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Home hemodialysis

A Systematic Review of the Qualitative Research on Barriers and Facilitators to Home Hemodialysis

Áine Earley[1] | Sinéad Lydon[1] | Rachael C. Walker[2] | Lisa Gannon[1] | Donal Reddan[3,4] | Lorna Durack[3,5] | Paul O'Connor[1,6]

[1]Department of General Practice, School of Medicine, University of Galway, Galway, Ireland | [2]School of Nursing, Faculty of Medical and Health Science, University of Auckland, Auckland, New Zealand | [3]Home Dialysis Unit, Merlin Park University Hospital, Galway, Ireland | [4]School of Medicine, University of Galway, Galway, Ireland | [5]Health Services Executive, Galway University Hospital, Galway, Ireland | [6]Irish Center for Applied Patient Safety and Simulation, University of Galway, Galway, Ireland

Correspondence: Paul O'Connor (paul.oconnor@universityofgalway.ie)

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ABSTRACT

Introduction: The growing prevalence of chronic kidney disease has led to an increased demand for kidney replacement therapies. Although a kidney transplant is the preferred treatment for patients, many patients require dialysis temporarily before receiving a transplant or are unsuitable transplant candidates requiring long-term dialysis. Home hemodialysis (home HD) is cost-effective and associated with improved patient outcomes; however, its adoption remains low. There is a need to understand the factors that may support or hinder the use of home HD. Accordingly, a systematic review of the qualitative literature was conducted to identify barriers and facilitators to home HD for patients, their carers/family, and healthcare professionals.

Methods: This systematic review was carried out following ENTREQ guidelines. Electronic searches were conducted on Medline (OVID), EMBASE, CINAHL (EBSCO), and PsycINFO. The COM-B and Theoretical Domains Framework (TDF) were used to collate the barriers and enablers identified within the papers through deductive content analysis.

Results: Thirteen studies met the inclusion criteria. Within the *capability* component of the COM-B model, lack of knowledge of home HD was identified as a barrier by healthcare professionals and patients. Within the *opportunity* component, the suitability of patients' homes (e.g., home modifications) and the healthcare system was identified as barriers to home HD. Fostering an environment of support and community was seen as a facilitator of home HD. Within the *motivation* component of the model, a lack of confidence and reluctance of patients to burden their family members with the responsibility of treatment were perceived as barriers. Improvements in the quality of life for the person receiving home HD were regarded as a motivator.

Conclusion: To encourage widespread home HD use, understanding its barriers and facilitators for patients and the healthcare system is key to developing and implementing effective interventions to increase uptake.

1 | Introduction

The demand for kidney replacement therapy (KRT) is rising. It is estimated that by 2030 those requiring KRT will double [1]. Although a kidney transplant is the optimal treatment for patients with kidney failure, not all patients are deemed suitable candidates, or they may require dialysis temporarily prior to transplant [2]. Conventional hemodialysis, performed in a clinical unit, remains the most widely used form of dialysis [1]. However, hemodialysis can also be performed outside of a hospital setting by

patients independently in their own homes; this form of KRT is referred to as home hemodialysis (home HD).

Interest in expanding the use of home HD has been growing due to the rising demands for KRT and compelling evidence of the positive effects extended treatment hours only achievable on home HD have on patients' lives and health parameters [3, 4], Home HD is associated with improved patient survival [3] and higher quality of life as compared to center-based HD [3, 4]. Additionally, home HD benefits the healthcare systems, with cost-effectiveness analyses consistently demonstrating cost saving over center-based HD [4]. However, despite these benefits, adoption of home HD remains low, with less than 3% of dialysis patients in Europe receiving home HD [4].

Previous research has primarily focused on identifying patient-level barriers to home HD [5, 6]. However, promoting more widespread use of home HD requires the consideration of potential barriers from the perspectives of healthcare professionals and the healthcare system. Therefore, the purpose of this systematic review is to apply an established model of behavioral change to synthesize the qualitative research on barriers and enablers to home HD as perceived by patients, their carers/families, healthcare professionals, and at the healthcare system level. Based on the findings, approaches to increase the uptake of home HD will be discussed.

2 | Methods

This review was carried out and reported in accordance with the [7] Enhancing Transparency of Reporting the Synthesis of Qualitative Research Framework (ENTREQ) [8]. A review protocol was registered on PROSPERO in December 2023 (Registration number: CRD42023491014).

2.1 | Search Strategy

Electronic searches were carried out in: Medline (OVID), EMBASE, CINAHL (EBSCO) and PsycINFO (EBSCO) in December 2023 and updated in October 2024. The search strategy (see Supporting Information 1) was developed with a research librarian using a combination of MeSH terms and free text terms and was informed by search terms used in previous systematic reviews [4, 5]. The strategy was adjusted as needed for each database and consisted of three separate sets of terms: (i) terms related to home-based dialysis; (ii) terms concerning barriers and enablers to initiating home HD; and (iii) terms pertaining to qualitative research. Screening was also performed on the reference list of included papers and three published reviews of home HD [4–6].

2.2 | Study Selection

2.2.1 | Inclusion and Exclusion Criteria

Studies were included if they: focused on exploring the barriers and/or enablers to home HD, or where data on home HD could be extracted from a study that also included other forms of KRT; included participants who had or could undergo home HD, were caregivers of someone receiving home HD, or were healthcare professionals involved in providing home dialysis services; used a qualitative design and reported qualitative findings (mixed method studies were included if qualitative findings could be extracted); and were published in English.

Papers were excluded if they: did not identify barriers and/or enablers to home HD; were focused on KRTs other than home HD; it was not possible to extract data on home HD; did not use a qualitative design, or it was not possible to extract the qualitative data from a mixed methods study; were not original research; did not include participants who had or could undergo home HD, or were carers of someone receiving home HD, or were healthcare professionals involved in providing home HD services; and were not published in English.

2.3 | Screening

The returns of the database searches were exported to Endnote for removal of duplicates and title and abstract screening by AE. Full text screening was carried out by AE. Any record for which suitability was unclear following full text screening was reviewed and discussed with the research team until consensus was reached on its eligibility. A detailed record of inclusion/exclusion decisions (see Supporting Information 2) at the full-text screening phase was maintained on Microsoft Excel.

2.4 | Data Extraction

Two independent reviewers (AE and LG) extracted the data from the included studies. A structured tool was developed, piloted, and revised to extract the following data: author; publication year; aims/purpose; country of publication; healthcare setting; study design; data collection methods; data analysis methods; participants characteristics; sample size; and barriers and enablers to home HD (entire results sections and supporting quotes were extracted). Any disagreements were resolved through discussion.

2.5 | Quality Appraisal

The Quality Assessment Tool for Studies with Diverse Design (QATSDD) [9] was selected to assess the quality of the included studies. This scale consists of 16 items rated on a 4-point Likert scale. All items were completed for mixed method studies, while 14 items were completed for qualitative studies. The scores were summed and converted to percentages to facilitate comparison across studies [9], with a higher score indicating higher methodological rigor. Quality scores were categorized based on criteria used in previous systematic reviews [10, 11], with scores below 50% considered low quality, scores between 50% and 80% considered medium quality, and scores above 80% considered high quality. Two authors (AE and LG) completed the assessment together. Any disagreement was resolved through discussion.

2.6 | Data Synthesis

Content analysis [12] was used by AE and LG to collate and organize the extracted data related to barriers and enablers to the uptake of home HD. A deductive approach was taken, guided by the Theoretical Domains Framework (TDF [13]; see Table 1). This approach was informed by McGown et al.'s [14] recommended strategies to improve the TDF's use in qualitative research. The analysis was carried out in three stages: (i) preparation, which involved becoming familiar with the data by repeatedly reading the extracted data; (ii) organizing, which consisted of inductively coding the data, grouping similar codes into categories, and mapping them to the TDF domains; and (iii) reporting, summarizing, and presenting the findings. No software was used to code the data.

The TDF is an elaboration of the COM-B model [13]. The COM-B model proposes that the interactions between capability, opportunity, and motivation cause the performance of a particular behavior [15]. Capability is defined as the individual's psychological (e.g., the psychological resources, skills and knowledge capacity for understanding) and physical (e.g., physical skills required to perform home HD) capacities [15]. Motivation is defined as all those brain processes that energize and direct behavior; this includes reflective (e.g., deliberate planning and decision making) and automatic (e.g., habit) practices [15]. Opportunity is defined as the factors that are outside the individual that make the behavior possible [15]. The purpose of the TDF is to make the COM-B model more usable for implementation researchers [13].

3 | Results

3.1 | Search Results and Selection

Database searches identified 2667 records. After reviewing the full text of 228 articles, a total of 13 studies met the inclusion criteria (see Figure 1 [7]).

3.2 | Characteristics of Included Studies

The characteristics of the included studies are summarized in Table 2, with further details available in Supporting Information 3. The sample size of the studies included ranged from 5 to 52 (mean = 24.6).

3.3 | Quality Assessment

The mean QATSDD [9] score was 61.1% (St Dev = 8.9%, 42.86%–72.81%). The qualitative studies average score was 62.6% (St Dev = 9.3%, 42.86%–73.81%), while mixed methods studies on average scored 55.6% (St Dev = 5.2%, 50%–60.42%). Studies were rated highly on items related to the description of the research setting, data collection, and fit between the research question and data collection methods. Studies tended to be rated particularly poorly on items referring to their use of a theoretical framework and stakeholder involvement in research design. See Supporting Information 3 for the QATSDD [9] score for each study.

TABLE 1 | Theoretical Domains Framework (TDF) domains and definitions (adapted from Cane et al. [13].

Com-B[a] components		TDF domains
Capability	Psychological	• Knowledge—knowledge about home hemodialysis. • Memory, attention and decision processes—the ability to retain information, and make decision related to home hemodialysis. • Behavior regulation—behaviours aimed at managing or changing objectively observed or measured actions within the context of home hemodialysis.
	Physical	• Skills—a proficiency to carry out the home hemodialysis procedure.
Opportunity	Social	• Social influence—interpersonal processes that can cause individuals to change their thoughts or feelings about home hemodialysis.
	Physical	• Environmental context and resources—any circumstance of a person's situation or environment that impacts upon the ability to carry out home hemodialysis.
Motivation	Reflective	• Social/professional role & identity—a coherent set of behaviors and displayed personal qualities of an individual in a social or work setting. • Beliefs about capabilities—a belief that someone is capable of carrying out home hemodialysis. • Optimism—a belief that home hemodialysis can be successfully carried out. • Beliefs about consequences—a belief that home hemodialysis can be achieved. • Intentions—a conscious decision to carry out home hemodialysis. • Goals—a desire to carry out home hemodialysis.
	Automatic	• Reinforcement—increasing the probability of carrying out home hemodialysis by arranging a dependent relationship, or contingency, between the response and a given stimulus. • Emotion—a complex reaction pattern, involving experiential, behavioral, and physiological elements that impact the willingness to carry out home hemodialysis.

[a]Capability, opportunity, motivation and behavior.

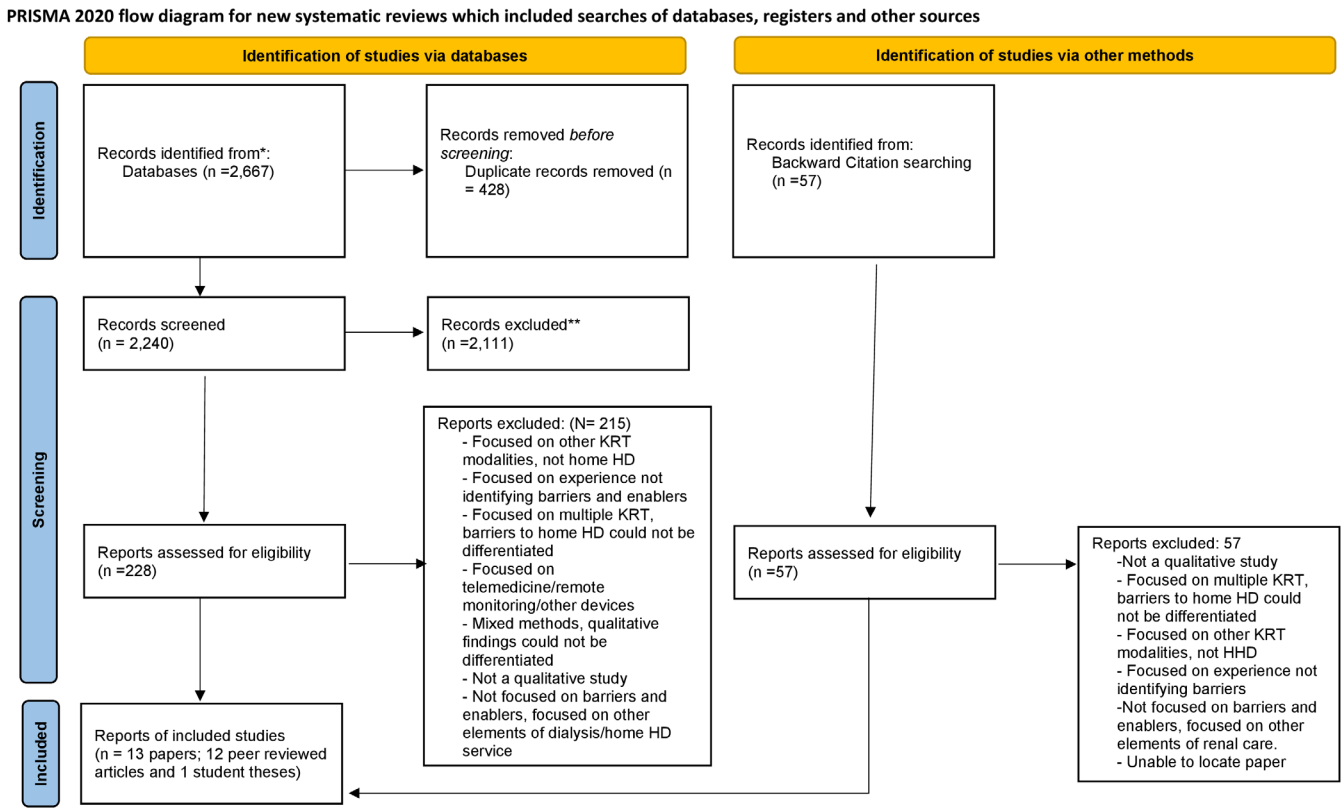

FIGURE 1 | PRISMA flow diagram.

3.4 | Synthesis of Findings

3.4.1 | Capability

Knowledge was the only TDF [13] *Capability* domain (see Table 1) used to classify barriers and enablers to home HD in the included papers. Patients' and healthcare professionals' knowledge about home HD were identified as crucial to the uptake and sustainment of home HD use [16–20]. Limited knowledge and experience of home HD for healthcare professionals working in the field of nephrology, was cited as a major barrier to home HD [19, 20]. "*Many clinicians acknowledge that they lack sufficient knowledge and awareness about home HD to be confident about it as a treatment option and suggested they needed more information*" [20] (p.7).

3.4.2 | Opportunity

Within the *Opportunity* component of the COM-B model [15], 'environmental context and resources' domain was the only TDF domain [13] (see Table 1) used to classify barriers and enablers to home HD in the included papers. However, there were a number of issues related to this TDF domain. Lack of home ownership was identified as a barrier to home HD by both patients and healthcare professionals [16, 19, 21]. In the study by Tong et al. [20] one clinician stated "*I think it could be a problem for them to manage themselves if they have little space in their house to put the dialysis machine and especially if they are not the owner of their house* …"(p.5). Another concern was the fear that home HD would medicalize their home [16, 20, 22–24]. "*Living with a hemodialysis machine at home was perceived by some patients to be an unrelenting reminder of their disease*" [24] (p.5). This issue is compounded by the fact that the home environment may lack the space or appropriate infrastructure (e.g., plumbing) to support having dialysis at home [19–25].

Insufficient government funding and reimbursement schemes were reported by both patients and healthcare professionals as barriers to the use and establishment of successful home HD programs [16, 19–21, 26]. "*The reimbursement provided was inadequate … some felt that the out-of-pocket cost were unfair because of the lower cost of home HD to the hospital*" [p.638] [16]. Many units also lack the resources and infrastructure necessary to provide home HD services [19, 25]. An important facilitator of home HD is a well-design system for the provision of home HD supplies and services to patients [16, 17, 19, 20, 24] "*you need to have also good logistics and structure for* [home HD] … *you cannot just have one patient. It's very difficult to have something for very few patients so you need to have a center or something in the region*" [20] (p.5).

Fostering an environment of support and connectedness for home HD patients is critical [16–19, 22, 23, 25, 26]. Clinicians reported that developing this sense of connection and relationships between patients, family members and staff in the unit was fundamental for success [16, 17, 25, 26]. For example, a home HD nurse was quoted as saying, *"even though patients are*

TABLE 2 | Summary of findings.

	N	%
Country		
Canada	5	38.46
Australia	1	7.69
United Kingdom	1	7.69
United States	1	7.69
New Zealand	1	7.69
Multiple countries (Europe and South America)	1	7.69
Italy	1	7.69
Not stated	2	15.38
Participants		
Patients	7	53.85
Carers/patients	2	15.38
Healthcare professionals	4	30.77
Methodology		
Interviews	8	61.54
Interviews and surveys	3	23.08
Focus groups	1	7.69
Capability		
Knowledge	5	38.46
Opportunity		
Environmental context and resources	10	76.92
Motivation		
Belief about capabilities	5	38.46
Emotion	8	61.54
Reinforcement	7	53.85

at home, it doesn't mean that they don't need that connection, or they don't need that touch, they actually need more of that more reassurance" [17] (p.219). Patients also recognized the importance of support [16, 18, 19, 22, 23], "*if you do not have a good partner to help you out, then you are in trouble...You are doing everything*" [23] (p.143).

3.4.3 | Motivation

Three of the TDF domains [13] were used to classify the barriers and enablers in the motivation component of the COM-B model [15]: 'belief about capabilities', 'emotion', and 'reinforcement' (see Tables 1 and 2). A lack of belief that a patient or carer would be capable of carrying out home HD was identified as a barrier, while a belief about capabilities (self-efficacy) was identified as a facilitator [16, 19, 22, 24, 27, 28]. Many carers and patients felt inadequate and doubted their ability to manage the responsibility of care especially if complications or technical issues were to occur [16, 22, 24, 27, 28], they feared they would be "*incapacitated by panic*" [24]. Clinicians and patients believed that having "*realistic expectations*" [23] and being an independent person is fundamental to an individual's success on home HD [18, 19, 22, 23]: "*If you're an independent person it's perfect for you. If you feel very needy and don't feel confident in yourself then it's probably not for you*" [22] (p.6).

The emotional burden of conducting home HD for the patient, and their carers, was identified as a barrier [16, 20, 22–24, 27, 28]. Patients had expected they would have more time and flexibility, when in reality they are faced with what was described as a tiring and unrelenting schedule [16, 22, 23]. There is also a concern about the burden on carers [16, 20, 22–24, 27, 28] "*I imposed the dialysis on my partner doing dialysis at the center has much less impact on her. She [the carer] is the one who puts up with the illness. Home dialysis means bringing the illness home*" [26] (p.5).

The implications for quality of life and empowerment of home HD, as compared to hospital dialysis, were identified as a facilitator in seven of the included studies [16, 18, 22–24, 26, 28]. Patients appreciated being active participants in their care and having the opportunity to adjust their dialysis session to suit them [16, 18, 22–24]. *"I'd rather be at home and be independent and do it myself instead of having to wait around, you know, that part of it just it's just not me ... I don't like the hospital environment; I don't like having to rely on people; I don't like doing things on other people's times*" [22] (p.6). Clinicians also recognized the potential opportunities that home HD offered patients as it related to quality of life [17, 20] "*It's a liberty for them to be treated at any time of the day, during the night, they can work and they can have other, family life, as normal as possible, that's the main benefit"* [20] (p.6).

4 | Discussion

Home HD is a cost-effective form of dialysis and is associated with an improved outcome for patients as compared to in-center dialysis [3, 4]. However, only a small percentage of dialysis patients utilize home HD [4]. If growth of home HD is to be achieved, there is a need to better understand the barriers and enablers of home HD for patients, healthcare providers, and the healthcare system. Identifying these barriers and enablers will then allow for the development of appropriate, effective, and pragmatic complex interventions to encourage the use of home HD. The purpose of this systematic review was to use a behavior change model to identify the barriers and enablers of home HD for patients and their carers/families, healthcare providers, and the healthcare system as described in the qualitative literature.

Capabilities refer to the psychological and physical abilities required to engage in home HD [15]. The most significant capabilities barrier to home HD was a lack of knowledge—for both patients and healthcare providers [16–20]. Patients cannot consider home HD as a treatment option if they are unaware of its existence, and if healthcare providers do not discuss it with them as a treatment option. One approach that could be taken to promote knowledge of home HD is incorporating social marketing

techniques into educational programs or campaigns. In recent years, there has been a growing interest, and success, in using social marketing techniques in educational programs to influence and promote health behaviors such as physical activity [29] or cervical screening [30]. Social marketing uses commercial marketing principles and approaches to influence or change a target population's behavior [31]. Previous studies have found undergoing educational programs improves clinicians comfort levels with home HD [32] and increases home HD uptake [33]. Therefore, the use of social marketing techniques could be an effective approach to increasing home HD awareness and knowledge, ultimately leading to changed behavior.

Opportunity is concerned with the factors that are outside of individual control that encourage the uptake of home HD [15]. There is the potential for the home environment to be a barrier in terms of lack of space, suitable infrastructure [19–25] and medicalizing the home [16, 20, 22–24]. Barriers were also identified in the healthcare system from lack of funding [19–21, 26] and improving systems to support the provision of home HD [16, 17, 19, 20, 24]. It is suggested that taking a human factors approach to these issues may have some merit. A human factors approach seeks to design work processes and systems to support human performance and patient safety [33, 34]. Therefore, taking a human factors approach to home HD can inform considerations about how a system can be designed to support, rather than discourage home HD. Such an approach could consider the design of dialysis devices, as well as the systems to support home HD from the perspective of the patient/carers, providers, and the healthcare system.

The TDF domain of social influence (the interpersonal processes that can cause individuals to change their thoughts, feelings or behaviors; [13]) was not used to classify any of the opportunity-related barriers or facilitators in the included papers. Although the need for a supportive environment was identified as an important facilitator of home HD by patients and providers [16–19, 22, 23, 25, 26], it is suggested that social influence, through current or former home HD patients encouraging and supporting other dialysis patients to move to home HD, could be an effective way to boost home HD uptake. Peer support programs have been shown to have some promise for people with kidney failure [35] and patients with type 2 diabetes [36]. Peer support can be defined as a process through which people with shared common experiences come together as equals to give and receive help based on the knowledge derived from their shared experience [37]. The focus of these types of interventions has been on in-center dialysis/patients with chronic kidney disease, with a comparatively lack of such programs for home HD patients [38]. We suggest that there is merit in the development and evaluation of peer support programs specifically for suitable candidates for home HD.

Motivation is concerned with internal processes that encourage or discourage the uptake of home HD [15]. One of the primary motivators identified for choosing home HD is the perceived improvements in quality of life [16, 18, 22–24, 26], a commonly reported benefit of home HD [3, 4]. Particular barriers identified within the motivation component were a lack of belief in patients' and their carers' capabilities to carry out home HD [16, 19, 22, 24, 27], and concern about treatment burden [16, 20, 22–24, 27, 28]. A potential strategy that could be used to address the lack of belief barrier is exposing prospective home HD patients and their carers to the equipment and procedures in a simulated setting [39]. This approach may especially be effective for initially hesitant patients, because it would allow them the opportunity to build their confidence and skills in a safe, controlled home-like environment prior to committing to doing home HD. Furthermore, patients have reported experiencing emergency scenarios at home that were not covered in training, leading some to transition back to in-center hemodialysis [16]. Simulation-based education could be used to train patients in managing such emergency situations, thereby addressing this critical training gap and contributing to the continued successful use of home HD. Further support for the use of simulation-based education in home HD training comes from one study that demonstrated its use was associated with a trend toward needing lower numbers of home visits by nurses for nocturnal home HD patients [39]. Another approach that could be used to address issues of lack of confidence (as well as other barriers such as treatment burden, inadequate housing or medicalizing the home) is the use of community home HD. This form of dialysis is well established in New Zealand and involves a patient independently performing dialysis in a shared house within their local community [40]. It allows patients to experience similar benefits associated with home HD such as freedom, flexibility, and greater self-efficacy [40]; it may also encourage individuals to try home HD as some patients subsequently transition to home HD after receiving community home HD [40].

5 | Limitations

There are a number of limitations that should be acknowledged. Firstly, although we aimed to increase the credibility of the analysis by using two reviewers to conduct the data extraction independently, the findings represent the reviewers' interpretation of the data presented in the included papers. Secondly, we only included the analysis of home HD and did not consider the barriers and enablers to other home-based therapies. Thirdly, most studies included in this review were conducted in countries such as Canada, New Zealand, and the United Kingdom, which have higher rates of home HD use and more established care pathways that support its use. Therefore, the transferability of the findings to other countries could be questioned. This is particularly the case for those countries with a lower uptake and/or limited resources dedicated to the delivery of home HD care. Finally, only qualitative data was considered in our review. This may lead to concerns about the transferability of the findings as we did not analyze quantitative data [41].

6 | Conclusions

Despite the benefits of home HD for patients and the healthcare system, it is only used by a small percentage of dialysis patients. Given there will be a growing requirement for dialysis over the coming decades, increasing the uptake of home HD is crucial in order to reduce the pressure on the already over-burdened hospital-based HD units. Applying a theoretical model to understand the barriers and enablers to home HD provides a systematic method for identifying and evaluating specific approaches

to how to develop interventions for increasing the uptake of home HD.

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Conflicts of Interest

The authors declare no conflicts of interest.

Data Availability Statement

The data underlying this paper is within the article and the Supporting Information.

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Supporting Information

Additional supporting information can be found online in the Supporting Information section.