













Experiences of completed and withdrawn unspecified kidney donor candidates in the United Kingdom: An inductive thematic analysis from the BOUnD study

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Objectives. This study sheds light on some controversial aspects of unspecified kidney donation (UKD) as well as the ways in which potential donors are screened and prepared for the donation experience and its aftermath. The aim of this study was to qualitatively investigate the experiences of individuals involved in the United Kingdom (UK) UKD scheme, including those who complete the donation, are eventually medically withdrawn, or self-withdraw. Better insight into the different experiences of these groups will provide useful guidance to clinical teams on how to better address the differing psychological needs of completed donors as well as those who do not proceed to donation.

Methods. A purposive sample was recruited through the Barriers and Outcomes in Unspecified Donation (BOUnD) study covering 23 transplant centres in the United Kingdom. Semi-structured interviews were audio-recorded and transcribed verbatim and subjected to inductive thematic analysis.

Results. Participants consisted of 15 individuals who had donated, 11 who had been withdrawn by the transplant team and nine who had self-withdrawn. The analysis resulted in six themes and 14 subthemes. The major themes were maximizing and sharing benefits;

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risk-to-motivation analysis; support; self-actualization/finding meaning; the donor as patient; and relationship with the transplant team.

Conclusions. The data demonstrate that, although all donors enter the process with a similar level of commitment, those who did not proceed to donation expressed dissatisfaction and lingering emotional consequences linked to lack of follow-up from transplant teams. The implication for the UKD programme is that from the beginning there needs to be a strategic and consistent approach to managing expectations in order to prepare those who embark on the donation process for all possible outcomes and their associated emotional consequences.

Statement of contribution

What is already known on this subject?

- Data from previous studies provide evidence that UKDs have comparable physical and psychosocial outcomes to directed donors.
- UKDs on the whole derive meaning and fulfilment from the experience and come away with positive feelings about the process.

What does this study add?

- So far there have been no studies that have captured data from those who present as potential donors and then do not proceed to donation, and how their experiences differ from those who do donate.
- This study provides guidance for transplant professionals in understanding the psychological consequences and varying experiences of these different groups of donors and will help to strengthen the UKD programme overall.

Background

Living kidney donation (LKD) is the gold standard treatment for end-stage kidney disease. Traditionally living donors are acquainted with their recipient, who is typically a friend or relative. Unspecified kidney donation (UKD) is a form of living donation whereby an individual voluntarily donates a kidney to someone they do not know. UKD has become a regular practice in only a minority of countries, yet where it is established these donations are having a significant impact on reducing the waiting list (Maple et al., 2020).

Despite this, UKD remains shrouded in controversy (Burnapp et al., 2019; Gare et al., 2017; Maple et al., 2020) and the scheme relies on unspecified kidney donors (UKDs) having good physical and psychosocial outcomes, in order to justify transplant professionals subjecting individuals who are otherwise completely fit and healthy to major surgery. Those coming forward as potential UKDs undergo a rigorous series of clinical investigations and consultations to ensure they are sufficiently physically and psychosocially robust to endure the donation process and survive with one kidney thereafter. The mental health component of this assessment includes a formal assessment by a psychologist or psychiatrist (Guidelines for Living Donor Kidney Transplantation, 2018). Data from studies looking at outcomes after UKD provide reassurance that many UKDs have comparable physical and psychosocial outcomes to those donating to someone they know, derive meaning from the experience, and come away with positive feelings about the process (Clemens et al., 2006; Lopes et al., 2011; Maple, Chilcot, Weinman, & Mamode, 2017; Padrão & Sens, 2009; Shrestha et al., 2008); however, long-term prospective data are lacking.

Following this extensive workup process, there are three potential outcomes: (1) proceed to donation; (2) withdrawal by the transplant team for a physical or psychosocial reasons; and (3) individuals withdrawing themselves. To date, there have been no studies that have captured data from those individuals who present as potential UKDs and then do not proceed, and how their experiences differ from those who do donate. As a consequence, there is little guidance for transplant professionals in understanding the psychological ramifications and varying experiences of potential and actual UKDs. A clearer understanding of the similarities and differences among the three groups of donors is essential in ensuring that appropriate support is provided. The aim of this study was to explore the psychological dimensions of individuals who proceeded to donation as well as those who did not, and to better understand the experiences of all individuals involved in the United Kingdom (UK) UKD scheme, irrespective of whether or not they proceeded to donation.

Methods

Study population

All participants were identified from individuals recruited to the Barriers and Outcomes in Unspecified Donation (BOUnD) study (Gare et al., 2017). The aims of this national study, involving each of the 23 transplant centres in the United Kingdom and funded by the National Institute for Health Research (NIHR), were to provide a comprehensive assessment of the UKD programme in the United Kingdom. BOUnD includes a large prospective study of individuals presenting as potential living kidney donors and follows them through to either donation or withdrawal from the programme, and thereafter. Participants of this study were identified from this sample once they had either donated or the decision had been made not to proceed. They were approached to participate after three months to allow for a period of reflection. Demographic characteristics were not deemed to be of significance, so a consecutive convenience sampling strategy was adopted whereby all individuals who expressed interest were recruited until data saturation was achieved. There were no explicit inclusion or exclusion criteria. Eligible participants were classified into three groups: (1) those who donated a kidney; (2) those who had been withdrawn by the transplant team for medical or psychological reasons; and (3) those who self-withdrew from the programme.

Interview script design and delivery

Participants underwent a semi-structured interview lasting approximately 30 min. The interview topic guide was developed using insights from existing research and two focus groups (held by the BOUnD research team in 2016) with individuals who had embarked on the UKD pathway, and had then either donated, withdrawn themselves or been withdrawn by the transplant team. It was based on five main headings: background to donation, experience of social groups, experience of transplant services, barriers to donation and experience post-donation/withdrawal. Interviews were conducted via telephone by two researchers who collaborated to ensure continuity and consistency in the style of interaction between researcher and participant.

Qualitative analysis

The interviews were audio-recorded and transcribed verbatim. The transcriptions included all of the interviewers' contributions as well as all utterances by the participants;

note was made of pauses or emotional interjections. The interviews were anonymized, and the transcripts were circulated to the study team. In order to ensure reliability, each researcher analysed all transcripts independently and then coding was then compared. The coding was conducted using NVivo 11 Plus, and discrepancies in coding were reviewed and reconciled by the coders and members of the team.

An inductive thematic analysis procedure was adopted. This widely used model is explicitly not linked to a pre-existing theoretical framework (Braun & Clarke, 2006) and is considered appropriate when investigating a diverse data set reflecting a range of experiences and attitudes (Bryman & Burgess, 1994). It allows for a rich description of the dataset (Braun & Clarke, 2006). The analysis conformed to the COREQ (Consolidated criteria for reporting qualitative research) checklist (Allison Tong, Sainsbury, & Craig, 2007). The researchers adopted a realist approach towards the data. Donors' articulated experiences were taken at face value; it was assumed that they were reporting honestly about their experiences, without reference to external validation (Joffe, 2011). Data analysis was performed by a multi-stage coding process: familiarization with the data; generating preliminary codes; gathering potential themes; reviewing the themes; refining the themes and labelling them; and conducting the write-up of the analysis (Braun & Clarke, 2006).

In order to gain familiarity with the data, an initial overview highlighted interesting features and began to identify relevant patterns across the data set. The initial codes were developed by identifying verbatim quotes from the original interview transcripts which informed a potential theme of interest (Attride-Stirling, 2001). Next, the authors developed a preliminary set of initial themes from the coding. This process included analysing the codes and considering how these could be combined to produce a coherent theme that encompassed a range of ideas around a common topic (Boyatzis, 1998). Descriptive themes were initially generated and then further refined and condensed into more meaningful analytical or theoretical categories. This grouping of codes into themes and subthemes was an iterative process that involved discussion between the coders and research team. The data were repeatedly scrutinized to ensure that all the significant responses were extracted and allocated to appropriate groupings, in order to ensure the greatest possible interpretive depth. Finally, further review of the data under each of themes was conducted, in order to generate the most robust possible answers to the research questions (Braun & Clarke, 2006; Kuper, Lingard, & Levinson, 2008).

Results

Thirty-five out of 37 individuals responded to the invitation to be interviewed, from 18 out of 23 transplant centres. Fifteen participants had donated, 11 had been withdrawn by the transplant team and 9 had self-withdrawn. Demographic data for participants are provided in Table 1. The median age was 53 years (IQR 15). The analysis suggested six key themes across all three participant groups: maximizing and sharing benefits; risk-to-motivation analysis; support; self-actualization/finding meaning; the donor as patient; and relationship with the transplant team. Each theme is discussed in detail below. Figure S1 provides a graphic illustration of the complex web of interactions between key and subthemes emerging from the data. Table 2 provides supporting quotations.

Theme 1: Maximizing and sharing benefits

Participants tended to have a sense of obligation to society or the world at large, encapsulated as: donating contributes to universal betterment by helping to create a fairer

Table 1. Demographic data

	<i>n</i>	%
Gender		
Female	15	42.9
Male	20	57.1
Ethnicity		
White	34	97.1
Non-White	1	2.9
Relationship status		
Single	12	34.3
Married/Civil or long-term partner	13	37.1
Widowed	5	14.3
Divorced/Separated	5	14.3
Children		
None	15	42.9
Yes – including under 21 years	8	22.8
Yes – over 21 years	12	34.3
Highest level of education		
No qualifications	4	11.4
High school leaver	2	5.7
Vocational qualification	5	14.3
College level	3	8.6
Undergraduate degree	14	40.0
Post-graduate degree	7	20.0
Religious beliefs		
Atheist	17	48.6
Christian	11	31.4
Another religion	6	17.1
Prefer not to answer	1	2.9

distribution of health. This was reflected in the responses of some participants to the effect that, if one has an advantage (such as two working kidneys) they have an obligation to share it so others can benefit. This broader, abstract social commitment in some cases appeared to override their personal commitment to their immediate family network (e.g., the possibility that someone in their family might need an organ in the future).

On the whole, across all three groups, participants appeared to be empathic and possess a strong sense of social justice, at least when applied in a health context. However, among the self-withdrawn group there were cases where the possibility that a family member might need a kidney in the future was a deterrent and their concerns for their family overrode the sense of wider obligation. Others in the same group ultimately felt that the obligation to themselves and their future health was greater than their sense of moral responsibility to benefit others, and as a consequence were not willing to accept the risks associated with living with a solitary kidney. For the medically withdrawn group, a great source of distress was their inability to carry through with an act that reflected their personal ethics or sense of altruism.

Theme 2: Risk-to-motivation analysis

For all participants, there was an implicit calculation during the preparation phase, balancing perceived risks against perceived benefits to one's self or others. Moral

Table 2. Main themes with corresponding subthemes and quotations

Main theme	Subtheme	Quote
Risk-to-motivation analysis	Moral responsibility	'the risk would be small to me, the benefit would be great for someone else and therefore I could make a call that said it was worth doing'. (SWD) 'They talked to me about the risk of dying and I said "well what better reason could I have to die than to offer somebody else some life?"' (MWD) 'it might not have a huge impact on my life but could have such a life-changing impact on one person or even if you have initiated a chain of donations, then several people's lives?' In terms of risk versus reward, the way I saw it was I was very much interested in doing it and wanted to find out more'. (SWD)
	Pragmatism	'I got to thinking well, you know, if the doctors are right, and they do believe that you can live on one kidney, and you have only got two, that means you have got a spare. So it fairly quickly dawned on me then, well I don't need it but somebody else does, so that's really how I got the ball rolling'. (D)
	Confidence in physical health	'I didn't really see any reason why not because I was in extremely good health and so I felt there's a very good chance of passing all the tests'. (D) 'quite honest with you I have always thought that having good health is ... it's not a right, it's a privilege, you know, and as you go through life you meet more people who struggle against all kinds of odds and do so with great bravery and I have been fortunate enough to be quite healthy' (MWD) 'it wasn't you're not going to be able to donate yet, just you're not ever going to be able to donate because we found something that is going to stop you'. . . . what they found was that in the platelet cells there was what they call a genetic mutation which meant that the protein cells were over-producing so that has landed me with a diagnosis of what they call some sort of sunbopsychemia. . . . you are no longer to do with what you were to do with and they have not washed their hands of you but they have moved on, but it's all been a bit traumatic to put it mildly'. (MWD)
Maximizing and sharing benefits	Test of determination/commitment	'that period between the diagnosis and until recently, it's been a real challenge. . . . not able to carry on doing whatever I was doing, and that and I think the accumulation of all of the stress around the stopping the operation and the diagnosis and everything, eventually it got to me and I burst into tears on one clinic appointment'. (MWD) 'No, I mean it was a big of digging around. I mean yeah, it was quite a long time ago now but I do distinctly remember not being able to find an email address and doing a bit of digging around for it'. (SWD)
	Support/approval	'One of the first people that I was referred to was a doctor on the Transplant Team whose job was to try and put me off really and warned me of possible consequences and difficulties and the risks and tried to. . . not tried to scare me but to make sure that I understood the ramifications of what I was doing and he did that well'. (SWD) 'I hoped nobody in my family ever needed the other one because they couldn't get it'. (LAUGHS). (MWD) 'Oh one it kept going back to. . . because I have a little sister who is very young, what if your little sister needs it and you have already given it away to some stranger? and all that sort of thing. Or even my dad, who is over 60 now, was like "what if I need it?" And obviously I get that like, family is obviously very important but I just always thought that giving your kidney to anyone is a fantastic thing to do, whether you are related to them or not, so I really thought it was kind of saving a life. . . . the chances of one of them also needing a kidney donation was so slim, but if it did happen then maybe they would be able to donate a kidney by somebody else doing the same thing I did'. (SWD) 'With most people I just thought well, it's up to them, you know, it's sort of. . . in some respects it's nothing to do with them, it's my choice. The only people really that affected me was my daughters; they were so anti the idea which upset me because I felt that their reasons were a bit selfish and they sort of said "well what if we need one?" and I said "well you haven't got anything wrong with your kidneys;. . . if they had wanted to (because the hospital had told me this), they could have gone in for some testing to make sure there were no indications, but they said no'. (D)
Support/approval	Privacy and disclosure of decision-making	'I mean I didn't really talk to anyone before I went forward in. . . I am quite happy to decide what I am going to do?' [04:49] I am not really the sort of person who needs to consult others'. (MWD)
	Practical and emotional support	'I had made up my mind that this was what I wanted to investigate, what I would like to do, and as I say, I am very much my own person' (SWD) 'Well my wife was fantastic, she was really supportive. Cause it must've been a bit hard work for her at times I should think, I was lucky I suppose I had lots of my friends came round to see how I was, yeah. Which did keep me going really'. (D) 'I will tell you the only thing that surprised me just slightly and it only surprised me because it wasn't something that I had thought of, and it was you asking about what my friends' reactions were and who I told. Now to be truthful I was quite. . . I wasn't expecting that to come up in the questions. . . . I was quite surprised that you were interested in who I had told and what their reaction was, that quite interested me' (MWD)
	Concern about social judgements/ approval	'You are mad, you are absolutely bonkers, why would you put yourself through that?' 'Oh no, what happens if something happens to you and the other one is damaged? and it was all doom and gloom mostly, mostly. . . That was a bit difficult to take because I am not good at taking compliments, and it was nice but it was like anybody would do it, or anybody

Continued

Table 2. (Continued)

Main theme	Subtheme	Quote
		could do, or lots of people are doing it, you know, it was just poo-pooing it, it was like 'I am not that great. I am not a Nelson Mandela or a Mother Teresa. I am just somebody that's trying to find ways of... leading a better life and doing something good, while I have got my time here' and it didn't seem like as big a deal as they were saying it was'. (MWD)
		'Embarrassed. They all thought I was doing something wonderful and great, and I didn't want that. I was just doing it because like I say, in my job I see so many people and I just wanted to help'. (MWD)
		'That is a very difficult one, you still want people to think... oh he thinks I am looking for somebody to praise me up, you know, and say 'Oh, you are a wonderful person' or something.
		But once I had made the decision it was irrelevant what anybody thought, you know what I mean? (MWD)
Self-actualization, finding meaning	Self-satisfaction/self-concept	'If I was to describe me donating the kidney as life-changing, it would be a sort of a minor bit of an understatement... what this has done for me first and foremost is actually allowed me to look at life completely differently now, completely differently, it's allowed me to change a couple of key bits of my own lifestyle, it's actually set me off on a slightly different path to the one I was going on'. (D)
		'Yeah, I think my self-esteem has taken a wee bit of a knock, and I will bury it and forget about it until something like this crops up again and then I get upset'. (MWD)
	Closure	'the one personal disappointment for me is that I've never had any letter or anything from this lady. Now it might be that she died or something terrible happened, I've never had any feedback so, I'm not blaming anybody in the NHS about that but just on a personal level it's slightly disappointing'. (D)
		'But it also was a sense that it's not for me completely resolved. Absolutely, it's something I would consider in the future. When I think about it from a purely logical perspective, I am so zffor it, ... I mean having been through the process and come across like some of the answers to that question, 'why wouldn't you do it?' there's things that don't particularly bother
		me apart from obviously the kind of social barriers with my family and friends, but from a purely individual perspective it's something that I'd think about doing again or revisiting.
		But yeah, but 'regret' I guess is the right answer'. (SWD)
		'We need good publicity to make people realise that, you know, you can donate while you're live, it's a fantastic thing to do' (D)
		'I mean I just would like to think that my positive experience will encourage at least one other person to do the same thing'. (D)
The donor as patient	Becoming an advocate for organ donation	'Everyone was, of course, just like anyone who has had an operation, I was in a ward for, I think I was there for 2 nights... I was in a ward with people for kidney... people with bad kidney diseases so people were... it was very kind of interesting and people were extremely... it was a very sort of warm atmosphere'. (D)
	Personal connection and empathy with people who are ill	'I have never had the chance to compare myself being like lots of standard patients in the hospital, but I felt that they really do care about what I did'. (D)
	Donor/patient status	'Well since dealing with you and being part of this, it has made me think about it which I wouldn't have otherwise and it does, with hindsight, make me wonder how their attitudes would be different, I got to thinking well why are you doing this research? And it must be different, they must deal with us more differently than somebody who is donating for their brother or their dad or their daughter, they must because there is no pressure, there is no urgency, there is no one ringing up checking, I don't know, it must be really intense having a familial donor process, and there just isn't that. The altruistic ones are just random people floating around in the system and I have nothing to compare it with, I absolutely don't, and I would never have even thought of how different we might be treated, had I not been involved with this little bit of research' (SWD)
		'if a nurse doesn't think it's good enough for her family or wouldn't say that her family should do it... I am not saying that everyone in the medical profession is saying it but I just felt like... you know, am I doing something completely extraordinary and ridiculous by giving away my kidney to a stranger, if a nurse is like 'well yeah, I wouldn't let my son do it. If you didn't believe that it was safe and... I know it wasn't really a safety thing, it was more just like... do you really think it's a great process and that people should be doing it? It seemed like a strange stance'. (SWD)
		'I think they put us on a little bit of a pedestal to be honest with you, because they can't quite understand why you do it, and Mr [Grouch] who did my surgery, part of the process was an interview with him, it takes about two hours and then as soon as you walk in he says 'my job is to spend the first hour trying to talk you out of doing this because no doctor should be operating on a well person to make them unwell, and he did do a really good job of trying to persuade me why should I be donating my kidney to somebody that I really don't know and may never know and one thing and another'. (D)
		'then it was just... I was just kind of shown the door and that was it, 'Oh no, you can't do it anyway, sorry, bye'. It just felt a bit abrupt I suppose... 'Yeah absolutely, and there was nothing that... you said that nothing came back from the hospital, no letter or confirmation?' 'No, nothing'. (SWD)
		'You didn't get any follow-up from that at all?' 'No, Not a letter or...? No'. (SWD)
Relationship with the transplant team	Influence of transplant team members on decision-making	
	Follow-up	

Continued

Table 2. (Continued)

Main theme	Subtheme	Quote
		<p>'So then I had nothing, apart from a call the day after the operation should have taken place from the donor nurse coordinator, I had no contact with the kidney people at all and I sat there waiting for 3 weeks before I had my appointment with the haematologist, who obviously I had never met before'. (MWD)</p> <p>'I would have preferred a more human kind of approach and I think despite the distance of travelling I would probably have... what I would have liked was a phone call in advance, you know, whether it was two weeks or a month ahead of my tests expiring to say 'your tests are going to expire, you should come in and have a talk with us' and I think that... because everything is nicer face-to-face than over the phone and certainly then I would feel as though... I wouldn't have felt as though the decision had been removed from me'. (SWD)</p>

Note. D denotes individuals in the donated group; MWD denotes individuals in the medically withdrawn group; and SWD denotes individuals in the self-withdrawn group.

responsibility, as discussed above, while the overriding factor, was not the only motivator in the calculus; they also thought pragmatically about the decision, were confident in their health, and presented as extremely determined individuals.

Pragmatism

This subtheme captured a particular attitude that presented as extremely analytical, objective, and logical. Donating a kidney was not seen as a big sacrifice but rather it was a logical thing to do because they only needed one. Logic also provided a means of rationalizing perceived risk.

Confidence in physical health

Participants were confident at the beginning of the workup process that they were sufficiently healthy and physically resilient to overcome any risks associated with donation, and tended to underestimate risks in relation to the rewards. For all groups, those who mentioned the medical risks of donation either downplayed them or weighted them in favour of the positive impact on the recipient. They appeared to have a stable and confident disposition that drove their behaviour. For the medically withdrawn group, confidence in their physical health was eroded after they were withdrawn from the process; they began the programme with the assumption that they were sufficiently fit, and their exclusion was usually due to a previously unknown medical condition. For many participants, this impacted their self-concept as a healthy individual. For the self-withdrawn group, two individuals realized through the screening process that the risk was greater than they initially thought given their current state of physical health. They expressed concerns about the impact of aging on their future physical health and on their general resilience to illness.

Test of determination/commitment

Participants from all three groups saw the intensive workup process as a challenge that tested their determination and persistence to continue. For completed and medically withdrawn participants, their motivation outweighed the challenges and obstacles that were put in their path. Some members of the self-withdrawn group, on the other hand, were evidently more deterred by the obstacles and inefficiencies in the process; this appears to reflect a lesser degree of determination as all participants were confronted with similar obstacles. There were some discussions around staff members trying to 'put people off' by accentuating the difficulties and risks. While some participants felt that some of this was inappropriately negative, many participants understood the ethical necessity for both the positives and negatives to be presented objectively. There was some uncertainty among participants as to whether the obstacles and delays in the recruitment process (e.g., difficulties contacting the coordinator, multiple visits for different purposes when they could have been combined) were deliberate tests of commitment as opposed to simple disorganization or lack of coordination.

Theme 3: Support

This theme included how the individual was supported, including approval/disapproval from others, whether this support was seen as necessary, and the extent to which it was material to the donor.

Lack of support from family

This included conflict or opposition to their donation. For those who self-withdrew, family conflict, negative opinions or expressions of concern were common factors in the decision. For example, some families pointed out that a family member might need the organ in the future. This type of disagreement was also present within the group who donated, further reflecting the high level of determination within that group.

Privacy and disclosure of decision-making

Many participants kept their intention to donate to themselves or only disclosed it within their immediate social network (partner and/or family). They reported great confidence in their decision from the outset and did not actively seek support or approval from others. Furthermore, many did not see a need for their families to be in contact with the transplant team and seemed surprised at the suggestion. Across groups participants tended to only share their intention to donate with their immediate social circle to start with and this broadened as they progressed through the process.

Opposition from partners and immediate family was an important reason for self-withdrawal. Those in the donated group often did not tell their loved ones, or deliberately told them late in the process, so as not to be influenced by negative feedback. Informing loved ones was seen as a necessity once they had completed the workup process as they would have to explain why they would be absent from work or social gatherings. Some participants expressed indifference when asked about the reactions of family and friends as they felt this was unimportant and irrelevant.

Practical and emotional support

While many of those who donated reported that they informed their loved ones of their decision to donate quite late in the process, many were subsequently grateful for their support, especially after donation, with tasks such as shopping, cooking, and travelling. Often those who donated did not anticipate how much they would rely on others. Many reported having had no previous experience with surgery, therefore little understanding of what support they might need.

Concern about social judgements/approval

Some participants were concerned that their motives would be misinterpreted as self-serving or self-aggrandizing. Others simply disliked being put on a pedestal for doing something that they perceived to be relatively straightforward and for which they had not sought the approval of others. Some participants feared or disliked being judged as 'mad' or not rational. Among those that self-withdrew, there was concern that others would think they were never serious about donating, were just seeking approval, or lacked resolve.

Theme 4: Self-actualization, finding meaning

Self-actualization referred to feelings about the outcome of the donation, the sense of personal accomplishment derived from it and implications of incompleteness for self-esteem and closure.

Self-satisfaction/self-concept

Those who donated for the most part felt a sense of personal accomplishment, growth, improved self-concept, or pride. For some, it was a profound learning experience which caused them to re-evaluate aspects of their lives such as their future career path. The sense of personal accomplishment was related to knowing about the outcome of their donation, whether or not they received correspondence from the recipient, how smoothly their process and recovery had been and what type of recognition they received from their family, social circle, or the transplant community.

Some donors were reticent to talk about accomplishment, downplayed the altruistic aspect of the experience, or denied it had much impact on their lives. For many participants in the medically withdrawn or self-withdrawn groups, lack of completion negatively impacted their sense of self-actualization. Withdrawing from the programme often caused feelings of guilt and upset and impacted on individuals' self-esteem. For some, there was a need for emotional support to process the experience. Although some expressed relief about not having to go through the operation, there was an overall feeling of disappointment and guilt.

Closure

Some donors felt that information about the recipient or a tangible object such as a letter was important for a sense of accomplishment and closure. Some medically withdrawn or self-withdrawn participants lacked closure because there was inadequate follow-up from the transplant team, and this greatly affected some individuals. Lack of closure was felt for a long time, sometimes as long as a year after the experience. Some in the self-withdrawn group hoped to re-enter the programme, thus choosing not to experience closure by not completely ruling out future involvement.

Becoming an advocate for organ donation

Many donors went on to become advocates for unspecified donation. Some became involved in the transplant community while others gave interviews on TV, radio, and print media. These donors believed that having had this experience and sharing it with others made them more credible as advocates or spokespeople for donations. Many had previously donated blood or intended to be deceased organ donors, and this experience reinforced their commitment. In all groups, many participants emphasized the need to promote unspecified donation and felt it should be more broadly known so that others might also consider donating.

Theme 5: The donor as patient

This theme relates to the complexity of the donor's role vis-à-vis the transplant team, their experience as a healthy person voluntarily undergoing a medical procedure, or envisioning themselves as a patient.

Personal connection and empathy with people who are ill

For donors, the experience of being a patient awoke them to some of the reality of kidney disease. Some talked about connecting with kidney patients on the ward during recovery. Many participants who did not proceed to donation still saw themselves as patients while

going through the screening process or visualized a scenario where they did become a patient.

Donor/patient status

Living donation is sometimes viewed as converting healthy individuals into patients. Responses varied when donors were asked if they were treated specially or differently to other patients, with many having not thought about it before being asked as part of the interview. It was noted that by being previously healthy they had nothing to compare the donation experience to. Some remarked that they felt appreciated while others felt they were treated no differently from any other patient.

Theme 6: Relationship with the transplant team

This encompassed the entire process and highlighted key issues related to the role of the transplant team.

Influence of transplant team members on decision-making

Overall there was a lack of consistency in the information provided by different staff members and at different transplant centres, particularly related to the degree of encouragement. Participants in the withdrawn groups reported that surgeons in particular communicated negative messages about preferring not to operate on healthy individuals or subject them to unnecessary risks. This led to one individual withdrawing from the programme. One nurse opined that she probably wouldn't let a member of her family undergo unspecified donation. Those who had donated said that for the most part, interactions with the transplant team were positive and encouraging. Further encouragement was not needed from transplant staff once the decision to donate had been made. On the whole, most donors remarked on the teams' professionalism and their dispassionate way of laying out the process and risks. The least positive relationships were between participants and surgeons.

Follow-up

The withdrawn groups predominantly felt they were left without sufficient follow-up to deal with the emotional or psychological consequences of not completing the process. Some expressed the wish for a letter or face-to-face interaction acknowledging that they had at least attempted to become donors. Some participants in the medically withdrawn group felt that their withdrawal was not properly explained by the team; there was either miscommunication or lack of adequate communication. One person who self-withdrew felt that the response from the team could have been less matter-of-fact and more sensitive to their psychological needs.

Many donors noted a difference in how they were treated before and after surgery. In contrast to the laborious process they went through before the donation, after surgery donors were admitted to a general surgical ward and treated similarly to other surgical patients. This gave some donors a heightened appreciation for what they had done, especially if they had never been in hospital before. Although most donors didn't want special treatment, they did look for some sort of recognition or acknowledgment from

medical staff. In follow-up appointments, some felt that there was insufficient time to address complications and have their needs fully supported.

Discussion

The aim of this study was to compare experiences of the UKD programme for individuals who donated, those who self-withdrew and those who were withdrawn by the transplant team. It provides an in-depth qualitative analysis of 35 interviews and is currently the largest study of its kind regarding UKD. It is the first study to fully explore withdrawn donors' perceptions, and the emergent themes provide direction for both further research and clinical practice, both of which will improve outcomes and enhance the experience for all those who embark on UKD, regardless of the outcome.

One of the most significant findings of this study relates to donors who withdrew voluntarily or were medically withdrawn. Some participants in the medically withdrawn group expressed the view that their exit from the programme was not dealt with sensitively by the transplant team. Many in the self-withdrawn group reported feeling that their initial commitment and investment in the programme was not acknowledged or valued. Members of both withdrawn groups noted the lack of a human approach and some reported that they felt the emotional consequences even a year later. For some, this lack of closure was a source of significant distress and created negative feelings about the entire process, which inevitably will colour the way they portray it to others. This residual regret, in clear contrast to the general feelings of accomplishment and satisfaction among the donated group, is often overlooked by transplant teams. More thought should be given to creating a proper end point for these groups, such as a letter of appreciation acknowledging their positive intentions and their investment in the process. The contribution of all living donors is acknowledged by National Health Service Blood and Transplant (NHSBT) after donation, and therefore, acknowledgement from the individual transplant team is not usually considered necessary.

At the same time, it is critical that medical teams manage expectations from the point of first contact. It should be made clear to potential donors that the process may not result in donation and they must be prepared for the possible disappointment and psychological distress this might incur. This approach capitalizes on the autonomy of self-withdrawn donors by encouraging them to take ownership of their decision and create their own sense of closure. In this way, the team can be sensitive to their feelings while at the same time managing any expectations of further support beyond what health care systems can reasonably provide. Additionally, potential donors should be informed about the transactional nature of surgery and that the intense relationship with the transplant team is transitory.

Findings from the completed and medically withdrawn groups support previous UKD research (Clarke, Mitchell, & Abraham, 2014; Massey et al., 2010; Tong, Chapman, Wong, & Craig, 2013) that demonstrates prospective UKDs to be both empathic and highly determined individuals who take leadership in their decision-making and care very much about the needs of others. Previous research has also indicated that the rapid growth of interest in UKD has been influenced heavily by media promotion (Maple et al., 2014) and a heightened empathetic response to such campaigns may explain why some individuals come forwards as potential UKDs. They appear to have a stable disposition that drives their behaviour; they tend to stick with their decisions and will only change in deference to greater expertise. Those presenting as potential UKDs are confident in their physical health and underestimate risk in relation to reward. Rudow (2012) describes this as 'blind

trust' and notes that this determination has both positive and negative connotations. While it can give donors the necessary drive to go through with donation, it also means that they may not use the evaluation period to reflect carefully on the potential risks and impacts in relation to potential rewards (Rudow, 2012). That is, the determination that motivates donors may also shade their judgement and short-circuit what should be a necessary period of reflection and evaluation. Clinicians should keep this in mind when dealing with potential donors and find ways to ensure that donors demonstrate comprehension of the risks and potential impacts of UKD in their particular circumstances. Ideally a period of evaluation or deliberation should be built into the process without lengthening it unduly, since the long duration of the workup is already a source of dissatisfaction for some.

Our data further reiterate findings from other studies that many living donors make their decision to donate instantly (Andersen et al., 2005; Brown et al., 2008; Gill & Lowes, 2008; McGrath, Pun, & Holewa, 2012), prompted by moral inclinations which are reinforced through rational deliberation. They are pragmatic in that once they identify a problem, they are motivated by their moral commitment to act upon it. Those who go through with donation or are medically withdrawn have high determination from the very beginning of the process, with relatively little consideration of the consequences. They therefore need less support in terms of decision-making but may benefit more from support for the physical, practical, and psychosocial impacts of the process, in addition to a more deliberate approach to helping them analyse the risks and burdens. This study demonstrated a lack of consistency in the information provided by different practitioners and transplant centres. This underlines the need, already identified in the literature, for a more standardized approach towards patient communication (Tong et al., 2013).

Transplant professionals have anecdotally stated that psychological screening (as opposed to medical evaluation) should occur earlier in the workup process [*REF: Donating a kidney to a stranger: Are healthcare professionals facilitating the journey? Results from the BOUnD Study – manuscript in preparation*]. However, this study has shown that those who are medically withdrawn or self-withdraw generally do not do so because of a psychological issue. Social reasons, such as opposition from loved ones, are reported to play a significant role. Early direct questioning and identification of potential social issues may forestall unnecessary medical tests and consultations. The medical team could strongly suggest that potential donors discuss their intention to donate with family earlier on in the process, in order to flag concerns that may prove decisive. In suggesting this, we emphasize that the absence of support is not necessarily a red flag; however, the presence of active opposition may possibly be and for this reason warrants further investigation. For those with no immediate social issues, the mental health assessment may take place at any time, as it will result in only a small proportion withdrawing from the study, but it should not be used as the first opportunity to ask about social concerns.

This study probes the issue of the extent to which UKD can be described as an altruistic act and the implications for ensuring the most positive experience for donors. While some studies report that donors derive significant psychological benefit from going through the UKD process (Boas, 2011; Clarke et al., 2014; Dor et al., 2011), overall the evidence to date is mixed: quantitative retrospective studies, while revealing an absence of psychological harm, fail to demonstrate a benefit for UKDs. Maple et al. (2017) found that psychological outcomes were equivalent for specified kidney donors and UKDs. While the present study demonstrated that completed donors found psychological benefit in completing the process, further prospective research is warranted to further document this. We hope that the prospective questionnaire study being conducted as part of BOUnD will help address

this gap in the literature. Although being motivated by social decency, utilitarianism and an abstract desire to do good for others, donors also act out of genuine empathy for the recipient. The benefit UKDs receive derives not just from knowing they did a good deed, but also from the acknowledgement they receive for it. Many UKDs only attain the highest level of self-satisfaction when they receive affirmation from the recipient (Maple et al., 2017; Slaats et al., 2018). Lack of recognition (e.g., a letter of thanks) impacts the level of satisfaction they ultimately feel from the process. The clinical implication for this is that donors ought to be forewarned from the outset that this is not always possible (the recipient may not be able to respond directly, or they may have difficulty putting their gratitude into words) and they may find this more difficult than they anticipate.

While Clarke et al. (2014) emphasize the importance of social relationships on the process and outcomes of UKD, we think the implications of social support need to be studied further with a view to tailoring a more individualized approach for each potential donor. It is a common assumption that a strong support group is needed for successful donation; however, our findings do not necessarily affirm this. A perceived lack of social support should not be an absolute contraindication for donation. It is possible that the same strong sense of autonomy and determination motivating some UKDs means that these individuals may not need the level of social support that transplant professionals assume. The scant existing literature on personality profiles and organ donation, primarily assessing personality traits several years after the donation, indicates that living kidney donors tend to show more adaptive personality traits and a high level of agreeableness, conscientiousness, and extroversion compared with the general population (Pollmann et al., 2017; Rudow, Iacoviello, & Charney, 2014). Given what we know about the stability of personality traits, this retrospective data may indicate why external validation from social networks is of less importance in the UKD population. This is an important area for further research in order to zero in on criteria for successful donations. Overall, our findings suggest that the issue of social support may be less important than previously assumed and that time spent delving into this during donor workup might be more profitably used in other ways. Previous studies have demonstrated that social support decreases after specified donation; however, this does not appear to have negative implications upon other post-operative psychosocial outcomes, which largely stay static (Maple et al., 2017).

Future studies might further explore the complexity of how to categorize and treat this group in order to manage their expectations better. While the uniqueness of UKDs is obvious to transplant professionals, their distinction from other surgical patients may require a more explicit explanation to potential UKDs. Emphasizing the fact that they are fit and healthy people who are turned into patients (a phenomenon not seen elsewhere in the health service) may help them to understand the reservations that may be held by some of the transplant team, and to appreciate why the process is so rigorous and may sometimes be perceived as onerous. Clarke et al. (2014) describe the phenomenon of 'the paradox of being the 'unobvious patient''. Participants must also be prepared for the possibility that the process may 'harm' them in some way; either physically by subjecting them to an operation they do not need or emotionally by uncovering a medical problem they were previously unaware of. Some UKDs have reported not identifying with the role of being a patient, but rather would be categorized as part of the transplant team. We feel that it is imperative that they continue to be classed as patients, primarily because the duty of care between the transplant team and UKDs is paramount and cannot be jeopardized.

Furthermore, the findings of this study corroborate evidence from the literature of negative attitudes among some medical professionals towards UKDs, suggesting that their

wish to donate is a form psychopathology (Clarke et al., 2014). Although there was no overt evidence of this attitude here, some members of the self-withdrawn group did report that their decision was influenced by the perceived negative opinion of their surgeon regarding the advisability of voluntarily undergoing major surgery. This finding underlines the necessity for a consistent approach that provides candidates with all the necessary clinical information in a non-prejudicial manner. Medical staff should be vigilant about not communicating their subjective opinions in this regard. If there is genuine concern about psychopathology, then this should be referred to the mental health professional on the team, who is in the best position to assess the candidate's psychological suitability. Conversely, if practitioners are expressing negative opinions about UKD in order to test the candidate's commitment, they must be mindful that doing so may eliminate donors who are highly motivated but also conscientious and highly influenced by authority and expertise.

A final interesting finding was that the post-operative recovery in hospital gave some donors a greater sense of empathy and identification with patients living with kidney disease; their abstract empathy became more real as they recognized their own physical vulnerability and shared that experience with people who were actually ill with the disease. This could be seen as one of the possible unanticipated psychological rewards of donation. Overall, there should be greater emphasis on ensuring that donors and transplant professionals fully understand and anticipate the range of possible physical and emotional consequences for UKDs and develop efficient strategies for mitigating them. One possibility would be to give donors the opportunity to be in contact with previous donors who could potentially act as expert donors guiding them through the process.

Limitations

One of the limitations of this study was that the interviews were conducted up to one year after the UKD workup and donation experience. Selecting individuals beyond a three-month time point permitted those who had donated time to recover from their surgery and to provide all participants with time to reflect upon their experiences. Some individuals had difficulty remembering specific details of their experience and there is the potential of recall bias. A second limitation is the lack of racial and ethnic diversity in the sample; however, in the United Kingdom those coming forward as potential UKDs are predominantly White (Maple et al., 2017) and this racial homogeneity is reflected in our sample. Nonetheless, it cannot be assumed that the findings of this study apply to other racial and ethnic groups. If we hope to promote UKD among Black and Asian minority ethnic groups (BAME), it would be helpful to try to enrol a more diverse sample for future projects (Living Donor Kidney Transplantation, 2014: *A UK Strategy*, 2020).

Conclusion

This study describes the motivations and experiences of individuals presenting as potential unspecified kidney donors; some of whom went on to donate and some of whom were withdrawn or withdrew themselves from the programme. The main findings of this study reinforce that completed UKDs on the whole have a positive experience and find fulfilment in the process, with no harm to either their physical or psychological health. The experience for self-withdrawn and medically withdrawn individuals, however, indicates a degree of distress that needs to be better addressed by transplant teams in order to support these individuals and forestall negative feedback that might endanger the UKD

programmes. For all groups, it is critical to develop a strategic approach to managing expectations from the outset in order to prepare them for all the possible outcomes and their associated emotions. A specific suggestion for those not proceeding to donation would be a standardized letter of acknowledgment. For the donated group, consideration should be given to building in a period of reflection in order to address their tendency to downplay risks and under-anticipate burdens. For all groups, the implications of social support or lack thereof need to be further assessed in an individualized manner. Current clinical guidelines must take these findings into account in order to develop proactive rather than reactive strategies that serve the needs of all UKD participants, whether or not the process culminates in a successful donation.

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Conflicts of interest

All authors declare no conflict of interest.

Author contributions

Mira Zuchowski (Data curation; Formal analysis; Methodology; Resources; Software; Validation; Visualization; Writing – original draft; Writing – review & editing) Nizam Mamode (Conceptualization; Funding acquisition; Methodology; Project administration; Supervision; Validation; Visualization; Writing – review & editing) Heather Draper (Writing – review & editing) Peter Gogalniceanu (Investigation; Writing – review & editing) Sam Norton (Methodology; Supervision; Writing – review & editing) Joseph Chilcot (Methodology; Supervision; Writing – review & editing) Alexis Clarke (Investigation; Writing – review & editing) Lynsey Williams (Investigation; Writing – review & editing) Timothy Auburn (Investigation; Writing – review & editing) Hannah Maple (Conceptualization; Data curation; Formal analysis; Funding acquisition; Methodology; Project administration; Supervision; Validation; Visualization; Writing – original draft; Writing – review & editing).

Data Availability Statement

The data that support the findings of this study are available on request from the corresponding author. The data are not publicly available due to privacy or ethical restrictions.

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Supporting Information

The following supporting information may be found in the online edition of the article:

Figure S1. Thematic schema: interactions between themes and sub-themes among donor groups.