

Young adults with kidney failure lived experiences of kidney replacement therapy decision-making

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Abstract

Background: Young adults living with kidney failure make decisions to select a kidney replacement therapy choice in partnership with healthcare professionals. However, little is known about how they experience kidney replacement therapy treatment decision-making and the impact this has on their well-being.

Objectives: To explore young adults living with kidney failure experiences of treatment decision-making. The treatment decision-making investigated is about the choice of dialysis and/or kidney transplant options.

Design: A qualitative interpretive hermeneutic phenomenology study.

Participants: Purposeful sampling was used to recruit young adults with kidney failure from social media, electronic media such as local kidney group websites and word of mouth. Semistructured interviews were conducted with ($n = 18$) participants aged 18–30 years.

Approach: Inductive analysis of the data were performed using Braun and Clarke's thematic analysis framework.

Findings: The five themes generated were (1) awareness and anticipation of future kidney replacement therapy decision; (2) health information and education; (3) engaging in decision-making, support and choices; (4) implementation of kidney replacement therapy and transitioning into the new normal life and (5) the impact of decision-making and choice on well-being.

Conclusions: Decision-making significantly affected young adults' psychosocial and mental well-being. Young adults had unmet informational and decisional needs and struggled to cope due to lack of support. A four-talk model, with an implement talk phase added to the existing three-talk (team talk, option talk, decision talk) shared decision-making model, would promote a focus on the implementation of choice and support the transitioning from previous life to long-term dependence on treatment.

KEYWORDS

interpretive phenomenology, kidney failure, kidney replacement therapy, shared decision-making, young adults

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INTRODUCTION

Young adults struggle to accept diagnosis of kidney failure and may feel overwhelmed with the burden of managing long-term illness, compared with children and older adults (Pankhurst et al., 2020). Lack of engagement in services, increased risk of medication nonadherence and high unexpected loss of kidney transplant occurs around the time of transitioning and following transfer to older adult services (Levine et al., 2018; Pankhurst et al., 2020). Research studies from Germany, Canada and United Kingdom show variations and barriers to transition for young adults from paediatric to adult services (Kerr et al., 2020; Nagra et al., 2015; Prüfe et al., 2017), despite guidelines for transition (Canadian Association of Paediatric Health Centres National Transitions Community of Practice, 2016; National Institute for Health and Care Excellence [NICE], 2016; Watson et al., 2011). Many young adults feel isolated and struggle to feel comfortable in adult centres (Prentice-Hoogervost & Mayers, 2022), which can worsen for those facing dialysis and kidney transplant (kidney replacement therapy [KRT]) decision-making (Murray et al., 2014; Pankhurst et al., 2020). Young adults need support especially when facing KRT decisions, to enable informed or shared decisions and self-management (Jose et al., 2021). This study explored experiences of how young adults with kidney failure made decisions to select a KRT.

LITERATURE REVIEW

The incidence and prevalence of kidney failure requiring KRT is increasing globally (Bikbov et al., 2020). In the United Kingdom, there is an increasing trend in the incidence and prevalence of adults requiring KRT for kidney failure, including young adults 18–30 years old (UK Renal Registry, 2023). More young adults started haemodialysis as their first KRT compared with pre-emptive kidney transplantation over the last decade (UK Renal Registry, 2023). Kidney failure initiates discussions about KRT options and choice decisions (Kidney Disease Improving Global Outcomes, 2024). Young adults with kidney failure can choose from KRT alternatives, which involve risks and uncertainty, and be supported during decision-making (NICE, 2021a). The complexity of healthcare decisions necessitates decision model development and use. While historically, paternalistic and physician-as-an-agent decision-making models dominated, with greater advocacy, a person-centred approach, with informed and shared decisions, has since developed (Charles et al., 1999; NICE, 2021b). Shared decision-making (SDM) is a collaborative partnership between patients and healthcare professionals (HCPs) to discuss available treatment and consider individual's values and preferences (NICE, 2021b). SDM incorporates the ethical principles of self-determination, autonomy and relational autonomy (Elwyn et al., 2012). Although various healthcare decision-making models are used, in the United Kingdom, the three-talk SDM model (Figure 1) (Elwyn et al., 2017) is recommended for clinical practice (NICE, 2021b).

The SDM process incorporates supportive tools such as patient decision aids, decisional coaching and motivational interviewing to

enhance knowledge and understanding of illness, available options, enable trade-offs and improve health outcomes (van Eck van der Sluijs et al., 2023; Savelberg et al., 2020). However, not all patients experience informed or shared decisions (Barrett et al., 2021; van Eck van der Sluijs et al., 2023; Ofori-Ansah et al., 2022). SDM continues to be poorly rated experiences by people with kidney disease (UK Kidney Association & Kidney Care UK, 2022). Barriers to SDM include poor communication and low health literacy, a lack of information, education, engagement and decisional support (Dinh et al., 2022; Muscat et al., 2021; Ofori-Ansah et al., 2022).

Despite guidelines that promote patients' rights to participate in healthcare decision-making, the embedment of SDM in routine care remains lacking (Coulter et al., 2022; NICE, 2021b). Older adults with kidney failure decision-making experiences are well documented (Barrett et al., 2021; van Eck van der Sluijs et al., 2023), however, young adults' experiences, are mostly reported together with older adults' (Levine et al., 2018). Most young adults with kidney failure are at a critical stage in their education and employment; they require support to participate in treatment decision-making and enable self-management (Jose et al., 2021; Murray et al., 2014). Limited studies have specifically explored young adults' experiences of KRT decision-making (Ofori-Ansah et al., 2022). Therefore, there is a gap in knowledge about how young adults make KRT decisions. This phenomenological study used the three-talk SDM model as a framework to explore young adults' treatment decision-making experiences, to understand how they engage with and make KRT decisions.

MATERIAL AND METHODS

The Consolidated criteria for reporting qualitative research (Tong et al., 2007) (Supporting Information S1: Data 1) was used to report this study.

Study design

This qualitative study applied interpretive hermeneutic phenomenology to explore the lived experience of treatment decision-making phenomenon. Heidegger asserts that human beings cannot be separated from the world they live in and their way of perceiving their experiences (Langdrige, 2007). The phenomenological experience is about meaning, 'letting that which shows itself to be seen from itself' (Heidegger, 1962, p. 38). Using interpretive hermeneutic phenomenology allowed the exploration of young adults' treatment decision-making experiences in relation to their sociocultural and psychological situatedness, to develop meaning and understanding of their experiences.

Patient and public involvement

An engagement group of people living with kidney failure was formed as part of patient and public involvement to inform the study.

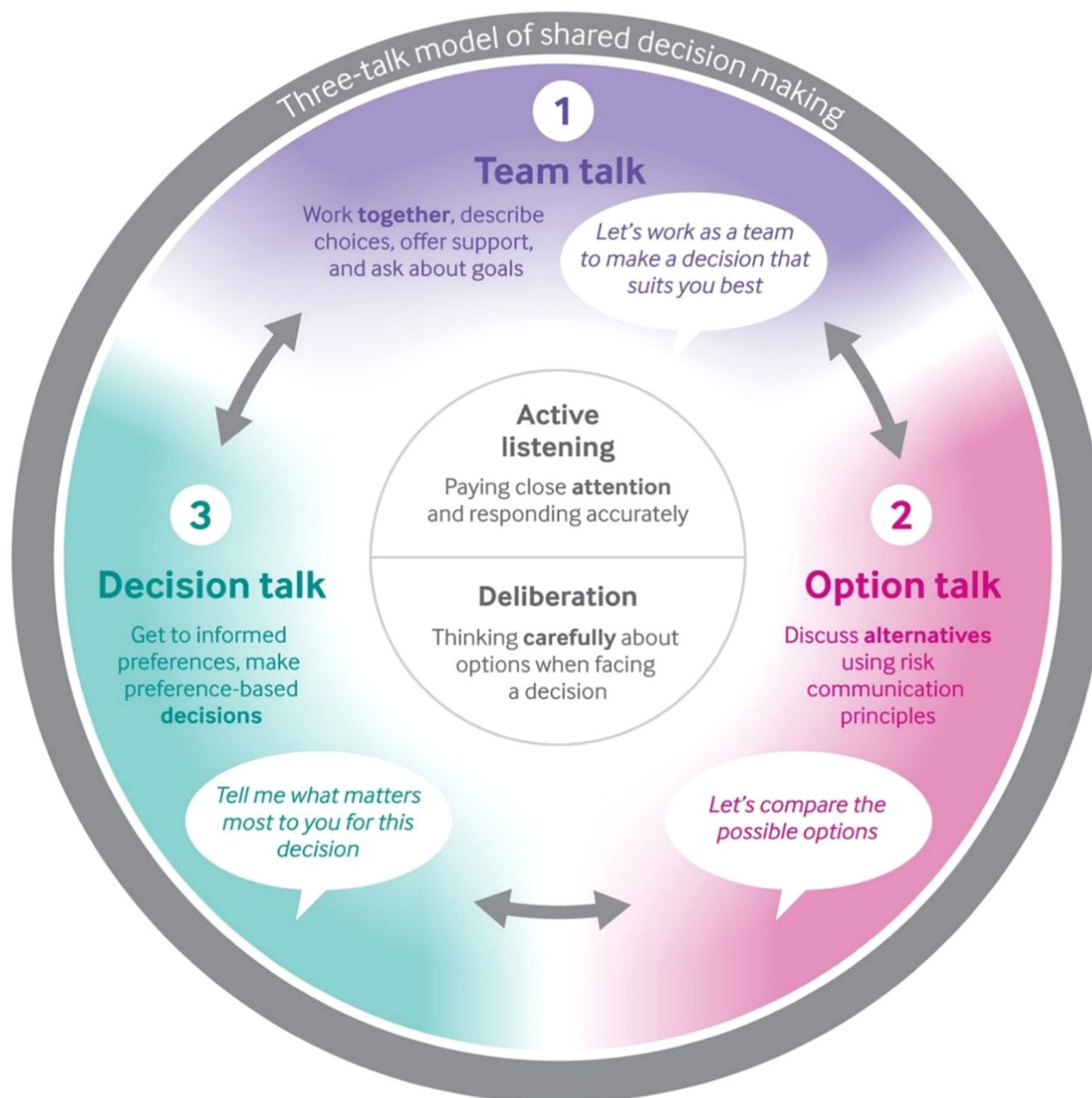


FIGURE 1 Three-talk model of shared decision-making (Elwyn et al., 2017). Permission granted by author to use model and image.

The engagement group reviewed the participant information sheet, consent form, recruitment poster and contributed to the development of a video advert for participants.

Participants and setting

Participants from different UK kidney centres were recruited through Facebook, Twitter, electronic media such as local kidney group websites, and word of mouth, between April 2019 to January 2020. Participants opted voluntarily into the study via text, telephone or email. Eligible participants (Table 1) received participant information sheets and interview dates and places were arranged.

Participants gave written consent before interviews commenced. No participants were known to the researcher (S. O.-A.) who recruited and conducted the interviews. All participants received a £20 gift card postinterviews.

Participants' characteristics

There were 39 expressions of interest of which 18 participants ($n = 9$ males; $n = 9$ females), mean age of 25.4 years, were recruited and interviewed. Most young adults were recruited from Facebook and Twitter (Table 2). Eleven participants ($n = 11$) had presented directly to an adult kidney centre and seven ($n = 7$) had transferred to adult kidney centres (Table 2).

Data collection

To understand the meaning of young adults' lived experiences of KRT decision-making, it was important to return to the root of their experience accessed through hearing each participant's narrative account. Semistructured interviews (Brinkmann & Kvale, 2015) were conducted face-to-face ($n = 2$) or virtually via Skype ($n = 16$) according

TABLE 1 Inclusion and exclusion criteria.

Inclusion criteria	Exclusion criteria
<ul style="list-style-type: none"> • Young adults were eligible if they were aged 18–30 years, diagnosed with kidney failure for more than 3 months and living in the United Kingdom. • Had made a decision about kidney replacement therapy and subsequently received dialysis or kidney transplant. • Able to communicate in English and voluntarily provide informed consent to participate in the study. 	<ul style="list-style-type: none"> • Young adults outside the age range, without kidney failure and not living in United Kingdom. • Young adults who cannot recall information about their experience.

TABLE 2 Source of expressions of interest and characteristics of participants.

Source of expressions of interest and characteristics of participants	
Source of expressions of interest	Number (n)
Facebook	27
Twitter	6
Local kidney group websites	2
Word of mouth	4
Total expressions of interest	39
Gender	
Male	9 (50%)
Female	9 (50%)
Ethnicity	
Caucasian	13
African	1
Asian	4
Age at diagnosis	
Childhood	6
Adolescence	1
Young adulthood	11
Employment status at time of interview	
Part-time or full-time	9
Unemployed	4
Living status	
Living with family (husband/partner and child)	4
Living with parents and siblings	11
Living alone	3
Education status at time of interview	
Higher education	4
College	1
Age (year)	
Age range	18–30
Mean age	25.4
Median age	25.5

to participants' request, using an interview guide (see Supporting Information S2: Data 2). Open questions were asked about knowledge about kidney disease, KRT education, treatment decision-making, impact of the decision-making process and choice experience. The interview guide was aligned with the three-talk model of SDM. A test interview was performed with a research team member using the interview guide to check suitability; no changes were necessary. Interviews were audio recorded and transcribed verbatim by S. O.-A. and lasted an average of 57 min (31.20–101.21 min [minutes]). Transcripts were returned to each participant for content verification and comments. Each participant agreed with the content; this member checking increases the credibility of the data (Birt et al., 2016), confirming the integrity and precision of the data collection and transcription as a true account of participants' lived experiences.

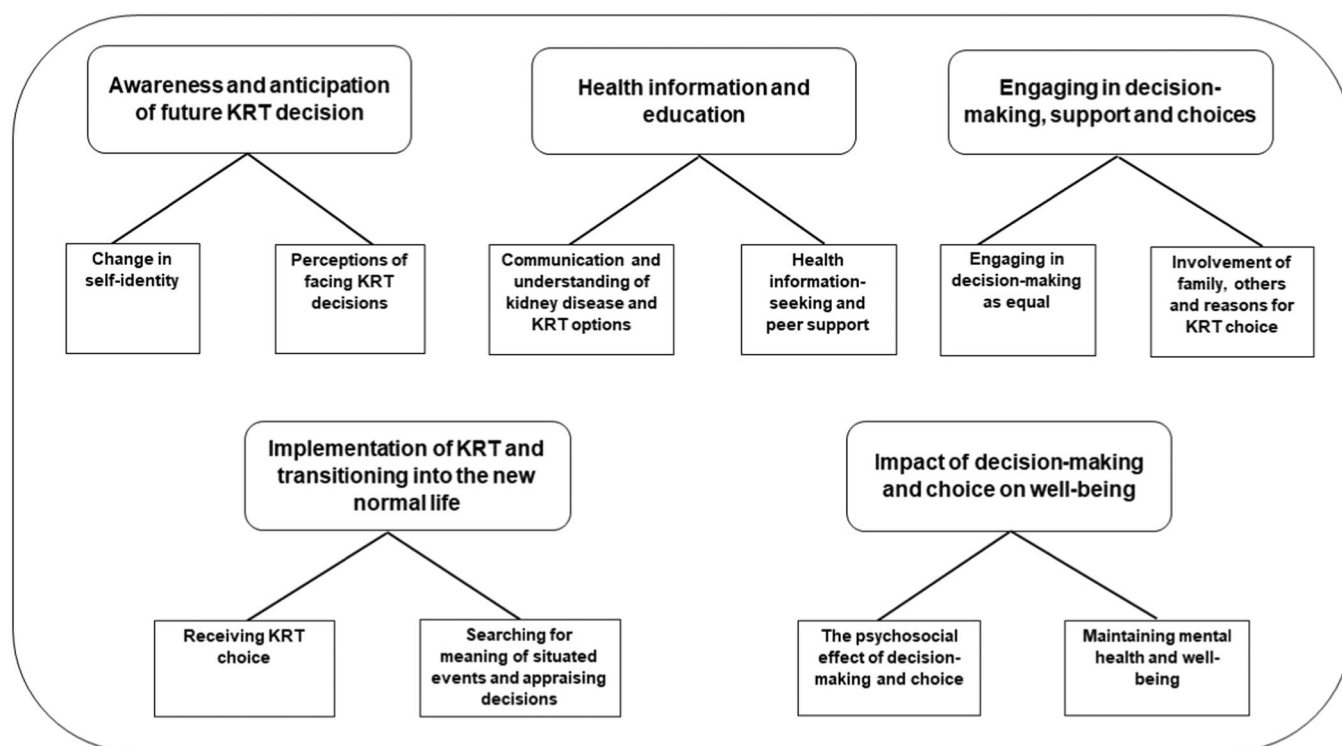
Data analysis

The data analysis and interpretation were conducted in several phases. Braun and Clarke's six-step reflexive thematic analysis approach (Braun & Clarke, 2021) was applied inductively to the raw data in the first phase (Table 3). This thematic analysis approach was chosen because it is flexible and compatible with interpretive methodological approaches; used to make sense of and interpret the meaning of lived experiences (Braun & Clarke, 2017). The preliminary themes were reviewed against the theoretical framework for alignment and further refinement in the later stage.

Meaning making was conceptualised as the person-in-context, focusing on the significance of each participant's experience first, and then the collective significance of participants' decision-making experiences. Microsoft Word and Excel were used to manage codes and the analysis process. Analytical saturation was determined inductively through the structured analysis and interpretation of text and no new codes or themes were generated. The themes were reviewed by the other researchers (M. E., C. M. and L. B.) for coherency, consistency and all were in agreement on the final themes presentation (Figure 2). The analytical interpretation of data helped to contextualise the findings and how each participant's experiences contributed to young adults' collective experiences of decision-making, to ensure trustworthiness and credibility of the findings. Finally, the preliminary analysis was compared and then aligned with team, option and decision

TABLE 3 Analysis process: Braun and Clarke's (2021) thematic analysis approach.

Analysis steps	Description
Step 1	The data were read and reread carefully for data familiarisation and noting initial patterns.
Step 2	The text was reread for deeper understanding and identification of units of meaning with no pre-set coding. Semantic ('explicitly expressed meaning') and latent (deeper 'conceptual level of meaning') (Braun & Clarke, 2021, p. 57) codes were developed and data segments that described key moments of the lived events, that related to the research question, were extracted.
Step 3	The initial themes generated were categorised and clustered, connections searched for commonality and grouped to form candidate (main) themes.
Step 4	Themes were then refined and mapped to ensure they provided meaning and understanding of participants' experiences of treatment decision-making.
Step 5	Themes were checked for coherency, consistency and accuracy, ensuring they provided meaning and interpretation of the decision-making experience and enhanced the dependability and trustworthiness of analytical process.
Step 6	Collated data extracts were organised into a coherent and consistent account, with quotes to illustrate themes.

**FIGURE 2** Thematic representation of young adults' experiences of kidney replacement therapy (KRT) decision-making.

talk phases of the SDM model, to understand the decision-making processes of young adults' experiences (see Figure 3).

Ethical considerations

Ethical approval was received from a university research ethics committee in 2019 as a Health Research Authority ethics approval was not needed. Ethical principles of autonomy, doing good and no harm and ensuring fairness were adhered to (World Medical Association, 2013). Voluntary participation enhanced self-determination and autonomy and power

imbalances were managed. Counselling and advocacy systems were in place to support participants. Confidentiality was maintained by assigning pseudonyms and anonymising all identifiable data. Information governance, and data protection legislation (General Data Protection Regulations, 2018) and University policies were followed.

Rigour and reflexivity

Rigour is demonstrated through credibility, dependability, transferability and sensitivity to the context (Moorley & Cathala, 2019). The

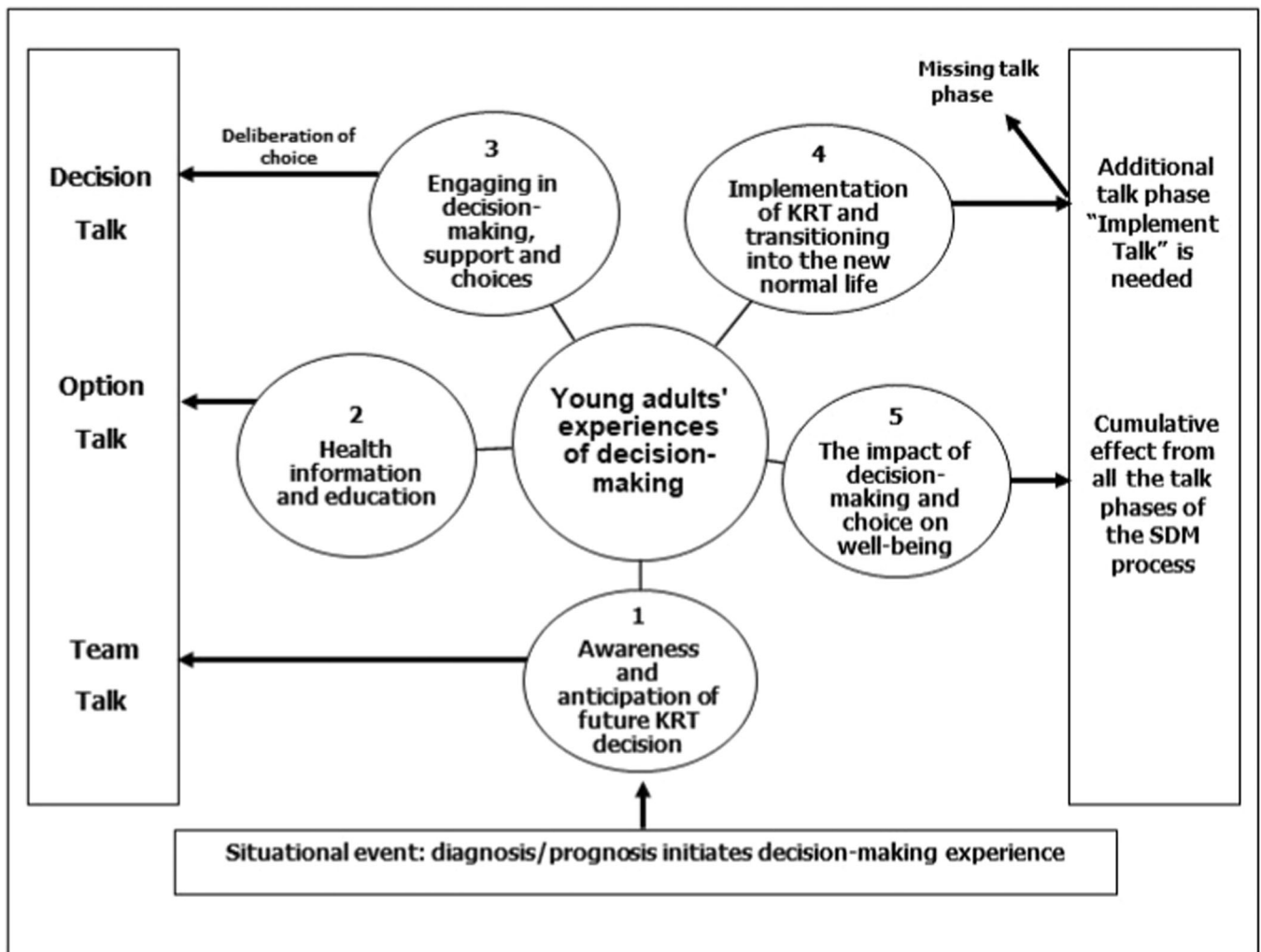


FIGURE 3 Thematic representation of young adults' experiences of kidney replacement therapy (KRT) decision-making aligned with the three-talk shared decision-making (SDM) model and indicating the need for an 'implement talk phase'.

research members were from nursing and social work backgrounds; one (S. O.-A.) had specialist knowledge and experience in kidney care, which was disclosed to participants before interviews to enhance transparency and build trust. All members had rich research knowledge and experiences. Methodological rigour and reflexivity were applied through clear articulation of the study objectives, transparency of recruitment, sensitivity to context, systematic analysis and maintaining an audit trail of the analysis. The interpretations and themes were grounded in the data to ensure contextualisation.

FINDINGS

Young adults had multiple KRT decision-making experiences at different time and had varying informational and decisional needs. KRT decision-making was perceived as choosing between life and death and negatively affected their well-being, but minimal psychological support was received. Five overarching themes and

subthemes (Figure 2) were generated. Illustrative quotes that illuminate participants' experiences are provided, with pseudonyms to protect their identities.

Theme 1. Awareness and anticipation of future KRT decision-Team talk phase

Awareness and anticipation of future KRT decisions concerns young adults' perceptions of their awareness of kidney failure and the required future KRT treatment to survive. This theme aligns with the team talk phase of the three-talk model of SDM. There are two subthemes: change in self-identity and perceptions of facing KRT decisions.

Change in self-identity

Participants articulated the beginning of their decision-making experiences to when they became aware that their kidneys had failed and would need future KRT. Receiving diagnosis/prognosis of

kidney failure and future KRT was perceived as bad news, prompting varied emotions for young adults and their families, especially parents. Participants felt life had 'thrown' kidney failure at them, bringing many changes to their lives and lacked understanding of what caused their illness. Young adults lost their previous healthy selves and took on new identities of being sick and incapacitated:

[...] it came as a little bit of a shock to me; from being a healthy fit person, who was hiking all the time, to sort of suddenly...having this new life of taking medication all the time [...] So, it kind of turned my world upside down... (Charlie, M, 26 years)

Young adults' reported changes in their ability to function and perform daily tasks, for example, physical limitations and losses experienced affected their lifestyles. The change was perceived as permanent, because of lost health and future dependence on KRT; this affected their engagement with KRT decision-making.

Perceptions of facing KRT decisions

Perceptions of facing KRT decisions embodies young adults' views of needing future KRT; they did not believe it at first. KRT decision-making was perceived as choosing between life and death; threatening their immediate and future life plans, therefore, they preferred not to think about it. As the need for KRT decisions and treatment became a reality, plans for education, employment and future careers were temporarily halted, changed or stopped:

...at the time I was training to be a primary school teacher [...] I thought this would be an opportunity to kind of further my career, ... it was very hard-hitting, very difficult to hear that ... I am going to have to put everything on hold and start this new treatment. (Aaron, M, 29 years)

Theme 2. Health information and education—Option talk phase

This theme describes participants' experiences of the communication of health information and education of kidney disease and KRT options and aligns with the option talk phase of the three-talk SDM model. The theme has two subthemes: communication and understanding of kidney disease and KRT options; health information-seeking and peer support.

Communication and understanding of kidney disease and KRT options

Young adults received planned (one-to-one or group) or unplanned (ad-hoc during routine clinics or hospital admission) KRT options

education, delivered by nurses or doctors during the option talk phase. Participants reported a lack of or suboptimal education about kidney disease and KRT options; few participants experienced good KRT education. Information received was considered one-sided and unbalanced as it focused on benefits, with little information on the risks, practical performance and implications on lives:

They didn't tell me about home haemo, they didn't tell me about any other option, it was just PD (peritoneal dialysis). So they went through all the positives, they didn't tell me about the negatives. So, every option that they give you, it hones into the positives. It's very one-sided ... (Nally, F, 23 years)

The limitation of time, space and some participants still in shock may have affected the absorption, utilisation and understanding of the information provided. These issues and the lack of or suboptimal information, contributed to low health literacy experienced by young adults.

Health information-seeking and peer support

The experiences of unmet informational needs, their lack of understanding of the practicalities and the lack of access to peers with KRT experiential knowledge, motivated health information-seeking elsewhere. While a few young adults asked HCPs for information, others searched electronically about disease and KRT, through peer support online, kidney charities' websites and social media:

...there was a lot of information I gathered as I was so young and terrified at the time. But having all that information and looking online and researching about it and looking at videos, that gave me full confidence of what was going to happen ... (Ben, M, 25 years)

Most participants felt they gained more information of their rights and roles in the SDM context and improved their knowledge and understanding independently and from their peers than from HCPs. Peer support allayed some of young adults' fears and anxieties, improving their confidence to self-manage and provided social support.

Theme 3. Engaging in decision-making, support and choice—Decision talk phase

This theme captures young adults' experiences of deliberation about treatment options and support to make informed or shared decisions about KRT and aligns with the decision talk phase of the three-talk SDM model. There are two subthemes: engaging in decision-making as equal; involvement of family, others and reasons for KRT choice.

Engaging in decision-making as equal

Participants perceived communication as one-way rather than two-way within the decision-making, with less deliberation and elicitation of values and preferences. Young adults could not engage in decision-making as equals because of low health literacy; the lack of awareness of their rights and knowledge about choices, led to disempowerment, especially in the first decision-making encounter:

...it makes me angry now...because at that time I didn't know. Like I didn't realise that I should have a choice. [...] only with experience do you start realising that there is a choice. ...if you have no sense to go forward to make your own choice, then choice is made for you. (Nally, F, 23 years)

Passive instead of active roles were assumed and choices suggested by HCPs accepted, especially during early decisions. Participants felt robbed of their decisional powers as many preferred informed autonomous or shared decisions. With improved knowledge, choices offered, support of family and friends, young adults weighed the risks and benefits and made trade-offs; felt empowered to self-advocate, make their voices heard and later made autonomous and shared decisions.

Involvement of family, others and reasons for KRT choice

Dialysis was considered an immediate option until kidney transplantation: a better option for long-term offering normalcy. Family, partners, friends, academic teachers, employers, HCPs and peers supported young adults during the decision-making processes. Family and friends acted as proxies for information and helped participants to deliberate options. Some offered to become donors and supported the management of treatment. Asking for or accepting kidney donation from family was difficult and emotional due to potential risks, but they were excited when donors were deemed suitable:

...it's a big thing for someone to sacrifice a kidney when it can affect them quite significantly as well, with the risk of operation and things like that. (Harry, M, 29 years)

Personal, social and family factors mattered to young adults and were considered during decision-making, before selecting preferred choices. Participants preferred treatment with minimal disruptions to daily routine while promoting some independence, control, freedom and quality of life:

...the PD (peritoneal dialysis) option that they discussed with me seems to be the best thing to do to get back to work...have my own independence [...] having that control [long silence] that's what is important to me. (Mina, F, 29 years)

In-centre hospital or community haemodialysis, 4 hours every other day, three times a week was considered burdensome, due to major interruptions of daily life and described as 'wasting their day or time'. Young adults in education, employment or with a child preferred peritoneal dialysis or nocturnal haemodialysis to free up daytime for college/university/work/childcare and social activities. Dislike of needles, blood phobia, dialysis access and body image influenced dialysis choice.

Theme 4. Implementation of KRT and transitioning into the new normal life—Implement talk phase

This theme describes young adults' experiences of implementing KRT choices and transitioning into their new normal life. This theme could not align with the three talk phases because this SDM model ends with choice selection. There are two subthemes: receiving KRT choice; searching for meaning of situated events and appraising decisions.

Receiving KRT choice

Receiving KRT relates to implementing the agreed choice, preparation and transitioning to long-term dependence on treatment. Young adults made decisions without fully understanding the impact on their lives, feeling unprepared and lacking support to transition to receiving and integrating KRT into their lifestyle. Restrictions (diet/fluid/alcohol) and rigid KRT regimens made participants avoid going out for meals or night outs; physical limitations and significant adaptations made KRT management difficult:

... with dialysis you feel quite fatigued, ... stops you from doing a lot of things, ...your diet is restricted [...] on fluid restrictions, [...] I was jealous of everyone else that was...able to drink as much fluid as they like and eat whatever they want... (Harry, M, 29 years)

Lack of understanding of the kidney transplant listing processes were reported. New medication routines, susceptibility to infection and possible rejection of transplanted kidney and experiencing dialysis heightened young adults' fears and anxieties, with subsequent poor adherence to treatment regimens. Disruptions to education experienced adversely affected their educational performance. Interruptions to work brought fear of losing livelihoods. Underachievement in career and family life were reported. However, planned support from teachers/lecturers/employers enabled hospital attendance, KRT and achievement of work-life balance.

Searching for meaning of situated events and appraising decisions

Young adults searched for meaning of their situated events and expressed dislike and anger. They felt different and not fitting in with

others in comparison to their healthy age-related peers; hid their diagnosis and treatment from friends initially, as they feared stigmatisation or rejection. Living with kidney failure, making KRT decisions and receiving KRT threatened young adults' life goals and brought significant distress. Fear of dying and being told KRT would make them better, drove participants to make decisions and accept treatment. They struggled to transition from their previous lives to permanent dependence on KRT, experienced decisional regrets, resentments and feeling life was unfair:

I mean, it [dialysis] really sucks [...] I was like I've made a terrible mistake ... so unhappy, ... I was so resentful that I now needed this machine to keep me alive. [...] I didn't maybe have the psychological support that I needed to make the transition from being carefree person to plugged into a machine person... (Zoe, F, 25 years)

Appraising situations and gaining better understanding, making friends, finding partners and achieving goals, improved confidence, self-esteem, self-image and social life. Accepting and integrating KRT into their lifestyles helped young adults to adjust and adapt.

Theme 5. Impact of decision-making and choice on well-being—Cumulative effect from all the talk phases of the SDM process including implementing KRT choice

This theme concerns the cumulative psychosocial impact of receiving kidney failure diagnosis/prognosis, making KRT decisions and receiving KRT on young adults' mental health and well-being. The theme has two subthemes: the psychosocial effect of decision-making and choice; maintaining mental health and well-being.

The psychosocial effect of decision-making and choice

The decision-making processes and implementing KRT brought significant emotions, psychosocial burden and affected young adults' well-being and mental health and their family. Most young adults experienced anger, hopelessness and guilt, blaming themselves for the disease. Families' guilt and blame, especially by mothers, worsened participants' psychological burden. Making KRT decisions and receiving treatment brought fear, anxiety and hopelessness but most young adults lacked psychosocial support. They felt HCPs underestimated the physical, psychosocial and mental effects of decision-making and receiving KRT treatment, on their well-being:

...I think they [nurses] underestimate the impact that it has psychologically and mentally and physically on your life as a whole [...] I wish I had more information ... the kind of mental, psychological, and counselling support before, during and after. (Zoe, F, 25 years)

Extreme fatigue, pain, limitations/restrictions and rigid treatment routines brought depression and self-imposed social isolation, and a

few young adults had suicidal thoughts. For example, one participant refused to attend haemodialysis for 2 weeks until police intervention. Home dialysis management, and the effect of transplant surgery on young adults and their donors, also brought psychological and financial burden for participants and families.

Maintaining mental health and well-being

Young adults struggled to cope and transition from previous lifestyle to their new normal life because of lack of psychological support. Denial, positive thinking, looking at things differently, positive distraction, work, socialising with friends and online gaming were used to maintain mental health and well-being:

I just kept myself entertained by playing video games a lot online at the time. ... it kept me sane ... not going crazy ... video games were like a joy for me to stop may be trying to end my life... (Harry, M, 29 years).

Religion also provided hope and comfort for some participants. Some compared themselves with people living with other long-term conditions and appreciated their situation. Developing skills to manage KRT, incorporating new routines into their life, searching for and receiving psychosocial support from kidney charities, enhanced their coping. A minority later received support from their kidney unit. Families, especially parents and partners, struggled to cope but tried to put on brave faces to support them.

Alignment of the themes with the three-talk SDM model

The five themes representing young adults' decision-making experiences were aligned with the three phases of the three-talk SDM model for further analysis and conceptual meaning of their experiences. The need for a fourth phase, an 'implement talk' phase, was thus identified, as the findings revealed decision-making about implementing therapy choices was also necessary, but currently omitted (see Figure 3).

DISCUSSION

This study is one of the first studies that focused on the lived experiences of KRT decision-making of young adults with kidney failure and has identified unmet informational and decisional needs. Receiving a diagnosis/prognosis of kidney failure, facing KRT decisions and treatment was perceived as bad news (Jackson, 2014) with major impact on young adults' life plans. The lack of knowledge and understanding of kidney failure, KRT options and processes involved, the awareness of future treatment and anticipation of KRT decisions, disturbed young adults' coherent sense of self. They experienced major changes in their self-identity with negative

outcomes and struggled to accept who they have become; adults with congestive heart failure (Van Bulck et al., 2019) and young adults with asthma and cancer (Sligo et al., 2019) experienced similar identity problems. Supporting people to understand their diagnosis/prognosis, how it may affect them and provision of emotional support, should enable better integration of the illness into their lifestyle, before treatment discussions begin.

A lack of time to come to terms with diagnosis/prognosis overshadowed the SDM process. Young adults' knowledge about the disease and goals were not adequately explored and they were unaware that KRT choices existed. Low health literacy affected participants' utilisation of health information which was similarly reported among adolescents and young adults with cancer (Pyke-Grimm et al., 2019) and older adults with kidney failure (Cassidy et al., 2018; Dinh et al., 2022). Information sharing is necessary for effective SDM; lacking information is a barrier to SDM (Muscat et al., 2021). KRT options information delivered to participants mostly focused on benefits but providing balanced information, including risks, promotes better evaluation (King et al., 2020). The inability of HCPs to explain treatment information to young adults in an understandable way reflects inequity of information sharing. Effective communication, framing and tailoring information can improve knowledge and understanding of disease, treatment options and enhance decision-making participation (Cassidy et al., 2018; Kidney Disease Improving Global Outcomes, 2024). Preference for autonomous or shared decisions was desired but participants lacked understanding of the decision-making process and their role and their values and preferences were not always elicited, despite guidelines (NICE, 2021a). In contrast, shared and informed decisions are preferred by older adults with kidney failure than autonomous decisions (Barrett et al., 2021).

Exploring preferences to identify what matters most to the decision-maker is encouraged during decision talk phase of the SDM model (Elwyn et al., 2012). People should be supported to make their own choices, rather than accepting choices suggested, as experienced by some young adults in this study. Personal, social and family related factors influenced their treatment decisions, which was similarly reported among middle and older adults with kidney failure (Shi et al., 2022). Unlike middle-aged and older adults, young adults are transitioning into adulthood and have other needs. Education, independence, careers, starting family and financial security mattered to young adults; these were considered during decision-making and trade-offs made. Supporting people to implement their selected treatment choice should form part of the decision-making process; existing models of SDM end with choice selection but lack treatment implementation. Feeling prepared and supported to implement KRT choice and transition to long-term dependence on KRT is vital. Better transition support for young adults can optimise skills development for self-management, reduce depression, decisional conflicts and regrets. Decisional conflicts and regrets have been highlighted among adolescents and young adults with cancer during treatment decisions (Mack et al., 2019). Problems experienced with the kidney transplant listing process and dialysis access preparation support previous findings (Elliott et al., 2022; Kayler et al., 2021).

Young adults considered KRT decision-making difficult and distressing, perceived as choosing between life and death, compelling them to make a choice. KRT decision-making and experiencing choice affected their physical, psychosocial and mental well-being but considered underestimated by HCPs, as young adults struggled to cope with little/no psychosocial support. The psychosocial effects of KRT identified supports previous findings (Hamilton et al., 2019; Harrington & Morgan, 2016). Psychological support could promote early acceptance of multiple losses experienced, development of coping strategies and better adaptations. The psychosocial burden on families due to their involvement in KRT highlighted by young adults has been previously reported (DePasquale et al., 2019); providing families with psychosocial support might reduce negative effects on both young adults and their families.

Based on the study findings, an 'implement talk phase' is proposed as an addition to the existing three-talk model of SDM, thus creating a four-talk model of SDM (Figure 4). The 'implement talk phase' provides a focus on implementing chosen treatment in this adapted SDM model, to ensure timely discussions about planning, preparing and implementing choice, so the individual can plan their lives before starting KRT.

The existing SDM models provide a generic approach to support people facing decision-making but are limited in addressing treatment implementation and transitioning needs, as experienced by young adults in this study. The lack of an implement talk phase could apply to health decision-making among other age groups with long-term conditions, such as diabetes, asthma, cancer, heart failure. The implement talk phase would offer HCPs the space to discuss the implementation of choice, support transitioning to long-term dependence on treatment and offer appropriate support. Interventional studies are needed to test the four-talk SDM model among young adults and other age groups and explore the treatment implementation and transitioning to KRT. Research to explore HCPs' perspectives of supporting young adults' decision-making would illuminate understanding of their experiences.

Strengths and limitations

Interpretive phenomenology enabled in-depth exploration of young adults' experiences of KRT decision-making. Reflexivity contributed to the study's rigour, transparency and credibility. Robust measures ensured accuracy, trustworthiness and authenticity of the research process. Whilst the study focused on young adults with kidney failure, the findings could transfer to other people facing healthcare treatment decisions, particularly with long-term conditions. Recruitment via social media allowed voluntary participation from a wide geographical area but required networking with people with kidney failure with social media influence and stakeholders such as kidney charities, to advertise the study on their network. Preference for virtual interviews may have limited the capture of all nonverbal communication experiences. There was limited consideration of any additional

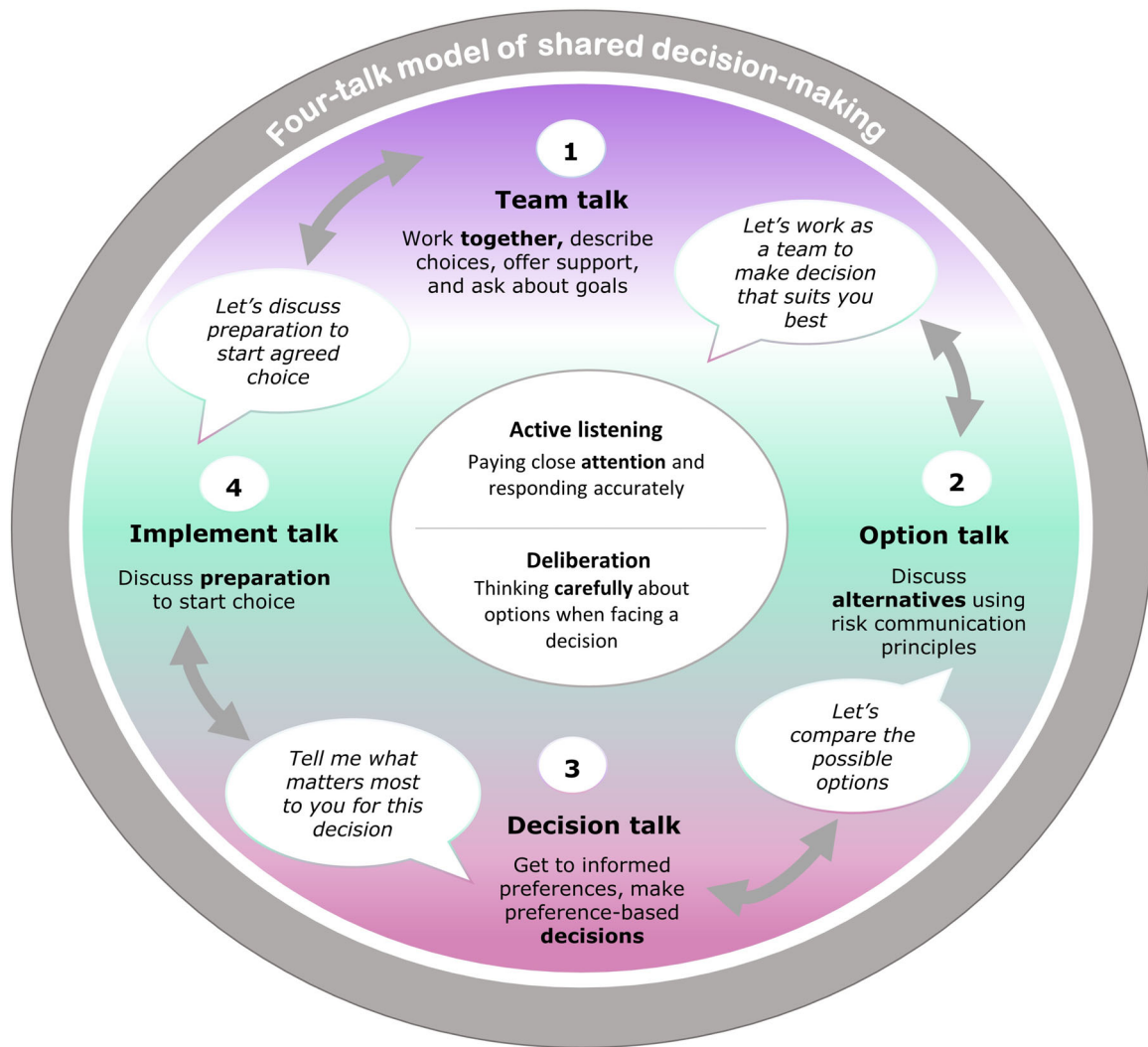


FIGURE 4 Four-talk model of shared decision-making.

TABLE 4 Multiprofessional team, role and education/training.

Multi-professional team	Role
Could include nurses (advanced kidney care, vascular access, pre-transplant and posttransplant nurses), doctors, psychologist and/or counsellor, dietician, social and/or welfare officer, pharmacist, youth and peer support workers.	These different professionals can provide specialist information and support the transitioning to long-term dependence on KRT treatment.
Education and competency training	<ul style="list-style-type: none"> • Could be part of competency skills in renal care to improve knowledge of SDM principles and risk communication skills. • Promote agency and better decision-making.
Education of health and social care and allied health professionals	<ul style="list-style-type: none"> • Should include knowledge and understanding of SDM principles and risk communication. • Practical skills using the four-talk model of SDM through role play and observation in clinical practice.

Abbreviations: HCP, healthcare professional; KRT, kidney replacement therapy; SDM, shared decision-making.

vulnerability among young adults from ethnic and/or minority communities who formed only a small group of the sample.

Implications for policy and practice

A comprehensive approach to treatment decision-making would address young adults' unmet informational and decisional needs, making their voices heard in decision-making. The four-talk SDM model offers a realistic and comprehensive approach to treatment decision-making, to prepare people for transition to long-term dependence on treatment. Usage in clinical practice would address the implementation of treatment decisions and support transition to long-term dependence on treatment. The implement talk phase will enable HCPs to discuss the implementation of treatment, explore readiness to start treatment, discuss vascular access preparation and timelines, pre- and posttransplant issues and management of chosen treatment. A multiprofessional team approach (Table 4) to young adults' decision-making is needed, to incorporate psychosocial support to address gaps. Provision of psychosocial support before, during and after the decision-making process would promote better mental health and well-being.

A policy review could drive a culture change to fully embed SDM in kidney practice, with commitment to achieving better SDM experiences in kidney care.

CONCLUSION

Treatment decision-making and experiencing treatment were considered difficult and threatened immediate and future life goals. Young adults experienced unmet informational and decisional needs, resulting in health information-seeking. Active participation and recognition as a decision-maker who can make autonomous decisions were preferred. Improvement of health literacy can enhance equal partnership and make young adults' voices heard. Decision-making and choice significantly affected young adults' physical, psychosocial and mental well-being but these effects were often underestimated. They struggled to cope but many lacked psychosocial support. The proposed four-talk SDM model would promote discussions about implementing the chosen decision and the smooth transitioning to a long-term dependence on KRT. Interventions with a multiprofessional team approach to SDM, incorporating psychosocial support, could improve young adults' decision-making experiences. Policy review regarding the SDM process in healthcare and culture change to promote and embed SDM in routine care is vital to improve decision-making experiences.

AUTHOR CONTRIBUTIONS

Sarah Ofori-Ansah: Principal project leader; funding acquisition; conceptualisation; project administration; Investigation; methodology; formal analysis and interpretation of data; visualisation; writing—original draft preparation, reviewing and editing; read and approved the final

manuscript. **Michelle Evans:** Review design and methodology; writing—review and editing manuscript; read and approved the final manuscript. **Lesley Baillie:** Review design and methodology; writing—review and editing manuscript; read and approved the final manuscript. **Calvin Moorley:** Review design and methodology; Writing—review and editing manuscript; read and approved the final manuscript.

ACKNOWLEDGEMENTS

The Institute of Health and Social Care, London South Bank University, funded the study. We thank Professor Nicola Thomas and Dr Janice Jones for their contributions and support during the conduct of the study and development of the article. The authors thank the engagement group and all the participants who gave their time to contribute and participate in the study. We also thank all the kidney charities, kidney patient groups, kidney patients with social media influence and healthcare professionals who contributed in different ways to the conduct of the study. We thank all the UK renal centres for providing data to the UK Renal Registry. The views and opinions expressed in this article are those of the authors and do not reflect the views of the UK Renal Registry or UK Kidney Association.

CONFLICT OF INTEREST STATEMENT

The authors declare no conflict of interest.

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SUPPORTING INFORMATION

Additional supporting information can be found online in the Supporting Information section at the end of this article.

How to cite this article: Ofori-Ansah, S., Evans, M., Baillie, L. & Moorley, C. (2024) Young adults with kidney failure lived experiences of kidney replacement therapy decision-making. *Journal of Renal Care*, 1–14. <https://doi.org/10.1111/jorc.12508>