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REVIEW

The experience of shared decision-making for patients with end-stage kidney disease undergoing haemodialysis and their families—A scoping review

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Abstract

Aim: To identify the experiences of shared decision-making (SDM) for adults with end-stage kidney disease undergoing haemodialysis (HD) and their family members.

Design: A scoping literature review.

Method: A scoping literature review, using Joanna Briggs Institute guidelines.

Data sources: Medline (OVID), EMBASE, CINAHL, Psych Info, ProQuest, Web of Science, Open grey and grey literature were searched covering years from January 2015 to July 2022. Empirical studies, unpublished thesis and studies in English were included. The scoping review was conducted using the Preferred Reporting Items for Systematic Meta analysis—scoping review extension (PRISMA-Scr).

Results: Thirteen studies were included in the final review. While SDM is welcomed by people undergoing HD, their experience is often limited to treatment decisions, with little opportunity to revisit decisions previously made. The role of the family/caregivers as active participants in SDM requires recognition.

Conclusion: People with end-stage kidney disease undergoing HD do and want to participate in the process of SDM, on a wide range of topics, in addition to treatment. A strategy is needed to ensure that SDM interventions are successful in achieving patient-driven outcomes and enhancing their quality of life.

Implications for clinical practice: This review highlights the experiences of people undergoing HD and their family/caregivers. There is a wide variety of clinical decisions requiring consideration for people undergoing HD, including considering the importance who should be involved in the decision-making processes and when decisions should occur. Further study to ensure nurses understand the importance, and influence of including family members in conversations on both SDM processes and outcomes is needed. There is a need for research from both patient and healthcare professional (HCP) perspectives to ensure that people feel supported and have their needs met in the SDM process.

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KEYWORDS

end-stage kidney disease, family/caregivers, haemodialysis people, shared decision-making

1 | INTRODUCTION

Kidney disease affects approximately 10% of the world's population and is soon predicted to be in the top five causes of death worldwide (National Kidney Federation, 2021; Tong et al., 2014). Chronic kidney disease is a life-limiting condition where people are faced with a complex illness trajectory, high symptom burden and high mortality (Bansal & Schell, 2018; Renal Association, 2020). The role of the nurse in haemodialysis (HD) is different to other areas of nursing. Along with specialist skills in managing dialysis they also have an increased opportunity to be involved in shared decision-making (SDM) conversation; and build rapport with people, over weeks, months and sometimes years (Vahdat et al., 2014). Renal nurses are therefore ideally placed to help facilitate decisions (Hill et al., 2022). Nurses are able to form effective relationships with people undergoing HD, and therefore have a central role to play in SDM. Nurses have been shown to be effective communicators and provide education, support and guidance for people with end-stage kidney disease undergoing HD (Hill et al., 2022). Moreover nurses have also been shown to be instrumental in facilitating discussions, advocating and involving families in other specialities including oncology (Friesen-Storms et al., 2015). However, this does not extend consistently to renal nursing.

People with end-stage kidney disease face a myriad of decisions relating to which renal replacement therapy: a kidney transplant, peritoneal dialysis (PD) or HD, is most suitable for them, alongside adjusting to the reality of living with a life-limiting condition while having to face the end-of-life care decisions (Farah et al., 2018; Renal Association, 2020). While globally, in the developed world HD is the most common treatment (Saran et al., 2017), evidence suggests that people are not informed (Song et al., 2013) or prepared for treatment (Dahlerus et al., 2016), nor are they active in deciding the modality type (Harwood & Clark, 2013). In addition, there is growing evidence indicating that decision-making in kidney disease is complex and may be difficult to convey in a person-centred way, leading to many people feeling as though they have not adequately received education (Axelson et al., 2015; Bomhof-Roordink et al., 2019). While the burden of family/caregivers in end-stage kidney disease has been noted in the literature, there remains questions around the decision-making processes (Sledge et al., 2022). Healthcare professionals (HCPs) and often nurses (Tariman et al., 2016) are seen as the initiators of the conversations; however, reports suggest they are ill equipped and underprepared to have these conversations (Kidney Care, 2022a, 2022b; Morton et al., 2010).

What does this paper contribute to the wider global community?

What problem did the study address? (i) People with end-stage kidney disease face complex decisions often in time-limited situations, including the need to start renal replacement therapy. (ii) Shared decision-making has been shown to be effective in facilitating decision-making, improving experience and outcomes in palliative care and other chronic illnesses. (iii) There is no agreed definition of shared decision-making within renal medicine and most research to date has focused on treatment options rather than the process of shared decision-making. *What were the main findings?* (i) This review highlights the process and experiences of people undergoing haemodialysis, including the type of decisions being made, the timing and who should be involved in the decision-making process. (ii) An acknowledgement of the active role family members play, in influencing both shared decision-making processes and outcomes is needed. (iii) People undergoing haemodialysis advocate that changing circumstances necessitate that the process and outcomes of decisions are revisited, yet this is not reflected in clinical practice and treatment decisions to date. *Where and on whom will the research have an impact?* (i) This study highlights the need for further high quality and diverse studies, which explore the experiences and expectations of all ages of people undergoing haemodialysis. This should include involving family/caregivers as part of the shared decision-making process. (ii) The lack of agreed definition or approach to shared decision-making highlights the need for policy development, for people undergoing haemodialysis, to help promote equity and quality of life. (iii) The findings point to the need for clinical practice guidelines to inform the process of shared decision-making for this patient population and their family/caregivers so that their choices can be facilitated in clinical practice.

2 | BACKGROUND

SDM refers to the process of making decisions between two parties where there is an exchange of information and consensus on the option chosen (Charles et al., 1999). SDM is advocated

by the Renal Association (2020) and National Institute of Clinical Excellence (2021) to provide a framework to help support shared decision (Renal Physicians Association, 2010; Seymour & Cassels, 2017). While no standard definition exists to describe SDM, usage of models have been encouraged and advocated for throughout health policy and the nephrology community (Kidney Disease Improving Global Outcomes, 2021; National Institute of Clinical Excellence, 2021; Renal Association, 2020; World Health Organisation, 2016). SDM in nephrology particularly end-stage kidney disease has received increasing attention, as it is associated with improving patient pain, satisfaction and can reduce decisional conflict as well as enhancing bereavement outcomes for families (Axelson et al., 2015; Culp et al., 2016; Harwood & Clark, 2013; Morton et al., 2010). Within nephrology, SDM has been advocated as a patient priority, and a key area of research (Kidney Care, 2022a, 2022b; Shi et al., 2022). Despite this, implementation in clinical practice is lagging particularly when compared to other specialities such as cancer for example (Enanya et al., 2015).

3 | RATIONALE FOR SCOPING REVIEW

Most systematic and meta synthesis reviews undertaken to date have focused on the type of renal replacement therapy (Shi et al., 2022), and systematic reviews have been undertaken on the factors influencing peoples' choices of treatment modalities and their involvement (Goff et al., 2015; Harwood & Clark, 2013; Murray et al., 2009 and Tong et al., 2014). Less attention has been placed on the array of decisions faced by both the person undergoing HD and their families (Brady et al., 2017). The aim of this review is therefore to scope the experience of SDM for people undergoing HD and their family/caregivers. For the purpose of this scoping review a broad definition of SDM as defined by Charles (Charles et al., 1999) was used. Charles presents the seminal origins of the definition upon which others have been built, comprised of four key components as shown below. (see Table 1).

4 | GUIDING DEFINITIONS

Throughout this research the following operational definition identified in Table 2 have been used.

TABLE 1 Components of Charles et al. (1999) shared decision-making model.

The involvement of people
The sharing of information
Building consensus together on the treatment options
Collaboratively agreeing the treatment option

5 | METHODS

5.1 | Design

The Joanna Briggs Institute method for scoping review was used to guide the review (Briggs, 2020), supported by the original scoping framework by Arksey and O'Malley (2005) and Tricco et al. (2018). The scoping review method was selected as the aim of the study was to include differing types of evidence aiding identification of gaps for further research. The Preferred Reporting Items for Systematic Meta Analysis extension for Scoping reviews (PRISMA-ScR) (Tricco et al., 2018) was used as a guide for reporting.

5.2 | Stage one: Identifying the research question

To meet the aim of the study, the following question was developed and guided through professional discussions and insight from clinical practice. This study focuses on the question, what is the experience of SDM for people with end-stage kidney disease undergoing HD and their family/caregivers?

5.3 | Stage 2: Search methods

An electronic search of the literature was undertaken on Medline, Embase, Cumulative Index to Nursing and Allied Health Literature (CINAHL), Psych Info and Web of Science from January 2015 to July 2022.

Search terms were defined in conjunction with a supervisory team and assessed by a subject librarian (see Table 3). A combination of Medical Subject Headings (MeSH) and free-text search terms for SDM and end-stage kidney disease were used. Search terms were based on previous reviews. The full Medline search is available in Data S1. Search results were imported into RefWorks®, a reference management software, to facilitate sharing and screening across the team.

TABLE 2 Study definitions.

Healthcare professionals (HCPs)—Nephrologists, nurse practitioners, nurse specialists and social workers that are involved in the end-of-life care decision-making process (British Renal Society BRS, 2020)
End-stage kidney disease (ESKD)—All people with end-stage kidney disease (older than 18 that have engaged in end-of-life decisions) (Renal Association, 2020)
Family/caregiver—Any friend, partner or relative who has a significant personal relationship with and provides a broad range of assistance for an older person or an adult. These individuals may be primary or secondary care givers and live with or separately from the person receiving care (Care Alliance, 2022)
Shared decision-making (SDM)—The involvement and sharing of information to build consensus on the treatment options, before finally collaboratively agreeing the treatment options (Charles et al., 1999)

5.4 | Stage 3: Inclusion and exclusion criteria

Using specified inclusion and exclusion criteria (see Table 4) the research titles and abstracts were initially screened independently by two of the authors (MMcP & FH) and disagreements arising screened by SMcl. Full manuscripts were then independently screened against eligibility by two reviewers (MMcP & FH), and a third reviewer (NC) resolved any conflicts of opinion. This resulted in a definitive list of included studies. In keeping with scoping reviews quality appraisal was not carried out but reported limitations of each research were included.

After the retrieved articles were uploaded to RefWorks the inclusion criteria was applied, and duplicates removed. Articles were screened by title abstract and then full research review.

5.5 | Stage 4: Charting the data

This stage involved extracting key elements of the research to provide an overview and to map the evidence into categories. A data

TABLE 3 Search terms.

Chronic kidney disease OR chronic renal failure OR ckd OR esrd OR renal insufficiency OR kidney failure OR end stage renal disease OR end stage renal failure or chronic kidney disease OR kidney failure or chronic kidney failure OR renal insufficiency OR Haemodialysis OR hemodialysis OR dialysis OR CKD OR CKF OR CRF OR CRD OR ESRF OR ESKF OR ESRD OR ESKD

Haemodialysis or hemodialysis or dialysis or haemodialyses or hemodialyses

Shared decision* OR sharing decision* OR informed decision* OR informed choice* OR decision aid* OR decision support

famil* OR caregiver* OR carer*

extraction table comprised of publication type, author, year, country, aims of study, study design, participants age, stage of kidney disease and key findings specifically related to the reviews aim; (decisions made, who was involved, factors and preferences) was developed. The charting tool was reviewed by the subject specialist librarian and the team members prior to usage (see Data S2). Data extraction were undertaken independently by two investigators (MMcP and FH).

5.6 | Stage 5: Collating, summarising and reporting the results

The data extraction table in stage four provided the basis of the initial analysis. A narrative descriptive approach for scoping reviews was undertaken to detail what is known about the types of decisions and SDM experiences for people undergoing HD. A thematic content analysis was used to describe patient and family/caregiver experience (Polit & Beck, 2017). Themes were selected by MMcP and then independently verified by two investigators (FH and SMcl). The final themes were then presented in the findings.

6 | FINDINGS

6.1 | Search outcome

From a total of 1058 research studies, 386 duplicated studies were removed leaving 672 studies screened for eligibility. After title and abstract screening 632 were excluded. Forty studies were sought for retrieval with two not being retrieved as they were conference presentations. From the remaining studies, 13 were excluded as they were not relevant. Five studies were excluded as it was not possible

Inclusion	Exclusion
Population people (>18 years) with advanced ESKD who are receiving HD, and family/caregivers of these individuals. Care givers (>18) of people who have ESKD and undergoing HD	Studies before 2015 or not including >18 years population and any study which focuses on Stage 4B/5 CKD or has a focus on any other renal replacement therapy
Studies: All study designs (including grey literature, evidence synthesis) that include people with ESKD carers/families written in English	Studies not published in English
Outcomes: patient and carer experience	Studies full text was available for
Date 2015–2022	Studies which focus on both PD and HD will be included provided that the data for HD can be clearly extracted without the experiences of PD influencing the results

TABLE 4 Inclusion and exclusion criteria.

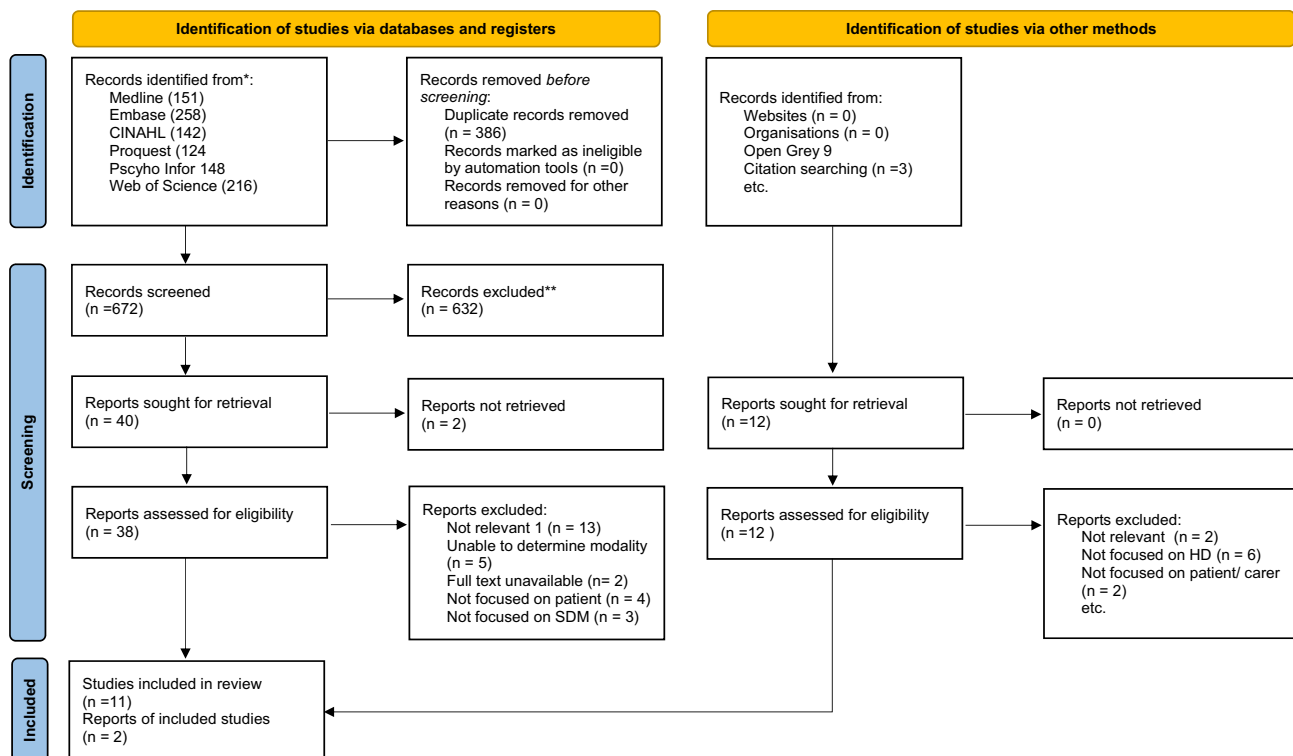
to separate treatment modality and a further two studies were excluded owing to availability of full text. Four studies were excluded as they were not focused on people and two had no reference to SDM. This left 13 studies in total which were included after full-text review, identified by bibliographic datasets, grey literature and hand searching (see Figure 1 for PRISMA).

6.2 | Study characteristics

All studies included, focused on SDM for people undergoing HD (Aresdt et al., 2019; Barrett et al., 2019; Finderup et al., 2021; Ghodsian et al., 2021; Han et al., 2019; Ho & Chen, 2021; Hussain et al., 2015; Ladin et al., 2017; Schellarts et al., 2021; Sledge et al., 2022; Thomas et al., 2016; Vandenberg et al., 2019; Woo & Pieters, 2021). Studies were mostly qualitative in nature with one survey and one literature review included in the final thirteen. There were no randomised controlled trials, longitudinal or experimental studies. The majority of studies were published in the United States (n = 5) (Barrett et al., 2019; Ladin et al., 2017; Sledge et al., 2022; Vandenberg et al., 2019 and Woo & Pieters, 2021); followed by the United Kingdom (n = 2), (Hussain et al., 2015; Thomas et al., 2016); and one from Sweden (Aresdt et al., 2019); Denmark (Finderup et al., 2021); Iran (Ghodsian et al., 2021); China (Han et al., 2019); Germany (Schellarts et al., 2021); and Taiwan

(Ho & Chen, 2021). Only one study identified a shared decision model (Ho & Chen, 2021). Study demographics included more men than women, in keeping with the renal population with ages of participants ranging from 46 to 80 (Aresdt et al., 2019; Barrett et al., 2019; Finderup et al., 2021; Ghodsian et al., 2021; Han et al., 2019; Ho & Chen, 2021; Hussain et al., 2015; Ladin et al., 2017; Schellarts et al., 2021; Sledge et al., 2022; Thomas et al., 2016; Vandenberg et al., 2019; Woo & Pieters, 2021). Within the studies, the demographics of people receiving HD had an average age of over 65 (Aresdt et al., 2019; Barrett et al., 2019; Finderup et al., 2021; Ghodsian et al., 2021; Han et al., 2019; Ho & Chen, 2021; Hussain et al., 2015; Ladin et al., 2017; Schellarts et al., 2021; Sledge et al., 2022; Thomas et al., 2016; Vandenberg et al., 2019; Woo & Pieters, 2021). People aged under 65 were not visible in the studies retrieved, meaning their experience of SDM is unknown.

All the studies reported SDM but did not provide a definition of what SDM was or what was involved. While the studies reported on the application of SDM to practice, they did not investigate the process of SDM or provide specific details. Indeed, all reported on one instance where SDM occurred but did not consider the longitudinal process of SDM (Aresdt et al., 2019; Finderup et al., 2021; Ghodsian et al., 2021; Han et al., 2019; Ho & Chen, 2021; Hussain et al., 2015; Ladin et al., 2017; Schellarts et al., 2021; Vandenberg et al., 2019; Woo & Pieters, 2021).



*Consider, if feasible to do so, reporting the number of records identified from each database or register searched (rather than the total number across all databases/registers).

**If automation tools were used, indicate how many records were excluded by a human and how many were excluded by automation tools.

From: Page MJ, McKenzie JE, Bossuyt PM, Boutron I, Hoffmann TC, Mulrow CD, et al. The PRISMA 2020 statement: an updated guideline for reporting systematic reviews. *BMJ* 2021;372:n71. doi: 10.1136/bmj.n71. For more information, visit: <http://www.prisma-statement.org/>

FIGURE 1 PRISMA-Scr Chart.

All the studies referred to intentional interactions between the person undergoing HD and HCPs and the process of deliberation. This was expanded to include the learning of knowledge and planning of further care (Aresdt et al., 2019). The values of people undergoing HD and HCPs was presented as being of utmost importance during these interactions, including religion, wanting to be a good patient and concern for others. These values are reported to underpin people's lives which in turn influenced their approach to SDM (Vandenberg et al., 2019).

Only one research study, (Ho & Chen, 2021) used Charles et al. (1999) SDM theory with another two studies including a reference to Charles et al. (1999) SDM theory in their reference list (Barrett et al., 2019 and Ladin et al., 2017). The other studies used the term SDM but did not include a definition or reference to support their findings underpinning their SDM approach (Aresdt et al., 2019; Finderup et al., 2021; Ghodsian et al., 2021; Han et al., 2019; Ho & Chen, 2021; Hussain et al., 2015; Schellarts et al., 2021; Thomas et al., 2016).

7 | THEMES

Thematic analysis resulted in two main themes: people and family caregivers' experiences.

7.1 | Patient experience of SDM while receiving HD

SDM was advocated by people and HCPs; throughout all the studies and was shown to help people make informed decisions, feel empowered and promote patient autonomy (Han et al., 2019). SDM was cited as being important to ensure a person-centred approach (Ghodsian et al., 2021); and overwhelmingly, people agreed that SDM improved quality of life and patient-reported outcomes (Barrett et al., 2019; Finderup et al., 2021 and Ghodsian et al., 2021).

Decisions involving SDM ranged from those around treatment initiation; (Aresdt et al., 2019; Barrett et al., 2019; Finderup et al., 2021; Ghodsian et al., 2021; Vandenberg et al., 2019) to treatment management (Aresdt et al., 2019; Barrett et al., 2019; Han et al., 2019; Vandenberg et al., 2019); to length and quality of life (Barrett et al., 2019; Han et al., 2019; Vandenberg et al., 2019); to shifting priorities (Sledge et al., 2022). Decisions relating to management of support packages; or goal fulfilment were not reported. Findings indicated that participants reported learning more about the concepts involved in discussions rather than a realistic exploration of the day-to-day restrictions of the treatment choice (Vandenberg et al., 2019). Nevertheless, it was highlighted that decisions around treatment have implications on many other aspects including loss of autonomy, family/caregiver burden and interruptions to daily life. Studies reported that this should be considered for further exploration (Han et al., 2019).

Throughout the studies, decisions were made solely between patient and HCPs. The structure and dialogues were not reported on; therefore it is not possible to determine who initiated the conversations and when. One research study (Finderup et al., 2021) reported that only one patient was responsible for the timing of initiating HD. Only one other study reported that in their sample of 15, one patient disagreed with the medical decision made and chose a different route to what was advised (Woo & Pieters, 2021).

While Vandenberg et al. (2019) and Sledge et al. (2022) recognised the dichotomy of people wanting to both be seen as a good patient and making the right decision for both themselves and their family/caregivers, people undergoing HD were generally happy with treatment decisions (Vandenberg et al., 2019). Several studies noted the centrality of the role of HCPs in the SDM process (Aresdt et al., 2019; Finderup et al., 2021; Hussain et al., 2015; Thomas et al., 2016; Vandenberg et al., 2019; Woo & Pieters, 2021).

From the patient perspective, it was evident that people wanted decisions to be revisited throughout the treatment journey, as their knowledge of treatment and choices together with confidence in communication grew (Finderup et al., 2021). Life changes also meant that decisions needed to be revisited as they had the potential to become obsolete or were no longer in the person's best interests (Finderup et al., 2021; Ghodsian et al., 2021; Han et al., 2019). Changes in relationships, complications from HD and new technology were among the reasons cited for revisiting previous decisions made. The timing of revisiting these decisions was a source of frustration for people with some noting the infrequency of visits from supervising consultants once they were established on HD (Schellarts et al., 2021; Woo & Pieters, 2021).

7.2 | Family/caregivers experiences of SDM and HD

Eight studies reported on the role of the family (Barrett et al., 2019; Finderup et al., 2021; Ghodsian et al., 2021; Han et al., 2019; Sledge et al., 2022; Vandenberg et al., 2019). Family/caregivers were only included in SDM discussions at the request of the person undergoing HD (Aresdt et al., 2019; Barrett et al., 2019; Finderup et al., 2021; Ghodsian et al., 2021; Han et al., 2019; Hussain et al., 2015; Sledge et al., 2022; Thomas et al., 2016; Vandenberg et al., 2019). In one research study, however, they actively sought to be engaged (Han et al., 2019). In terms of family, Finderup et al. (2021) found that spouses were most commonly actively involved in the SDM process. Children, including adult children were rarely involved.

It was noted throughout the studies that family were present throughout all stages of the patient's journey. Family had to learn to navigate a complex situation and therefore sought information (Woo & Pieters, 2021) while balancing the needs of both the person undergoing HD alongside their own needs (Vandenberg et al., 2019). Families reported struggling to make decisions based on those that affirm life or had the potential to cause death, even when in the best

interest of their loved one (Hussain et al., 2015). Role conflict was common, particularly when decisions were controversial or had a direct impact on family members (Ladin et al., 2017). Family/caregivers experiences also had ramifications for the patient, effectively adding an unspoken pressure, to select life-affirming treatment options (Thomas et al., 2016).

Partners were often intentionally involved by people in SDM as a conscious choice (Sledge et al., 2022). One reason cited included the personal values of the people undergoing HD. Further, they wished to consider the needs of those around them (Sledge et al., 2022). Family members influenced self-determination and the autonomy of the person undergoing HD and were often present throughout the entire process (Ho & Chen, 2021). Han et al. (2019) recommended that family dynamics and the relationships between the patient and their family as well as between family and HCPs, requires consideration. Control features throughout the studies demonstrating how people try to take control of either the process of SDM (Hussain et al., 2015); or their emotions in response to the SDM process (Ladin et al., 2017; Sledge et al., 2022).

Overall, patient involvement in SDM was dependent on family (Finderup et al., 2021). From the study it is evident that the influence of family should not be underestimated and should be considered throughout the patient journey (Barrett et al., 2019; Finderup et al., 2021; Ghodsian et al., 2021; Han et al., 2019; Hussain et al., 2015; Sledge et al., 2022; Thomas et al., 2016; Vandenberg et al., 2019). However, only one study highlighted that nearly a third of people did not complete SDM due to lack of family involvement and initiation difficulties by the MDT (Finderup et al., 2021). The importance of revisiting decisions previously made at significant junctures such as when life-changing events occur, not just in the patient's life but also in that of the patient family/caregivers should be considered (Finderup et al., 2021; Ghodsian et al., 2021).

8 | DISCUSSION

Some of the studies indicate that SDM should be prioritised (Aresdt et al., 2019; Barrett et al., 2019; Han et al., 2019; Finderup et al., 2021). Nurses who participate in SDM had a higher job satisfaction, an increased sense of achievement and felt valued members of the multidisciplinary team (Friesen-Storms et al., 2015). However, while policy recommended that SDM is a collaborative process, evidence relating to people undergoing HD and their families focused on the decision outcome, not the process of SDM (Finderup et al., 2021; Ghodsian et al., 2021; Murray et al., 2009). It can be argued that this is similar to SDM experiences in other clinical conditions such as cancer, (Larvionava et al., 2021; Mori et al., 2013) and respiratory care (Basile et al., 2018). Little is known about the actual process of SDM where nurses are key stakeholders.

Based on the results of the review, it is clear that the status of SDM for people undergoing HD appears to be complex and focused on choosing the modality and the initial stages of dialysis (Hussain et al., 2015; Thomas et al., 2016; Ladin et al., 2017;

Aresdt et al., 2019; Barrett et al., 2019; Ghodsian et al., 2021; Han et al., 2019; Vandenberg et al., 2019; Woo & Pieters, 2021; Finderup et al., 2021; Schellarts et al., 2021; Ho & Chen, 2021; Sledge et al., 2022;). The role of the nurse in particular to provide holistic care has not been adequately considered in terms of communication, education and time, resulting in a gap in care provision (Tariman et al., 2016). People want to participate in decisions that are not solely medically driven but located within wider end-of-life care decisions (Hussain et al., 2015; Thomas et al., 2016; Ladin et al., 2017; Aresdt et al., 2019; Barrett et al., 2019; Han et al., 2019; Vandenberg et al., 2019; Finderup et al., 2021; Ghodsian et al., 2021; Ho & Chen, 2021; Schellarts et al., 2021; Woo & Pieters, 2021; Sledge et al., 2022;). Furthermore, it is highlighted that treatment decision-making factors have implications on other aspects including loss of autonomy, caregiver burden and interruptions to daily life (Han et al., 2019).

Findings indicate that as people progress in their journey their knowledge, acceptance and confidence also changes and this needs to be recognised within the decision-making process. In the beginning, lack of understanding and feeling overwhelmed (Aresdt et al., 2019) alongside the need to be a good patient played a role, (Ladin et al., 2017). Respect for the multidisciplinary team (Aresdt et al., 2019; Barrett et al., 2019; and Woo & Pieters, 2021;) and impact of people pleasing (Finderup et al., 2021; Han et al., 2019; Ho & Chen, 2021; Vandenberg et al., 2019; Sledge et al., 2022;) also meant that decisions made are not always reflective of the patient wishes. Nurses who are often the access point to the rest of the multidisciplinary team must be acutely aware of this and seek out opportunities to ensure that people's wishes are being met. The findings, noted that patient and family knowledge and confidence in HCPs improved as time progressed, resulting in them feeling more equipped to be involved in decision-making (Finderup et al., 2021; Han et al., 2019; Sledge et al., 2022).

The importance of knowing the clinical team was also apparent to ensure person-centred decision-making (Aresdt et al., 2019; Barrett et al., 2019; Finderup et al., 2021; Ghodsian et al., 2021; Ho & Chen, 2021; Hussain et al., 2015; Thomas et al., 2016; Vandenberg et al., 2019; Woo & Pieters, 2021). Patient and family involvement with SDM improved with time and the experience gained through becoming familiar with the treatment (Finderup et al., 2021). SDM should therefore be an evolving process, with consideration given to both the person undergoing HD and their family. Any decision taken will have a bearing on both, patient and family outcomes and their relationship with each other and the wider multidisciplinary team. Considering the complex nature of HD, the limited scope of decisions evident in the literature and the potential of any decision to affect both the person on dialysis and their family meant that there was a reluctance at times for either the person or their family to make the final decision. Therefore, in the majority of cases, HCPs had the final say.

The age of participants seen throughout the studies was over 65 (Barrett et al., 2019; Ghodsian et al., 2021; Han et al., 2019; Ladin et al., 2017). People over 65 years had a 61% less chance of being involved in SDM (Schellarts et al., 2021). The absence of younger

participants may be explained by them more commonly using other renal replacement options (Renal Association, 2020).

Despite the core principles of SDM, many people agreed with physicians in making their final choices suggesting that decisions were often medically driven instead of person-centred (Barrett et al., 2019; FINDERUP et al., 2021; Han et al., 2019; Ho & Chen, 2021; Kim et al., 2022; Ladin et al., 2017; Schellarts et al., 2021; Sledge et al., 2022). Many of those involved further felt that they did not receive the level of SDM that they desired, particularly in areas such as finances, and quality of life that they felt were important and underdiscussed (Barrett et al., 2019). Time allocated to SDM was also an issue with patient and families often feeling time spent was too short, Vandenberg et al. (2019) supported by Ladin et al. (2017). Further research is warranted to investigate potential mismatch, between what people want to know, timing of such information and the reality of what happens in practice. The role of the nurse in initiating and facilitating these discussions is also unclear and requires further research. Combined studies that look at all aspects of SDM from the perspective of both patient and family would also be beneficial. Without this detail it is difficult to measure the extent of patient or family/caregivers' engagement with SDM.

Communication is very important. Recognition of the length of time a person has spent undergoing HD, their expectations and values need to be considered (Han et al., 2019). HCPs should carefully consider the length of time a person has been on dialysis when initiating and having conversation about SDM. Throughout all decisions, the power balance needs to be considered to ensure the appropriate exchange of information (Aresdt et al., 2019). As time passes, many people undergoing HD become expert in their own right, meaning this balance shifts (Ho & Chen, 2021; Hussain et al., 2015; Ladin et al., 2017; Schellarts et al., 2021). This highlights the complexity for SDM for people undergoing HD.

9 | SUMMARY OF MAIN FINDINGS

While SDM is advocated, this synthesis indicates that there are gaps in our understanding of both the process and the needs of the patient and family. Most research on SDM to date for this population has focused on treatment options yet such decisions trigger other questions and conversations (Aresdt et al., 2019; Barrett et al., 2019; FINDERUP et al., 2021; Ghodsian et al., 2021; Han et al., 2019; Ho & Chen, 2021; Hussain et al., 2015; Ladin et al., 2017; Schellarts et al., 2021; Sledge et al., 2022; Thomas et al., 2016; Vandenberg et al., 2019; Woo & Pieters, 2021). SDM has an important role in ensuring people undergoing HD can make evidence informed choices and SDM has been indicated as a key priority for consideration (Kidney Disease: Improving Global Outcomes, 2021; Renal Association, 2020). Furthermore, given the life changing nature of HD it is necessary to engage all stakeholders at an early stage, particularly nursing staff. Nursing staff are ideally placed in renal nursing to facilitate these discussions. However, appropriate education and support is needed (Cassidy et al., 2018). Evidence regarding the

timing of SDM is unclear. It is evident it should occur in a timely manner prior to commencing HD, however given the nature of the disease trajectory, it is not always possible to have such conversations impacting on implementation of meaningful SDM in practice (Charles et al., 1999). People report that their confidence in relation to having conversations about SDM increases with time spent on HD (Harwood & Clark, 2013). This is also true of the family and carers experience as they try to make sense of a complicated situation (Sledge et al., 2022). This means that the success of SDM in the initial stage of HD may be limited (Aresdt et al., 2019; FINDERUP et al., 2021; Ghodsian et al., 2021; Vandenberg et al., 2019).

SDM is vital and much more is needed to help support people and their families to ensure decisions consider both their desire to live, alongside the side effects of treatment (Sledge et al., 2022; Vandenberg et al., 2019). SDM brings benefits for people, helping them to feel more prepared and better able to deal with both treatment and complications (Sledge et al., 2022).

Many of the studies claim to have engaged SDM but lacked any definition or reference to any SDM framework. Further participation in SDM is not defined, in any study meaning it remains unclear what the reality of SDM is for people undergoing HD. It is clear that attempts to provide SDM have been undertaken but these have not been underpinned by theory or clear in operational definitions (Hussain et al., 2015). Introduction of these measures would help inform clinical practice. It is evident that future studies are needed to consider patient and family needs. In addition, factors to encourage participation on SDM, including the development of SDM models, specific to people undergoing HD, taking into account for the changing nature of the disease trajectory needs to be considered as a priority. These measures will help support people undergoing HD and their families to make decisions.

10 | RELEVANCE TO CLINICAL PRACTICE

This scoping review highlights a range of gaps in the understanding of SDM for people undergoing HD. The findings noted that the majority of studies on SDM for this population focused more on treatment decisions, and less on the wider personal and life decisions and choices. Throughout this journey, nurses are ever present and therefore further research into their role, expectations and educational needs would be beneficial. Furthermore, it highlights a need for SDM to be understood as a process which reflects the knowledge, stage and confidence of the person undergoing HD and their family/caregivers. The review highlighted the importance of family/caregivers and the need for their voice to be heard in the process.

Studies are needed to explore personal experiences of participation and engagement in the process of SDM for people undergoing HD and how the nurse supports them (Aresdt et al., 2019). Practice changes are needed to ensure regular ongoing discussions about all aspects of treatments for both people and their family and opportunities to revisit decisions as a priority (Barrett et al., 2019). Standardisation of treatment options should be considered to ensure that all people receive equitable

care. The impact of any interventions needs to be formally evaluated to inform the evidence base (Finderup et al., 2021). The extended role of the HCP, their knowledge, and attitudes towards SDM in HD settings requires exploration, to ensure that they are equipped to partake in SDM (Finderup et al., 2021). Further studies are needed to consider the needs and expectations of all age groups, particularly younger people on HD who have not been considered in the studies to date. From this scoping review, it is clear that nurses need to have the skills to initiate conversations to ensure that SDM is occurring, particularly as they are often the first to recognise a change in both the condition and life of a person undergoing HD (Briggs, 2020). What this will entail and how best to support HCPs in particular should be a key priority. Evidently, there is a fine balance between ensuring that people have all the appropriate information to aid decision-making, while guiding people to the most suitable decision, cognisant of need to ensure patient choice is at the forefront (Ladin et al., 2017; Sledge et al., 2022). Additionally, decision-making theory ought to be incorporated into any induction program to renal replacement therapies (Hussain et al., 2015).

11 | STRENGTHS AND LIMITATIONS

This scoping review followed the Joanna Briggs protocol for scoping review and examined SDM for people undergoing HD (Briggs, 2020). Limitations include that much of the literature focused on all renal replacement therapies. A limited number of these (n=2) was readily extracted for HD alone meaning many were excluded. In addition, only studies written in English were included which may have limited the studies included. The lack of a specific program (Ghodsian et al., 2021) or definition of what SDM should be means it is difficult to ascertain what SDM as defined by Charles et al. (1999) actually occurs.

12 | CONCLUSION

This scoping review has demonstrated the experiences of patient and family/caregivers undergoing HD. SDM is important from initiation of treatment through to living with HD; however, success is limited by communication (Harwood & Clark, 2013), decisional ability and the time sensitive nature of decisions required. These key areas warrant further exploration (Ladin et al., 2017). Family appears to have a role in SDM although this needs carefully balanced against the wishes of the person undergoing HD in ensure no undue influence by family (Vanholder et al., 2021). The families understanding of their own role further needs considered. It is evident renal HCPs are ideally placed to undertake SDM and should consider the progressive nature of knowledge for people undergoing HD, while being cognisant of the issues faced both by themselves, people and families.

AUTHOR CONTRIBUTIONS

Mari Mc Peake: conceptualisation (EQUAL), investigation (EQUAL), formal analysis (LEAD), methodology (EQUAL), project management

(LEAD), writing—original draft preparation (LEAD); Felicity Hasson: conceptualisation (EQUAL), investigation (EQUAL), project management (EQUAL), validation (LEAD), writing—review and editing (LEAD); Neal Cook: conceptualisation (EQUAL), investigation (EQUAL), project management (EQUAL), validation (LEAD), writing—review and editing (EQUAL); Sonja Mc Ilfatrick: conceptualisation (EQUAL), investigation (EQUAL), project management (EQUAL), validation (EQUAL), writing—review and editing (EQUAL).

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CONFLICT OF INTEREST STATEMENT

The authors have no potential conflicts of interest with respect to the research authorship, or publication.

DATA AVAILABILITY STATEMENT

The data that support the findings of this study are available from the corresponding author upon reasonable request.

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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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