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REVIEW
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Education and training of home hemodialysis patients in Europe: a scoping review

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ABSTRACT

Introduction: Home hemodialysis (HHD) began in the 1960s; it has largely moved to the dialysis centers in recent decades, particularly across Europe. HHD patients account for <2% of the dialysis patient population. Training programs aimed at addressing the benefits, enablers and obstacles of home hemodialysis may therefore be relevant when considering this modality of renal replacement therapy (RRT). The aim was to conduct a scoping review of studies about training in HHD patients.
Methods: Using Arksey and O'Malley's framework, three databases were searched on CINAHL, PubMed and Scopus. The search included studies published in English from August 2013 to August 2023.
Results: Five studies met the scoping review criteria (two observational, two qualitative and one narrative review). Three education themes were identified: technique and management of the dialysis machine, self-cannulation of arterio-venous fistulas and safety.
Conclusion: The educational fields described represent a systematic approach to foster the growing use of home hemodialysis, but to date, further research is needed to investigate the feasibility and effects of educational training to understand if they meet the educational needs of patients. Finally, in Europe, there are obstacles to the implementation of home hemodialysis concerning health costs, logistics, but above all, the lack of specialized and dedicated medical and nursing staff.

Keywords: Education, Home hemodialysis, Nursing, Renal replacement therapy, Training

Introduction

Hemodialysis has changed the lives of millions of patients worldwide, 1 in 10 people has been diagnosed with chronic kidney disease, and 10.5 million people have kidney disease, most of whom require dialysis treatment or a kidney transplant (1,2). Home hemodialysis (HHD) began in the 1960s, and it has largely moved to dialysis centers in recent decades (3). Particularly across all of Europe, patients on HHD represent <2% of dialysis patients historically; this has been attributed to cost and logistics (4,5). More recently, there has been increased attention to the choice of home dialysis. This is based on the good evidence that home therapy offers innumerable advantages for the patient, especially in terms of quality of life, and lower values of risk of cardiovascular death and hospitalization compared to hemodialysis performed in dialysis units (4).

The inflexibility and rigidity of inpatient hemodialysis are among its major drawbacks, as patients have little control over the three-week slots lasting 3-4 hours (6). Additionally, the need for transportation to and from the dialysis center, with long travel and waiting times for patients, is reported by patients as a negative experience (2,6). Finally, the introduction of new HHD machines in recent years to simplify the technology and reduce the burden provides a new opportunity for an HHD renaissance. In recent decades, many global renal health institutions have strongly advocated for increased access and adoption of home hemodialysis (7,8). Furthermore, the coronavirus disease 2019 (COVID-19) has further underlined the importance of performing HHD, considering that dialysis patients are at a higher risk of developing severe outcomes of COVID-19 compared to the general population. Recent Canadian and Italian studies have shown that in-center dialysis patients were up to 3 times more likely to test positive for COVID-19 than home dialysis patients (8). The US Renal Data System recently reported that the COVID-19 hospitalization rate for hemodialysis patients at the center

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was 3-4 times higher than for patients receiving dialysis at home. (9,10). There is ample evidence that the lack of patient education is one of the major factors leading to the low rates of home hemodialysis development globally, with the majority of patients undergoing dialysis in centers (7,8,11) as the patient is asked for greater awareness through appropriate education with the aim of increasing acceptance of the need for lifelong renal replacement therapy (RRT) while encouraging self-care (12,13). Education and training programs aimed at addressing the benefits, enablers, and barriers to HHD among patients with end-stage renal disease (ESRD) may therefore be relevant to improving patients' choice of HHD.

This scoping review aimed to explore the training and education of home hemodialysis patients in Europe. Furthermore, this focused review aimed to map the range of literature on the topic to identify gaps that may inform future healthcare practice and research. Additionally, this scoping review aimed to map the range of literature on the topic to identify gaps that may inform future healthcare practices and research.

Methods

The current scoping review aimed to explore the training and education of home hemodialysis patients. The scoping review followed the five-stage methodological framework developed by Arksey and O'Malley (14) and included (1) identifying the research question; (2) identifying the studies relevant to the research question; (3) study selection; (4) charting the data; (5) collating, summarising, and reporting the results. This framework allowed the inclusion of various study designs and educational tools, such as photo and video consultations, to be thoroughly investigated.

Search strategy

The inclusion of the studies was limited to the European geographical area. Table 1 shows the inclusion and exclusion criteria. Three large digital databases were searched – CINHAL, PubMed, and Scopus for articles about remote consultations. Additionally, the reference lists of selected studies were checked for further appropriate articles. The search was performed in August 2023. After identifying the digital libraries, specific keywords were searched for the required data. The search strategy included a wide range of keywords to increase the sensitivity and inclusiveness of the search (Table 2).

Study selection

The initial screening process identified 159 studies, of which 16 were duplicates. Figure 1 illustrates the search collection and screening process using Preferred Reporting Items for Systematic Reviews and Meta-analyses (PRISMA) extension for the scoping reviews checklist (15). After screening of titles, abstracts, and introductions, 17 were selected for full-text review, with only 5 meeting all the inclusion criteria. Two authors independently reviewed and assessed the studies for eligibility, and consensus was reached in all four studies.

Results

A total of five studies published between August 2013 and August 2023 were included in this scoping review. Two studies used a qualitative design (16,17); two studies were observational (18,19), and one study used a review design (20). One study was conducted in the United Kingdom (16), one study in Finland, Belgium and the United Kingdom (19), one study was conducted in France (17), one study was conducted in the Netherlands (20), and one study was conducted in Ireland (18). Three common training themes identified across the studies were: (1) Technique and management of the dialysis machine, (2) Self-cannulation of arterio-venous fistulas, and (3) Safety.

Technique and management of the dialysis machine

Training to learn the handling of the dialysis machine and the technique of dialysis was identified in all of the five studies. Guerraoui et al. (17) in their qualitative study demonstrated a favorable attitude of almost all participants regarding the educational aspect delivered via a dialysis workshop composed of four educational sessions. Patient experiences were collected in the form of video testimonials, which utilized the method of constructivist pedagogy. At the end of the workshop, the patients were thus able to recognize and manage the different types and techniques of the hemodialysis machine. Gangaram et al. (19) describe a structured training path in the use of hemodialysis machines in dialysis centers by experienced personnel through frequent training sessions. Home independence training required an average of 9.6 (range 8-19) sessions. Bonenkamp et al. (20) also carried out a structured training course in their studio. He referred to the importance of early identification of a potential HHD patient and timely initiation of a comprehensive pre-dialysis patient

TABLE 1 - Inclusion and exclusion criteria

Selection Criteria	Inclusion Criteria	Exclusion Criteria
Language	English Language	Not English
Dates	Publications from 2010 to 2023	Publications before 2010
Study Type	Qualitative research Quantitative research Systematic review Mixed Methods	Conference abstracts, reports, and case studies, news articles and editorials, and unpublished primary studies that were ambiguous and vague about remote care
Topic	Training education in home hemodialysis	Training education in peritoneal dialysis or in-center dialysis

TABLE 2 - Search strategy

Step	Search Limiters
1	"renal care" OR "kidney care" OR "kidney disease" OR "chronic kidney disease" OR CKD OR nephrology OR dialysis OR hemodialysis OR "end-stage kidney disease" OR ESKD OR "end-stage renal disease" OR ESRD "OR end-stage kidney failure" OR ESKF OR "renal replacement therapies" OR HD
2	"patient education" OR education OR "educational status"OR "educations program"
3	"home dialysis" OR "home hemodialysis" OR "home hemodialysis"
4	1 AND 2 AND 3
5	Limiters—Year (August 2013 to August 2023)
6	Limiters—English
8	Limiters—Geography (United Kingdom and Ireland, Europe, North Territories)
9	5,6,7 Journal Article OR Review

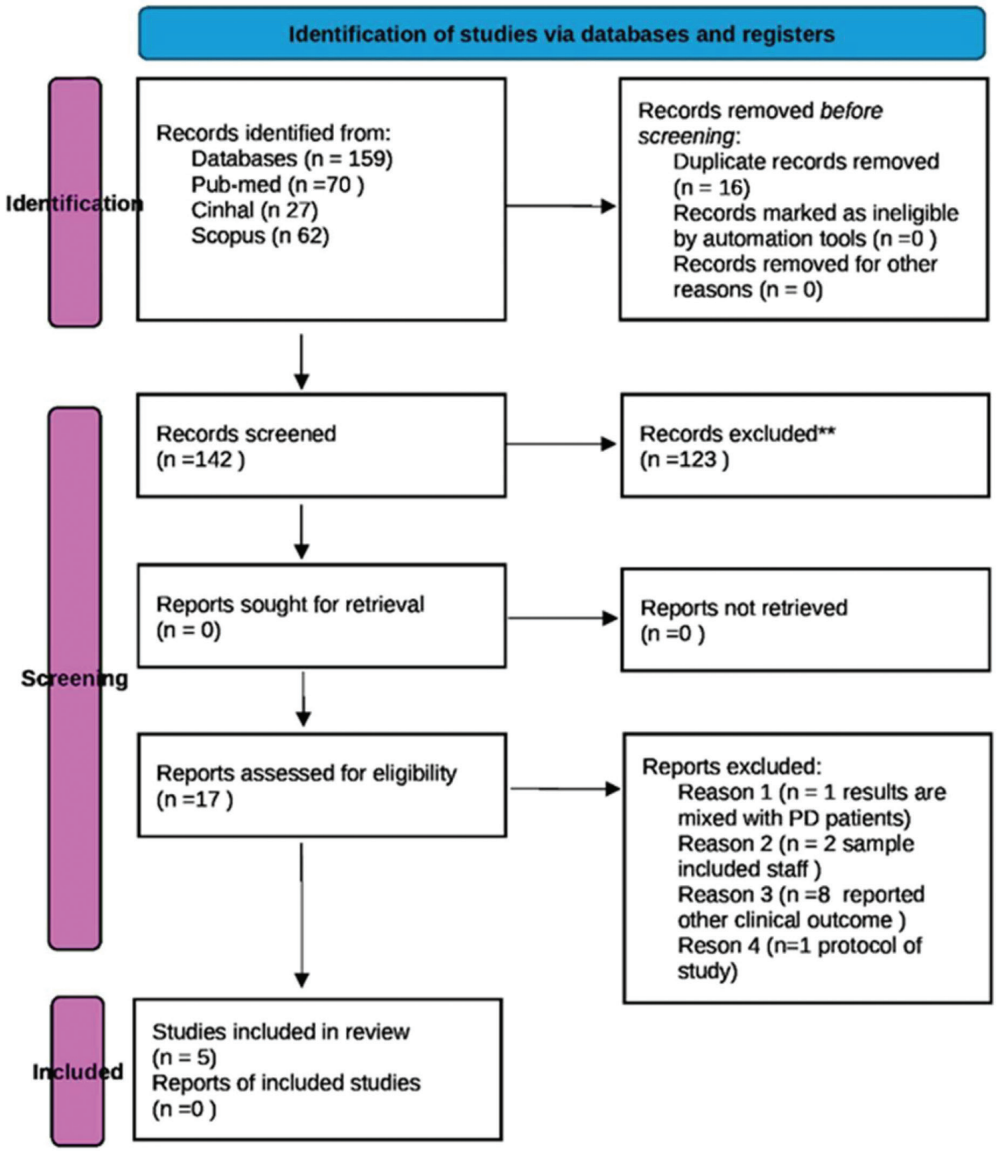

FIGURE 1 - Search results and source selection and inclusion process (15).

TABLE 3 - Summary of studies included in the scoping review

Title	Autors	Year	Country	Aim	Design	Sample	Setting	Provider	Key Findings
Design of therapeutic education workshops for home hemodialysis in a patient-centered chronic kidney disease research: a qualitative study	Abdallah Guerraoui, Roula Galland, Flora BelkahlaDelabruyere et al.	2022	France	The aim of this study was to identify and describe the needs of CKD patients and caregivers for RRT with HHD and design therapeutic education workshops.	Qualitative Research	10 HHD patients 80% males 20% female	Dialysis clinic conference rooms.	Medical and Nursing Staff	The training was focused on: • HHD representations (Self-puncture fistula) • Benefits and constraints of HHD • Recognize the different types of machines for HHD (technique and management of dialysis machines) • Safety
Nocturnal HHD with low-flow dialysate: Retrospective analysis of the first European patients.	Gangaram, V., Vilpakka, M., Goffin, E., Weinhandl, E. D., Kubisiak, K. M., & Borman, N.	2020	UK Finland Belgium	The aim of the present study is to review the outcome of a European cohort of patients treated with nocturnal therapy using a low-flow dialysate system	Observational Study	21 Patients 75% Male; 25 % Female	Hemodialysis center and Home	Expert in HHD training	The Training was focused on: • Safety precautions for establishing the dose requirement for anticoagulation • (to prevent clotting in the filter) • Securing needles • Needle dislodgement • Blood leakage • Machine management
Home hemodialysis in the Netherlands: State of the art	Bonenkamp, A. A., van Gelder, M. K., Abrahams, A. C., Boereboom, F. T. J., Cornelis, T., Luik, A. J., Özyilmaz, A., van der Sande, F. M., van Eck van der Sluijs, A., Gerritsen, K. G. F., & van Jaarsveld, B. C.	2018	Netherlands,	This narrative review aims to provide a thorough overview of current practices and literature on HHD.	Narrative Review	Not Declared	Hemodialysis Center	Multidisciplinary team	The training comprises all aspects of HD: • Preparation of the dialysis fluid, Machine setup, • Self-cannulation • Access to assessing dry weight • The training program should train patients to act appropriately in case of acute events • Safety

Title	Autors	Year	Country	Aim	Design	Sample	Setting	Provider	Key Findings
Patients' and carers' experiences of interacting with home hemodialysis technology: implications for quality and safety	Rajkomar, A., Farrington, K., Mayer, A., Walker, D., & Blandford, A.	2014	UK	The aimof this study has been on how the design of HHD technology and the broader care context can facilitate the learning process, support the patient, and ensure safety during dialysis.	Qualitative Research	19 HHD Patients 47% males 53% female	Hemodialysis Center and home	Hospital staff	The Training was focused on: • Learning to use the technology, • Usability of the technology • Managing safety during dialysis, • Self-cannulation
Home hemodialysis in Ireland	Connaughton, A. Jamal J. McWilliams, P. O'Kelly, J. Ormond A. Butler, N. McEntee, E. Tierney, G. Lambe, M. Denton, C. Magee P. J. Conlon	2013	Ireland	The aim of this study was to assess the outcomes in patients commenced on the HHD programme.	Observational Study	17 HHD Patients 58% Male 42% Female	Hemodialysis center	Nephrologist and specialist nurse	The training was about the patient's ability: • Self cannulation • Safety

education program to provide both patients and caregivers with information about chronic kidney disease, the different types of RRT, conservative therapy and self-management of the machine (from dialysis fluid preparation to dialysis machine setup). The training program generally lasted 6-12 weeks and was dependent on each patient's knowledge and skills. Rajkomar et al. (16) focused on ethnographic observations on how to use the dialysis machines through training sessions that varied from three times a week to daily. In this study he identifies three major themes at the heart of the analysis: learning to use technology, usability of the technology, and safety management during hemodialysis. Finally, Connaughton's observational study (18) conducted in Ireland described that any patient who wants to perform HHD needed assessment of suitability undertaken by a nephrologist and a specialist nurse. This includes assessment of household facilities, water supply, electricity supply, plumbing and an assessment of patient organizational and dialysis machines skills.

Self-cannulation arterio-venous fistula

Self-cannulation training was identified in four of the five studies included in this scoping review. All four studies affirm the importance of training patients to self-cannulate to achieve the greatest possible independence. Guerraoui et al. (17) reported through semi-structured interviews that patients had difficulty self-cannulating, while being aware that the acquisition of this skill was essential to cope with HHD. They were concerned about the sensation of pain caused by the insertion of the fistula needle. Additionally, patients reported the need to have a good understanding of the anatomy of their arterio-venous fistula (AVF) to understand if self-cannulation was being performed correctly. Gangaram et al. (19) instead focused on training related to the cannulation technique. Patients enrolled in the study were instructed to perform double cannulation of the fistula using the buttonhole technique or the constant site technique with blunt needles due to reduced pain perception. Bonenkam et al. (20) describes that in the Netherlands patients were trained in "Tandem-hand" cannulation in less than three weeks: the first week the nurse inserted the needle under the physical guidance of the patient, the following week the patient inserted the needle under the physical guidance of the nurse, finally the following week the patient performed the cannulation alone in the presence of the nurse. Bonenkam, as Gangaram and colleagues (20) set out to educate patients using the buttonhole technique often used by patients who fear self-cannulation as it was defined as less painful. Additionally, the buttonhole technique improved AVF survival, including reduction of aneurysm formation and the need for vascular access surgery. Connaughton et al. (18) highlighted in their study the need for the patient to be hemodynamically and clinically stable to undergo HHD. Once the patient's stability has been ascertained, it is proposed to start an intensive training of 4-6 weeks, which allows the patient to acquire skills and abilities in self-cannulation and in the management of the AVF. Additionally, all patients enrolled in the study were trained to access the AVF using the loop technique during the HHD program.

Safety

Patient training and education to ensure patient safety during HHD were considered in all studies. Bonenkamp et al. (20) and Guerraoui et al. (17) have considered the need to train patients to intervene urgently in the event of acute events or complications, both clinical and related to the functioning of the dialysis machine during or after treatment, instructing them to identify critical situations that cannot be resolved on their own in which it was necessary to alert the reference dialysis center. Gangaram et al. (19) considered it a priority in the study to provide patients with instructions on the dose of anticoagulant therapy with the aim of making them independent by guaranteeing the appropriate dosage for their specific needs. A further aspect, relating to safety, taken into consideration in the study concerns the importance of instructing patients to secure the fistula needles in order to avoid needle dislodgement and any complications that compromise the duration and use of the vascular access. Rajkomar et al. (16) instead highlighted the importance of educating patients in the use of technology and how it affects the safety of treatment. The study shows educational strategies that allow safety during dialysis treatment, such as anticipating water or electrical problems, interpreting and intervening in situations such as dialysis machine alarms and making considered decisions about whether or not to continue or stop the dialysis treatment if their safety is being compromised.

Discussion

This scoping review found only five European studies that included training and education in HHD patients and the importance of communication based on trust, active listening, empathy, and simple language adapted to the patient's characteristics (21). All studies emphasize the importance of patient education in HHD. Common training issues identified were dialysis machine technique and handling, self-cannulation, and safety. The review identified several factors that need to be recognized to promote education for patients' suitability for HHD. European guidelines also illustrate that dialysis centers should utilize an interdisciplinary team approach, which delivers structured educational programs on different modalities of RRT (22) with a patient-centered approach. Anxiety about self-cannulation and life-threatening complications involving vascular access are of particular concern in home hemodialysis and are perceived by patients as barriers that can be addressed in a supportive and dedicated environment that promotes patient education. Patient education about the use of vascular clamps, vascular catheter closure devices, one-way valves and especially on the risks of bleeding and air embolization requires ongoing educational monitoring that does not end with the normal training period (23). Despite the demonstrated benefits of patient education, there is no consensus on the most effective methods and strategies for organizing and delivering it. Although several studies exist, strategies on how to best educate patients are remarkably scarce. Indeed, there is no standardized approach regarding when to begin education, who should be involved, what topics to cover, or how to structure educational programs (24).

The new generation of machines designed specifically for home hemodialysis is smaller, intuitive to use, easy to troubleshoot, robust and reliable, quick to set up, and requires minimal waste disposal (24). In particular, the design of the interface of the dialysis machine technology can facilitate learning for the patient by providing contextual information-which provides a step-by-step guide for the entire hemodialysis treatment. This includes preparation of the dialysis machine, monitoring the dialysis machine during treatment, recognition and management of dialysis complications, right up to discontinuing the dialysis treatment and post-dialysis disinfection of the dialysis machine.

The treatment of HHD is complex and requires many steps to be performed in the correct order, and even fatal accidents involving HHD machines have been reported. A study conducted in Italy found that patients and providers believe that delivering HHD means abandoning the sense of security provided by a supervised dialysis unit (25) In support of this, the technological assistance provided by devices such as pressure gauges, scales and dialysis machines that transmit data to dialysis centers is essential for patient safety but it has been repeatedly demonstrated that it is not possible to rely exclusively on these alarms to detect malfunctions or critical situations, therefore patients should be encouraged to identify self-care strategies that reduce the likelihood of distraction during the entire dialysis process as well as avoiding dialysis when they are alone or already tired (22).

Furthermore, in addition to playing a fundamental role in patient education, doctors and nurses are responsible for training caregivers and family members, who are key figures in providing care throughout the disease process. In the specific context of hemodialysis, caregivers support patients with numerous daily activities, including dietary management, symptom management, and medication administration. However, without adequate training, family members encounter serious difficulties in providing care; this lack of training exposes the entire family unit to critical issues, including stress, anxiety, and both physical and psychological distress.

In this regard, Sotoudeh et al. (26) demonstrated the effectiveness of Family-Centered Care in enhancing caregiver skills. Many families attribute their difficulties to a lack of specific knowledge about the disease and caregiving practices; therefore, implementing a model that actively involves family members in problem-solving can be a crucial strategy for increasing their awareness and resilience and significantly improving patient outcomes (26,27).

To our knowledge, this is the first scoping review to identify the training of HHD patients. The results suggest that the technological systems used today are safe, of high quality, supported in the most advanced centers by telemedicine, and allow people to perform HHD therapy safely, at home, where education and care support programs allow the patient and the caregiver to overcome fears and barriers and obtain excellent clinical outcomes and therefore improve quality of life. This allows the patient to face the challenge of change by undertaking a home hemodialysis journey in which they feel safe, engaged and empowered to manage their RRT.

Strengths and limitations

This is the first scoping review aimed at identifying recent evidence of training and education in the home hemodialysis patient. The review also adhered to the Arksey O'Malley Framework and PRISMA scope review guidelines. This review is not without limitations. The review only included studies published between 2013 and 2023 in English only, and relevant articles outside these dates and in other languages may have been lost. Furthermore, all studies were developed only in Europe, and this offered a narrower scope of investigation; therefore, the results of this review may not fully reflect evidence of education domains from non-European countries. Finally, the studies included in this review were not assessed for quality, as stated in the goals of the scoping review; it is useful for identifying the nature and extent of research evidence rather than assessing its quality (15).

Practical implications and future research

The results of this review require careful consideration of factors facilitating or favoring educational interventions in patients to promote the provision and development of HHD in Europe. The findings potentially impact the future delivery of HHD, allowing health care providers to improve the delivery of HHD by implementing education in this field, with a summary of recommendations outlined in Table 4.

TABLE 4 - List of recommendations

Number of recommendations	Type of recommendation
1	Facilitate learning through experiential learning
2	Promote Digital Health Technologies for Patient Education
3	Encourage interaction with other patients through storytelling and peer-mentoring
4	Ensuring specialist training for home dialysis nurses and nephrologists
5	Develop transitional care unit programs in dialysis centers

First, we recommend HHD training, which includes transmission of the know-how in relation to knowledge transfer and knowledge transformation of the person to whom the training is transmitted. We therefore believe in training courses that place a strong emphasis on experiential learning, where the patient's reflexivity is emphasized to help them define their goals and develop action plans. This also allows patients to develop self-knowledge of their hemodialysis treatment and underlying disease management by the emergence of self-care strategies that consolidate the ability to think critically and make decisions (28).

Secondly, we recommend the use of digital health technology as it can improve behaviors, build skills and promote empowerment. Additionally, patient education delivered in standard formats with a wide range of multimedia content (video, audio, interactive games, etc.) may be more appropriate for certain topics and learning styles. These programs should consider patients' literacy levels and include

interactive modes that use games and avatars to encourage learning. (28,29) We also believe that virtual reality (VR) simulation tools, such as headsets, could be effective for all aspects of education related to vascular access, especially self-cannulation. The simulation allows you to follow standardized procedures, allowing you to practice and correct errors without risk (29).

Thirdly, we recommend encouraging interaction with other patients in educational pathways through, for example, storytelling and peer mentoring to foster connection between people who are having the same experience.

Fourth, we suggest, to ensure successful implementation of the HHD, the specialist training of healthcare professionals who are adequately educated and competent, but also equipped with additional training in, for example, shared decision-making, bias awareness and communication skills. All skills that have the potential to support patients in making decisions about their hemodialysis treatment and disease management. To support this specialist training, we recommend the development of transient care unit (TCU) programs built within dialysis centers. TCUs composed of multidisciplinary teams aim to improve patient awareness of all aspects of RRT, including dialysis treatment modalities. Patients are guided by healthcare professionals to make an informed decision about whether to continue with HHD or remain on hemodialysis (HD) at the dialysis center.

Fifth, we suggest, to ensure successful HHD implementation, consideration should be given to the digital technology requirements, i.e., reliable internet connections, devices and applications compatible with HHD machines to provide remote monitoring and support. This is coupled with the patients and carers digital literacy skills, which may impact the ability to use digital technology effectively and safely (30).

Sixth, we suggest the construction of learning assessment scales to assess patients' health literacy, provide feedback, and ensure learning objectives are achieved.

Conclusion

The findings of this exploratory review underscore the current state of education for home hemodialysis patients in Europe. Taken together, the educational domains described represent a systematic approach to fostering the growing use of HHD. Home dialysis provides a more physiologic approach to dialysis and, in many circumstances, can lead to better clinical outcomes than traditional in-center hemodialysis. Patient education should not only concern the management of those who have chosen the HHD option but also foresee the interventions and processes that can promote this choice during the pre-dialysis phase of the patient's disease management.

The review provides important educational strategies for dealing with home hemodialysis in an autonomous but, above all, safe way. Further research is needed to investigate the feasibility and effects of education training to establish whether they meet the educational needs of patients and their careers. In this regard, adopting a multidimensional assessment of educational outcomes, supported by the use of validated tools and scales, allows for a deeper understanding of the effectiveness of learning throughout the entire care pathway. This approach helps consolidate crucial dimensions such as patient autonomy, awareness of their condition, and the bond of trust with healthcare professionals.

However, to date, there are several obstacles in Europe to the implementation of HHD; they concern health costs, logistics, but above all, the lack of specialized and dedicated medical and nursing staff. In fact, the promotion of dedicated staff would contribute both to the growth of dialysis professionals within institutions and to offering an educational experience centered on direct patient care. All of this would avoid the default assignment of patients to in-center hemodialysis in favor of a shared decision-making model that includes education and time to consider home therapy.

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