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Ekpenyong, Mandu Stephen, Alfred, Stephen Hope, Foluke, Bosu-Arije Stella, Jallow, Oley, Manju, C Pallam and Mathew, Nyashanu (2022) Decision-making process in the selection of home hemodialysis treatment by adult patients with end-stage renal disease in the United Kingdom: a systematic literature review. CHRISMED Journal of Health and Research, 9 (4). pp. 209-218. ISSN 2348-3334

**DOI:** [https://doi.org/10.4103/cjhr.cjhr\\_69\\_22](https://doi.org/10.4103/cjhr.cjhr_69_22)

**Publisher:** Wolters Kluwer Medknow Publications

**Version:** Published Version

**Downloaded from:** <https://e-space.mmu.ac.uk/631626/>

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**Additional Information:** This is an Open Access article which appeared in CHRISMED Journal of Health and Research, published by Wolters Kluwer

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## A Systematic Literature Review

# Decision-making Process in the Selection of Home Hemodialysis Treatment by Adult Patients with End-stage Renal Disease in the United Kingdom: A Systematic Literature Review

### Abstract

**Introduction:** In the UK, the number of people diagnosed with renal disease is on the increase. As a result, there will be more people in need of renal replacement therapy (RRT). Despite the mounting evidence showing that home hemodialysis (HHD) treatment is clinical and cost-effective as well as amendable to suit patients' lifestyle, the number of patients choosing this dialysis modality is low. The aim of this study is to explore factors influencing decision-making process in the selection of HHD treatment for adult patients with end-stage renal disease in the UK. **Methods:** A systematic literature review methodology was utilized to review, critique, and synthesize the literature on the low uptake of HHD among adult patients. Systematic searches involving the databases Google Scholar, EMBASE, MEDLINE, PsycINFO, and CINAHL were carried out for articles published from 2008 to 2021. A search was conducted from June 1 through December 23, 2020. Eight articles met the study inclusion criteria. We followed preferred Reporting Items for Systematic Reviews and Meta-analyses in designing the research and reporting. **Results:** This systematic review revealed that patient information needs, dialysis education, training and support, and patient decision-making preference were the major factors influencing decision-making of adult patients. **Conclusion:** Deciding over which dialysis modality to choose can be challenging for many adult patients. Dialysis education, training, and support should not stop at the predialysis stage but should continue during treatment.

**Keywords:** Decision-making, dialysis modality, home hemodialysis, predialysis education and end stage, renal disease, renal replacement therapy

### Introduction

End-stage renal disease (ESRD) has become a serious public health concern given the rising number of people who are diagnosed across the world.<sup>[1]</sup> Kidney failures in the early stages are often reversible, whereas chronic kidney failures are often not reversible, and the patient will have to live with the condition for the rest of their lives.<sup>[2]</sup> According to the 2002 guidelines of the Kidney Disease Outcomes Quality Initiative, there are five stages of chronic kidney disease (CKD) with respect to the damage and function of the kidney.<sup>[3]</sup> The progression of CKD does normally result in ESRD, which as its name implies, is the last stage of a kidney ailment.<sup>[4]</sup> ESRD can be life threatening and poses tremendous physiological, psychological, and financial challenges to patients.<sup>[5,6]</sup>

When a patient's condition gets to ESRD, then renal replacement therapy (RRT)

is required.<sup>[7]</sup> Several types of RRT are available. Renal transplantation is generally seen as the most cost-effective approach for suitable patients, with the other modalities of RRT being hemodialysis (HD) and peritoneal dialysis.<sup>[8]</sup> Home modalities have been found to offer significant benefits in multiple clinical parameters important to the management of patients with ESRD and are also more cost-effective for the health-care system.<sup>[9]</sup> Home HD offers the opportunity to make the HD treatment more closely to patient's needs.<sup>[8,9]</sup> Evidence in the literature supports the cost-effectiveness of HHD when compared to hospital-based/in-center HD.<sup>[10]</sup> In a dialysis unit, the patients are subject to the scheduled time available for treatment and travel to and from the health facility. In contrast, at home, the patient schedules his/her own treatment time, does not have to travel to a dialysis center, and has the best possible person inserting the needles for them. The freedom and control

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**How to cite this article:** Ekpenyong MS, Alfred SH, Foluke BA, Jallow O, Manju CP, Mathew N. Decision-making process in the selection of home hemodialysis treatment by adult patients with end-stage renal disease in the United Kingdom: A systematic literature review. *CHRISMED J Health Res* 2022;9:209-18.

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**Submitted :** 26-May-2022  
**Revised :** 10-Aug-2022  
**Accepted :** 23-Dec-2022  
**Published :** 17-Mar-2023

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### Access this article online

**Website:** [www.cjhr.org](http://www.cjhr.org)

**DOI:** 10.4103/cjhr.cjhr\_69\_22

### Quick Response Code:



of dialyzing at home are powerful draws to this treatment modality.<sup>[11]</sup> All the basic supplies such as dialyzers, lines, needles, gauze pads, home scale, and laboratory supplies are paid for by the patient insurance, just as they are in a center. Nonetheless, there are some out-of-pocket expenses the patient needs to consider before choosing dialysis at home. The two biggest areas that need to be evaluated are water revisions and electrical connections. The cost of furnishing and installing waste and water piping that will be required is estimated at between \$750 and \$1500.<sup>[11]</sup>

According to a report commissioned and published by the National Health Service in 2012, there were over 1.8 million people diagnosed with CKD in England.<sup>[6]</sup> The prevalence rate of adult patients undergoing RRT across the UK is on the increase. A 3.1% increase in adult patients undergoing RRT across the UK between 2015 and 2016 was reported.<sup>[8]</sup> The report also noted a small increase in the number of patients receiving home HD (HHD). ESRD is a serious health-care issue given its debilitating effects on patients and the high treatment costs to public finance.<sup>[12]</sup>

Further, the study found that the high cost to provide RRT takes a disproportionately large portion of the health budget of a country relative to the size of CKD patients.<sup>[13]</sup> For most patients suffering from ESRD, HD is the treatment of choice worldwide. In the UK, HHD treatment is more prevalent than peritoneal dialysis after 90 days of treatment.<sup>[14]</sup> Castledine *et al.* noted that the report of the UK renal registry recorded a greater percentage of ESRD patients undergoing HD treatment, while two-tenth received PD and one-tenth received a kidney transplant after 90 days of dialysis treatment.<sup>[15]</sup> This shows the high number of patients requiring HD treatment. Although HD treatment is offered either in the hospital or at home,<sup>[1]</sup> more ESRD patients prefer hospital-based HD treatment more than a self-managed HD treatment at home.<sup>[16]</sup>

The National Institute for Health and Care Excellence describes HHD as an innovative approach of dialysis that can be safely and independently administered at home by ESRD patients or their family members.<sup>[17]</sup> The schedule for HD is done either on an intermittent or continuous basis depending on the patient's preference or medical condition. For patients in critical care, a continuous schedule is recommended.<sup>[18]</sup> Nonetheless, HD in general and home HD, in particular, have their advantages and disadvantages. Some of the advantages of HHD include greater improvement in nutrition, overall quality of life, longevity, self-control, and flexibility.<sup>[19]</sup> On the other hand, some of the disadvantages associated with HD include vascular-related complications and dialysis-related complications.<sup>[1,19]</sup> These two complications can lead to headaches, nausea bleeding, vomiting, muscle cramps, hypotension, and confusion.<sup>[1,20]</sup>

It is highly recommended that the planning for dialysis should start when the patient's CKD is at stage 4 in preparation for stage 5 ESRD.<sup>[9]</sup> At stage 4, the patient

should have received ample information to be able to decide on the various options on offer for RRT. This is because when patients progress to ESRD, the condition does have a significant impact on their lifestyles, and they need to know the various treatments and options on offer to live reasonably well for the rest of their lives. For this reason, call for early education of patients to enable them to make informed decisions has been recommended.<sup>[5]</sup> In light of this, it is reasonable to say that when it comes to time to choose the most appropriate treatment for ESRD, the decision may often be stressful may often be stressful because each option has different advantages and disadvantages so it is important to learn as much as possible.

Patients' preferences for treatment that best suits their lifestyle, clinical conditions, and availability of treatment are some of the main factors determining the type of dialysis chosen.<sup>[21]</sup> In this study, the decision-making process refers to the different stages the patients go through from CKD stage 4 until the selection of a dialysis modality.

Nonetheless, the research found that the overall benefits of HHD outweigh hospital-based dialysis. Harwood and Leitch found that many patients on HHD experienced improved quality of life due to the reduced need to travel for dialysis, higher autonomy, and greater flexibility to fit around the recipient's occupational and social roles.<sup>[22]</sup> It is instructive to understand as health-care professionals what are the driving factors as to why fewer numbers of people do not choose HHD and the decision-making process behind their modality choice. Doctors and nurses have a vital role to play in enabling CKD patients to make informed decisions.<sup>[23]</sup> The patient needs to be at the heart of the decision-making process.

In identifying the problem to study for this review, two systematic literature reviews on dialysis modality were found.<sup>[16,24,25]</sup> The systematic review<sup>[22]</sup> looked at decision-making and covered more than dialysis to include transplantations and conservative management. Harwood and Clark systematic review was the first study to investigate the decision-making in dialysis modality as there was barely any understanding as to why patients decide to choose or decline home-based dialysis. Thus, their systematic review was aimed at knowing why patients select home dialysis. The current study aims to focus on the decision-making about HHD.

## Material and Methods

### Search strategy

A search was conducted from June 1 through December 23, 2021, on eight databases including Medline, CINAHL, Web of Science, Embase, PubMed, PsycINFO, Scopus, Nursing and Allied Health Source, and ScienceDirect. In addition to the online databases, citation scanning from articles was also carried out to complement the search results.<sup>[23,24,25]</sup> It was done using the following combinations of keywords utilizing

different operators to identify relevant materials that might prompt further relevant information. Were applied in the search process. Table 1 shows the keywords used.

### Inclusion and exclusion criteria

Table 2 outlines the inclusion and exclusion criteria that guided this study and help to streamline the literature search. In summary, the final studies (8) retained met the following inclusion criteria: peer-reviewed articles in English that were published between 2008 and 2021 relating to adults suffering from ESRD in the UK, quantitative and qualitative studies, and mixed methods were included in the study. Figure 1 shows the data screening process.

Following the critical appraisal of the selected studies, it emerged that the selected studies used a variety of research strategies. Two studies used a survey, two used a qualitative research strategy including applying grounded theory, three used a mixed-method strategy, and one used a qualitative longitudinal patient narrative approach. All the studies were either entirely or partly conducted in the United Kingdom and in relation to HHD involving adult patients with ESRD.

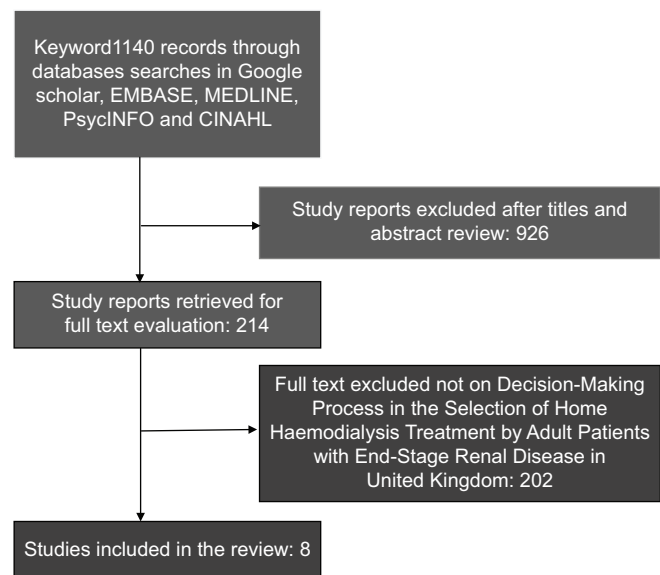
### Quality assessment and screening and selection of studies

Quality assessment was completed for all included papers and used to describe reporting quality rather than inclusion and exclusion purposes. Titles and abstracts were screened

against the inclusion/exclusion criteria above. Articles meeting these criteria were selected for full-text screening. The 2018 Critical Appraisal Skills Programme tool was used to appraise the included articles. Appendix 1 shows the results of the quality appraisal.

### Study selection

Two reviewers (EMS and OJ) independently screened titles and abstracts. We retrieved the full text for any article considered potentially relevant by at least one reviewer. To ensure accuracy, two reviewers (BAFS and NM) then independently screened full-text articles for inclusion in this review. We resolved disagreements by discussion.



**Figure 1: preferred Reporting Items for Systematic Reviews and Meta-analyses flowchart illustrating articles screening process (p. 4)**

**Table 1: Keywords used (pg. 3)**

Haemodialysis/hemodialysis	Dialysis modality
HD	Dialysis modality renal replacement therapy
HHD	Dialysis treatment ESRD
Decision-making	Predialysis education

HD: Hemodialysis, ESRD: End-stage renal disease

**Table 2: Inclusion/exclusion and justification (pg. 4)**

Inclusion criteria	Exclusion criteria	Justification
Retaining only literature that is pertinent to the research question	Discard any literature that is not pertinent to the research questions	This is to streamline the focus of the search to the core issues of the study (Moule and Hek, 2011)
Only primary and secondary studies published between 2008 and 2019	Any primary and secondary studies published before 2008	This is to narrow down the research to a specific period (Moule and Hek, 2011), and this research is interested in findings in the last 10 years
Only peer-review articles published in academic journals	Unpublished papers including theses and report or guidelines	They deliver strong evidence since their technique and results have been authenticated (Sandelowski <i>et al.</i> , 2006)
Related to adults with ESRD over the age of 18 years and above	Related to young people below the age of 18 years	This is to reach the target of the study (Whittemore and Knafl, 2005)
Related to patients with 5 ESRD receiving home dialysis treatments	Related to patients below 5 ESRD	The subjects of the study are patients with ESRD who are at the initiation stage or undergoing dialysis treatment. They are the target population of the study (Russell, 2005)
Only materials published in English will be consulted	Documents in foreign languages will not be included	The researcher can limit the search to a specific language for a variety of reasons including a linguistic barrier (Aveyard, Payne, and Preston, 2016)
The UK included in the study as the only location or among the locations	The UK not included in the study	The location of the research is also an important criterion (Aveyard, Payne, and Preston, 2016). The interest of the research is limited to the UK

ESRD: End-stage renal disease



## Data extraction

Two reviewers (EMS and OJ) independently abstracted data using pro forma [Table 3]. This was done in duplicate to increase accuracy and reduce measurement bias. We resolved any disagreements with the help of a third and fourth reviewer (SHA and PM). Information was extracted from eligible articles based on predefined criteria. Information such as the author's name, year of publication, research aim, the study design, sample size, data analysis methods, and key findings were extracted and included in the data extraction table. Extracted data from the included articles are summarized in Table 3.

## Thematic analysis

For the data analysis, this systematic literature review adopted the inductive thematic analysis with the essentialist/realist approach.<sup>[26]</sup> The inductive thematic analysis approach was considered appropriate as the study aimed to identify the major themes of the studies under review regarding factors influencing the decision-making process in the selection of HHD for adult patients. According to Aveyard and Payne, the thematic analysis approach is used to identify themes from within or across a data set. In addition, thematic analysis is used to bring out distinct core themes both between and within the transcripts.<sup>[27]</sup>

In searching for themes, the reviewers coded the data with similar findings under different broad headings.<sup>[26,27]</sup> The coding helps to reduce the data into a different heading.<sup>[26,27]</sup> The codes were identified to respond to the research questions.<sup>[25,26]</sup> There are no hard and fast rules to identify themes from a dataset given the subjective nature of the process. Thus, the subjectivity of qualitative research means that researchers employing thematic analysis will have to rely on their experience and knowledge to assign themes to the data under review. Moreover, even among experienced researchers, they do ask other researchers to re-examine the coded data to minimize as much as possible the subjectivity and bias of the process and to ensure that the themes have not been arbitrarily identified.<sup>[27]</sup>

In determining the major themes of the review, this study grouped extracts from the data with similar messages and focus. Extracts with similar messages and focus were subsequently labeled.<sup>[26]</sup> After several revisions, the labels were modified to develop a broader theme that captured the similar messages and essences of the extracts. From the coding and labeling, the study identified three major themes from the studies under review as major factors influencing adult patients' selection of HHD as a treatment option of RRT in the UK. The three major themes are as follows: (i) patient information needs, (ii) patient dialysis education, and (iii) patient decision-making preferences. The above-identified themes were reflected in the studies.<sup>[14,22,28-33]</sup>

## Results

### Patient information needs

The study<sup>[4,7,28-33]</sup> identified patient information needs as a critical aspect of dialysis modality selection. The studies underscored the important role of information provision behind adult patients' treatment options. The studies showed that lack of adequate and balanced information does lead adult patients away from selecting HHD treatment and opting for in-center HD treatment instead. This suggests that failure to take into consideration the information needs of the patients could lead to less optimal decision-making. Patients value information that enabled them to understand their renal disease and treatment options. The studies reviews<sup>[13,30]</sup> confirmed the positive relationship between information needs and decision-making.

### Patient dialysis education

In addition to the identification of the patient's information needs, the studies also emphasized the importance of dialysis education in the decision-making process for the selection of home dialysis treatment. According to findings by Drukker *et al.*, a significant number of patients opted for HD treatment options after attending predialysis education.<sup>[13]</sup> This was further observed by stating that PDE is highly valued by most patients and clinical staff as an important aspect in supporting patient decision-making.<sup>[34]</sup> Even though all the studies agreed about the importance and value of PDE, there were disagreements about the most effective method of delivery. Two studies stated that some PDE failed to incorporate the points of view of the patients. Following a survey of 242 predialysis patients in a single center in the UK, Braun and Clarke observed that it was important to incorporate factors influencing patients' decisions in the development of PDE programs.<sup>[28,30]</sup>

Several studies noted that PDE should be complemented with other forms of education as patients learn about the disease and treatment options in various ways.<sup>[8,17,35]</sup> Other studies argued that dialysis education should not be limited to the predialysis stage alone but should continue throughout the treatment. Hope observed three forms of vicarious learning experiences by patients as follows: the planned learning (formal education), unplanned learning experiences (informal education), and the historical vicarious learning experiences (through family medical history).<sup>[32]</sup> Although in general, the patients felt that they had received adequate information to make their choices, 63% still felt that their chosen modality was medically superior. Bryman proposed that PDE should be customized to fit patients' needs and backgrounds. This would allow for the exploration of the impacts of treatment options and the provision of ongoing emotional support.<sup>[29]</sup>

### Patient decision-making preferences

Winterbottom *et al.* carried out two qualitative studies in the UK in relation to decision-making and patients' experiences

**Table 3: Data extraction table (pg 5)**

Authors and publication date	Aim/purpose, research questions, or hypothesis	Study design and method of data collection used	Sample size	Data analysis method	Themes identified	Findings
Combes, G, Sein, K and Allen K (2017) <sup>[36]</sup>	To look at qualitative case studies to explore barriers and success factors for home dialysis	Semi-structured interviews	96 clinical and managerial staff and 93 dialysis patients in four hospitals' renal units in the UK	Data were analyzed using a form of thematic analysis, the framework method	Predialysis education, ongoing RRT education; training of clinical staff; patient emotional support	Although PDE is useful, not all patients will benefit, because some find decision-making in the predialysis period too complex or are unable to engage with education due to illness or emotional distress
Combes, G; Sein, K, Allen K, Girling, A and Lilford, R (2015) <sup>[31]</sup>	To examine more broadly the barriers and facilitators to increasing the uptake of home dialysis	Mixed method case study	Seven hospitals in the West Midlands	Logistic regression model	Increasing HHD uptake; using performance targets in hospital; individualized patient education; patient emotional needs	To increase uptake in HHD, individualized patient education which allows exploration of the impacts of treatment options and the provision of ongoing emotional support
Jayanti, A, Neuvonen, M, Wearden, A, Morris, J, Foden, P, Brenchley, P, Mitra, S (2015) <sup>[33]</sup>	To examine the decision-making preferences of patients	Combined cross-sectional and prospective design	535 ESRD patients enrolled in the cross-sectional study and 30 patients who started dialysis were prospectively evaluated in five UK centers	All analyses were carried out using SPSS 20. Patient characteristics between groups were compared using ANOVAs, Chi-square tests, and Kruskal–Wallis tests using conventional two-sided 5% significance level	Individual patient preference for decision-making Autonomous decision-makers and delegators; individualized approach	ESRD patients prefer information but may not want to be actively involved in the decision-making process
McCarthy, K., Sturt, J., and Adams, A (2015) <sup>[15]</sup>	To study the different ways of how patients, learn about dialysis modality	Grounded theory methodology using unstructured interviews	20 predialysis patients in the UK	Thematic analysis and secondary coding	Patient information; patient education; formal and informal ways of learning; peer contact and support	Three themes of vicarious learning experiences identified by patients: Planned learning (formal education), unplanned learning experiences, and historical vicarious learning experiences
Winterbottom A, Bekker HL, Conner M and Mooney A. (2014) <sup>[38]</sup>	To study the decision-making approach of patients regarding dialysis modality	Semi-structured in-depth interviews	20 with CKD at different stages of decision-making	Thematic analysis	Inadequate patient information; inadequate emotional support; illness interfering with decision-making	There was a similarity in the patterns of patients with ESRD in response to the illness Themes from the data included the perception of the cause of illness

*Contd...*

**Table 3: Contd...**

Authors and publication date	Aim/purpose, research questions, or hypothesis	Study design and method of data collection used	Sample size	Data analysis method	Themes identified	Findings
Hope, J. (2013) <sup>[32]</sup>	To explore the patient perspective on the main barriers to a range of self-care or home dialysis therapies, including HHD	Longitudinal patient narrative approach	None	Personal experience	Individualized approach; training for staff; patient unmet emotional needs; continuous dialysis education	Significant barriers to all aspects of informed decision-making around home therapies are based on perception. Creating decision aids and education programs to tackle these perceived barriers, actively encouraging home therapy takes up, focusing on QOL in clinical decision-making, offering peer support, and expanded in-center self-care. Treatment options may increase awareness and uptake of self-care therapies
Appleby S. (2013) <sup>[26]</sup>	To introduce shared care using a “named nurse” model To devise a seamless transition from shared care to HHD; To introduce a learning program for both patients and nursing staff To increase patient choice by offering flexible dialysis times	Survey and quasi-experimental	145 dialysis patients	Descriptive statistics	Shared decision-making; individualized approach; staff training	After the program, patients were able to choose more convenient HD times and the waiting time for HHD reduced
Chanouzas D, Ng K.P, Fallouh B and Baharani J (2012) <sup>[30]</sup>	To study the influence of personal attributes on the selection of dialysis modality	Survey questionnaires	242 predialysis patients in the UK	Descriptive statistics	Family influence, predialysis education; emotional needs	Patients who had chosen PD scored some factors significantly higher than HD: written information, fitting with lifestyle, and family home/work. Patients who chose HD scored the past medical history factor higher. 63% felt that their chosen modality was medically influenced

HD: Hemodialysis, RRT: Renal replacement therapy, HHD: Home HD, ESRD: End-stage renal disease, CKD: Chronic kidney disease, PDE: Pre-dialysis education, PD: Peritoneal dialysis

of the disease and found a varying degree of results. Other studies also assessed patients’ involvement in the selection of modality treatment. These studies found the decision-making process to be rather complex.<sup>[5,6,30]</sup> The decision-making process could be dictated by several factors such as doctors’ advice, family involvement, and emotional distress.

Furthermore, in some situations, the decision-making can be clinically driven, while in others, it can be patient-centered or a combination of both.<sup>[34]</sup> Eight of the studies showed that the involvement of patients in the decision-making was critical.

Given the complexity of the decision-making process, three studies advocating for the shared decision-making

model stated that it should not be left alone to either the clinical staff or the patient. According to the findings of Combes *et al.*, higher education is not a critical attribute for decision-making, although it is an important driver for information seeking.<sup>[31]</sup> Instead, Combes *et al.* called for a better understanding of patients' decision-making preferences.<sup>[31]</sup> Therefore, the decision-making process should be individualized just like the development of PDE programs. This view was shared by Drukker *et al.*, underscoring the fact that the decision-making around dialysis modality was largely individual taking into consideration several factors such as "the patient's lifestyle, the influence of their family and doctors, written information, and other demographic factors."<sup>[13]</sup> In addition, Combes *et al.* reported that the case for individualizing the decision-making process is also because the process needs to be culturally sensitive taking into consideration the values, lifestyle, and preferences of the patients.<sup>[31]</sup>

## Discussion

The purpose of the review was to respond to the research question as to what is the decisions making process in the selection of home haemodialysis treatment for adult patients with End-Stage Kidney Disease. Three themes were identified and this include patient information needs, dialysis education, and decision-making preferences. These themes are in line with the findings of other studies calling for a holistic approach toward meeting the information needs of patients.

### Addressing patient information needs

Modality decision-making can be "an intellectually and emotionally demanding process."<sup>[7]</sup> Patients' involvement in the decision-making process of making a modality choice is paramount. However, Combes *et al.* has shown that this is not a straightforward process but a complex one and can vary according to several factors.<sup>[31]</sup> Preference for seeking information does not translate to the preference for autonomous decision-making. Younger age, being a female, marital status, higher autonomy tendency, and white ethnicity background were strong indicators of the type of patients that would have a strong preference for decision-making. This goes to show that not every patient would like to be involved in the decision-making process. As Combes *et al.* stated that some patients would passively delegate the task to their health-care professionals.<sup>[31]</sup> However, what is not clear from Combes *et al.* study is whether the patient's preference would have changed if they were offered to take part in a shared decision-making process.<sup>[31]</sup>

Another study found that patients' preferences for involvement in decision-making improved significantly after undergoing training.<sup>[33]</sup> After a period of shared care with the help of a dedicated nurse, more than 50% of the patients were able to move to some form of self-care

modality choice, while more than 25% selected HHD as modality choice.<sup>[24]</sup> This outcome was supported by another study where it was observed that the use of modality education will increase patient's preference and ability to get involved in shared decision-making, which could boost the uptake of home therapies including HHD.<sup>[24]</sup> Nevertheless, it has been argued that the implementation of the shared decision-making process can be challenging in clinical practice given the complexity of deciding which could be moderated by several known and unknown factors.<sup>[37]</sup> In addition, Winterbottom *et al.* noted that these factors could range from "the timeframe, level of education, sociocultural background, and advice from clinicians."<sup>[38]</sup> Sociocultural factors also play a role in patient's preferences for decision-making.

### Extending dialysis education

Studies are increasingly finding that dialysis education should not stop at the predialysis phase.<sup>[5]</sup> Simple and comprehensible predialysis education has been reported to improve patients' choices of home dialysis, especially from centers with well-established home dialysis program.<sup>[39]</sup> Adult patients might not select HHD treatment at the initial stage, but with continuous education and training, the patients can transition into HHD treatment after building their confidence. Planning for dialysis should preferably start when the patient's CKD is at Stage 4 in preparation for Stage 5 ESRD.<sup>[29]</sup> At Stage 4, the patient should have received ample information to be able to decide on the various options on offer for RRT. This is because when patients progress to ESRD, the condition does have a significant impact on their lifestyles, and they need to know the various treatments and options on offer to live reasonably well for the rest of their lives. For this reason, a call for early education of patients to enable them to make informed decisions has been recommended.<sup>[5]</sup> In another study, Davies and Davenport argue that allowing patients to incorporate their personal preferences into all the information provided is a good decision-making method to help the patient reach a decision.<sup>[40]</sup> This view is supported by another study, which found that patients do acquire information in more than one way apart from PDE.<sup>[32]</sup> In addition, one study went further to warn against patient education that largely focuses on providing information alone. The author argues that the availability of information alone will not necessarily enable the patients to make better and more informed choices.

### Identifying decision-making preferences

The literature review revealed that patients do have different preferences for deciding. Therefore, it is essential to assess patient's decision-making preference, whether the preference is for shared decision-making or independent decision-making (IDM). Two types of decision-makers are "autonomous decision-makers" and "delegators."<sup>[31]</sup> View and experience on the involvement of the patient in making



the final decision are very important.<sup>[30]</sup> The review found some patients can make their own decision on the basis of the information provided, while others will want a shared decision with their doctors and family members.<sup>[30,41,42]</sup> This supports another study that reveals that predialysis education alone is not enough for every patient to decide based on that.<sup>[43]</sup>

This finding also echoed in another study which found that quite often information-seeking preference does not necessarily translate to decision-making action.<sup>[44,45]</sup> Moreover, patient's decision-making preferences are not static but dynamic. At the starting point, some patients would prefer supervised care of HD treatment probably in an in-center facility than at home, while IDM patients might be comfortable with self-care home therapy with little to no supervision. During the treatment, patients who initially preferred supervised care of HD treatment could change to self-care HHD after some exposure to more information and better dialysis education and training.<sup>[46-48]</sup>

### Implications for research

The review found some gaps in knowledge that need to be filled to increase our understanding of the decision-making process regarding HHD. A key gap identified is the lack of a specific study focusing on the views and experience of carers and family members of patients opting for HHD. Most of the studies are largely focused on patients, nurses, and doctors. If carers and family members are included, they are only considered marginally but not as a key group. It will be important to know the experiences of this group as it will also bring further insights into the design and delivery of RRT/OE to facilitate the decision-making process and further enhance the experience of HHD for adult patients with ESRD.

### Conclusion

The literature review aimed to determine the decision-making process regarding the selection of HHD as the modality of choice for adult patients with ESRD in the UK. The low uptake of HHD is well documented in the UK although dialysis modality is both clinical and cost-effective for both patients and hospitals. Research has focused on the barriers and facilitators of home dialysis to understand the factors withholding the uptake of home dialysis. The review critically examined eight studies and made three main findings. It was found that the decision-making process is not simple and straightforward but a complex and challenging one as well as unique.

### Acknowledgement

Our sincere gratitude goes to all the University of Wolverhampton library staff who supported the literature search for this study.

### Financial support and sponsorship

Nil.

### Conflicts of interest

There are no conflicts of interest.

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## Appendix

Appendix 1: Critical appraisal tools used for qualitative articles								
Qualitative articles	Combes G, Sein K and Allen K (2017) <sup>[36]</sup>	Combes G; Sein K, Allen K, Girling A and Lilford R (2015) <sup>[31]</sup>	Jayanti A, Neuvonen M, Wearden A, Morris J, Foden P, Brenchley P, Mitra S (2015) <sup>[33]</sup>	McCarthy K, Sturt J and Adams A (2015) <sup>[15]</sup>	Winterbottom A, Hope J (2013) <sup>[32]</sup>	Bekker HL, Conner M and Mooney A (2014) <sup>[38]</sup>	Appleby S (2013) <sup>[26]</sup>	Chanouzas D, Ng K.P, Fallouh B and Baharani J (2012) <sup>[30]</sup>
Was there a clear statement of the aims of the research?	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Is a qualitative methodology appropriate?	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Was the research design appropriate to address the aims of the research?	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Was the recruitment strategy appropriate to the aims of the research?	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Was the data collected in a way that addressed the research issue?	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Has the relationship between researcher and participants been adequately considered?	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Have ethical issues been taken into consideration?	Yes, ethical consideration was clearly stated	Yes, ethical consideration was clearly stated	Yes, ethical consideration was clearly stated	Yes, ethical consideration was clearly stated	Yes, ethical consideration was clearly stated	Yes, ethical consideration was clearly stated	Yes, ethical consideration was clearly stated	Yes
Was the data analysis sufficiently rigorous?	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Is there a clear statement of findings?	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
How valuable is the research?	The researcher identified areas needing more research	The researcher identified an area of limitation	Very valuable	The researcher identified areas needing more research	The researcher identified an area of limitation	Very valuable	The researcher identified areas needing more research	The researcher identified an area of limitation