitative study. *Nutrients*, 13(7), 2299.

Miller, H.M., Tong, A., Tunnicliffe, D.J., Campbell, D., Pinter, J., Commons, R.J. et al. (2017) Identifying and integrating patient and caregiver perspectives for clinical practice guidelines on the screening and management of infectious microorganisms in hemodialysis units. *Hemodialysis International*, 21(2), 213–223.

Mitchell, A., Farrand, P., James, H., Luke, R., Purtell, R. & Wyatt, K. (2009) "Patients' experience of transition onto haemodialysis: a qualitative study". *Journal of renal care*, 35(2), 99–107.

Monaro, S., Stewart, G. & Gullick, J. (2014) A 'lost life': coming to terms with haemodialysis. *Journal of Clinical Nursing*, 23(21-22), 3262–3273.

Moore, C., Skevington, S., Wearden, A. & Mitra, S. (2020) Impact of dialysis on the dyadic relationship between male patients and their female partners. *Qualitative Health Research*, 30(3), 380–390.

Morris, A. & Lycett, D. (2021) Behavioural strategies to self-manage low-potassium diets in chronic kidney disease. *Journal of Renal Care*, 47(3), 160–168.

Murtagh, F.E., Burns, A., Moranne, O., Morton, R.L. & Naicker, S. (2016) Supportive care: comprehensive conservative care in end-stage kidney disease. *Clinical Journal of the American Society of Nephrology*, 11(10), 1909–1914.

Nilsson, E.L. (2019) Patients' experiences of initiating unplanned haemodialysis. *Journal of renal care*, 45(3), 141–150.

Onbe, H., Oka, M., Shimada, M., Motegi, E., Motoi, Y. & Okabe, A. (2013) Defining the culture and attitude towards dietary management actions in people undergoing haemodialysis. *Journal of Renal Care*, 39(2), 90–95.

Page, M.J., Moher, D., Bossuyt, P.M., Boutron, I., Hoffmann, T.C., Mulrow, C.D. et al. (2021) PRISMA 2020 explanation and elaboration: updated guidance and exemplars for reporting systematic reviews. *BMI*, 372, 372.

Parker, W.M., Ferreira, K., Vernon, L. & Cardone, K.E. (2017) The delicate balance of keeping it all together: using social capital to manage multiple medications for patients on dialysis. *Research in Social and Administrative Pharmacy*, 13(4), 738–745.

Pizzol, D., Xiao, T., Yang, L., Demurtas, J., McDermott, D., Garolla, A. et al. (2021) Prevalence of erectile dysfunction in patients with chronic kidney disease: a systematic review and meta-analysis. *International Journal of Impotence Research*, 33(5), 508–515.

Rezaei, Z., Jalali, A., Jalali, R. & Khaledi-Paveh, B. (2018) Psychological problems as the major cause of fatigue in clients undergoing hemodialysis: a qualitative study. *International Journal of Nursing Sciences*, 5(3), 262–267.

Salter, M.L., Kumar, K., Law, A.H., Gupta, N., Marks, K., Balhara, K. et al. (2015) Perceptions about hemodialysis and transplantation among African American adults with end-stage renal disease: inferences from focus groups. *BMC Nephrology*, 16(1), 1–10.

Sass, R., Finlay, J., Rossum, K., Soroka, K.V., McCormick, M., Desjarlais, A. et al. (2020) Patient, caregiver, and provider perspectives on challenges and solutions to individualization of care in hemodialysis: a qualitative study. *Canadian Journal of Kidney Health and Disease*, 7, 2054358120970715.

Schrauben, S.J., Cavanaugh, K.L., Fagerlin, A., Ikizler, T.A., Ricardo, A.C., Eneanya, N.D. et al. (2020) The relationship of disease-specific knowledge and health literacy with the uptake of self-care behaviors in CKD. *Kidney International Reports*, 5(1), 48–57.

Sciberras, A. & Scerri, J. (2017) Facilitators and barriers to treatment with haemodialysis among persons in mid-adulthood: an interpretative phenomenological analysis. *Scandinavian Journal of Caring Sciences*, 31(4), 695–701.

Sein, K., Damery, S., Baharani, J., Nicholas, J. & Combes, G. (2020) Emotional distress and adjustment in patients with end-stage kidney disease: a qualitative exploration of patient experience in four hospital trusts in the West Midlands, UK. *PLoS One*, 15(11), e0241629.

Sellars, M., Morton, R.L., Clayton, J.M., Tong, A., Mawren, D., Silvester, W. et al. (2019) Case-control study of end-of-life treatment preferences and costs following advance care planning for adults with end-stage kidney disease. *Nephrology*, 24(2), 148–154.

Senteio, C.R. & Ackerman, M.K. (2022) Count me out: perceptions of black patients who are on dialysis but who are not on a transplant waitlist. *Health Communication*, 37(9), 1167–1179.

Shah, J.M., Ramsbotham, J., Seib, C., Muir, R. & Bonner, A. (2021) A scoping review of the role of health literacy in chronic kidney disease self-management. *Journal of renal care*, 47(4), 221–233.

Shahgholian, N. & Yousefi, H. (2015) Supporting hemodialysis patients: a phenomenological study. *Iranian Journal of Nursing and Midwifery Research*, 20(5), 626–633.

Shahgholian, N. & Yousefi, H. (2018) The lived experiences of patients undergoing hemodialysis with the concept of care: a phenomenological study. *BMC Nephrology*, 19(1), 1–7.

Sharma, S., King, M., Mooney, R., Davenport, A., Day, C., Duncan, N. et al. (2019) How do patients from South Asian backgrounds experience life on haemodialysis in the UK? A multicentre qualitative study. *BMJ Open*, 9(5), e024739.

De Silva, I., Evangelidis, N., Hanson, C.S., Manera, K., Guha, C., Scholes-Robertson, N. et al. (2021) Patient and caregiver perspectives on sleep in dialysis. *Journal of Sleep Research*, 30(4), e13221.

Sousa, H., Ribeiro, O., Costa, E., Frontini, R., Paúl, C. & Amado, L. et al. (2021) Being on hemodialysis during the COVID-19 outbreak: a mixed-methods' study exploring the impacts on dialysis adequacy, analytical data, and patients' experiences. *Seminars in Dialysis, Wiley Online Library*, 34(1), 66–76.

Sousa, H., Ribeiro, O. & Figueiredo, D. (2021) End-stage renal disease is not yours, is not mine, is OURS: exploring couples lived experiences through dyadic interviews. *Hemodialysis International*, 25(3), 361–371.

Sutherland, S., Durley, K.E., Gillies, K., Glogowska, M., Lasserson, D.S., Pugh, C. et al. (2021) 'You see the empty bed which means it's either a transplant or a death': a qualitative study exploring the impact of death in the haemodialysis community. *BMJ Open*, 11(6), e046537.

Tadesse, H., Gutema, H., Wasihun, Y., Dagne, S., Menber, Y., Petrucka, P. et al. (2021) Lived experiences of patients with chronic kidney disease receiving hemodialysis in felege hiwot comprehensive specialized hospital, northwest Ethiopia. *International Journal of Nephrology*, 2021, 2021–2028.

Taylor, M.J., Hanson, C.S., Casey, J.R., Craig, J.C., Harris, D. & Tong, A. (2016) "You know your own fistula, it becomes a part of you"—patient perspectives on vascular access: a semistructured interview study". *Hemodialysis International*, 20(1), 5–14.

Tong, A., Flemming, K., McInnes, E., Oliver, S., & Craig, L. (2012) Enchancing transparency in reporting the synthesis of qualitative research: ENTREQ. *BMC Medical Research Methods*, 12, 181. https://doi.org/10.1186/1471-2288-12-181

Vafaei, A.A. & Nobahar, M. (2017) The care preferences of patients under hemodialysis. *Journal of Renal Injury Prevention*, 6(3), 210–215.

Ware, J.E., Richardson, M.M., Meyer, K.B. & Gandek, B. (2019) Improving CKD-specific patient-reported measures of health-related quality of life. *Journal of the American Society of Nephrology*, 30(4), 664–677.

Wongboonsin, J., Merighi, J.R., Walker, P.F. & Drawz, P.E. (2021) Travel arrangements in chronic hemodialysis patients: a qualitative study. *Hemodialysis International*, 25(1), 113–122.

Yapa, H.E., Purtell, L., Chambers, S. & Bonner, A. (2020) The relationship between chronic kidney disease, symptoms and health-related quality of life: a systematic review. *Journal of renal care*, 46(2), 74–84.

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SUPPORTING INFORMATION

Additional supporting information can be found online in the Supporting Information section at the end of this article.

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