African Journal of Nephrology
Official publication of the African Association of Nephrology
Volume 27, No 1, 2024, 3-8

ORIGINAL ARTICLE

Know thy donor: a qualitative study investigating the experiences of living kidney donors at Tygerberg Hospital, Cape Town, South Africa

Julian C Hellig, Chantelle J Scott, Andre van der Merwe

Division of Urology, Department of Surgical Sciences, Faculty of Medicine and Health Sciences, University of Stellenbosch, South Africa.

ABSTRACT

This study aimed to understand the experiences of living renal donors at Tygerberg Hospital, a tertiary referral hospital in Cape Town, South Africa. A qualitative, descriptive phenomenological study design was used. Semi-structured interviews were conducted with 12 kidney donors and transcribed verbatim. Thematic analysis was used, and the main themes that illustrated the donors' motivation to provide their organs were: 1) to save a life, 2) interpersonal relationships and family acceptance, 3) selfless unsung heroes, 4) life after donation – it goes on, and 5) no regrets. Our findings highlight the positive overall experience of donors.

Keywords: kidney donor experiences; transplantation; qualitative research; South Africa.

INTRODUCTION

Living renal donors present a fascinating juxtaposition of a sick patient with end-stage kidney disease (ESKD) and a healthy individual who voluntarily donates a kidney and exposes themselves to the risks of a major operation and a future with a solitary kidney [1]. Qualitative research allows an insight into the lived experiences of these individuals, about which there have been no such studies recorded in a South African context.

Our standard institutional practice is to perform live retroperitoneoscopic donor nephrectomies [2]. The patient-related benefits of laparoscopic donor nephrectomies, such as shorter hospital stay, less pain and improved cosmesis, have been well documented [3]. Two studies noted that consent for organ donation is influenced by religion, socioeconomic status and ethnicity [3,4]. Davis et al. found that Black donors faced the most barriers due to the adverse responses experienced when offering to donate and the refusal of recipients to accept a kidney from a living person [5]. McGrath (Australia) and Shaw and Bell (New Zealand) demonstrated the financial consequences for donors, mainly related to additional travel and accommodation costs and time away from work [6,7].

The ethical delivery of transplant services is hindered by personal and cultural beliefs, previous illegalities around organ procurement and limited resources. Furthermore, some healthcare workers are reluctant to refer brain-dead patients as potential donors as it might reflect their perceived inability to have cured the demised patient [8]. Inadequate empowerment by healthcare professionals has also been described, but financial concerns did not emerge as a barrier [4].

Despite the potential challenges, several authors found that donors had an overall positive experience, although the fact that donors could perform a meaningful deed for a close family member may mask some negative aspects [1,6,9]. Some donors had improved self-esteem, a resetting of values and personal growth [10] Their wish to donate was altruistic and done to improve the recipient's quality of life. Their relationship with the recipient enhanced their willingness to donate, as they did so for a

Received 30 June 2023; accepted 20 November 2023; published 28 February 2024.
Correspondence: Julian Hellig, julianhellig@icloud.com.

DOI: https://doi.org/10.21804/27-1-5943.

family member or a loved one. Andersen noted that, in some instances, donors who had an unsuccessful recipient outcome suffered severe physical and mental reactions [1]. Generally, the long, good donor–recipient relationship is explained by the gravity of the donation process and family members' support. Family dynamics and underlying tension regarding implicit or explicit pressure to donate may adversely influence the relationship between the donor, non-donor family members and the recipient [10].

Meyer et al. found that live donors can address the long-term impact of donation if they are resilient individuals [10]. The joy of seeing the recipient regain normal functionality trumped their own adverse experiences [11]. Andersen further revealed that some donors experienced dissatisfaction in the early postoperative period but returned to normal a year after donation [1].

METHODS

The Health Research Ethics Committee of Stellenbosch University granted ethical approval. A qualitative, descriptive phenomenological study design was used. Phenomenology is a form of qualitative research that focuses on studying an individual's lived experiences within the world [12].

Context: This study's primary investigator (JCH) is a urology registrar. He is a White male and fluent in both English and Afrikaans. The Urology and Nephrology divisions at Stellenbosch University are responsible for kidney transplants at Tygerberg Hospital (TBH). Urology registrars are involved with the perioperative and long-term care of these patients. JCH was not, however, involved in the care of any of the patients in this study. AvdM is the professor and head of the Division of Urology at TBH. He has considerable experience in transplant surgery and performs most of our institution's laparoscopic donor nephrectomies. CS is a genetic counsellor with extensive experience in qualitative research.

The inclusion criteria were patients 18 years and older who had a laparoscopic donor nephrectomy between 2015 and 2020, had access to transport and lived close to TBH. Patients who had developed severe physical or mental health concerns or disabilities post-transplant, unrelated to the kidney donation process, were excluded. Purposive sampling was used to ensure that participants with successful and unsuccessful transplants were interviewed. Twelve patients were selected and provided written in-person or verbal telephonic consent.

Semi-structured interviews using a topic guide were conducted. One participant was interviewed in person at TBH by JCH and CS. The remaining 11 were interviewed telephonically by JCH. The interviews ranged between 14 and 32 minutes. All duration of the interviews were audio-recorded and transcribed verbatim by JCH, and no identifying data were recorded. Data were collected until saturation was reached, as defined by Faulkner [13].

Descriptive thematic analysis, as reported by Braun and Clarke, was performed [14]. JCH and CS independently coded the transcripts. The coding process and deriving of themes were conducted manually. Relevant quotes were selected to illustrate the findings. Validity was ensured by having two independent researchers assess the data and identify relevant themes.

RESULTS

Participant description

The participants' sociodemographics, relation to the recipient and the outcome of the transplant are summarised in Table 1.

Themes

Each theme is described below using illustrative quotes. The participants will be referred to using the letter "P" with the corresponding number, for example, participant 1 is identified as P1.

To save a life

Several reasons motivate a healthy person to undergo a potentially self-detrimental operation to save another person's life. It became evident that the instinct to serve others by donating a life-preserving organ was central to most donors. P8 stated: *"Uhm, yes, I would if it would mean saving someone's life… Yes, I definitely advise it, and there are people out there that need donors, and you need to help others and save lives."* Similarly, P6 stated: *"My reason was to save my daughter's life. She was just 21 and had a full life ahead of her."*

The donor realises the recipient's impending doom and that there will be dire consequences if they do not assist. P3 stated: *"Seeing her in pictures, I could not take it. She was so bad. If I didn't come forward, she was going to die."*

The primal instinct to serve your family was brought to life by P7: *"We always say we will be there for our family and give our dying breath for them, and this was the way to show up."*

The participants recognised the importance of the recipient's role within the greater family context and wanted to buy them time. P4 stated: *"I did not donate because she is my sister, but rather because she has two kids who are young and dependent on her as a mother."*

The participants remain steadfast in their pursuit to save a life, regardless of the challenges they may encounter and physical setbacks. This notion is reaffirmed when donors understand they can live a healthy life with one kidney. P3

Table 1. Participant sociodemographics and outcome of transplant.

Participant	Age (years)	Gender	Relation to recipient	Outcome of transplant	Employment status
1	34	Male	Son	Successful	Employed
2	32	Female	Niece	Successful	Unemployed
3	41	Male	Brother	Successful	Employed
4	32	Male	Brother	Successful	Employed
5	30	Female	Sister	Unsuccessful	Employed
6	43	Female	Mother	Successful	Employed
7	40	Male	Uncle	Successful	Employed
8	39	Male	Cousin	Successful	Employed
9	44	Female	Sister	Successful	Employed
10	42	Female	Sister	Successful	Employed
11	53	Male	Uncle	Unsuccessful	Employed
12	31	Female	Daughter	Successful	Unemployed

explains: *"Yes, I wanted to save my sister. I don't believe I have to die with all my organs. They told me I can survive until 80 with one kidney."* The satisfaction of saving a life and allowing the recipient to regain their quality of life cannot be understated. P12, who donated to her father, shared: *"I am feeling very good. You know, it feels nice for me that actually I saved his life because there were two of my friends and family members who also suffer from kidney problems, and they died. So I am happy that I could keep him alive."*

There was a religious undertone with some donors, which contributed to their sense of responsibility and purpose. P7 remarked: *"I believe there is a reason for everything, and there are things on our paths not by our design, but by God. Everything worked out from there [initial tests], and I believe that we are here for a purpose, and maybe this was mine."* A great sense of achievement and contributing factor to donation can stem from religious underpinnings as elucidated by P8: *"From a religious perspective, there is an Islamic saying if you save the life of one person, it is the equivalent of saving the whole of humanity."* Religion is an essential foundation for certain donors.

Interpersonal relationships and family acceptance

The donors generally felt that their relationships had either remained the same or strengthened. P9 secretly hoped to gain family acceptance: *"You know, in some families, there is always a black sheep. I am the black sheep in our family. At that time, I did not think of it as such. As I went through the tests and all of that, I realised I am doing something big, and they are going to accept me… I think it was a way to get accepted and be closer to her."* However, she admitted that it did not lead to the anticipated acceptance. Merely donating an organ was not the remedy to poor relationships.

Participants who already had good relationships with their family members felt that donation strengthened their relationships. P6 highlighted the beauty and sincerity of a mother–daughter relationship: *"My relationship with my daughter is really excellent, because we just love each other."* P4 maintains a great relationship with his sister: *"Our relationship is very good. She's always messaging me and posting things [on social media] about me and thanks me for donating my kidney."* This participant highlighted how his sister's public appreciation on social media contributed to his self-esteem and feeling of family acceptance. The participants commented on how they would receive text messages from the recipients to thank them for saving their life. P11 donated to his nephew and mentioned: *"It's his birthday now, and every year on the date of the operation he will phone me or WhatsApp me to say it's because of me that he is still alive."*

Spousal or family acceptance of the donation is essential for donors to decide. P1 stated: *"And I said okay, I'll donate a kidney. I spoke to my wife, and we agreed on it."* P6 noted: *"I approached my family, and they supported me and said I can do it. So, I decided, let me do it."*

Indecision arose if all parties were not on board. Family or spousal support can be a motivating factor, while its lack can be a barrier and create tension. Regarding barriers to donation, P8 said: *"Maybe fear from family members, but I put them at ease after I explained to them the process that was explained to me by the nurses. My husband, on the other hand, was not very happy."* P10 shared a similar sentiment

regarding her husband: *"Uhm, the difficult part was really that my husband was not really impressed by the fact that I want to donate my kidney, but he came around, and at the end, it was my decision."* Spousal tension mainly arose from the fear of losing their loved one. This was highlighted by P11: *"Me and my wife lost a daughter. They were very close to each other, so I spoke to my wife, and she was not very happy with it. But I told her if it was her family, I would not stand in her way, and I went forward to help my sister."*

Selfless unsung heroes

Selflessness and being an unsung hero are fundamental to organ donors. Many of the participants acted so selflessly and only realised the gravity of their deeds during the interviews. P1 said: *"I don't have a problem donating my kidney if she is willing for it. Whoever is a match, we can decide from there. And basically, I just went for it. Nothing went away from me, so me just doing my part, it felt like. I can, now that you mention it, say that I saved her. But I have never put so much thought into it. It was successful."*

The participants often described just *"going for it"*. Their responses spoke volumes about being both an unsung hero and selfless at the same time. It is not an easy decision and saying *"I just went for it"* implies their potential suffering pales compared to the possibility that a functional kidney presents to the recipient.

P8 stated: *"I have not really thought about it as my psychological mindset was my cousin was doing well; she was getting better. I was focusing on her more. Yes, not a lot of focus on me as I am healthy."* The participants demonstrated that the recipient's well-being was more important than their own. P8: *"For my own experience, it was a selfless deed, and for the person receiving your kidney having a better life, that was my coping mechanism, if that makes sense, to make someone else's life better."*

Life after donation – it goes on

None of the donors suffered any serious complications or physical setbacks after the donation. P3 remarked: *"The only difficulty I had after I was discharged was the left leg at the groin. They took it out close to there, and it was so painful. It was a mission to get into the car. It took some time [a week]."* P4 had a similar experience: *"There was pain for a couple of weeks. I slept with a pillow under my left side to relieve the pain. I was able to get up and move, but not as quick and fast as usual. After a month, I could sleep properly and walk without pain."*

Initial concerns regarding surgical scars were mentioned. P5 had anxiety about being *"ruined"* by the scars but was relieved by the outcome: *"I was nervous that they were going to ruin me, but it actually looks good."* Most participants agreed that the scars were not bothersome and had no impact on their self-image or intimate relationships. P3 explained: *"No, nothing [no impact] at all. They didn't do a big opening. They did it with cameras. There are three holes and the hole they took the kidney out of. You can't even notice I have a scar."* This emphasises one of the many benefits of retroperitoneoscopic donor nephrectomies.

Life goes on as normal. P1 reflected on his *"new life"*: *"I'm living a normal life, nothing has changed. I am still the same person and having one kidney doesn't affect anything."*

Donors were inspired to reach for greater heights and achieve new goals. P3 expanded on his exploits: *"I was always a runner, but started doing ultra-marathons after I donated my kidney."* P7 explained his new healthier lifestyle: *"I feel like a better person; it was so good to stop smoking."*

P4 presented a humorous take on why one should donate and encouraged others to do the same: *"Yes, if I had a third kidney, I would go back and give my sister another kidney. I would donate again. If you can survive with one kidney, two kidneys are a luxury."*

P12 reflected on life with one kidney and concluded that after an initial period of feeling that something was missing, her life soon returned to normal: *"At first it felt weird though, because it felt like something is missing inside of me, but as time went on, you adapt to it, but it didn't bother me so much like something is missing out of my body…"*

Contrary to most positive experiences, P9 followed a different course. She had adverse experiences pre- and post-transplant. She struggled to lose weight for the operation and had an anxiety attack during the renogram (nuclear medicine scan to check kidney function). This shows that certain individuals may struggle with certain aspects of the process. Then two years later, she had *"flashbacks"* that she perceived negatively: *"I had a setback in September, two years after the kidney was taken out. I had flashbacks of the operation and stuff that happened before the operation and waiting in the recovery area before the operation."* One needs to be cognisant of certain donors' possible negative perceptions.

No regrets

The participants unanimously expressed no regrets even though two transplants were unsuccessful; one had acute and the other chronic rejection.

The donors possessed resilience and tenacity in the face of adversity. P4's recipient suffered chronic rejection, but he was still grateful that he could buy the recipient more time and had no regrets. *"No, I don't regret my decision. I did my*

research and spoke to the doctors at Tygerberg. We all knew it was temporary. There is a chance it can even fail just after the transplant the next day. So, me giving my kidney was just to give her more time. I have no regrets because it is a temporary thing."

P5 shared the same sentiment. Her sister's kidney was rejected after a week: *"I still would have donated the kidney to her because, like the doctor said, it is the body that rejected the kidney. It is not because of her, or me, or the doctor. It is the body that made the decision to reject the kidney. I still feel good because it worked for a week."* The ability to *"buy time"* for a loved one is an important motivator for donors.

DISCUSSION

Overwhelmingly, donors have a strong altruistic desire to save or prolong the life of a family member, as noted in previous studies [1,6,9]. This was an overarching theme among donors and is often, but not always, fortified by religious beliefs. As all donors in this study were related to the recipient, it is unclear if this sentiment will remain the same if they were donating to a stranger.

One donor revealed that the need for family acceptance played a role in her decision to donate a kidney. However, her relationship with the recipient remained unchanged and did not equate to family acceptance. Most of the donor–recipient relationships either remained strong or improved, which is similar to the findings reported by Andersen [1]. The donation process creates strong bonds between the two parties and family members usually act to enhance the relationship. Gill and Lowes found that donors derived personal satisfaction from a positive outcome, and none of the donor–recipient relationships were negatively affected [15]. Access to pre- and post-transplant psychological support that highlights the potential relationship changes may lead to improved psychosocial outcomes [16].

Donors are truly selfless, unsung heroes and, at times, almost acted nonchalantly, only realising the true nature of their deed after being directly questioned about it. Similarly, Briancoin found that the benefits to the recipient far outweigh the difficulties encountered by the donors [11].

Consent for organ donation is influenced by religion, socioeconomic status and ethnicity, with higher rates noted in more affluent, better-off socioeconomic groups than those requiring treatment in the state sector [3]. In our state-sector cohort, donors from various ethnic backgrounds presented voluntarily. They will act as future advocates for organ transplantation in their communities, demonstrating that donors can stem from all walks of life. Transplant programmes should identify and overcome barriers such as financial burden, enhance cultural safety and include traditional values in order to address the low donation and transplant rates [17].

In the United States, Davis et al. identified Black ethnicity as a barrier to organ transplantation [5]. However, in our study, all participants were of African or mixed-race backgrounds and, therefore, this does not appear to be a barrier in our population. None of the donors mentioned ethnicity or culture as a determining factor and none were discouraged by possible historical dogma.

Meyer et al. found that donors possess resilient traits [10]. Our donors showed resilience despite several challenges, such as long waiting periods, multiple or repeated tests and unavoidable delays in management due to resource constraints.

In our sample, the donors experienced postoperative pain but tolerated it well. They accepted it as being a part of the process. At our institution, all live donor nephrectomies are performed laparoscopically, which likely contributes to favourable outcomes and quality of life, as documented by Muller [3]. An older study [1] suggested that laparoscopic donor nephrectomy could not be recommended over open surgery, but we could not draw a comparison as open donor nephrectomies are not performed at our institution.

All donors remained largely unaffected by the surgery and had no major complications, nor were they perturbed by the surgical scars. They were all able to return to normal physical activity within reasonable timeframes, and 11 of the 12 participants had no adverse consequences after the event, reaffirming that life goes on as normal after the operation, a theme documented by Meyer et al. [10]. One participant had "flashbacks" and bad memories of losing weight and becoming anxious during a renogram. This is important to consider, and management must be tailored to meet donors' different needs.

Two of the transplants were rejected. Despite this, the relevant donors had no regrets and would still encourage others to donate. They took solace in the fact that the transplant had succeeded, at least briefly. Any additional time, even if it was brief, that the donor could spend with their loved ones made it worthwhile. This is contrary to the findings by Andersen [1] that donors who had unsuccessful recipient outcomes suffered from severe physical and mental reactions.

None of the donors suffered significant financial loss, which is contrary to the experience of McGrath [6] and Shaw [7], but in keeping with the findings of Bailey [4]. This is important to note as state-sector patients might already be financially disadvantaged. Previous studies demonstrated a

negative financial impact on donors as many of them had personal costs in terms of travel, accommodation during the transplant process and time away from work, which led to financial difficulties [6,7]. Despite initial resistance by some employers, our participants were allowed sick and special leave for the workup, surgery and recovery.

All donors had an overall positive experience and are strong advocates of organ donation, with some even stating that they would donate again if they had a third kidney and believing they do not have to die with all their organs intact. This positive outlook is largely due to the excellent preparation by the entire multidisciplinary transplant team. An overall positive experience of donation has been found in many other studies.

Some of the challenges that caused distress for both donors and recipients was the long duration of the workup to become a donor, resulting in occupational issues and excessive travel to and from the hospital. At times, this may be unavoidable due to resource limitations. Multiple blood tests, especially in donors who fear needles, and anxiety or claustrophobia during scans (CT and renogram) are potential barriers.

There are limitations in this study that can be addressed in future research. These include that 11 of the 12 interviews were telephonic (largely due to the COVID pandemic at the time), so true human interaction and detecting body language were lacking. Each participant was interviewed only once, and follow-up interviews may have afforded them time to process their emotions and experiences and a chance to add additional information. The participants did not have any major surgical or health-related complications. Donors who may have suffered more serious complications could have a different outlook and should be sought.

Future studies can better elucidate the donor–recipient relationship if the recipient is included to correlate their experiences. Lastly, some participants had already donated a few years prior to the interviews which may have led to recall bias. A prospective or longitudinal study with interviews pre-, peri- and post-operatively would allow a more thorough understanding of the process.

CONCLUSION

This study sheds a positive light on kidney transplantation in our setting, highlighting the donors' lived experiences, and will, we hope, serve as a reference point for healthcare workers and prospective donors alike.

Conflict of interest

The authors have no conflicts of interest to declare.

REFERENCES

1. Andersen MH (2008). Patient-reported outcomes following living donor nephrectomy [doctoral thesis]. Oslo, Norway: University of Oslo.
2. Van der Merwe A, Heyns CF. Retroperitoneoscopic live donor nephrectomy: review of the first 50 cases at Tygerberg Hospital, Cape Town, South Africa. S Afr J Surg. 2014; 52(2):53-56.
3. Muller E. Organ donation and transplantation in South Africa–an update. Contin Med Educ. 2013; 31(6):220..
4. Bailey PK, Ben-Shlomo Y, Tomson CR V, Owen-Smith A. Socioeconomic deprivation and barriers to live-donor kidney transplantation: a qualitative study of deceased-donor kidney transplant recipients. BMJ Open. 2016; 6(3):e010605.
5. Davis LA, Grogan TM, Cox J, Weng FL. Inter- and intrapersonal barriers to living donor kidney transplant among black recipients and donors. J Racial Ethn Health Disparities. 2017; 4(4):671-679.
6. McGrath P, Holewa H. 'It's a regional thing': financial impact of renal transplantation on live donors. Rural Remote Health. 2012; 12:2144.
7. Shaw RM, Bell LJM. 'Because you can't live on love': living kidney donors' perspectives on compensation and payment for organ donation. Health Expect. 2015; 18(6):3201-3212.
8. Etheredge HR, Penn C, Watermeyer J. A qualitative analysis of South African health professionals' discussion on distrust and unwillingness to refer organ donors. Prog Transplant.. 2018; 28(2):163-169.
9. Pradel FG, Limcangco MR, Mullins CD, Bartlett ST. Patients' attitudes about living donor transplantation and living donor nephrectomy. Am J Kidney Dis. 2003; 41(4):849-858.
10. Meyer KB, Bjørk IT, Wahl AK, Lennerling A, Andersen MH. Long-term experiences of Norwegian live kidney donors: qualitative in-depth interviews. BMJ Open. 2017; 7(2).
11. Briancon S, Germain L, Baudelot C, Bannay A, Virion JM, Thuong M. Quality of life of living kidney donor: A national report. Nephrol Ther. 2011; 7:S1–39.
12. Neubauer BE, Witkop CT, Varpio L. How phenomenology can help us learn from the experiences of others. Perspect Med Educ. 2019; 8(2):90-97.
13. Faulkner SL, Trotter SP. Data saturation. In: Matthes J, Davis CS, Potter RF, editors. The international encyclopedia of communication research methods. London: Wiley; 2017.
14. Braun V, Clarke V. Using thematic analysis in psychology. Qual Res Psychol. 2006; 3(2):77-101.
15. Gill P, Lowes L. Gift exchange and organ donation: Donor and recipient experiences of live related kidney transplantation. Int J Nurs Stud. 2008; 45(11):1607-617.
16. Ralph AF, Butow P, Hanson CS, Chadban SJ, Chapman JR, Craig JC, et al. Donor and recipient views on their relationship in living kidney donation: Thematic synthesis of qualitative studies. Am J Kidney Dis. 2017; 69(5):602-616.
17. Walker RC, Abel S, Reynolds A, Palmer SC, Walker C, Tipene-Leach DC. Experiences, perspectives, and values of Indigenous peoples regarding kidney transplantation: Systematic review and thematic synthesis of qualitative studies. Int J Equity Health. 2019; 18(1):204.