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Reflections of unspecified anonymous kidney donors on their motivation and the impact of donation on their mental health: A qualitative study

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Introduction

Living donor kidney transplantation is the treatment of choice for patients with end-stage-renal disease, because it affords the best patient and graft survival (Coemans et al., 2022; Wolfe et al., 1999). Over the past two decades several strategies have been employed to expand the living donor pool, including the introduction of unspecified kidney donation. Unspecified kidney donation refers to a form of living donation whereby a healthy person donates an organ to an unknown recipient, i.e. some they do not know or have never met. Unspecified kidney donors (UKDs) are also known as altruistic, anonymous or non-directed donors (Dor et al., 2011). An unspecified donor can donate directly to a patient at the top of the waiting list or donate in a kidney-exchange program to trigger a chain of donations (Roodnat et al., 2010). The Netherlands was the first European country to implement unspecified kidney donation in 2000 (Zuidema et al., 2009). Currently, the Netherlands and the UK have the highest number of living donor kidney transplants in Europe as well as the highest proportion of UKDs in the living donor pool (Burnapp et al., 2020). In recent years UKDs have accounted for 7–11% of all living donors in the Netherlands (Dutch Transplant Foundation, 2020).

Even though UKDs currently make an invaluable contribution to the living donor pool, unspecified kidney donation remains the topic of much debate concerning the mental health and motivation of these healthy individuals who are willing to undergo surgery for someone they do not know with no obvious benefits for themselves. Although altruism is seen as one of the fundamental principles of organ donation (Moorlock et al., 2014), the motives of UKDs have often been pathologised and perceived as rooted in mental illness, because of the assumed lack of emotional benefit for the anonymous donor (Challenor & Watts, 2014; Henderson et al., 2003). Consequently, UKDs have been portrayed as either "lunatics" or saints" (Henderson et al., 2003). Previously, motives for UKDs have been defined as ethically acceptable (such as altruism, religious beliefs or wishing to reciprocate to society) or unacceptable (such as monetary compensation, a desire for media attention, a desired selection of the recipient by gender, race or ethnicity, and a remedy for psychological malady) (Adams et al., 2002; Kranenburg et al., 2008). Following these theoretical articles, several empirical investigations have shown that UKDs appeared to be caring and highly determined individuals with a strong sense of social responsibility and a genuine, intrinsic motivation to help somebody with their donation (Balliet et al., 2019; Clarke et al., 2014; Kurleto et al., 2020; Massey et al., 2010; Wadström et al., 2019; Zuchowski et al., 2021). Compared to specified/related kidney donors, who donate to a loved one, unspecified kidney donors do not benefit from seeing their recipient getting better. Nevertheless, Maple et al. (2014)did find no significant differences in personality or psychosocial outcomes of the donation between UKDs and Specified Kidney Donors (Maple et al., 2014). Studies on the mental health of UKDs have shown that their mental health has been found similar (or better) when compared to the general population (Massey et al., 2010, 2022; Timmerman et al., 2013). With regard to the psychological outcomes of unspecified kidney donation, previous studies have found no significant increase in psychological symptoms up to a year after donation (Maple et al., 2014; Timmerman et al., 2015). Massey et al. (2022) found no significant change in

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psychological symptoms between pre-donation and post-donation up to (on average) 6 years after donation (Massey et al., 2022). While these studies have found no change in mental health among the majority of donors, in other studies a minority of donors reported adverse events or an increase of psychopathology, such as anxiety and depression, after donation (Bramstedt, 2018; Rodrigue et al., 2011; Timmerman et al., 2013). With regard to the potential positive influence of donation on mental health or experience of benefits among UKDs, evidence is mixed. A number of retrospective qualitative studies demonstrated a positive impact on wellbeing, quality of life, satisfaction, and self-esteem of UKDs (Clarke et al., 2014; Kurleto et al., 2020; Rodrigue et al., 2011; Zuchowski et al., 2021). Massey et al. (2022) also found evidence for psychological benefits of the donation in their quantitative study. They found that UKDs had a significantly higher emotional and social well-being than the Dutch general population (Massey et al., 2022). On the contrary, Timmerman et al. (2015) and Maple et al. (2014) found no significant improvement or benefits in their prospective studies over time among all living donors (Maple et al., 2014; Timmerman et al., 2015).

One limitation of the aforementioned studies is the use of instruments to measure generic concepts that may not be sensitive enough to capture donation-specific experiences and benefits. Moreover, most studies were quantitative. Based on the current data it remains unclear whether the fluctuations in mental health are attributable to the donation process or not. Quantitative studies often draw conclusions regarding findings for the majority, but leave no room for a closer look at the experiences of minorities or for understanding of attributions between donation and (fluctuations in) mental health. Qualitative studies are needed to better understand the extent to which UKDs attribute positive mental health or psychological complaints to the donation process and vice versa. Existing qualitative studies among UKDs focused on their motivations and experiences, but little attention has been given to the relationship of these factors with mental health. In addition, previous literature on psychological outcomes of UKD did not distinguish between donors with and without a history of psychopathology. Over the years our centre has allowed UKDs with pre-existing mental health problems to donate, although only after a thorough psychiatric evaluation and after consultation with both the GP and the current psychologist/psychiatrist. We, therefore, have the unique possibility to investigate the interplay between donor motivation and mental health. Analysis of this unique group and the interplay between donation and mental health is of great clinical value to mental health clinicians and the living donation teams performing a psychological evaluation of UKDs worldwide. Therefore, this large retrospective qualitative study aimed to investigate the following questions: How do UKDs describe their motivation for donation and their mental health? Secondly, do they describe a relationship between the donation and their mental health? Thirdly, to what extent are there differences in themes according to whether or not donors have (had) mental health problems?

Measures

Study design

The present qualitative analysis is part of a larger mixed-methods study on the experiences and mental health of UKDs. Ethical approval for the study was obtained from the institutional review board (METC -2017-1180). All procedures complied with the ethical standards outlined in the Helsinki Declaration of 1975, as revised in 2013. The analysis and reporting of the study conforms to the COREQ checklist (see Supplementary Files) (Tong et al., 2007).

Research team

The research team consisted of all authors (3 psychologists, 2 nephrologists and 1 prior unspecified donor coordinator). The second author collected the data. She was involved in the initiation and coordination of the UKD program from its inception and was known to all participants through her previous role as unspecified donor coordinator, however, during the study she was not involved in the clinical care pathway. Data analysis was conducted by the first and second author. The first author is a psychologist (MSc.) with experience in qualitative research. She was not involved in the care for unspecified kidney donors. All other authors were part of the living donor team.

Study sample and recruitment

All UKDs who donated a kidney at the Erasmus MC Transplant Institute in the Netherlands between 2000 and 2016 were invited to participate (N = 142). Donors were included if they were above the age of 18 years and had donated anonymously to the waiting list or through a domino-paired exchange programme. The domino-paired exchange programme is the Dutch equivalent of an altruistic donor chain. In this procedure the UKD donates to the recipient of an incompatible donor-recipient couple who participated in the national Kidney Exchange Program and in turn, the donor of the incompatible couple donates to the waiting list or to the recipient of another couple from the exchange program, provided that the potential donor of that couple also donates a kidney (Roodnat et al., 2010). Exclusion criteria were death, therapeutic donors (who underwent nephrectomy for medical reasons) or donation anonymously through the paired exchange program (donors from an incompatible donor-recipient couple). All donors underwent medical and psychological screening, as part of the standardized living donor work-up in our Transplant Institute. All eligible UKDs received a letter from the Erasmus MC Transplant Institute that included information on the study. They were called two weeks later to assess willingness to participate. If applicable, an interview appointment was made.

Data-collection

A semi-structured interview was conducted with each participant between February 2018 and August 2019. All interviews were audio-recorded with permission and informed consent forms were signed at the beginning of the interview. To ensure rigor, we used an interview protocol to ensure a consistent method of data collection. All interviews were conducted by the second author (WZ) which lasted approximately 45 min. The interview protocol (see Supplementary Material) was developed by the multidisciplinary research team and covered the donors' motivation for the donation, questions about the donors' mental health history, and questions about whether their mental health improved or deteriorated in the run up to the donation, around the donation and/or after the donation. We also asked whether participants would, in retrospect, make the same decision to donate again. If medical issues arose during the interview, these were communicated to the nephrologist with permission of the donor. If mental health issues arose, these were discussed with the donor, and, if desired, communicated in writing to the donors' General Practitioner (GP) for further follow-up. Most interviews took place in the out-patient clinic (combined with the yearly check-up). In some cases, data was collected at the donors' home, depending on participants' preference, mobility and health. In all settings data was collected individually to ensure privacy. Socio-demographic and medical characteristics were obtained from patients records or donor database and checked for accuracy at the beginning of the interview. In addition, some quantitative measures were administered, which were published elsewhere(Massey et al., 2022).

Data management and analysis

All interviews were audio-recorded and transcribed verbatim. Each transcript was anonymized and given a unique study number which was used to identify quotes in this publication. NVivo 12 supported data management and coding. Transcripts were coded independently by the first and second author (MP and WZ). We independently coded the

interviews in batches of 20 interviews at a time, using an inductive thematic analysis in which we followed the six steps described by Braun and Clarke (Braun & Clarke, 2006). Both coders began by reading a selection of transcripts and independently assigning descriptive codes to sections of text that were relevant to the research questions. After this we discussed the codes assigned. This resulted in an extensive initial code framework, which we adjusted and extended with codes we identified while coding the next batch of transcripts. After each round of coding conceptual overlap and newly emerging themes were discussed and the codebook was revised accordingly. Simultaneously, we considered how different codes could be combined into overarching themes or subthemes. Through this process the descriptive codes were redefined and condensed into more meaningful and analytical categories. The data and the code framework were repeatedly scrutinized by the first and second author to ensure that all the significant responses were extracted and allocated to appropriate themes. In each phase of the analysis coding discrepancies were discussed until agreement was reached. When necessary, the last author (EKM, *psychologist* (*PhD*)) was consulted. To assess whether differences in themes existed according to whether or not donors have (had) mental health problems we divided donors in three groups: donors who never experienced mental health problems (group 1), donors who experienced pre-donation mental health problems in their past that were no longer present during or after the donation (group 2), and donors who experienced mental health problems during and/or after the donation and/or during the interview (group 3). Group 3 includes people who had pre-donation mental health diagnoses that continued during and/or after the donation. Nvivo crosstab queries were used to check the distribution of themes across the different groups. To increase transparency and credibility of the findings we included quotations from each group and marked them with a group identifier to make clear if this quotation belongs to a donor with or without (a history of) mental health problems.

Results

Participants

During the study period 142 unspecified donors had donated a kidney, either to a patient on the deceased donor waiting list or in an exchange procedure. At the moment of inclusion 8 donors in this cohort had died. Cause of death was unrelated to living donation and occurred after a median of 52 months (range 31–164) after donation. Another 8 donors were therapeutic donors. Of the 126 remaining eligible donors, 106 gave consent to participate (84%). Reasons for non-participation are outlined in the Supplementary Material. Both positive reasons, such as having achieved closure, and negative reasons, such as dissatisfaction, were reported. Socio-demographic and medical characteristics can be found in Table 1. Median age at donation was 59 (range 21–89 years).

Presence of psychopathology

Sixty-four participants (60%) had never experienced mental health problems (group 1). The remaining 42 (40%) participants received a psychiatric diagnosis and/or mental health treatment at some point in their lives. The self-reported prevalence of psychopathology in our donor cohort is similar to the lifetime prevalence of psychiatric disorders in the general Dutch population, which was found to be 42.7% (de Graaf et al., 2012). An overview of the self-reported diagnoses can be found in Table 2. Nineteen donors (18%) experienced mental health problems before the donation, but did not mention any psychiatric complaints at time of or after the donation (group 2). Twenty-three donors (22%) reported having (had) mental health problems at time of the donation and/or after the donation (group 3). Twelve of them were still in treatment at time of the interview. Six donors (1 from group 2 and 5 from group 3) suggested they had not been totally honest about their mental health problems during the psychological screening (predonation).

Table 1
Socio-demographic and medical characteristics (N = 106).

Socio-demographic characteristics	
Female gender: N (%)	57 (53.8)
Age (years) at donation: median (range)	59 (21–89)
Age (years) at study: median (range)	67 (25–94)
Ethnicity: n (%)	
- European	105 (99.1)
- Asian	1 (1)
In paid employment: n (%)	56 (52.8)
Highest level of education	
- Primary school	5 (4.7)
- Secondary/high school	48 (45.3)
- Further/higher education	53 (50.0)
Marital status: n (%)	
- Married/living together/partnership	61 (51.9)
- Single/divorced/widowed	51 (48.1)
Has children: n (%)	65 (61.3)
Has religious affiliation: n (%)	46 (43.4)
Medical characteristics	
Time (months) since donation: median (range)	71.50 (23–153)
Registered in deceased donor register: N (%)	92 (86.8)
Registered to donate body to science: N (%)	2 (1.8)

Table 2
Prevalence of the self-reported psychiatric diagnoses and psychiatric problems during the interview.

Psychiatric diagnoses	Group 2 Donors with mental health problems before the donation only [a] (n = 19)	Group 3 Donors with mental health problems during and/or after the donation [b] (n = 23)	Group 2 and 3 combined [c]
Depressive disorder	7	14	21
ADHD	1	5	6
Borderline Personality disorder	0	6	6
Addiction	2	4	6
Autism Spectrum Disorder	2	2	5
Burnout	3	2	5
Anxiety Disorder	2	3	5
PTSS	1	2	3
Personality Disorder NOS	0	1	1
Eating disorder	0	1	1
Schizophrenia	0	1	1

[a] This group of donors did not mention any psychopathology at time of donation or at time of the interview.
[b] The prevalence of self-reported diagnoses in this column incorporates all diagnoses that participants received across their lifespan (not necessarily the diagnoses they received treatment for during or after the donation).
[c] The total number of psychiatric diagnoses does not add up to the number of donors who experienced psychopathology (n = 42), because of the presence of comorbidity in some donors.

Overview of themes

In total 8 themes were identified. Three themes reflected the donor motivation: wanting to help somebody, inspired by religion or principles, and improving self-image. Table 3 presents quotations illustrating the motivation of participants. Five themes reflected the impact of the donation on participants' life and mental health: satisfaction and happiness, empowering experience, life-changing experience, brief psychological distress, and ongoing negative emotions. Table 4 presents quotations illustrating the impact of the donation on participants' life and mental health. A thematic scheme of the motivation for donation and

Table 3
Quotations reflecting donor motivations.

THEME	GROUP 1	GROUP 2	GROUP 3
Wanting to help somebody	"I wanted to give someone a better life. I became a donor to make someone happy, because having to be on dialysis all the time, is just miserable." (110 male) "We have two kidneys and you can have an excellent quality of life with one healthy kidney, while the other one can possibly give someone else the same quality of life." (154 male) "I had this personal reason to pass on life. My sister just died of Alzheimer's. My husband had cancer. Things you cannot do anything about and this was something I could do." (247 female) "Altruism is a pretty word, but it did come from a certain kind of selflessness. I just liked it that I could help somebody." (42 male)	"I like to give something to people who are having a hard time. It just sucks that people have to die young or have to start dialysis. I thought that if I can do something about that, I'd like to do that. I read up about unspecified kidney donation and concluded that the risk for me wasn't so big that I didn't want to take it." (173 female) "I just wanted to do something for another person." (89 male) "My donation was about helping somebody, because it might save someone's father or mother who wants to keep living. And I can do without that kidney." (322 female)	"I thought if I'm able to live a good life anyway, why wouldn't I donate a kidney? It's in my blood to help someone if that person needs help." (24 female) "I initially wanted to donate to my aunt, but it was already too late for that. Then I looked into living kidney donation and I learned that it is also possible to donate anonymously. Then I was like: I can't help my aunt anymore, but I could help someone else." (172 female) I like to give something to people who are having a hard time. If I am able to do something about that, then I am happy to do that. I thoroughly read up about it and concluded that the risks weren't such that I didn't want to take them." (302 male)
Inspired by religion or principles	"I donated based on my Christian belief. It is written somewhere that anyone who has two shirts should share with the one who has none." (94 male) "My wife and I always believed that we could help somebody else and also based on my religious background I said that if I can help someone I have to do that." (253 male) "I'm not the kind of person to collect money for charity. I donated my kidney and did my share." 262 female) "I think my motivation is that I am a social democrat and one of their principles is to create a certain equilibrium in society. To me that matched with	"The idea of love thy neighbour, I mean, I am a member of a Christian church. I hardly read the newspaper, but I was drawn to that article [about anonymous donation]. To me it was like a hint, it didn't come out of thin air. (89 male) "Like the Christians say, you're not on this earth just for yourself. I try to live my life in a way so that I can give to others as well." (374 female) "To me it is pure math. I believe that everybody should donate a kidney. So why don't I do it? Moving from words to deeds. If you believe it should be like this, then you have to act on it." (466 male)	"I think, it was a process that started way earlier, for me at least. (…) I think that people develop their own thoughts/ideas about donation but in the end that society as a whole benefits." (417 male)

Table 3 (*continued*)

THEME	GROUP 1	GROUP 2	GROUP 3
	donating my kidney." (427 male)		
Improving self-image	"You expect to be seen as a hero for a moment" (426 male)	"An important motive for me was that you kind of bolster your self-esteem, so to speak." (186 male)	"I was so proud my body could do all this. Mentally I might be a little unstable every now and then, but physically there is nothing wrong with me." (172 female) "I was convinced that I wanted to donate and leave something positive behind and I had the impression that my body was ruined but that turned out not to be the case. So I was really happy when I got accepted." (215 female) "I was involved in some quite nasty things and I feel like I have to compensate for that the rest of my life." (417 male)

impact on mental health after the donation is provided in Fig. 1.

Motivation for donation

Wanting to help somebody

Donors described themselves as being caring and sociable persons. Some mentioned enjoying giving rather than receiving and/or have a tendency to put others before themselves. The biggest reason for donors to donate their kidney to a stranger was to help somebody in need and to share their good health. The majority of donors described themselves as being assertive, perseverant and independent thinkers. The caring personality of these donors is also expressed through other altruistic acts. Many UKDs had made other donations (e.g. blood or bone marrow) and were active volunteers. A small group of donors wanted to donate a part of their liver or lung and two donors reported having donated a part of their liver after their anonymous kidney donation. Regarding the kidney donation, donors were absolutely determined to donate, even when facing questions and criticism from friends and relatives. They found it natural to donate as it would cause them only a little discomfort and they were able to live a good life with one kidney while the recipient gets a chance at life. Some donors knew a kidney patient and experienced consequences of kidney failure first hand, while others learned about the possibility of living kidney donation through the media. Some donors explicitly mentioned the wish to do something meaningful or talked about their donation in terms of compensation. It was important for them to help someone, because they had been unable to help a loved one who suffered a disease or had received medical help themselves. This theme was mentioned by 77% of donors without mental health problems (group 1) and by 66% of donors with mental health problems before or during/after the donation (group 2 and 3 together).

Inspired by religion/principles

Some donors said, that their wish to help someone was derived from their Christian worldview (love thy neighbour) or from the idea of the common good. For the latter group, the donation was the result of the wish for equilibrium in society, or merely an alternative form of charity. This theme was mentioned by 16% of donors without mental health problems (group 1) and by 17% of donors with mental health problems

Table 4
Quotations reflecting the impact of the donation on participants' life and mental health.

THEME	GROUP 1	GROUP 2	GROUP 3
Satisfaction and happiness	"Up until today I am grateful that I was able to donate my kidney." (94 male) "I was glad for [the recipient] and I was also glad that the donation worked out well for me." (385 female) "I was very satisfied that I was able to do this and felt good about it. And if I were to make a balance of my life, considering the good things and the bad things, the donation is a big tick on the good side." (451 male) "I'm glad that I donated my kidney. I got a bit more positive about lots of things, as if everything got mixed up with a scoop of positivity." (513 male)	"Knowing that there is someone who is able to live another 15 years with my kidney, that is just great. It is a personal enrichment if you can do something like this. (…) All acts of love change your own heart as well." (182 male) "I felt good for doing something for another human being" (217 female) "We were glad that it worked out well and that I had a smooth recovery. I wanted this and I was very happy about it afterwards." (249 female)	"I am glad that I was able to help these people, I am just glad." (44 male) "A life has been taken away from me and I was able to give someone a piece of life back. Passing on life, that was a beautiful experience to me." (76 female) "Right after the donation I got this feeling, wow, it is really special that I was able to give somebody his life back. Because that is what it is. That gave me an intimate feeling of satisfaction" (117 male) "It makes me feel peaceful; somebody has my kidney and was very happy with it. I might idealize it a bit in my mind, but yes, it still feel good about doing it." (380 female)
Empowering experience	"The donation gave me a boost and I felt stronger about myself." (23 male) "The donation made me mentally stronger, in the sense of that I think it worked out well for me and the environment looks at me in a certain way, it commands respect." (102 male) "In one way or another you are a little proud on yourself. The donation made me feel good, honestly. (…) You do something that not many people do. That made me feel like: I just did it!" (369 female) "I am not sure whether I am fooling myself, but I think that, since the donation, I am more self-confident in life, although I've never been short of that before the donation." (426 male)	"I've been euphoric for a year! I just thought: 'it worked!'. It's the same as with dreading the birth of a child. That hurts of course, but afterwards it was all worth it. I had that joy for a long time." (45 female)	"Look, I was out born out of a rape, so I always thought that I shouldn't have been born. Now, because of the donation I think: it still is important that I exist, because I was able to help somebody." (119 female) "I felt better after the donation. My own children didn't speak to me anymore but after the donation strangers or acquaintances sent me flowers. It made me feel like: "I just did it" and my self-esteem has improved." (215 female) I″ believed I did something good. I am still like: I did something what has improved the life of somebody else." (282 male) "The donation did me good. When I think of my parents they would have done the same and it feels like a pat on the shoulder from my father: 'you did well, girl'". (420 female)
Life-changing experience	"I had a euphoric period that started one month after the donation." [participant talks about how he changed jobs following the donation and learned important truths about his family.] "In hindsight I thought about whether the donation might have been a catalyst for what happened then." (103 male)	"The donation is the best thing that ever happened to me. I see you look surprised, but it is true. You think your life sucks, but then you get to do something as beautiful as this." (45 female)	"The donation has enriched me. As the depression marks a difficult period in my life, the donation marks a very beautiful period in my life. It really was a highlight for me." (337 female) "The donation was a turning point for me. I can't say it is only been good since then, but things did get better, and before that it was always bad. […] I didn't expect this to happen after 15 years of depression. […] It must have been the words of the donor coordinator who said that I made someone happy, that someone can continue with his life." (414 female)
Brief psychological distress	"The first days after the surgery have been unpleasant, because I was vomiting a lot from the morphine which caused extra pain due to the abdominal wound. I was so full of self-pity that I wasn't even aware that the doctor told me that the surgery went well and that the recipient was happy." (354 female)	"About 7 months after the donation I got a terrible burn-out. (….) During my recovery I learned that I have the classic personality characteristics that put people at risk for burn-out (…) You have to take care of yourself on the one hand but on the other hand I'd been through a series of life events, including the kidney donation." (182 male)	"Two weeks after the donation I suddenly got very anxious. I already had it in the hospital, right after the donation, but the anxiety subsided soon [after getting antidepressants]." (24 female) "After the surgery I felt terrible bad. I constantly walked in circles, searching for my kidney and was crying uncontrollably." 342 (female)
Ongoing negative emotions	"It's like delivering a package, after that you're just dismissed." (451 male) "Yes, it still hurts me, when we talk about it now. It feels like a hangover: the disappointment about how I was treated still remains, it cannot be changed. You don't expect to be treated like a princess, but I expected a basic amount of care, and I was angry because I didn't get that." (341 female) "From the moment I got hospitalized on you are just a patient and you are dealt with. Physically I was treated very well, but the emotional psychological care was zero. (…) Afterwards I had the feeling that I was neglected. Because I received so much attention beforehand that created the expectation that it came with the donation process. And then it wasn't, because after I got approved as donor I was just a regular patient." (403 female)	"I would not do it again [the kidney donation]. I feel like I've never been as good as before, physically I mean. Mentally I feel the same, but I feel like my physical health has deteriorated." (173 female) "I felt down because you did something and you receive respect from a lot of people, but in the end I lose again because things did no go well here. [Donor talks about his frustrations concerning the financial compensation of the costs he made for the donation.] "I am still frustrated, because another hospital does offer free parking." (397 male)	[Donor talks about his recipient finding out about him writing a blog about his donation experience. The wife of the donor asked him to remove the blog, because it had caused a lot of turmoil in their family.] "That was very hard to me. I felt like they should have been glad, 'you got a new life'. To me it was like that they didn't like it that it was my kidney, that it came from me. The only way I was able to process this was by thinking that maybe it had to do with their faith, that it's not allowed or something." (282 male) "No, I would not make the same decision again, because I expected to be thanked. […] "I felt desperate for a very long time. I felt not seen, not heard, not valued. 'You're good enough to give your kidney, but besides that you're useless.' This was not beneficial for my self-esteem. Any normal person would not go so far for their self-esteem, but I did. […] For me the costs exceeded the benefits." (342 female)

before or during/after the donation (group 2 and 3 together).

Improving self-image

Some donors mentioned a generally low sense of self-esteem prior to donation. They felt insecure about their capabilities or felt unloved. For these donors the donation was a means to bolster their self-image and a way to prove that they (or their bodies) were capable of doing something meaningful. Others suggested that for them, the donation was an atonement for the damage they had done to others earlier in life, such as involvement in criminal behaviour. This theme was mentioned by 2% of donors without mental health problems (group 1) and by 24% of donors with mental health problems before or during/after the donation (group 2 and 3 together).

Mental health after the donation

Satisfaction and happiness

Donors mentioned a positive influence of the donation on their level of happiness. They felt good about helping somebody and used several different words to describe this good feeling: joy, a sense of satisfaction, and gratefulness for the opportunity to become a UKD. A small group of donors specifically mentioned that the donation contributed to a more positive outlook on life. Most experienced a smooth recovery and, except for two donors, all would make the decision to donate again. This theme was mentioned by 52% of donors without mental health problems (group 1) and by 60% of donors with mental health problems before or during/after the donation (group 2 and 3 together).

Empowering experience

Many donors suggested that the donation was a boost for their self-esteem and self-confidence. They mentioned feeling proud of themselves for being a living donor. This feeling of empowerment was increased by receiving respect and attention from others, who are generally impressed by the kidney donation. A few donors suggested that they still use the donation to make a good first impression. This theme was mentioned by 55% of donors without mental health problems (group 1) and by 41% of donors with mental health problems before or during/after the donation (group 2 and 3 together).

Life-changing experience

For a small group of donors, the donation was an extraordinary experience, because it was one of the highlights of their life or because it brought about important changes, such as quitting an addiction such as smoking or drinking. For a few donors the donation led to a boost in personal growth (e.g. a better understanding of their life story, skills and goals in life) and one donor mentioned a reduction in self-harm after the donation. This theme was mentioned by 3% of donors without mental health problems (group 1) and by 19% of donors with mental health problems before or during/after the donation (group 2 and 3 together).

Brief psychological distress

Few donors mentioned a temporary increase in psychological complaints shortly after the donation. One donor, who suffered from postpartum depression in the past, got very anxious after the donation. She received medication and the anxiety subsided after a few weeks. Two donors experienced burn-out shortly after donation, but stated this was caused by other stressors that caused tension at time of the donation (e.g. moving houses or stress at work). Three donors struggled with "feeling empty" or "feeling asymmetrical" after the donation: they missed the physical presence of their kidney. Two of these donors both suffered from multiple psychiatric disorders. This theme was mentioned by 5% of donors without mental health problems (group 1) and by 12% of donors with mental health problems before or during/after the donation (group 2 and 3 together).

Ongoing negative emotions

Some participants suggested they expected to get special attention or recognition from hospital staff or society, because of their altruistic act, and were disappointed and sad when the hospital staff did not treat them accordingly. Some participants felt frustrated about donation related expenses, such as travel costs, and were dissatisfied about the financial compensation they received. A few of these donors were still frustrated and emotional about this at time of the interview. One donor, who got diagnosed with bladder cancer after the donation, worried about that she might have put her recipient at risk for cancer as well. Two female donors regretted their decision to become a living kidney donor. Both donors were dissatisfied about the hospital care they received and criticised the lack of empathy from the hospital staff and/or the reimbursement procedure for donation related expenses. Also, both of them struggled with the scar from the kidney donation and underwent plastic surgery at their own costs. One of these donors mentioned she suffers from persistent numbness in her leg since the donation. The other donor said that her suffering increased after the donation, probably because she was disappointed in the impact of the donation on her life or mental health. This theme was mentioned by 5% of donors without mental health problems (group 1) and by 10% of donors with mental health problems before or during/after the donation (group 2 and 3 together).

Discussion

In this qualitative study we explored the motivation for donation and mental health of the cohort of unspecified kidney donors (UKDs) of our transplant centre. This study included 106 altruistic donors and is the largest qualitative study regarding unspecified kidney donation to date. The novelty of this work comes from its comparative analysis of donors who had or did not have mental health problems prior to the donation. We found that for the majority of UKDs with or without pre-existing mental health problems, the donation was an empowering experience with a positive impact and did not seem to harm their mental health.

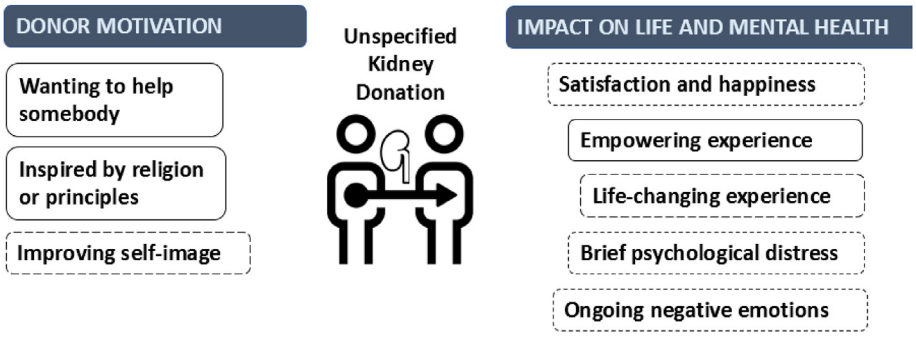

Fig. 1. Themes reflecting the motivation of UKDs and the impact of the donation on their mental health.
Themes surrounded by a dashed line were reported more often by donors with (a history of) mental health problems compared to donors without mental health problems (percentages are reported in the text).

Psychological benefits of UKD have been reported in previous studies (Kurleto et al., 2020; Rodrigue et al., 2011; Wadström et al., 2019; Zuchowski et al., 2021), but this qualitative study contributed to a deepened understanding of those benefits by its qualitative design, comparative analysis and large sample size. Almost all donors reported an increase in happiness and feelings of satisfaction and accomplishment after the donation, and they attributed these changes to the donation. They referred to the donation as an empowering experience, which seems to be caused by an internal feeling of pride on the one hand and an external endorsement in the form of receiving acknowledgement from others on the other hand. Importantly, participants who experienced mental health problems seemed to share in the empowering effect of the donation on their lives or sense of self. The theme of donation being an extraordinary and life-changing experience was more commonly reported among those who had experienced mental health problems than among those without. For these donors the donation was a highlight in an otherwise difficult life.

Although the psychological benefits were experienced by many donors following the donation, this was not the main motivation for most donors. In line with previous research, we found that the most common reason for donors to donate their kidney to a stranger was to help somebody in need and to share their good health (Balliet et al., 2019; Clarke et al., 2014; Henderson et al., 2003; Novogrodsky et al., 2019; Zuchowski et al., 2021). A novel finding of this study is that a small group of donors expected to gain psychological benefits beforehand; they perceived the donation as a way to bolster their self-image or self-esteem. This expectation was expressed more often by donors who have (had) mental health problems than by donors without. Similar findings have been reported by Henderson et al. (2003) who found that some donors were motivated by a desire to make up for past wrong-doing or by personal experience with hardship (Henderson et al., 2003). This finding is relevant to the long-standing debate on the motivation and mental health of UKDs and the questions whether pure altruism really exists (Moorlock et al., 2014). Mauss, one of the founding fathers of the gift-exchange theory argued that a gift is never free of some kind of reciprocity (Mauss, 1990, as cited by Ashworth et al. (Ashworth, 2013)). The rewards of a gift, however, are not limited to an economic exchange, but might also entail psychosocial rewards, such as inclusion in society or making a claim of identity (Ashworth, 2013). Also Titmuss (1970), who discussed the gift in blood donation wrote that: “No donor type can be depicted in terms of complete, disinterested, spontaneous altruism. There must be some sense of obligation, approval and interest; some feeling of ‘inclusion’ in society; some awareness of need and the purposes of the gift.” (as cited in Ashworth et al. (Ashworth, 2013)). Challenor and Watts, who investigated how prospective altruistic kidney donors construct their decision to donate, concluded that: “Altruistic donation can also be thought of in terms of a possible response to loss in the donor's life, a way of making concrete feelings about loss that cannot be spoken about. This suggests a profound rethinking of the notion of ‘altruistic’ in which donation becomes an embodied and psychological response to perception of a socially and technologically constructed need” (Challenor & Watts, 2014). In line with these researchers we believe that motivations of UKDs will often be mixed, as was the case among the participants of this study. An assessment and discussion of the motivation for donation should therefore always be a part of the psycho-social evaluation of potential donor candidates.

Another particularly notable findings is that a small group of donors experienced a brief increase in psychological distress after the donation. These were mainly donors who had mental health problems during and/or after the donation (although not all donors with psychopathology had poorer outcomes). Similar negative experiences have rarely been described by other studies on experiences with and outcomes of UKD. This reported increase of psychological symptoms was mostly brief and transient, but a small group of donors reported ongoing negative emotions. Whereas a temporary increase of psychological distress would is to be expected for anyone undergoing a kidney donation surgery, the themes ‘Brief increase of psychological symptoms’ and ‘Ongoing negative emotions’ occurred more often in donors with than in donors without a history of mental health problems. Importantly, the ongoing negative emotions, for most of these donors, entailed frustrations and disappointment, rather than psychiatric symptoms such as feelings of depression and anxiety. Most of the donors reporting brief distress or ongoing negative emotions after donation were nevertheless still satisfied with their donation and did not regret their decision to donate.

Practical implications

The current study offers a unique contribution to informing the care for unspecified kidney donors, due to its large sample size and the inclusion of donors with pre-existing mental health problems (which is not common in the existing literature and in clinical practice). Firstly, our findings can be used to inform policies or procedures concerning the psychosocial screening of UKDs in transplant centres worldwide. Over the past 20 years many psycho-social screening guidelines have been developed to optimize living donor safety, but there still is great variability between transplant centres regarding mental health assessment of living kidney donors and criteria used for inclusion or exclusion from donation (Duerinckx et al., 2014; Lennerling et al., 2013; Potts et al., 2018). Our transplant centre currently uses a psycho-social assessment tool to evaluate UKDs, developed by the European Platform on the Ethical, Legal and Psychosocial Aspects of organ Transplantation (the EPAT-tool). In this tool 14 “red flags” are identified that can help to “identify donors who are at risk of developing negative psychosocial outcomes and may need further assessment and/or extra psychosocial support during the donation process” (Massey et al., 2018). We accept donors with (a history of) psychopathology if this does not have a significant impact on current psychosocial functioning, reasoning, and decision-making. We do this only after consulting their GP and current psychologist/psychiatrist to assess psychological stability and resilience. Doing so, our centre acts in agreement with the statement of the European Association of Psychosomatic Medicine that “psychiatric diagnosis in itself should not lead to automatic exclusion from donation” and therefore each donor candidate should be evaluated on a case-by-case basis. The findings of the current study support this approach, because among the majority of donors with (a history of) psychopathology the donation had an empowering and positive effect and did not appear to harm their mental health. In addition, a case-by-case evaluation increases and respects the autonomy of individuals with a mental illness. Secondly, if “red flags” are identified during the psycho-social assessment the kidney donation team has the difficult task to accept or decline a donor candidate based on mental health grounds. The EPAT manual suggests that when “red flags” are present, a subsequent session should be planned to further explore these issues. This allows the screener time to reflect and cross check information with family members and/or other professionals, such as the GP or (prior) mental health services involved in the candidate's care (Massey et al., 2018; Potts et al., 2018). This triangulation is important, because in the current study six donors with (a history of) mental health problems suggested they have not been totally honest about their mental health during the psychosocial evaluation (these six donors voluntarily shared this information, in practice the number might be higher). Finally, the current study showed that transplant professionals should not only be aware of ‘red flags’ before donation but should also be aware of red flags afterwards, and offer aftercare accordingly. Various issues seemed to have contributed to the mainly temporary deterioration in mental health in a minority of donors, including having mental health problems at time of the donation, but also going through other life events (which requires a certain level of resilience to cope with several stressors simultaneously), medical complications and their experience in the hospital. Similar risk factors for a deterioration in mental health after living kidney donation have been found previously, including a history of depression, predonation life dissatisfaction, the experience of medical complications, the financial

strain of a kidney donation, and the feeling that once the surgery was over they did not receive enough attention (Jowsey et al., 2014). Outcome registries are currently focused on physical outcomes (e.g. creatinine levels/kidney functioning), but there is a need for long-term monitoring of psychological outcomes as well. This would help shed light on questions regarding the differences and overlap in experiences and outcomes among the various types of donor. For example, gender differences in the experience of unspecified living kidney donation and its impact on mental health are an interesting topic for further research, which an outcome registry could help facilitate.

Limitations

This large qualitative study gives insight into the motivations and mental health of UKDs in relation to the donation. Nevertheless, there are some limitations to this study. Firstly, a limitation of the study is the retrospective design, whereby findings may be subject to memory lapses or recall bias. Moreover, there is a wide variation in time since donation which we did not take into consideration in the analysis. Secondly, the quality and rigour of this qualitative study could have been improved by providing the option for member reflections (Tracy & Hinrichs, 2017). Thirdly, participants were classified as having (a history of) psychopathology if they reported having received a diagnosis during the semi-structured interview. We did not check if the self-reported diagnoses during the interview were accurate, because it went beyond the scope of this study to perform a complete psychiatric assessment that encompasses all psychiatric disorders and verify self-report with external sources. However, through the use of an interviewer that was known to the participants, we created a safe environment for the participants that helped them speak openly about their mental health. We also believe that people do not easily label themselves with certain psychiatric disorders out of fear for stigmatization. On the other hand, the fact that the interviewer was known to the participants could have introduced bias, for example in an attempt to avoid disappointment or embarrassment. Given the high level of disclosure we did not feel this relationship negatively influenced participants' responses, but rather boosted study participation and honesty.

In conclusion, for most of the UKDs in this study, the donation has positive psychosocial consequences. Both donors with and without (a history of) mental health problems reported increased happiness and improved self-esteem. Some experienced a brief increased in psychological distress, commonly attributable to (a combination of) other stressors. A very small group of donors experienced ongoing negative emotions, such as worry and disappointment, caused by the donation. Two of 106 donors regret their decision to donate. This study presents unique and reassuring data regarding the ongoing debate about the mental health evaluation of living donors. We argue that the presence of psychopathology in donor candidates should not automatically lead to an exclusion from donation, because among the majority of donors with or without pre-existing mental health problems the donation had an empowering and positive effect and did not seem to harm their mental health. A case-by-case approach to psychosocial evaluation is needed to assess if a donor candidate can be accepted as a donor. Moreover, transplant teams should be alert to post-donation red flags and offer aftercare appropriately.

Declaration of competing interest

The authors declare that they have no known competing financial interests or personal relationships that could have appeared to influence the work reported in this paper.

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Appendix A. Supplementary data

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