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Jones, Emma; Shakespeare, Kate ; McLaughlin, Leah; Noyes, Jane

BMJ Open

DOI:

[10.1136/bmjopen-2022-071348](https://doi.org/10.1136/bmjopen-2022-071348)

Published: 10/08/2023

Publisher's PDF, also known as Version of record

[Cyswllt i'r cyhoeddiad / Link to publication](#)

Dyfyniad o'r fersiwn a gyhoeddwyd / Citation for published version (APA):

Jones, E., Shakespeare, K., McLaughlin, L., & Noyes, J. (2023). Understanding people's decisions when choosing or declining a kidney transplant: a qualitative evidence synthesis. *BMJ Open*, 13(8), e071348. Article e071348. <https://doi.org/10.1136/bmjopen-2022-071348>

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BMJ Open Understanding people's decisions when choosing or declining a kidney transplant: a qualitative evidence synthesis

Emma Louise Jones ¹, Kate Shakespeare,² Leah McLaughlin ¹, Jane Noyes ¹

To cite: Jones EL, Shakespeare K, McLaughlin L, *et al.* Understanding people's decisions when choosing or declining a kidney transplant: a qualitative evidence synthesis. *BMJ Open* 2023;**13**:e071348. doi:10.1136/bmjopen-2022-071348

► Prepublication history and additional supplemental material for this paper are available online. To view these files, please visit the journal online (<http://dx.doi.org/10.1136/bmjopen-2022-071348>).

Received 04 January 2023
Accepted 26 July 2023



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¹School of Medical and Health Sciences, Bangor University, Bangor, UK

²Betsi Cadwaladr University Health Board, Clinical Psychology Dept, Royal Alexandra Hospital, Rhyl, UK

Correspondence to

Dr Jane Noyes;
jane.noyes@bangor.ac.uk

ABSTRACT

Objectives To synthesise qualitative research exploring patients' perspectives, experiences and factors influencing their decision-making preferences when choosing or declining kidney transplantation.

Design A qualitative evidence synthesis.

Data sources Electronic databases were searched from 2000 to June 2021: PubMed, MEDLINE, CINAHL, Embase, PsycINFO, Web of Science, ProQuest Core Databases for Dissertations and Theses, and Google Scholar.

Eligibility criteria Qualitative studies exploring and reporting decision-making preferences of people with kidney disease, which reported influencing factors when choosing or declining kidney transplantation, published in English from high-income and middle-income countries.

Data extraction and synthesis Titles were screened against the inclusion criteria. Thematic synthesis was done with the use of the Critical Appraisal Skills Programme qualitative checklist to assess study quality, and assessment of confidence in the qualitative findings was done using the Grading of Recommendation, Assessment, Development and Evaluation Confidence in the Evidence from Reviews of Qualitative Research.

Findings 37 studies from 11 countries reported the perspectives of 1366 patients with kidney disease. Six descriptive themes were developed: decisional preferences influenced patients' readiness to pursue kidney transplantation, gathering sufficient information to support decision-making, navigating the kidney transplant assessment pathway, desire for kidney transplantation, opposed to kidney transplantation and uncertainties while waiting for the kidney transplant. A new enhanced theoretical model was developed to aid understanding of the complexities of decision-making in people with kidney disease, by integrating the Theory of Planned Behaviour and the Adaptive Decision Maker Framework to incorporate the novel findings.

Conclusion The synthesis provides a better understanding of the extremely complex decision-making processes of people with kidney disease, which are aligned to their kidney transplantation preferences. Further research is needed to better understand the reasons for declining kidney transplantation, and to underpin development of personalised information, interventions and support for patients to make informed decisions when presented with kidney replacement options.

STRENGTHS AND LIMITATIONS OF THIS STUDY

- ⇒ Rigorously conducted qualitative evidence synthesis with application of Grading of Recommendation, Assessment, Development and Evaluation Confidence in the Evidence from Reviews of Qualitative Research to assess confidence in synthesised findings.
- ⇒ Thirty-seven studies from 11 countries were included, reporting the perspectives of 1366 patients with kidney disease.
- ⇒ Forty summarised findings were developed and were assessed as having high or moderate level of confidence.
- ⇒ The majority of studies were from high-income, English-speaking countries, which may limit the transferability of the findings to different contexts.

PROSPERO registration number CRD42021272588.

INTRODUCTION

It is estimated that kidney disease affects around 11–13% of people globally,¹ and approximately 5% of people affected go on to develop end-stage kidney disease (ESKD). ESKD is managed by kidney replacement therapy including haemodialysis, peritoneal dialysis, kidney transplantation and supportive end-of-life conservative care (no active treatment where people will die from their kidney failure). Kidney transplantation can be from either a deceased donor or a living donor, and can be performed preemptively before needing dialysis treatment.²

Kidney transplantation is considered the optimum and most common cost-effective kidney replacement therapy for people with ESKD that improves quality of life and provides freedom from dialysis.^{3–6} People live longer following kidney transplantation compared with being on dialysis.⁷

Shared decision-making

For people with kidney disease, discussion of treatment options and preferences through shared decision-making is recommended 1 year in advance of needing kidney replacement.^{2–8} Shared decision-making gives patients the opportunities to deliberate and carefully weigh the advantages and disadvantages of each individual treatment, using the best available evidence and educational programmes while being supported by healthcare professionals.^{9–11}

People who are medically suitable for a kidney transplant should have the opportunity to decide to choose or decline kidney transplantation. It is unclear how people who are potentially suitable for kidney transplantation decide or decline. Studies suggest that expectations of improved quality of life and preconceptions of returning to a normal life following kidney transplantation^{12–13} can be overshadowed by uncertainties around the unpredictability of graft survival, fears of returning to dialysis or needing a future kidney transplant, as well as the side effects and associated comorbidities of anti-rejection medication.^{14–17} In the UK, the national rate of deceased donor kidney transplant survival after 5 years is 86% (ranging 81–92%), and for a living donor kidney transplant is 92% (ranging 86–97%).¹⁸ There is limited evidence of more detailed or nuanced description and understanding of kidney transplant decision-making, and even less on why people refuse or disengage from kidney transplantation despite being suitable.

Several systematic reviews^{19–25} have explored patients' views and experiences, broadly focusing on decision-making and kidney replacement treatment choices. However, these reviews did not explore reasons for declining or opting out of kidney transplantation or report specifically on the factors which influenced their decisions.

METHODS

We followed the Enhancing Transparency in Reporting the Synthesis of Qualitative Research framework for reporting this qualitative evidence synthesis (QES).²⁶

The aim of this QES was to better understand the decision-making process and reasons why potentially eligible patients choose or decline a kidney transplant. The Sample, Phenomenon of Interest, Design, Evaluation, Research type²⁷ tool was used to define the research question and eligibility criteria (box 1).

Review question

Why do people choose or decline kidney transplantation?

Review objectives

- ▶ To synthesise qualitative research studies exploring the perspectives, views, experiences and decision-making preferences aligned with choosing or declining kidney transplantation by people with kidney disease.

Box 1 Application of the Sample, Phenomenon of Interest, Design, Evaluation, Research type criteria to the research question and eligibility criteria of the current study

- ⇒ Sample: adults aged 18 years and over with kidney disease reported in the literature who are making decisions about kidney transplant.
- ⇒ Phenomenon of interest: (Shared) decision-making processes and outcomes of patients with kidney disease, resulting in choosing or declining kidney transplantation; individual and contextual factors that influence choice and decision-making.
- ⇒ Design: any qualitative research design using any qualitative research methods such as interviews or focus groups, observations or discourse analysis.
- ⇒ Evaluation: descriptions of decision-making, attitudes, preferences, perceptions, views, choices, outcomes, contextual and personal factors that influence the choice.
- ⇒ Research type: primary qualitative research, mixed-methods where the qualitative component is reported separately.

- ▶ To explore how the findings of this review can enhance our knowledge of the decision-making process leading to patients choosing to opt out of kidney transplantation.
- ▶ To identify what psychosocial, cultural, economic or environmental factors influence decision-making processes when considering kidney transplantation.

Theoretical model

Two underpinning theories were used, the Theory of Planned Behaviour and the Adaptive Decision Maker Framework, to help understand the findings and relationships between concepts, and provided further insight of the factors affecting kidney transplant decision-making.

Search strategy and selection criteria

Comprehensive searches were conducted in PubMed, MEDLINE (via EBSCO host), CINAHL (plus full text via EBSCO host), MEDLINE (via Ovid), Embase (via ProQuest Dialog), PsycINFO (via ProQuest), Web of Science (via Bangor University platform), ProQuest Core Databases to search ProQuest Dissertations and Theses, Google Scholar, www.opengrey.eu and PROSPERO, from 2000 to June 2021. Reference lists of included studies were screened. Search strategies are included in online supplemental file 1.

Types of studies

Inclusion criteria

- ▶ Qualitative studies reporting decision-making processes, experiences, views and perspectives of people with kidney disease when making decisions about kidney transplant.
- ▶ Adult patients (aged 18 years and older) with kidney disease (not on kidney replacement therapy), on haemodialysis or on peritoneal dialysis, patients with a transplant or with failing transplant.
- ▶ Studies were included if the research question addressed descriptions of decision-making, attitudes,

preferences, perceptions, views, choices, outcomes, contextual and personal factors that influence choice.

Exclusion criteria

- ▶ Studies were excluded if they included the perspective of caregivers, healthcare professionals, children or adolescents (aged 17 years or younger), or did not include or address patient's decision-making processes.
- ▶ Non-English articles were excluded.

Initial screening

Title and abstracts were reviewed and screened against inclusion and exclusion criteria and duplicates removed in Mendeley. Full-text articles were retrieved and reviewed by ELJ, and a sample was checked by a second reviewer to ensure that the inclusion and exclusion criteria had been

applied accurately and a list of papers to be included was reached. Any disagreements were resolved through whole team discussion and consensus. [Figure 1](#) is a flow diagram of study processing.

Selecting a sample of studies

A sampling framework was developed to ensure the included studies captured a maximum variation of concepts and represented a broad range of participant demographics. Study characteristics were extracted into a table and included author(s), country of study, study design, aim of study, sample and participant demographics ([table 1](#)). We assembled the studies that met the inclusion criteria in date order (most recent first) and worked back in time using the sampling framework until we assembled a maximum variation and manageable

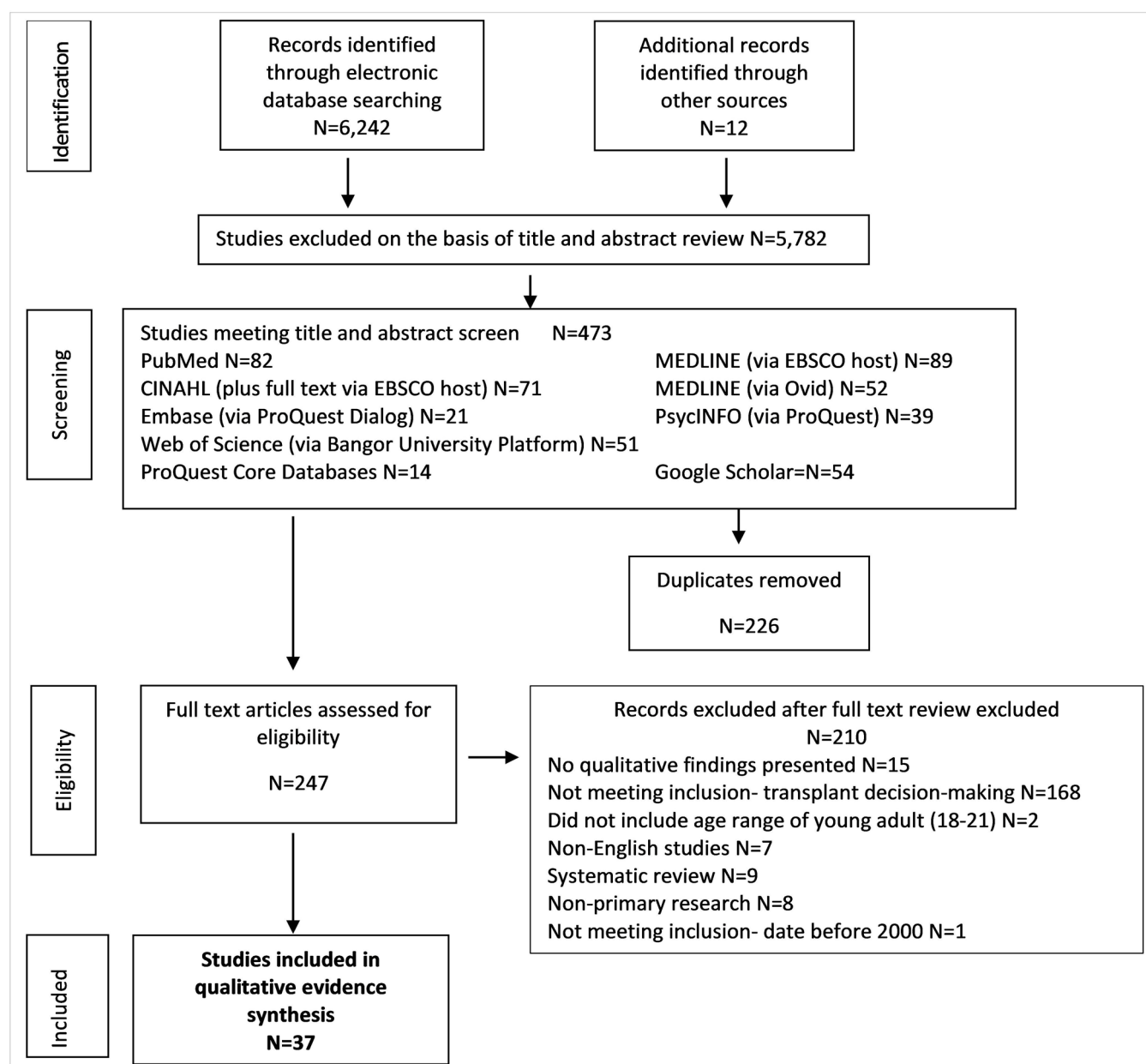


Figure 1 Flow diagram of study processing.

**Table 1** Characteristics of included studies

Study author(s), year	Country	Number of participants	Population with CKD	Data analysis	Data collection
Waterman <i>et al</i> (2020) ³⁷	USA	40	Dialysis, CKD stage 3–5 not on dialysis	Grounded theory	Structured interviews
Baillie and Lankshear (2014) ⁴⁵	UK	16	PD	Ethnography thematic analysis	Semistructured interviews, observation
Calestani <i>et al</i> (2014) ⁵⁶	UK	53	CKD stage 5 (on/ not on kidney Tx waiting list, being assessed for kidney Tx, kidney Tx recipients)	Thematic analysis	Semistructured interviews
Campbell-Crofts and Stewart (2018) ³⁶	Australia	12	CKD stage 3b–5 not on dialysis	Thematic analysis	Semistructured interviews
Chong <i>et al</i> (2016) ⁵⁹	South Korea	8	Dialysis	Content analysis	Semistructured interviews
De Carvalho Conceição <i>et al</i> (2019) ⁴³	Brazil	22	HD	Content analysis	Semistructured interviews
Ghadami <i>et al</i> (2012) ³⁹	Iran	18	Kidney Tx recipients	Content analysis	Semistructured interviews
Gordon (2001) ⁴⁰	USA	79	HD	Ethnography content analysis	Semistructured interviews
Gordon <i>et al</i> (2011) ⁶⁸	USA	162	Dialysis, CKD not on dialysis	Thematic analysis	Semistructured interviews
Keddis <i>et al</i> (2019) ⁴⁹	USA	12	Dialysis	Grounded theory	Semistructured interviews
King <i>et al</i> (2020) ⁴¹	USA	28	Dialysis, CKD not on dialysis	Thematic analysis	Semistructured interviews
Lønning <i>et al</i> (2018) ⁵²	Norway	15	Dialysis	Inductive thematic analysis	Semistructured interviews
Morton <i>et al</i> (2010) ⁵³	Australia	95	Satellite unit HD, in-centre HD, CAPD, APD, HHD, kidney Tx recipients	Thematic analysis	Semistructured interviews
Pronk <i>et al</i> (2018) ⁶⁶	The Netherlands and UK	20	Dialysis/CAPD, CKD not on dialysis	Grounded theory	Semistructured interviews
Rosenthal <i>et al</i> (2016) ⁵⁰	Canada and USA	7	Nocturnal HHD	Grounded theory	Semistructured interviews
Senghor (2019) ⁶⁹	France	15	HD, PD	Thematic analysis	Semistructured interviews
Spiers and Smith (2016) ⁵¹	UK	10	APD, CAPD, HHD, hospital HD, CKD not on dialysis	Interpretative phenomenological analysis	Semistructured interviews
Wachterman <i>et al</i> (2015) ⁴²	USA	16	HD	Constant comparative analysis	Semistructured interviews
Moran <i>et al</i> (2011) ⁶⁴	Ireland	16	HD	Phenomenology	Qualitative interviews
Wong <i>et al</i> (2020) ⁶⁰	USA	36	HD	Descriptive phenomenology	Open-ended interviews
Ka and Ward-Smith (2007) ⁴⁶	USA	12	HD	Phenomenology	Open-ended interviews

Continued

Table 1 Continued

Study author(s), year	Country	Number of participants	Population with CKD	Data analysis	Data collection
Kaufman <i>et al</i> (2006) ⁵⁸	USA	132	HD, kidney Tx recipients, being assessed for kidney Tx	Ethnography	Open-ended interviews, observation
Devitt <i>et al</i> (2017) ³⁸	Australia	146	Dialysis	Thematic analysis	Interviews, life story narrative
Herlin and Wann-Hansson (2010) ⁶³	Sweden	9	HD	Phenomenology	Interviews
Yngman-Uhlin <i>et al</i> (2016) ⁶⁵	Sweden	8	HD	Content analysis	Interviews
Hart <i>et al</i> (2019) ⁴⁴	USA	28	Dialysis	Grounded theory	Focus groups, semistructured interviews
Lewis <i>et al</i> (2019) ⁴⁷	USA	26	Kidney Tx waiting list, kidney Tx recipients	Thematic content analysis	Focus groups, semistructured interviews
Nonterah and Gardiner (2020) ⁵⁵	USA	30	Kidney Tx waiting list, not on kidney Tx waiting list	Grounded theory	Focus groups, semistructured interviews
Browne <i>et al</i> (2016) ³⁴	USA	40	Dialysis	Thematic analysis	Focus groups
Burns <i>et al</i> (2017) ⁵⁴	Australia	6	Dialysis	Thematic analysis	Focus groups
De Groot <i>et al</i> (2012) ⁶⁷	The Netherlands	27	LD Tx recipients, DCD Tx recipients	Theory-based analysis	Focus groups
Ghahramani <i>et al</i> (2014) ⁶¹	USA	23	Dialysis, CKD stage 5 not on dialysis	Thematic analysis	Focus groups
Salter <i>et al</i> (2015) ⁴⁸	USA	36	HD	Thematic content analysis	Focus groups
Sharma <i>et al</i> (2019) ⁷⁰	UK	24	HD	Thematic analysis	Focus groups
Sheu <i>et al</i> (2012) ⁵⁷	USA	50	HD, PD, kidney Tx recipients	Thematic analysis	Focus groups
Tong <i>et al</i> (2009) ³⁵	Australia	63	CKD stage 1–5 not on dialysis, HD, kidney Tx recipients	Thematic analysis	Focus groups
Waterman <i>et al</i> (2006) ⁶²	USA	26	LD Tx recipients, DCD Tx recipients	Content analysis	Focus groups

APD, automated peritoneal dialysis; CAPD, continuous ambulatory peritoneal dialysis; CKD, chronic kidney disease; DCD, deceased donor; HD, haemodialysis; HHD, home haemodialysis; LD, living donor; PD, peritoneal dialysis; Tx, transplant.

sample for synthesis. We had chosen not to consider studies before 2000 as these studies would not have been sufficiently contemporary.

A detailed table of characteristics of included studies is seen in online supplemental file 2.

Quality appraisal

The quality of included studies was independently assessed by ELJ; 30% of the studies were additionally assessed by JN, LM and KS, using the Critical Appraisal Skills Programme²⁸ checklist for qualitative research to assess methodological limitations of included studies (online supplemental file 3). Each study was assessed for

richness using a simple scale of 1–5.²⁹ No studies were excluded based on quality.

Data extraction and data synthesis

Thomas and Harden's³⁰ three-stage method of thematic synthesis was used. Qualitative data which included findings, themes and supporting quotes were uploaded verbatim into NVivo software (V.11). The first and second stages involved line-by-line coding of each study, to inductively develop codes into descriptive themes and were carried out by ELJ and overseen by JN, LM and KS. The final stage involved using two underpinning theories to aid understanding of the complexities of kidney

transplant decision-making in people with kidney disease, by integrating the Theory of Planned Behaviour³¹ and the Adaptive Decision Maker Framework³² to further develop these theories to accommodate the novel findings not covered by the existing theories.

Confidence in the synthesised findings

The Grading of Recommendation, Assessment, Development and Evaluation Confidence in the Evidence from Reviews of Qualitative Research approach was applied in the QES.³³ Assessments of methodological limitations, coherence, adequacy of data and relevance of evidence were fed into an overall assessment of confidence for each synthesised finding (online supplemental file 4). All studies included were assessed as valuable or very valuable when addressing the review question and offered new insights into the phenomenon of interest.

Author reflexivity

The all-female review team represented diverse perspectives on a range of related research foci including kidney disease and kidney transplantation. ELJ considered her own views on kidney transplantation having previously worked as a renal nurse and maintained a reflexive stance throughout the stages of this review process. A reflexive journal was used throughout the research process to capture the thoughts, assumptions and reflections of ELJ during the synthesis and especially during the analysis and interpretation of the data. Weekly meetings were held to discuss data processing and findings.

Patient and public involvement

Patients were involved in developing the review question and provided comments on data and emerging themes through discussions with individuals and presentations to wider groups which included people living with kidney disease.

FINDINGS

Included studies

Thirty-seven studies conducted across 11 countries were included (table 1): the UK (n=5), Sweden (n=2), the Netherlands (n=2), Norway (n=1), France (n=1), Australia (n=5), Canada (n=1), the USA (n=17), South Korea (n=1), Brazil (n=1) and Iran (n=1) (table 1). Publication dates of included studies ranged from 2001 to 2020 with the majority being after 2010 (n=30 studies). The age range of the 1366 patients was 18–93 years. There were more men (n=748) than women (n=607) (not all gender characteristics in one study were included³⁴). Patients from each kidney disease treatment modality were included: people with kidney disease (not on kidney replacement therapy), haemodialysis, peritoneal dialysis, transplant and failing transplant. Data were collected using semi-structured interviews, focus groups and observations.

Qualitative evidence synthesis

Six descriptive themes were developed as being central to how individuals made their decisions about whether

to choose or decline a kidney transplant, and explicitly how and when decisions were made at various points in the clinical pathway. For people with kidney disease, the process was multifaceted; decision-making was evident throughout the person's lifetime during various stages of their kidney disease including pre-dialysis, dialysis, post-transplant and failing transplant. The themes were generally mapped onto the conceptual areas of the two underpinning theories; however, there were gaps not accommodated by the theories. The themes and subthemes are discussed below and shown in figure 2.

Descriptive themes

Decisional preferences influenced patients' readiness to pursue kidney transplantation

The high burden of being diagnosed with kidney disease was incomprehensible to most people. Contemplating treatment decisions when faced with several alternative kidney replacement options was overwhelming particularly when no individual kidney replacement was appealing.

Number of alternative kidney replacement therapies affect decision-making

Patients at earlier stages of kidney disease lacked perception of their declining kidney function and ignored the importance of making decisions or considering treatment options.^{35–37} Patients not yet on dialysis were reluctant to engage and explore their options or make preliminary treatment decisions.

Well, the whole thing is overwhelming [...] Because I haven't even thought about considering transplant. (patient with stage 3 chronic kidney disease (CKD))³⁷

In studies where there were higher numbers of patients in ethnic minority groups,^{34 37–43} patients lacked shared decision-making and often had a poorer understanding of the alternative kidney replacement options.

I don't know [what I could do next about coming to a decision about ESRD [end-stage renal disease]]. I just listen, I just follow the doctor's lead. (African American with stage 5 CKD)⁴¹

Urgency to decide, being time pressured to make a decision and being in denial of kidney disease diagnosis affect kidney transplant decision-making

Patients with earlier stages of kidney disease delayed treatment decisions; there was a disjunction between the patients' perception of feeling well and the urgency to decide. Some patients reported fluctuating preferences; decisions that were made were tentative at best.^{35–37 40 41 44 45}

I didn't take it seriously at first because I felt no symptomatic situation, you know. Then it got to a point where my kidney function was degrading [...] that kind of woke me up a little bit. (patient with stage 5 CKD)³⁷

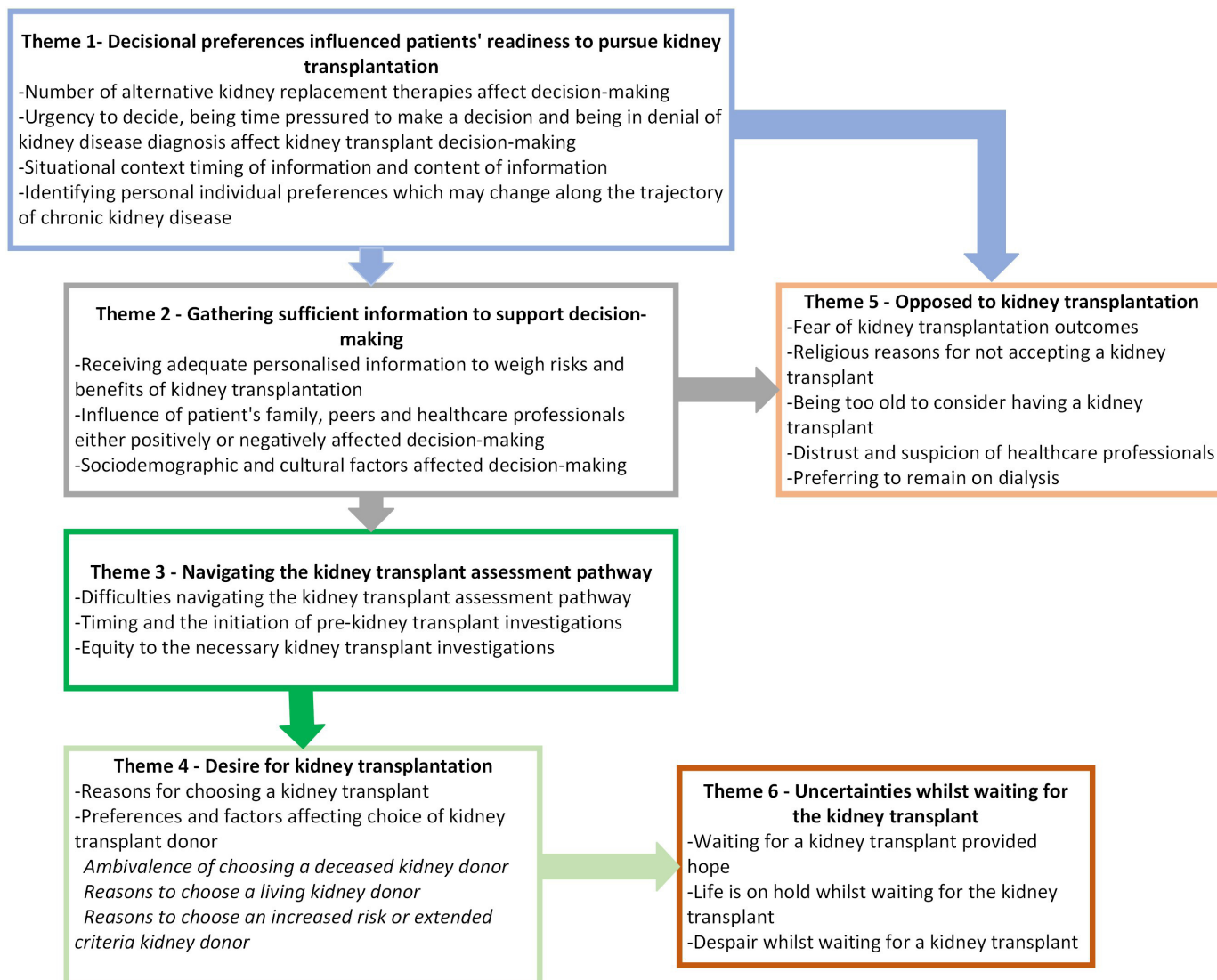


Figure 2 Qualitative evidence synthesis themes and subthemes.

Situational context timing of information and content of information

The timing of receiving educational information affected decision-making; patients described feeling overwhelmed and confused when provided with large volumes of information, others reported being devastated when given leaflets about dialysis soon after being diagnosed with kidney disease.^{37 44 46 47}

I felt like I was being bombarded ... it was information overload that I was getting, so there was this confusion. (focus group transplant candidate)⁴⁴

Patients from ethnic minority backgrounds were mistakenly viewed as being uninterested in kidney transplantation; however, they were often in doubt of the information they received and needed more information to support their decision-making.^{38 39 41 42 47 48}

The biggest problem is that not enough information is available, and available timely, so that people have a chance to think and digest and maybe talk about it with other people before they make those kinds of

decisions regarding transplant. (African American on dialysis)⁴⁸

Identifying personal individual preferences which may change along the trajectory of CKD

Some, mainly younger patients, preferred and chose to delay transplantation for specific reasons; for example, to finish higher education; wait and recover from surgeries; or wait to retire due to financial restrictions.^{40 42 49 50} Women reported responsibilities of taking care of their children or wanting to wait for their children to be older before considering kidney transplantation.⁵⁰

My son's 8; I want him to be a bit older, simply because I want him to be able to take care of himself. (woman on nocturnal home haemodialysis)⁵⁰

Gathering sufficient information to support decision-making

Gathering sufficient information to support individual decision-making was not a linear process. Receiving

information that was individualised, understandable, culturally sensitive and in the correct language helped patients make informed decisions.

Receiving adequate personalised information to weigh the risks and benefits of kidney transplantation

Patients were aware that kidney transplantation did not guarantee a problem-free future and were concerned about possible health complications. Knowledge gaps made patients more vulnerable to misinformation and misinterpretation.^{34 35 40 44 50–54} Some were on dialysis before they heard about kidney transplantation.

I'm a new dialysis patient and I know absolutely nothing about the transplant process or anything. At the clinic that I attend it's kind of hush-hush. They don't say anything about it. (African American on dialysis)³⁴

Influence of patient's family, peers and healthcare professionals either positively or negatively affected decision-making

Kidney healthcare professionals played a supportive, advocative, empathetic role by delivering and reinforcing information, and provided specialist knowledge that enabled patients to make decisions.^{34 46 47 55}

They [healthcare professional] pull up a chair. They will have full conversations with you. They would come around every couple of months and make sure that you remember that you have choices. (African American on dialysis talking about their social worker)⁴⁷

Family members provided emotional support by attending pre-dialysis education and clinic appointments.^{45 56 57} Patients in Indigenous ethnic minority groups were either well supported within their communities or faced disapproval where kidney transplantation was negatively viewed.^{38 49}

It is kinda taboo to take any person's body part and put them in yours. ...A lot of elders don't approve of it...why do you want to bring any kind of weirdness into your family, evil kind of thing... (Native American)⁴⁹

Sociodemographic and cultural factors affected decision-making

Older patients views varied: some believed they had lived a full life and preferred others who were younger to benefit from a transplant; in contrast, others hoped for a transplant to regain a normal life and were determined to pursue kidney transplantation ignoring healthcare professionals' advice that they may be unsuitable.^{40 52 53 58}

I suppose my expectations are a bit high. But, I have a relative who received a transplant and he had a good 10 years. (aged over 65 years on dialysis)⁵²

Patients from ethnic minority backgrounds did not always receive adequate information; they reported they would have viewed kidney transplantation more

favourably if they were in receipt of sufficient information.^{38 39 41 47–49}

Navigating the kidney transplant assessment pathway

Navigating the pre-kidney transplant assessment pathway leads many patients to a successful kidney transplant. However, the journey to determine patient suitability is complex and extremely confusing to navigate. Financial inequalities disadvantaged some from accessing the necessary transplant investigations.

Difficulties navigating the kidney transplant assessment pathway

Patients most commonly reported difficulty in navigating the pre-transplant assessment process. The numerous time-consuming appointments caused confusion about what tests were required and did not recall going through assessments to be placed on the transplant waiting list.^{37 42 56 59}

So many tests are done at once. I don't even know what tests were done when... Didn't I get tested for that last time? (participant 2 on dialysis)⁵⁹

Timing and the initiation of pre-kidney transplant investigations

Where kidney transplant discussions were not initiated early enough after diagnosis, some patients avoided and delayed engaging in the transplant process. Patients on dialysis were often too tired and exhausted to absorb the information about the various transplant investigations.^{36 38 55 56}

It might have just been the time that I received [the information], I wasn't, my brain wasn't focused and I wasn't able to concentrate on that much information, so maybe giving it to me in less detail, slower [would have been better]. (aged mid-20s on transplant waiting list)⁵⁶

Equity to the necessary kidney transplant investigations

Insufficient medical insurance coverage disadvantaged those with low incomes living in America, South Korea and Brazil, who were unable to afford time off work for transplant tests or get to hospital appointments.^{34 37 38 42 43 49 55 59–62} Lack of access to interpreters also created barriers. Some expressed concerns and fears of losing welfare benefits after transplantation and had concerns about being well enough to return to work.⁵⁵

Before I do the transplant I have to think about how I am going to pay my rent, how am I going to get money for food. I have to consider being out of work for 3 months. (black Latino patient on dialysis)⁶⁰

Those who lived further away from the transplant centres reported difficulty getting to appointments and finding their way around large unfamiliar hospitals.^{37 40 42 55 56 59 61} Some had to relocate to be nearer transplant centres to access dialysis and transplantation services.

Desire for kidney transplantation

Individual personal preferences, attitudes and beliefs underpinned decision-making. There was a sense of urgency for patients who had not yet commenced dialysis to receive a kidney transplant and avoid dialysis.

Reasons for choosing a kidney transplant

Patients described their experience of living in the hope of receiving a kidney transplant, and an overwhelming desire for freedom from the constraints and demands of dialysis and return to a normal life.^{35 38 42 44 45 47 49 52–54 56 58 59 63–65}

Of course I think of the future. The future for me is a transplant... that I am waiting for, and then I hope that everything will work out fine so that I can go back to work full time. (aged between 35 and 45 years on dialysis)⁶³

Older patients often desired kidney transplantation and described wanting to see children and grandchildren grow up. Others expressed they wanted a transplant so they could enjoy retirement.^{52 58}

People from ethnic minority backgrounds described kidney transplantation as positive. Their 'faith in God' and spiritual strength would take care of them. Those from Indigenous backgrounds dreamed of returning home to be with their families.^{38 49 55 61}

...so I just try to remain positive knowing that God will take care of it. Yeah. I have faith. I really believe that. (male black/African American)⁵⁵

...but in my spirit I really want to be able to go home. ...The most important thing to me at the moment is that I do the right thing and [then] be able to get a kidney... because I'm really suffering. (Indigenous Australian on dialysis)³⁸

Preferences and factors affecting choice of kidney transplant donor

Patients who chose a kidney transplant had preferences on the type of donor they were willing to accept.

Ambivalence of choosing a deceased kidney donor

Many patients waiting for a deceased donor kidney transplant were ambivalent. They had mixed feelings and internal conflict desiring a kidney transplant while simultaneously feeling they were hoping for someone else to die to receive 'their' kidney.^{41 43 51 54 62 65 66}

I probably will be quite selfish about it and just be like well (pause) that's good (pause) for me. Cos I don't know the person that's gonna pass away. That sounds horrible. (woman on dialysis)⁵¹

Reasons to choose a living kidney donor

Patients who reported wanting a living donor understood the benefits of living donor kidneys coming from a healthy individual would last longer than a deceased donor. Others were desperate to avoid dialysis and wanted to actively solicit for an organ.^{41 49 58 61 67}

Reasons to choose an increased risk or extended criteria for kidney donor

Some patients were willing to accept a kidney that was from a higher-risk donor (for example, from a donor with increased risk of infective diseases) to avoid a life of being on dialysis and improve their health, and healthcare professionals were trusted to make decisions.^{44 68}

Why not? [I am] trying to get off dialysis [and accepting an increased risk donor kidney would] give me a chance to live. (European American, late 30s)⁶⁸

Opposed to kidney transplantation

There were numerous reasons which underpinned patients' decisions to decline kidney transplantation.

Fear of kidney transplantation outcomes

Overwhelmingly, patients reported they were fearful of death, not waking from general anaesthetic and post-transplant-related complications (cancer and diabetes); they also feared no health improvements and poorer quality of life.^{37 40 42–44 46–48 53 61–63 69}

Death. That's the big one. Or that my body rejects [the kidney]. Those things scare me. (American patient with stage 5 CKD talking about fears and possible risks of kidney transplant)³⁷

Patients who had previously been transplanted reported negative personal past experiences affected their decision-making and prevented them to seriously reconsider another kidney transplant.

I'd gone from managing dialysis to all of a sudden, supposedly feeling much better but I felt rotten. I had skin cancers, I had all sorts of complications from the medication. (woman with stage 3 CKD and was transplant recipient)³⁵

Concerns were expressed about adverse side effects of immunosuppressive medication used to prevent kidney rejection, and being unable to adhere to strict medication regimens to keep a transplant functioning. Women considering pregnancy reported the teratogenic effects on pregnancy deterred them from wanting a kidney transplant.

The toxicity of cyclosporine, wanted ...a guarantee that [the drug is] not going to cross the placenta...I didn't want to have a baby that was sick... (woman on nocturnal home haemodialysis)⁵⁰

Some patients felt squeamish about having another person's body part inside them.^{40 42 51 69} Not wanting to be 'cut on'⁴⁸ was a term used mainly by African Americans to convey that they were tired of scars and needed to get over previous surgeries before considering a kidney transplant.

Religious reasons for not accepting a kidney transplant

Religious and cultural beliefs deterred some patients from pursuing kidney transplantation. Some believed their illness was ‘God’s will’; Jehovah’s Witnesses reported their scriptures prevented them from receiving blood from another person.^{40 55 59 60}

I don’t believe in taking somebody’s kidney that’s passed. Whatever I have, even if it shuts down, that’s it. It’s God’s reason for it to shut down. (woman on dialysis)⁴⁰

Being too old to consider having a kidney transplant

Some older patients believed they were too old to consider having a kidney transplant and preferred those who were younger to benefit from a kidney transplant. If they were younger, they may have thought differently.

[There are] so many young people waiting for a transplant... I’ve lived this long and they haven’t had a chance yet. (woman in mid-60s on dialysis)⁴⁶

Distrust and suspicion of healthcare professionals

There was a distrust and suspicion of privatised health-care systems (mainly America and South Korea). Some patients believed there were financial incentives and motivations within the ‘transplant’ system that led to discrimination and disparities in access to transplantation.

I believe the one gets it [kidney transplant] is who has the most money to pay for it. (African American on dialysis)³⁴

Preferring to remain on dialysis

Some patients chose to remain on dialysis, particularly when dialysis was going well and they felt well. Some patients were adjusted to dialysis and were able to maintain their independence and freedom, and felt part of a community while on dialysis.^{34 38 40 42 43 48 50 53 61 62 69}

For this man who was a farmer from a rural community, nocturnal haemodialysis offered *freedom to do what you have to do during the day. I dialyze at night, and then during the day I can do whatever I need.* (man on nocturnal home haemodialysis)⁵⁰

Uncertainties while waiting for the kidney transplant

Initially, when placed on the kidney transplant waiting list, patients were excited and waited patiently to be called; the longer they waited, the more frustrated they became, and envisaged they may never receive a transplant.

Waiting for a kidney transplant provided hope

The initial excitement of being placed on the transplant list provided hope for a normal life, free from the constraints of dialysis.

Hopefully I’ll get a kidney soon and that’ll be the end of it [dialysis], you always live in hope... there’s light

at the end of the tunnel. (woman waiting for kidney transplant)⁶⁴

Life is on hold while waiting for the kidney transplant

Waiting for a kidney transplant was stressful and tiring; the longer patients waited, the more they became disappointed and uncertain. Having support from family, friends and healthcare professionals was reported as essential for helping patients cope while waiting.^{38 42 51 52 54 56 59 63–65 70}

I look at life as if it’s on hold until I get a transplant... because you’re not doing what you want to do... it (dialysis) it’s like I’m bonded to it (dialysis). (woman waiting for kidney transplant)⁶⁴

Despair while waiting for a kidney transplant

Patients conveyed loss of hope, resentment and cynicism, and were suspicious of the transplant waiting list. The worry and concern their health may deteriorate while they waited was a burden.

I packed a bag,... I had a phone installed upstairs, I got a mobile phone... thinking, you know, they’re gonna call me. And then you gradually realise, they’re not gonna call you! (woman waiting for kidney transplant)⁵¹

Theory development from descriptive themes

The Theory of Planned Behaviour³¹ and the Adaptive Decision Maker Framework³² were not sufficiently nuanced to provide understanding of the complexities of decision-making in people with kidney disease. Prior beliefs and knowledge greatly shaped people’s decision-making and were therefore added to the model to help conceptualise and contextualise the findings (shown in blue in [figure 3](#)). Patient beliefs and personal history were constructed on their past, their lives and their personal views, and all these issues shaped their decision preferences. Individual decisions were encapsulated and formed from exposure to the world they lived in.

DISCUSSION

People with kidney disease chose kidney replacement options that best aligned with their often preconceived personal preferences (which could be gender and age related), attitudes, beliefs, culture, economic situation and religion. Incomplete and inadequate knowledge about kidney transplantation limited people’s understanding of the benefits of kidney transplantation. People who received individualised, culturally sensitive, understandable information and who were well supported by their family and healthcare team were more likely to pursue kidney transplantation. Those on dialysis were motivated and encouraged to pursue kidney transplantation by witnessing positive peer experiences. Some people from ethnic minority backgrounds were ambivalent to the benefits of kidney transplantation and had more difficulty

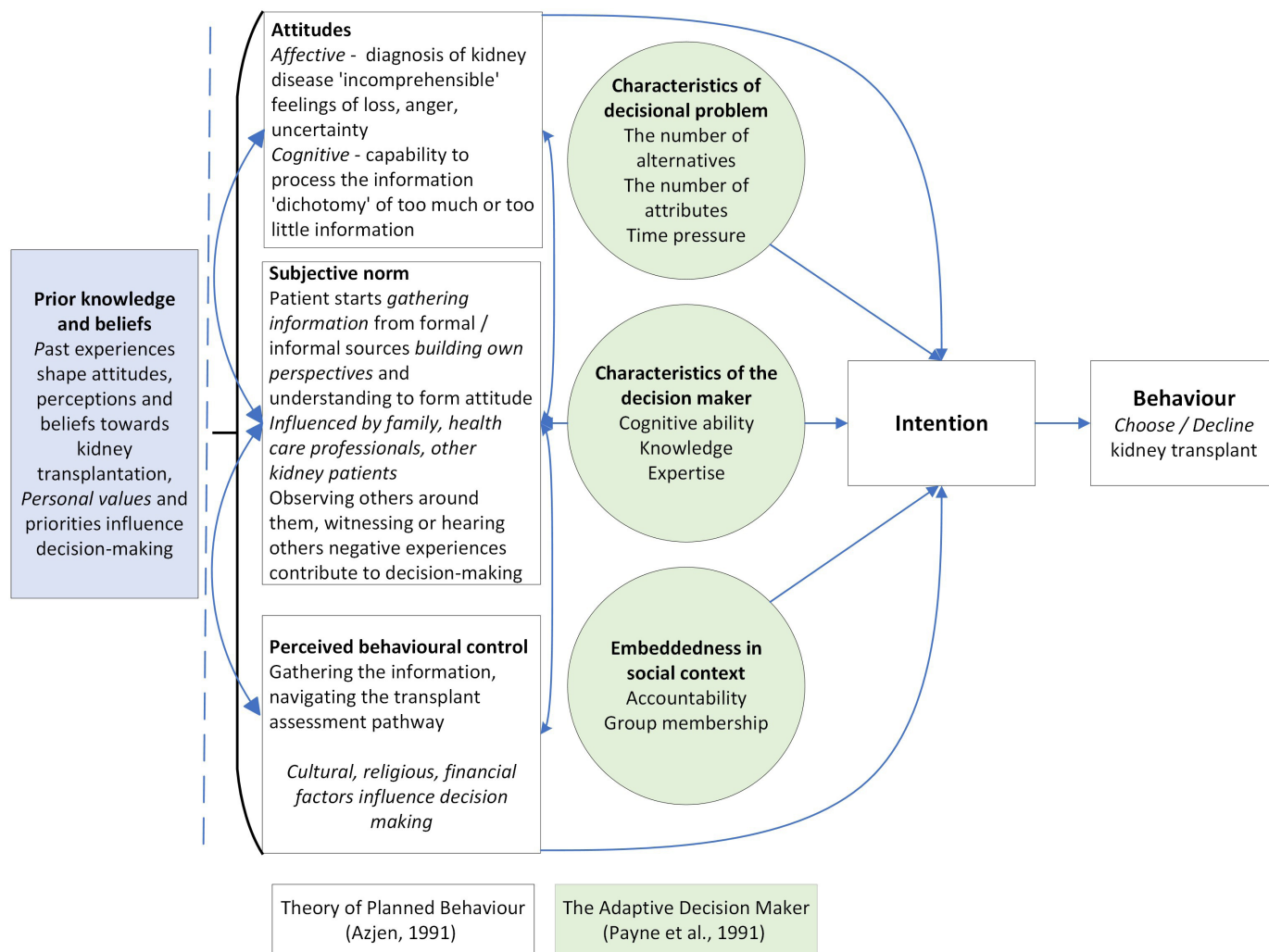


Figure 3 Enhanced theoretical model of the Theory of Planned Behaviour and the Adaptive Decision Maker Framework.

navigating the kidney transplant assessment pathway. When patients were diagnosed, they faced a number of alternative kidney replacement treatment options. Too many treatment options led to confusion and uncertainty of what treatment best suited them. Time pressures to make decisions quickly impacted on a person's readiness to pursue kidney transplantation. Those who had specifically chosen kidney transplantation and who were on the kidney transplant waiting list experienced optimism and believed that there was light at the end of the tunnel. The longer patients waited for a kidney transplant, the more their hopes diminished, often believing they may never receive a kidney.

From a policy, clinical practice and outcomes point of view, kidney transplant is considered the 'best treatment'.³⁻⁷ Interpreting the findings from a patient perspective required a reflexive approach to negate the professional orientation and potential biases of two of the clinical authors. Some of the patient narratives articulated an alternative perspective as to what 'best treatment' meant for them and this was sometimes at odds with current clinical practice recommendations (such as to increase the number of transplants as they bring about

the best outcomes for patients⁶). This tension between patient and professional conceptualisation of 'best treatment' was highlighted and discussed at length by the clinical and non-clinical authors (including a renal health psychologist), and in further engagement with patient and public representatives. It was clear that some patients felt that they were making the best decision for themselves which is the purpose of shared decision-making interventions used in these types of clinical situations. We do not however have a complete understanding of these important issues and many people are contributing to this debate as highlighted by one peer reviewer who felt that the tension between education and patient voice may be in part due to culture and context. On the latter point, the evidence was not sufficiently detailed to come to a more secure understanding.

Recently published studies using a variety of methodologies can however be used to triangulate and add weight to our findings. In line with our QES, treatment-related decisional conflict and indecision about kidney transplant remains common but not fully understood.⁷¹⁻⁷⁷ A large European survey across 38 countries reported factors influencing the patient's choice of kidney replacement



therapy. The timing and content of information on kidney treatment modalities differed across countries: in some countries, transplant availability was limited and quality of life was an important factor that was considered when selecting treatments. Reinforcing our findings, fears and concerns about age and health status was also important to how people made decisions.⁷¹ New qualitative studies reinforce that older people consider that a kidney transplant is either too high risk or is essential to regain freedom from dialysis.⁷² Perspectives of patients who had received less-than-ideal kidney transplants in Canada were explored.⁷³ Patients balanced risks of dying while waiting for an optimal kidney and were willing to accept a less-than-ideal quality kidney transplant as they desired freedom from dialysis. Rosaasen et al⁷³ also reinforced our review findings of the perceived benefits of receiving an increased risk kidney transplant would result in less time on the waiting list. Employment figures of people following kidney transplant are inconsistent. A recent European study which aimed to gain insight into work functioning following kidney transplantation found over half of those in the study were employed and reported to function well at work despite side effects of immunosuppressant medication, fatigue and anxiety; patients self-reported that their work functioning was higher than before kidney transplantation.⁷⁴

In a wider global context, people from Indigenous ethnic backgrounds similarly described barriers, economic and logistical obstacles limited their access to kidney transplantation. Challenges of living in rural areas left them feeling vulnerable.^{75 76} A systematic review of Indigenous peoples' perspectives from the USA, Canada, Australia and New Zealand⁷⁶ supports our findings that cultural taboos act as a deterrent from accepting a transplant, and supports the common finding across studies that a lack of accessible information left people uninformed about treatment options. Indigenous people often lived remotely and needed to relocate nearer to hospitals to access dialysis and transplantation facilities. Similarly, a qualitative study reported the perspectives of 28 people with kidney disease living in rural Australia who faced economic, logistical and psychological obstacles to accessing dialysis and transplant.⁷⁵ People living in Pakistan also reported feeling disenfranchised from and unable to afford transplant investigations or the transplant.⁷⁷

Strengths and limitations

To the best of our knowledge, this is the first QES that specifically explores factors influencing patient decision-making to choose or decline a kidney transplant. A strength is that rigorous Cochrane methods and processes were used. The 37 studies included in this review did not explicitly focus on the stated phenomena of interest. Some of the studies included only a small amount of data to help build up an overall understanding of the phenomena of interest and that is what makes this review novel. The QES configured the studies to identify new

patterns and meanings that were not always apparent when reading single studies. The majority of the findings were reported as having high confidence. The analysis process involved multiple researchers with different perspectives. Non-English studies were excluded, while studies only from middle-income and high-income countries with kidney transplant programmes similar to the UK were included, which may limit the transferability of the findings to some contexts.

Further research

There remain important gaps in understanding as highlighted above. The inclusion of non-English-language studies and evidence from low-income countries are needed to provide a more comprehensive global and equity perspective. The evidence in the synthesis predated COVID-19 and the current economic crisis. Further research is needed to explore and understand how COVID-19 and the cost-of-living crisis will impact on kidney transplant decision-making. Following kidney transplantation, patients who are immunosuppressed remain clinically vulnerable and at risk of becoming seriously ill from COVID-19 compared with the general population, and it is not clear if people may decide against kidney transplantation due to fears of the risks to their health. The cost-of-living crisis may further create inequalities and barriers, and concerns about loss of employment and loss of state benefits following transplantation are already known to affect decision-making. It is not yet known if the current crisis will further affect people and decline the opportunity of kidney transplantation.

Implications for policy and practice

It is relatively common for an eligible patient to decline a kidney transplant. It is likely that some patients are making misguided decisions based on inaccurate prior beliefs and misconceptions, which could be amenable to targeted psychosocial and educational interventions. There are a number of patient decision-making aids to support people to make decisions about kidney replacement therapy.⁹ There is however insufficient evidence, policy content or decision pathways noted in UK clinical guidance to support people who decline kidney transplantation. The current decision aids focus on dialysis options, conservative care and choosing kidney transplantation including living donor kidney transplantation.⁹ Findings can be used to improve education that is provided to patients and to inform the further development of strategies and interventions to underpin better shared decision-making and more robust clinical guidelines and pathways that directly address this issue. For example, in the UK, Getting it Right First Time and Access to Kidney Transplant Kidney Quality Improvement Partnership Transplant First have been set up with the remit to maximise the number of UK patients transplanted.⁶ In order to optimise the impact of this type of initiative, healthcare professionals can draw on the findings from this QES to

develop a clearer understanding of the reasons why some people decline kidney transplantation.

Conclusion

This QES provides additional evidence to understand the extremely complex decision-making processes of people with kidney disease which are aligned to their kidney transplantation preferences and contribute to existing theory on how and why people choose or decline kidney transplantation. Clinical practice requires further evidence-based evolution in order to better accommodate the needs of these patients and to make sure that they attain optimal and cost-effective outcomes from personalised treatment options for kidney disease.

Twitter Jane Noyes @janenoyes

Acknowledgements Thank you to Pauline Goodlad, librarian at John Spalding Library and BCUHB Libraries, for assistance with search strategies; and Yasmin Noorani, academic support librarian at Bangor University, for assistance with designing search terms and search strategy for this review.

Contributors ELJ drafted the protocol, undertook initial searches, drafted initial tables of searches, data analysis and synthesis, drafted the manuscript and is the guarantor for the data. KS, LM and JN supported in drafting the protocol, data analysis and synthesis, and manuscript preparation.

Funding This synthesis is part of a KESS2 East (Knowledge Economy Skills Scholarships) PhD scholarship (BUK2E040). KESS, a pan-Wales higher-level skills initiative, supported by European Social Fund (ESF) through the Welsh Government, was awarded to ELJ and is part funded by two charitable organisations hosted within Betsi Cadwaladr University Health Board charities; Friends of Renal Care (number: 1138976) and Kidney Patient Association (number: 1120824), as well as a third patient endowment fund. Kidney Wales Charity (registered charity number: 700396) has also financially contributed to this study. The Welsh Kidney Research Unit (WKRU) provides support to ELJ and will support dissemination of the study findings on its website.

Competing interests None declared.

Patient and public involvement Patients and/or the public were involved in the design, or conduct, or reporting, or dissemination plans of this research. Refer to the Methods section for further details.

Patient consent for publication Not required.

Ethics approval Ethical approval for this specific qualitative evidence synthesis is not applicable since data used were collected from previously published research in the literature. All studies included in this review received ethical approval prior to data collection by their primary investigator.

Provenance and peer review Not commissioned; externally peer reviewed.

Data availability statement All data relevant to the study are included in the article or uploaded as supplemental information.

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ORCID iDs

Emma Louise Jones <http://orcid.org/0000-0001-5784-822X>

Leah McLaughlin <http://orcid.org/0000-0003-0185-6639>

Jane Noyes <http://orcid.org/0000-0003-4238-5984>

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