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ORIGINAL ARTICLE

Non-medical barriers reported by nephrologists when providing renal replacement therapy or comprehensive conservative management to end-stage kidney disease patients: a systematic review

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ABSTRACT

Background. Large international differences exist in access to renal replacement therapy (RRT) modalities and comprehensive conservative management (CCM) for patients with end-stage kidney disease (ESKD), suggesting that some patients are not receiving the most appropriate treatment. Previous studies mainly focused on barriers reported by patients or medical barriers (e.g. comorbidities) reported by nephrologists. An overview of the non-medical barriers reported by nephrologists when providing the most appropriate form of RRT (other than conventional in-centre haemodialysis) or CCM is lacking.

Methods. We searched in EMBASE and PubMed for original articles with a cross-sectional design (surveys, interviews or focus groups) published between January 2010 and September 2018. We included studies in which nephrologists reported barriers when providing RRT or CCM to adult patients with ESKD. We used the barriers and facilitators survey by Peters *et al.* [*Ruimte Voor Verandering? Knelpunten en Mogelijkheden Voor Verbeteringen in de Patiëntenzorg*. Nijmegen: Afdeling Kwaliteit van zorg (WOK), 2003] as preliminary framework to create our own model and performed meta-ethnographic analysis of non-medical barriers in text, tables and figures.

Results. Of the 5973 articles screened, 16 articles were included using surveys ($n = 10$), interviews ($n = 5$) and focus groups ($n = 1$). We categorized the barriers into three levels: patient level (e.g. attitude, role perception, motivation, knowledge and socio-cultural background), level of the healthcare professional (e.g. fears and concerns, working style, communication skills) and level of the healthcare system (e.g. financial barriers, supportive staff and practice organization).

Conclusions. Our systematic review has identified a number of modifiable, non-medical barriers that could be targeted by, for example, education and optimizing financing structure to improve access to RRT modalities and CCM.

Keywords: CAPD, chronic haemodialysis, ESKD, kidney transplantation, peritoneal dialysis

INTRODUCTION

Large international differences exist in the access to renal replacement therapy (RRT) modalities and comprehensive conservative management (CCM) for patients with end-stage kidney disease (ESKD) [1]. In 2016, the number of prevalent patients with ESKD treated by dialysis varied between 112 per million population (p.m.p.) in Bangladesh and 3251 p.m.p. in Taiwan [2]. Most patients received conventional thrice weekly in-centre haemodialysis as in many countries home-based dialysis modalities [home haemodialysis (HHD) and peritoneal dialysis (PD)] are not available. The number of patients living with a functioning kidney transplant varied between 25 p.m.p. in South Africa and 693 p.m.p. in Portugal [2]. Exact numbers on the prevalence of CCM are lacking. In a survey in 2010 in 11 European countries, nephrologists estimated that ∼15% of their patients with ESKD received CCM [3].

Currently not all patients with ESKD receive the most appropriate treatment with respect to clinical and psychosocial

outcomes and patient preference [4]. Kidney transplantation (Tx) is associated with the greatest longevity, highest quality of life and lowest costs [5–7]. However, several patients are unsuitable for this treatment due to, for example medical contraindications. In this case, other forms of RRT or CCM could be more appropriate [8–10].

Various barriers have been described for specific RRT modalities or CCM. Many studies have described barriers experienced by patients such as demographic barriers, medical barriers, psychosocial barriers and socioeconomic barriers [11–13]. In contrast, a few studies have described barriers experienced by nephrologists. These studies usually focused on medical barriers such as comorbidity and medical contraindications [14–17].

An overview of non-medical barriers experienced by nephrologists is lacking. Such an overview may identify modifiable barriers that could be targeted by interventions to improve access to all RRT modalities and CCM. If access is improved, then more patients may receive the treatment that is most appropriate for them.

The aim of this systematic review was to provide an overview of non-medical barriers experienced by nephrologists when providing the most appropriate form of RRT or CCM to adults with ESKD.

MATERIALS AND METHODS

Search strategy

We systematically searched EMBASE and Medline via Ovid. Medical Subject Headings (MeSH) terms, text words and synonyms for nephrologist were combined with terms relating to RRT (haemodialysis, PD, Tx) and CCM and synonyms for barriers or subheadings related to barriers (e.g. resource allocation, ethics, organization and administration). References in all included articles were reviewed but this did not result in extra articles to be included. A detailed search strategy is provided in the Supplementary Methods.

Eligibility criteria

We included original peer-reviewed articles published between January 2010 and September 2018. We restricted to this time period as barriers may have changed over time, and to keep the number of abstracts manageable. We included studies with a quantitative or qualitative cross-sectional study design (survey, interviews or focus groups). The article needed to describe non-medical barriers (outcome) reported by nephrologists (population) when providing other than conventional in-centre haemodialysis [thus non-conventional haemodialysis (NCHD), HHD or PD], Tx or CCM to adult patients with ESKD.

We defined non-medical barriers as barriers not related to medical contraindications or comorbidity. The barriers must be experienced after referral of the patient to a nephrologist and before initiation of RRT, therefore excluding problems with referral to nephrology care or problems with the treatment itself (e.g. ultrafiltration failure or transplant rejection).

To avoid misinterpretation of the qualitative research findings, we only included articles in English.

Studies on barriers for nephrologists and other healthcare professionals (e.g. nurses) or patients were only included if barriers for nephrologists were described separately. If the study failed to meet inclusion criteria, then we noted the primary reason for exclusion (in order of priority: publication type, study design, population or outcome).

Study selection

Duplicates were removed. Two authors (R.W.d.J. and V.S.S.) independently reviewed all retrieved abstracts using Rayyan software [18]. Disagreement between the reviewers was resolved by discussion. Any article that was judged relevant on the basis of its title or abstract was retrieved in full-text form. Full texts were reviewed by the first author (R.W.d.J.) to assess eligibility for this study. In case of doubt, the article was discussed between R.W.d.J. and V.S.S.

Data extraction and data synthesis

The following data were collected from the included articles by one author (R.W.d.J.) using a standardized data extraction form: name of first author, journal, year of publication, country where research was undertaken, study method (survey, focus group or interviews), treatments discussed, sample size, response rate for surveys, any information on age and/or gender of the participants, qualitative methodology and analysis technique (qualitative studies) or question type (e.g. dichotomous, categorical) for quantitative studies.

One author (R.W.d.J.) repeatedly read the results reported in both qualitative and quantitative articles (in text, tables and figures) to extract barriers (defined as 'circumstance or obstacle that may prevent the provision of RRT or CCM'). As we did not use the original transcripts of the qualitative studies, meta-ethnography was used to identify barriers [19].

Due to heterogeneity in questions and answers, the option to perform a meta-analysis of the quantitative data was not appropriate. We therefore decided to analyse the results from quantitative studies in a qualitative manner. Thus results from quantitative articles were coded in the same way and were collected regardless of the degree of importance of the barrier in the original article.

The barriers were coded using a coding frame based on the barriers and facilitators assessment instrument (*a priori* framework) [20]. Among many other models for implementation, this framework consists of structural, organizational, individual provider and patient, and innovation-related barriers [21]. Developed after literature study and consensus procedure, this instrument originally assesses barriers for implementation of preventive healthcare. We merged two categories to create a model with three categories: barriers on the patient level, healthcare professional level and healthcare system level. Next we used the factors from the literature review by Peters *et al.* [22] and our own data to create subcategories (Figure 1). The categorization of the data was repeatedly deliberated between R.W.d.J. and V.S.S. to refine the model. During this process, a minority of the data were recoded or placed in another subcategory.

Quality assessment

One author (R.W.d.J.) assessed the study quality for the quantitative and qualitative studies, using, respectively, the method of Greenhalgh *et al.* and the Critical Appraisal Skills Programme Qualitative checklist [23, 24].

FIGURE 1: Modification of barriers and facilitators instrument into our model. Subcategories added to the model are marked with an asterisk. Several characteristics from the model of Peters *et al.* [22] were not used. Characteristics of patient not used: age, gender, marital status, health status, new/known patient, number of patient contacts, previous experiences, responsibility. Characteristics of healthcare professional not used: age, experience, gender, involvement, knowledge of medical background, lack of time, quality of doctor–patient relationship, quality of screening. Characteristics of the context not used: attention from the media, information and administration systems, laws/regulations, opening hours of practice, practice building, practice population, size of practice, type of practice/healthcare organization. Characteristics of innovation not used: applicability, attractiveness, clear definition, compatibility, complexity, cost–effectiveness, didactive benefit, discomfort for patient, image, observability, specificity/flexibility, time investment, tryability, visible results.

RESULTS

Included studies

Of the 5973 abstracts screened, 77 articles were reviewed in full-text format. Sixteen articles met the inclusion criteria [25–40] (Figure 2).

Table 1 presents the characteristics of the included articles. Most studies were conducted in developed countries and two surveys were conducted internationally [25, 32]. Methodology used consisted of surveys ($n = 10$), interviews ($n = 5$) and focus groups ($n = 1$). The studies provided information on non-medical barriers for NCHD ($n = 2$), HHD ($n = 2$), PD ($n = 4$), both PD and HHD ($n = 3$), Tx ($n = 2$) and CCM ($n = 3$). Sample sizes varied from 16 to 286 nephrologists. Most participants, from studies providing information about gender ($n = 9$), were male. Various qualitative methodologies and

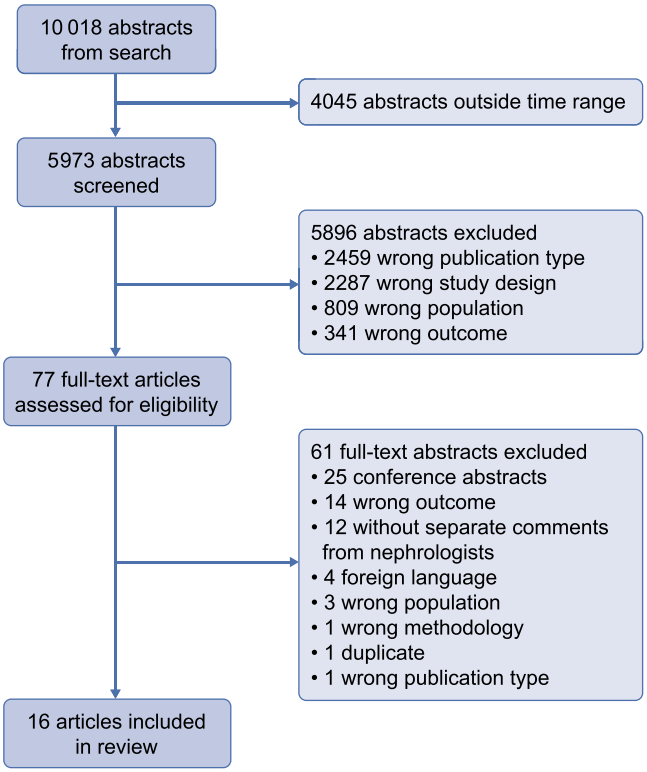

FIGURE 2: PRISMA (Preferred Reporting Items for Systematic Reviews and Meta-Analyses) flow diagram.

analyses and questions about barriers (e.g. yes–no, scale, top-5) were used. Response rate on surveys varied between 2.7% and 80.8%.

Several studies or individual researchers were (partly) supported by a grant from a governmental institute, a dialysis provider or a pharmaceutical company [26, 30, 33, 35–37, 40].

Quality assessment of included studies

Quality assessments of the included studies are provided as supplementary material (Tables S1 and S2). Quality of most studies was moderate to good. Most qualitative studies contained sufficient information on the study design, data collection and data analysis. Information on the relationship between the researcher and participants and ethical issues (e.g. information to participants, confidentiality) was not adequately reported by the majority of included studies. Most quantitative studies contained a clear research aim often related to opinion or attitude of nephrologists. Opinions can be investigated not only with surveys (quantitatively) but also with interviews (qualitatively). Most studies used self-designed surveys with mainly closed-ended questions. These surveys were usually pretested on potential participants but were not validated. Not all original surveys could be obtained, which made it impossible to assess formulation and content of the questions. In most studies, complete and clear results were presented.

Barriers to CCM and different RRT modalities

An overview of all non-medical barriers as experienced by the nephrologists is presented in Table 2 separated for NCHD, HHD, PD, transplantation and CCM. Barriers for HHD, PD and CCM were described both in quantitative and qualitative studies, barriers for NCHD were only described in quantitative studies and barriers for transplantation were only described in qualitative studies.

Table 3 contains all themes, description and illustrative quotations (indicated by Q1 till Q26 in the text below).

Barriers on the patient level. Patient's attitude, role perception and motivation could limit the care provision by attachment to professionals and concurrent lack of motivation to take responsibility for one's own treatment (Q1). This attitude could result from a lack of knowledge and limited health literacy or from concerns about particular aspects of the treatment (e.g. surgery, immunosuppressive medication, alarms of the dialysis machine) (Q2).

Characteristics of the socio-cultural background (e.g. distrust, religious or language barriers) often challenged nephrologists when informing patients about the different treatment options for ESKD (Q3–4). The provision of home dialysis modalities was limited by unsuitable living circumstances and distant locality (Q5–6). Patients often had to invest time and financial resources to apply for home dialysis or transplantation. They did not always have caregivers or social support to pursue home dialysis or transplantation (Q7). Finally, nephrologists reported patient adherence and poor hygiene as barriers for home dialysis and transplantation (Q8).

Barriers on the level of the healthcare professional. Nephrologists recognized that their own attitude, role perception and motivation influenced the uptake of NCHD, PD, transplantation and CCM (Q9–10). Nephrologists also reported lack of knowledge, fears and concerns, in particular about home dialysis and CCM (Q11–12). Selection of patients for CCM was hampered by nephrologists' uncertainty about eligibility. In addition, nephrologists reported lack of skills and confidence to communicate with patients about RRT and CCM. Lastly, nephrologists were sometimes frustrated by the lack of uniformity in working style [e.g. following guidelines and dealing with risks (Q13–14)].

Barriers on the level of the healthcare system. Financial barriers were reported for all RRT modalities and CCM. Additional costs for water and electricity, home adaptation and assistance with home dialysis were often not reimbursed (Q16), and some nephrologists suggested that private doctors may not promote pre-emptive transplantation as they would lose income when a patient was not treated with dialysis first (Q15). Lack of skilled staff (nephrologists, nurses, surgeons, transplant coordinators) was reported as a barrier for all dialysis modalities and transplantation. Several nephrologists reported competition between treatment modalities as conventional haemodialysis was widely available and different forms of non-conventional dialysis had to share financial measure and patient interest (Q17–18). In addition, nephrologists experienced various external pressures: other nephrologists and other specialists were not in favour of certain treatments, pressure from the patient's family, and several transplant nephrologists mentioned the need to protect their centre's reputation (Q23–24).

Table 1. Characteristics of included articles

References	Country	Methodology	Modalities discussed	No. of adult nephrologists[a]	Gender	Age	Qualitative methodology and qualitative data analysis as reported in the original article[b]
Qualitative studies							
Combes *et al.* [26]	UK	Interview	HHD, PD	29	NR	NR	NR
Ghahramani *et al.* [29]	USA	Focus group	Kidney transplantation	16	60% male	Median age 58 years	NR Thematic content analysis
Grubbs *et al.* [30]	UK, USA	Interview	CCM	59	76% male	≤45 years 58% 46–65 years 34% ≥66 years 9%	Narrative and thematic analysis Constant comparative analysis
Hanson *et al.* [31]	Australia, New Zealand	Interview	Living kidney donor transplantation	41	80% male	30–39 years 15% 40–49 years 37% 50–59 years 32% >60 years 7%	Grounded theory Thematic analysis
Ladin *et al.* [33]	USA	Interview	CCM	35	80% male	NR	NR Thematic and narrative analysis
Tong *et al.* [38]	Italy, Portugal, France, Germany, Sweden, Argentina	Interview	HHD	28	69% male[c]	20–29 years 2% 30–39 years 14% 40–49 years 41% 50–59 years 31% 60–69 years 12%[c]	Grounded theory Thematic analysis

References	Country	Methodology	Modalities discussed	N of adult nephrologists[a]	Gender	Age	Response rate	Barriers
Quantitative studies								
Allen *et al.* [25]	International[d]	Survey	NCHD[e]	259	NR	NR	15.6%	Indicate per statement ($n = 4$) if barrier or not (dichotomous) Provide other barriers (open question)
Dahlan *et al.* [27]	Saudi Arabia	Survey	PD	124	90% male	30–39 years 14.5% 40–49 years 33.0% 50–59 years 39.5% >60 years 3.0%	62.9%	Indicate per statement ($n = 10$) if major role or minor role (dichotomous)
Desmet *et al.* [28]	Belgium	Survey	PD	97	NR	NR	80.8%	Select 3 most important of 12 statements
Jayanti *et al.* [32]	International[f]	Survey	HHD	272	NR	35–44 years 22.4% 45–54 years 35.7% 55–64 years 29%	NR	Indicate per statement ($n = 6$) if barrier or not (dichotomous)
Ludlow *et al.* [34]	Australia	Survey	HHD, PD	44	NR	NR	26%	Indicate per statement ($n = 18$) if agree/neutral/disagree (categorical)

								Provide other barriers (open question)
Parvez *et al.* [35]	USA	Survey	CCM	265	71% male	20–29 years 1.0% 30–39 years 29.7% 40–49 years 30.8% 50–59 years 19.4% 60–69 years 16.0% ≥70 years 3.4%	2.7%	Indicate per statement ($n = 8$) if (strongly) agree/neutral/(strongly) disagree (categorical)
Savla *et al.* [36]	Bangladesh	Survey	PD	43	NR	NR	NR	Select five most important of unknown number of statements
Thumfart *et al.* [37]	Germany	Survey	NCHD[d]	286	NR	<45 years 23% 45–54 years 44% >55 years 33%	13.9%	Indicate per statement ($n = 3$) if agree/uncertain/disagree (categorical) Indicate per statement ($n = 4$) if barrier or not (dichotomous)
Walker and Marshall [39]	New Zealand	Survey	PD	30	NR	NR	48%	Indicate importance per statement ($n = 8$) on 3-point scale (categorical)
Walker *et al.* [40]	New Zealand	Survey	HHD PD	49	NR	NR	70%	Indicate importance per factor ($n = 15$) on 7-point scale (categorical)

N/A, not applicable; NR, not reported.
[a]Trainees, paediatric nephrologists, etc., excluded.
[b]See Bristowe *et al.* for more information on qualitative research theories in nephrology [92].
[c]Gender and age distribution of all participants (including nurses).
[d]Respondents from USA (26.7%), Europe (21.5%), South America (12.9%), Canada (11.9%), Asia (10.9%), Africa/Middle East (10%) and Australia/New Zealand (6.1%).
[e]Non-conventional haemodialysis includes nocturnal haemodialysis (NHD), short daily haemodialysis (SDHD), long, thrice weekly conventional haemodialysis. NHD and SDHD included both home and in-centre HD.
[f]Respondents from Europe (61.4%), Middle East (9.6%), Asia (8.8%), North America (7.7%), South and Central America (5.9%), Oceania (3.7%) and Africa (2.9%).

Table 2. Non-medical barriers to particular treatment modalities as experienced by nephrologists assessed by quantitative and qualitative studies

	Quantitative studies					Qualitative studies				
Barriers	NCHD	HHD	PD	Tx	CCM	NCHD	HHD	PD	Tx	CCM
Barriers on the patient level										
Attitude, role perception, motivation	Allen *et al.* [25]	Ludlow *et al.* [34]	Dahlan *et al.* [27], Desmet *et al.* [28], Ludlow *et al.* [34]	No studies available		No studies available	Tong *et al.* [38]		Ghahramani *et al.* [29], Hanson *et al.* [31]	
Knowledge			Walker and Marshall [39]						Ghahramani *et al.* [29], Hanson *et al.* [31]	Grubbs *et al.* [30], Ladin *et al.* [33]
Fears and concerns							Tong *et al.* [38]		Ghahramani *et al.* [29]	
Socio-cultural background		Ludlow *et al.* [34], Walker *et al.* [40]	Ludlow *et al.* [34], Walker *et al.* [40]				Tong *et al.* [38]		Ghahramani *et al.* [29], Hanson *et al.* [31]	Grubbs *et al.* [30], Ladin *et al.* [33]
Unsuitable living circumstances		Ludlow *et al.* [34], Walker *et al.* [40]	Ludlow *et al.* [34], Walker and Marshall [39], Walker *et al.* [40]				Tong *et al.* [38]			
Patient effort and investments	Allen *et al.* [25]	Ludlow *et al.* [34]	Ludlow *et al.* [34]						Ghahramani *et al.* [29], Hanson *et al.* [31]	
Social support		Walker *et al.* [40]	Savla *et al.* [36], Walker and Marshall [39], Walker *et al.* [40]						Ghahramani *et al.* [29], Hanson *et al.* [31]	Ladin *et al.* [33]
Adherence and hygiene		Walker *et al.* [40]	Savla *et al.* [36], Walker *et al.* [40]						Hanson *et al.* [31]	
Barriers on the level of the healthcare professional										
Attitude, role perception, motivation	Thumfart *et al.* [37]		Dahlan *et al.* [27], Desmet *et al.* [28]	No studies available	Parvez *et al.* [35]	No studies available			Hanson *et al.* [31]	Grubbs *et al.* [30], Ladin *et al.* [33]
Knowledge and expertise	Allen *et al.* [25], Thumfart *et al.* [37]	Ludlow *et al.* [34]	Dahlan *et al.* [27], Desmet *et al.* [28], Ludlow *et al.* [34]				Combes *et al.* [26]	Combes *et al.* [26]		Grubbs *et al.* [30], Ladin *et al.* [33]
Fears and concerns			Dahlan *et al.* [27], Desmet *et al.* [28]		Parvez *et al.* [35]		Tong *et al.* [38]			Ladin *et al.* [33]
Working style							Tong *et al.* [38]		Hanson *et al.* [31]	Ladin *et al.* [33]
Difficulty in selecting patients					Parvez *et al.* [35]					
Communication skills							Combes *et al.* [26]	Combes *et al.* [26]		Grubbs *et al.* [30]

Barriers on the level of the healthcare system										
Financial barriers	Allen *et al.* [25], Thumfart *et al.* [37]	Jayanti *et al.* [32], Ludlow *et al.* [34]	Ludlow *et al.* [34], Savla *et al.* [36]	No studies available		No studies available	Tong *et al.* [38]		Hanson *et al.* [31]	Grubbs *et al.* [30], Ladin *et al.* [33]
Supporting staff	Thumfart *et al.* [37]	Jayanti *et al.* [32], Ludlow *et al.* [34]	Dahlan *et al.* [27], Desmet *et al.* [28], Ludlow *et al.* [34], Savla *et al.* [36]						Hanson *et al.* [31]	
Competition with other treatment modalities		Jayanti *et al.* [32]	Desmet *et al.* [28]				Tong *et al.* [38]			
Organizational culture	Thumfart *et al.* [37]	Jayanti *et al.* [32]							Hanson *et al.* [31]	Ladin *et al.* [33]
Facilities	Allen *et al.* [25]	Jayanti *et al.* [32], Ludlow *et al.* [34]	Dahlan *et al.* [27], Ludlow *et al.* [34]				Combes *et al.* [26], Tong *et al.* [38]	Combes *et al.* [26]	Hanson *et al.* [31]	
Practice organization		Ludlow *et al.* [34]	Desmet *et al.* [28], Ludlow *et al.* [34]		Parvez *et al.* [35]		Combes *et al.* [26]	Combes *et al.* [26]	Hanson *et al.* [31]	Ladin *et al.* [33]
External pressure									Hanson *et al.* [31]	Grubbs *et al.* [30], Ladin *et al.* [33]
Scientific evidence, prognostic tools	Allen *et al.* [25]	Jayanti *et al.* [32], Ludlow *et al.* [34]			Parvez *et al.* [35]					Grubbs *et al.* [30], Ladin *et al.* [33]
Pre-dialysis education		Ludlow *et al.* [34]	Dahlan *et al.* [27], Ludlow *et al.* [34]				Combes *et al.* [26], Tong *et al.* [38]	Combes *et al.* [26]	Ghahramani *et al.* [29]	

Table 3. Themes, description and illustrative quotes

Subthemes	Description	Quotes
Barriers on the patient level		
Attitude, role perception, motivation	Patients are attached to professional care, do not want to have responsibility or simply refuse particular treatments	(Q1) The Portuguese don't like the responsibilities. I think the majority of patients want others to care [for them] [38].—Portuguese nephrologist on HHD
Knowledge	Patients have misperceptions about treatments or limited health literacy	
Fears and concerns	Patients are afraid of several aspects of the treatment such as undergoing surgery, medication side effects or the dialysis machine	(Q2) The patients that are very afraid of everything in the dialysis room, when an alarm of the machine calls, they get very, very scared so I think that at home they will be very scared, because they would [not] feel safe [38].—Italian nephrologist on HHD
Socio-cultural background	Including language barriers religious beliefs, distrust in healthcare professionals, cultural barriers, low socioeconomic level and poor education	(Q3) There are people for instance that practice medicine in a hospital that has been in existence from the 1800s and up until the late 1960s or 1970s, people of African American heritage were not very trusting for a good reason. It's not that way anymore, but there are people still alive today that remember the 60s and find it very difficult to give their trust in a physician that comes out of that system [30].—American nephrologist on CCM (Q4) I think language barriers do play a role as well. It's a lot easier to convince someone of the benefits of live donor transplants if you can have a full frame conversation with them. . . It's very hard to have a delicate conversation through an interpreter [31].—Nephrologist on transplantation
Unsuitable living circumstances	Includes inadequate housing, insufficient supply of power and/or water, distant location	(Q5) 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. . . maybe the costs of the electricity or hydraulics [38].—Italian nephrologist on HHD (Q6) It's very difficult to implement when you have limitations. Because you need the thing that. . . a lot of regions in Argentina don't have. . . good water [38].—Argentinian nephrologist on HHD
Patient effort and investments	Patients have to invest financial measure, time and efforts for training for home dialysis or travelling to the hospital	
Social support	Patients' lack of support to pursue transplantation or perform home dialysis	(Q7) If they're a professional type person, a good advocate for themselves, then they'll go out and get a donor. Whereas if they haven't gone to university or haven't finished high school then they don't have a social network around them, then actually finding a donor is quite difficult [31].—Nephrologist on transplantation
Adherence and hygiene	Patients may be non-adherent or have poor personal hygiene	(Q8) If you think someone's going to be noncompliant but you're not really sure. . . with a deceased donor you might be a bit more likely to just give it a go. Whereas if it's a live donor, you think about the consequences for their relationship if they don't take the pills and they lose their kidneys [31].—Nephrologist on transplantation
Barriers on the level of the healthcare professional		
Attitude, role perception, motivation	Nephrologists' perception about their role (healing patients, protecting kidney donors), personal opinion on survival versus quality of life, lack of motivation for non-conventional treatments	(Q9) I suspect some of it is—well, in my case it's about a sense of failure of being unable to help, to heal, and to do the job that I was trained to do to make someone better [30].—English nephrologist on CCM (Q10) I know of a doctor who feels people shouldn't be transplanted till they have been on dialysis for a period because when they get their transplant they'll be more compliant [31].—Nephrologist on transplantation
Knowledge and expertise	Nephrologists received little or no training about non-conventional treatments, nephrologists reported a lack of expertise	(Q11) None [time spent on training about home therapies]. I very rarely get involved with PD peritonitis but that's about it, nothing else and nothing on home haemodialysis [26].—English nephrologist on HHD and PD
Fears and concerns	Nephrologists are afraid of complications of home dialysis	(Q12) I don't think that security of dialysis at home is the same as in the centres. In the centres we've got a lot of protocols. . . They are all alone [38].—French nephrologist on HHD
Working style	Nephrologists report differences in individual ways to handle situations (strictly following regulations, dealing with risks)	(Q13) Some people are very regimented by guidelines, and not necessarily personal patient issues. Sometimes, the longer you've been practicing, the more likely you are to consider you can probably get

Continued

Table 3. Continued

Subthemes	Description	Quotes
		across a problem as opposed to being more junior; you're less likely to take a risk [31].—Nephrologist on transplantation (Q14) I wouldn't say that I present [options] neutrally for them to make a decision. . . because my own bias is that the [patients] that I'm presenting [dialysis] to are generally the ones that I think it would be beneficial [33].—American nephrologist on CCM
Difficulty in selecting patients	Nephrologists have problems with selecting suitable patients for CCM	
Communication skills	Nephrologists have limited skills or lack confidence to discuss treatments	
Barriers on the level of the healthcare system		
Financial barriers	Financial incentive to conventional haemodialysis, lack of funding for home adaptation, insufficient reimbursement, cost of supplies	(Q15) Every time they lose a dialysis patient. . . they lose income [31].—Nephrologist on transplantation (Q16) For home haemodialysis in countries like Argentina, Chile, Uruguay, you have financial and economic limits. It's very expensive. The very big cost is around the machine, the dialysis machine and the water treatment (. . .) [38].—Argentinian nephrologist on HHD
Supporting staff	Lack of adequately trained nurses and surgeons	
Competition with other treatment modalities	Financial measures have to be divided between several treatment modalities, conventional centre haemodialysis is widely available	(Q17) We have an in clinic environment more or less every 10 kilometres in capital cities and every 30 kilometres in rural areas. . . why should you buy additional equipment to comfort people to get treatment at home?. . . there is just simply no need to do it at home. . . [38].—German nephrologist on HHD (Q18) We had a priority to set up extended dialysis with a nightshift dialysis. . . because. . . the patients wanted that. So that's what we've basically done the last two months and that means also that half of our clinics are not—I mean right now they're more recruiting for nocturnal dialysis rather than offering them additional options with a home haemodialysis (. . .) [38].—German nephrologist on HHD
Organizational culture	Strict rules and procedures may limit uptake whereas supportive culture, cooperation with colleagues and enthusiasm may stimulate uptake	(Q19) The transplant team have a meeting, we're not invited. They make their decisions and we need to live with them. If we disagree, we either live with it or take our business elsewhere. It usually spurs them on to think harder [31].—Nephrologist on transplantation
Facilities	Lack of space, dialysis supplies and training facilities	(Q20) You need to have also good logistics and structure for [home haemodialysis]. . . [38].—Swedish nephrologist on HHD
Practice organization	Insufficient coordination of care, poor communication between dialysis and transplant centres and availability of other services (e.g. psychological support) may limit uptake	(Q21) There's no coordination as a a-stop shop, which there really should be if you're asking people to travel 4, 5, 6 hours down to the city to see them, which they do, and then make them come back repeatedly for different tests [31].—Nephrologist on transplantation (Q22) [Conservative management] does take some collaboration between us and primary doctors and other supports. . . We as a nephrology division can't do [conservative management] on our own. . . without any of those additional services to help out [33].—American nephrologist on CCM
External pressure	Decision making is influenced by opinions from other nephrologists, other medical specialists or the family of the patient and transplant nephrologists needed to protect their centres interests	(Q23). . . If a cardiac surgeon does an open heart [surgery] in an 85-year-old and the patient develops renal failure tomorrow how can I come and say, 'I don't want to dialyze this patient because she's 85,' or something like that. So, what am I supposed to do at that time [30]?—American nephrologist on CCM (Q24) There is a strong motivation for transplanting hospitals to protect their credibility and maintain their performance, and to some extent this leads to gatekeeping to avoid high-risk patients [31].—Nephrologist on transplantation
Scientific evidence, prognostic tools	Lack of scientific evidence, no tools to estimate prognosis with or without dialysis	(Q25) We really don't know who's going to do well and who doesn't. So I always err on the side of—at least give them a trial, see how it goes [30].—American nephrologist on CCM
Pre-dialysis education	Insufficient pre-dialysis education due to complexity of information, lack of time and lack of staff	(Q26) I think nephrologists don't talk about it to the patients in most cases. Many patients don't know that it is a possibility [38].—Portuguese nephrologist on HHD

Three aspects of the organization of healthcare—organizational culture, facilities and practice organization—also limited the provision of RRT modalities. Strict division between dialysis and transplantation centres prevented efficient communication, knowledge transfer and involvement in each other's specialization (Q19). Lack of space, supplies and training facilities limited the uptake of non-conventional dialysis forms (Q20). Problems with the coordination of care and cooperation with other healthcare professionals limited the provision of transplantation and CCM (Q21–22).

Moreover, a perceived lack of scientific evidence and lack of prognostic tools limited the uptake of NCHD, HHD, PD and CCM (Q25). Finally, insufficient pre-dialysis education, caused by complexity of information, limited time and lack of staff, was reported as a barrier for home dialysis and transplantation (Q26).

DISCUSSION

This systematic review identified non-medical barriers experienced by nephrologists when providing different RRT modalities (other than conventional in-centre haemodialysis) or CCM to adult patients with ESKD using a modified model of barriers and facilitators [22]. We found barriers on the patient level, on the level of the nephrologist and on the level of the healthcare system for all RRT modalities and CCM. Barriers for HHD and PD largely overlapped.

The importance of these barriers probably varies by country [41]. In some countries, a treatment modality may not be available at all (e.g. HHD in several countries [42] including Hungary [43] or Donation after Circulatory Death (DCD) Tx in Poland [44]), whereas other countries would like to increase the uptake of a certain modality (e.g. Tx in Spain by using uncontrolled DCD kidney donors [45]). Barriers in initiating a treatment modality could be different from those limiting its expansion.

In the following paragraphs, we will discuss our findings and their relationship with other studies grouped by level of barriers.

Barriers on the patient level

All of the patient-related barriers as experienced by nephrologists in this study were confirmed in studies with patients.

In line with our findings (Q1), many patients reported not wanting to perform home dialysis because they did not want to take responsibility for their therapy, had low self-confidence or preferred professional care [46, 47]. Nephrologists perceived a capability willingness gap; they believed that patients were capable of several dialysis-related tasks, but assumed that patients were generally not willing to perform these tasks [48].

The provision of home dialysis was also limited by unsuitable living circumstances (Q5–6), which is confirmed for instance by Canadian patients reporting barriers for PD [46].

Moreover, we found that nephrologists were limited by the patient's lack of knowledge when providing PD, transplantation or CCM. We believe that lack of knowledge influences the provision of all RRT modalities as a substantial number of ESKD patients reported lack of knowledge and lack of information about treatment options [49–51].

Religion as a socio-cultural barrier was mainly described in studies about transplantation. Both Christian and Muslim patients reported religious beliefs against transplantation [52, 53]. Religious beliefs against organ transplantation are also seen in other religions, e.g. Buddhism [54]. Most studies on the influence of religion do not focus on CCM but on dialysis withdrawal and palliative kidney care [55, 56]. It seems that patients' modality choice is barely influenced by religious beliefs [57].

In agreement with our findings, patients reported that they needed to invest a lot of time and money to pursue home dialysis or transplantation. Training for home dialysis caused patients to miss work and the reimbursement provided was inadequate, particularly if patients required home modifications [58, 59]. Several patients from developed and developing countries reported that they were unable to receive a transplant because of healthcare access problems (such as insurance issues, no dentist, transportation problems) and financial constraints [60–62].

Finally, patients also reported being limited by a lack of social support when considering transplantation or home dialysis (Q7) [46, 63]. Lack of social support can lead to less favourable evaluation for transplantation, whereas the presence of social support can improve eligibility for home dialysis [64, 65].

Barriers on the level of the healthcare professional

Since we found much information on this subject, we believe that the attitude, role perception and motivation of the nephrologist are important barriers on the level of the healthcare professional. Nephrologists' enthusiasm about the modality has been associated with a higher uptake and nephrologists with a positive attitude tended to report fewer barriers [66, 67].

Our finding of nephrologists' lack of knowledge and expertise (Q11) is supported by results of several surveys among both recently graduated and experienced nephrologists [68–70]. Lack of knowledge may be partly caused by lack of scientific evidence (as described below as barrier on the level of healthcare system) and may result in a negative attitude towards the treatment or a difficulty in selecting patients.

Furthermore, in our study, nephrologists reported fears or concerns about complications and safety of home dialysis (Q12). Interestingly, Bouvier *et al.* described that nephrologists from centres with low prevalence of PD reported more concerns about complications [67]. Safety of home dialysis may be increased by offering assisted home dialysis, performing home visits and remote patient monitoring [71].

Offering CCM was associated with specific barriers: many nephrologists experienced moral concerns, problems with the selection of patients and discomfort about initiating what was expected to be a difficult discussion [30, 33].

Barriers on the level of the healthcare system

In our review, we described many barriers related to the organization of RRT provision, such as lack of staff, financial

barriers and insufficient facilities. As the organization of kidney care varies markedly between and within regions of the world [72], the nature and the importance of healthcare system-related barriers likely varies as well. For example, 82% of the low-income countries reported a shortage of nephrologists compared with 42% of the high-income countries [41]. In developed countries, home dialysis therapies are generally cheaper than in-centre haemodialysis, whereas they may be more expensive in developing countries since high nursing costs are a major factor in the overall costs of in-centre haemodialysis in developed countries [73]. Many physicians described perverse economic incentives that resulted in more expensive therapies being promoted [30, 38].

Moreover, we found that nephrologists were limited by external pressures when offering transplantation or CCM (Q23–24). The protection of a transplantation centre's reputation influenced the decision to offer transplantation, and nephrologists may use 'cherry picking' to select the best candidates to uphold the centre's graft and patient survival rate [74].

We found that nephrologists reported a lack of guidelines, scientific evidence and prognostic tools as barriers to HHD and CCM (Q25). Symptoms, quality of life and survival of patients with Stage 4 chronic kidney disease (CKD) or patients with Stage 5 CKD not undergoing dialysis are currently being investigated in large studies [75–77]. In addition, guidelines about CCM have recently become available [78, 79] although the evidence for their recommendations is solely based on observational studies comparing RRT and CCM. A randomized controlled trial comparing dialysis and CCM was initiated in 2017 (ISRCTN17133653, Prepare for kidney care) [80].

Remarkably, in our study, lack of donor kidneys for transplantation was not reported as a barrier, whereas we believe this is actually a major barrier. The causes for the lack of kidneys are different for living and deceased donors; the number of living donors may be influenced by legislation and financial constraints for potential living donors, whereas the number of deceased donors may be influenced by donor consent system and legislation about the use of different types of donors [81–84]. Increased availability of kidneys could result, among other things, from actively promoting living donation, organizing financial support for living donors, changing legislation and using kidneys fulfilling expanded donor criteria [81, 82, 85, 86]. Changes in legislation, however, may not be the most important driver in changing the hospital setting. Increased funding of more designated staff and infrastructure to facilitate donor procurement may have more of an effect.

Lastly, a substantial number of nephrologists experienced difficulties with pre-dialysis education (Q26) [87]. We believe that this important barrier is associated with other barriers such as patients' language barriers, nephrologists' attitude and lack of knowledge, and lack of staff (especially nursing staff). In addition, nephrologists reported lack of time, a large amount of complex information that has to be transferred and a restricted range of teaching methods as causes for difficulties with education [26, 39, 88]. However, the quality and quantity of pre-dialysis education may influence, for instance, home dialysis uptake [89, 90].

Strengths and limitations

This is the first systematic review summarizing non-medical barriers on the level of the patient, healthcare professional and healthcare system as experienced by nephrologists when providing the most appropriate treatment to adults with ESKD. Our study included articles about RRT treatment modalities and CCM to make comparison between modalities possible. Moreover, our findings were reported by nephrologists themselves, while in other reviews, nephrologists were not questioned about barriers. In these reviews, the authors composed a list of barriers themselves based on the literature. The risk of selection bias was reduced by two independent authors performing study selection and frequent discussion on the data, themes and interpretation within the author team.

As most studies were performed in developed countries, our findings may not be generalizable to developing countries. In addition, our results may be influenced by limitations of the study designs and reporting of the included articles. Results from the surveys may be influenced by selection and response bias and we were unable to assess the relative importance of the barriers as this was a qualitative analysis. Though relevant, we were unable to investigate relationships between the different non-medical barriers (e.g. language barriers of the patient and suboptimal communication skills of the healthcare professional may lead to problems with pre-dialysis education) as this analysis may be complex and requires a different study design. Finally, data extraction and quality assessment were performed by one author. However, consultation took place on a regular basis between the first two authors to increase the reliability of the data extraction and quality assessment.

CONCLUSION

Within this systematic review, we found a large number of non-medical barriers experienced by nephrologists for the provision of different RRT modalities (other than conventional in-centre haemodialysis) and CCM to patients with ESKD. Modalities could have similar barriers, and a successful approach of a barrier for one modality may also work if the barrier is experienced for another modality. The nature and importance of these barriers may vary by country, which needs to be investigated in further research [91]. This overview of non-medical barriers may support the development of interventions to target modifiable barriers. Guided by nephrologists' experiences, interventions could focus on improving education and optimizing the financing structure of healthcare systems. Education could increase knowledge, which may influence attitude and motivation and could reduce fears and concerns of both patients and nephrologists. Financial stimulation could increase the uptake of home dialysis, CCM or transplantation, by for instance reimbursing home modification, employing extra nursing staff and financial compensation for living donors. These kinds of interventions may improve the access to RRT and CCM so that more patients receive the treatment that is most appropriate for them.

SUPPLEMENTARY DATA

Supplementary data are available at ndt online.

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AUTHORS' CONTRIBUTIONS

R.W.d.J., V.S.S. and K.J.J. were responsible for the study design and first draft of the manuscript. R.W.d.J. and V.S.S. were responsible for the literature selection. All authors (R.W.d.J., V.S.S., J.G.H., M.M., Z.A.M. and K.J.J.) were responsible for data interpretation and approved final submission of the manuscript.

CONFLICT OF INTEREST STATEMENT

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Kidney function and symptom development over time in elderly patients with advanced chronic kidney disease: results of the EQUAL cohort study

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ABSTRACT

Background. Initiation of renal replacement therapy often results from a combination of kidney function deterioration and symptoms related to chronic kidney disease (CKD) progression. We investigated the association between kidney function decline and symptom development in patients with advanced CKD.

Methods. In the European Quality study on treatment in advanced CKD (EQUAL study), a European prospective cohort