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The Tangible Benefits of Living Donation: Results of a Qualitative Study of Living Kidney Donors

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Background. The framework currently used for living kidney donor selection is based on estimation of acceptable donor risk, under the premise that benefits are only experienced by the recipient. However, some interdependent donors might experience tangible benefits from donation that cannot be considered in the current framework (ie, benefits experienced directly by the donor that improve their daily life, well-being, or livelihood). **Methods.** We conducted semistructured interviews with 56 living kidney donors regarding benefits experienced from donation. Using a qualitative descriptive and constant comparative approach, themes were derived inductively from interview transcripts by 2 independent coders; differences in coding were reconciled by consensus. **Results.** Of 56 participants, 30 were in interdependent relationships with their recipients (shared household and/or significant caregiving responsibilities). Tangible benefits identified by participants fell into 3 major categories: health and wellness benefits, time and financial benefits, and interpersonal benefits. Participants described motivations to donate a kidney based on a more nuanced understanding of the benefits of donation than accounted for by the current “acceptable risk” paradigm. **Discussion.** Tangible benefits for interdependent donors may shift the “acceptable risk” paradigm (where no benefit is assumed) of kidney donor evaluation to a risk/benefit paradigm more consistent with other surgical decision-making.

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Living donor kidney transplantation is the preferred treatment for end-stage renal disease due to superior recipient outcomes and the shortage of deceased donor organs.^{1,2} Although the risks of living kidney donation (LKD) are very low, there are indeed demonstrable perioperative and lifetime

risks.³⁻⁶ The predominant framework used in living donor evaluation and selection evaluates donors based on acceptable levels of risk to the donor. The Kidney Disease: Improving Global Outcomes Living Kidney Donor Work Group recently published guidelines advocating for the use of quantitative

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acceptable risk thresholds, such as a projected lifetime risk of kidney failure, when making donor selection decisions.⁷ However, it has been argued that living donors may experience benefits from donation and that those benefits should be considered in the living donor evaluation process.^{8,9}

The emotional and psychosocial benefits of living organ donation have been well documented.¹⁰⁻¹² Prior studies found that living kidney donors expect benefits in personal growth, interpersonal relationships (particularly their relationship with the recipient), self-esteem, social engagement, and spiritual life.¹⁰⁻¹⁶ However, donors may experience additional tangible benefits or measurable quality of life improvements following donation. Some of these benefits may be amplified in or unique to interdependent donors: donors who share households with and have caregiving responsibilities for their recipient.⁹ For these interdependent donors, a loved one with end-stage renal disease may cause harms, which could be mitigated with kidney transplantation, such as financial hardship, stress, caregiving burden, and strained household dynamics.^{8,17,18}

Although living donor candidates are screened for psychosocial issues including social support and living arrangements, Organ Procurement and Transplantation Network policies do not currently require potential benefits to be considered in donor selection,¹⁹ and centers may vary in their consideration of interdependency and potential benefits. The inclusion of benefits in living donor evaluations would shift the “acceptable risk” paradigm currently used to one that balances both the risks and benefits to the donor. Such a framework also necessitates an understanding of those benefits experienced directly by the donor, as opposed to those experienced by the recipient or society more broadly. This study aimed to use qualitative methods to identify and describe the tangible benefits of LKD that are not routinely considered in living kidney donor evaluation and selection.

METHODS

Study Population

Participants were recruited from the Wellness and Health Outcomes in Live Kidney Donors (WHOLE) study, an ongoing cohort study of living kidney donors. The WHOLE study was established in 2011 and has enrolled 3186 donors, 55% of whom have agreed to be contacted for future research studies and were eligible for recruitment into this interview study. The WHOLE study recruits participants by phone or in person immediately following donation.

For this interview study, WHOLE study participants who had donated a kidney at our center and who had agreed to be contacted for future research were contacted by phone from June to July 2017. No limits were set for time since donation to capture a wider range of donation experiences, and all donors were eligible regardless of donor and recipient outcomes. The only exclusion criterion was inability to complete a phone interview in English. The first 28 participants were randomly selected from a cohort of living kidney donors who had agreed to be contacted for future research. The following 28 participants were purposively sampled from the same cohort to capture a larger number of nonwhite participants, as well as participants we hypothesized would have had caregiving responsibilities for their recipients such as spouses and parents. This was done to ensure sample participants

could provide the most broad and comprehensive picture of living donor experiences possible within our cohort.²⁰ Donors whose recipients experienced complications were not excluded from the study. Donors who participated in a paired kidney exchange were not distinguished from donors who donated directly to their recipient.

Interview Design

A semistructured interview design was used to gather rich, detailed descriptions of donor experiences while prompting donors to reflect on potential benefits hypothesized by the study team.²⁰ An interdisciplinary team including a transplant surgeon, researchers with qualitative research experience, and a living organ donor designed the interview guide (**Appendix 1, SDC**, <http://links.lww.com/TXD/A290>). Interview questions were based on prior literature on experiences of living donors as well as the potential benefits hypothesized by the study team.¹⁰⁻¹⁶ Interviews were carried out over the phone by a medical student trained in semistructured interviewing (M.R.), lasted a median of 32.1 minutes (range, 13.2–93.5 min), and were audio recorded and subsequently transcribed verbatim. The semistructured, in-depth interview asked participants to describe their caregiving responsibilities before donation, motivations to donate, expectations for life after donation, to what extent reality met those expectations, and any personal benefits of donation. The interviews were scheduled at any time convenient for the participant, but participants were not compensated for their time. This study was approved by the Johns Hopkins School of Medicine Institutional Review Board (NA_00044282).

Qualitative and Quantitative Analysis

Themes were derived from transcripts by 2 independent coders with backgrounds and training in qualitative methods (A.S., a research program coordinator, and S.R., a qualitative research data analyst). A qualitative descriptive approach to analysis was used, a process designed to facilitate understanding of a common experience or phenomenon.^{21,22} The themes were derived using a constant comparative approach, which allows themes to be redefined and reapplied throughout the analytical process.²³ The 2 coders initially coded 3 interview transcripts, and a Kappa coefficient was used to calculate an inter-rater reliability of 0.77. Differences in coding were reconciled by consensus, and the 2 coders coded 4 more transcripts ($\kappa = 0.87$). This process was repeated 3 more times, until all transcripts were coded ($\kappa > 0.89$), and all differences in coding were reconciled. Coding was performed using NVivo 11 (QSR International), a qualitative analysis software widely used in qualitative healthcare research.²⁴ Of themes identified, 82% were identified after 20 interviews, and 97% were identified after 40 interviews, indicating that thematic saturation was reached.^{20,25} The Standards for Reporting Qualitative Research were used in the preparation of this article.²⁶

Defining “Interdependent Donors” and “Tangible Benefits”

As we have previously defined,⁹ interdependent donors are those who share households with and caregiving responsibilities for their recipient, such that the donor’s and the recipient’s well-being are connected to and interdependent on each other. For the purpose of this study, we defined “interdependent donors” as those who reported living with their recipient at

the time of donation and/or having caregiving responsibilities for their recipient before donation.

Tangible benefits were defined as those experienced directly by the donor and directly affecting the donor's daily life, well-being, and livelihood. Using this definition, all the benefits identified by study participants were categorized as "tangible" or "nontangible" by 2 independent coders (M.H., S.R.). Differences in categorization were reconciled by discussion until consensus was reached. Benefits considered nontangible are those that primarily affect the recipient, society, or do not directly affect the donor's daily life, well-being, and livelihood.

RESULTS

Study Population

In total, 56 living kidney donors participated (Table 1). Most participants were female (70%) and white/Caucasian (75%). The median (interquartile range) age was 47 (37–55), and the median time since donation was 9.4 (6.4–12.4) years. Of participants, 27% donated to a spouse or partner, 21% were adult children who donated to a parent, and 18% were parents who donated to a child (of any age). Of the 56 participants, 39% reported having caregiving responsibilities for their recipient before their donation, and 39% reported living

with their recipient at the time of donation. Based on these responses, 54% of participants were classified as being in an interdependent relationship with their recipient.

Tangible Benefits of LKD

Participants in this study identified 44 unique benefits of LKD. Of those, 26 were classified as "tangible." Among the tangible benefits, 5 were related to health and well-being, 7 to time and finances, and 14 to interpersonal relationships (Table 2). Benefits highlighted in the following sections were selected based on prevalence and importance conveyed by participants.

Health and Well-being Benefits

Several participants noted benefits to their short-term well-being as well as long-term health. One participant recalled their smoking cessation 1 year before donation, referencing the health requirements required of potential donors before donation (participant 35: child to parent, interdependent). Another participant emphasized health benefits more than 6 years postdonation, saying as a result of donation: "I think I'm more health conscious. I try to stay fit. I work out all the time ... I do my best to stay healthy and take care of myself so I can keep that kidney healthy. I also make sure that I have a physical every year" (Participant 5: spouse, interdependent).

TABLE 1.
Characteristics of the Study Population (n = 56)

Participant Characteristics	
Donor age (y), median (IQR)	57.7 (45.2–65.9)
Race, n (%)	
White/Caucasian	42 (75%)
Black/African American	9 (16%)
Other	5 (9%)
Hispanic/Latino, n (%)	1 (2%)
Education, n (%)	
High school/GED	12 (25%)
Associate's degree	8 (14%)
Bachelor's degree	17 (30%)
Graduate degree	17 (30%)
Years since donation, median (IQR)	9.4 (6.4–12.4)
Donor outcomes, n (%)	
Chronic kidney disease	5 (9%)
On kidney transplant waitlist	2 (4%)
Diabetes	4 (7%)
Hypertension	8 (14%)
Hyperlipidemia	14 (25%)
Depression/anxiety	10 (18%)
Donor–recipient relationship, n (%)	
Spouse/partner	15 (27%)
Child to parent	12 (21%)
Parent to child	10 (18%)
Other, nonrelated	7 (13%)
Sibling	6 (11%)
Other, related	5 (9%)
Anonymous	1 (2%)
Recipient on dialysis pretransplant, n (%)	38 (68%)
Shared household with recipient, n (%)	22 (39%)
Had pretransplant caregiving responsibilities, n (%)	22 (39%)
Interdependent relationship with recipient, n (%)*	30 (54%)

GED, general educational development (high school equivalent); IQR, interquartile range.

*Interdependent relationship defined as those donors who shared a household with their recipient and/or had pretransplant caregiving responsibilities for the recipient.

TABLE 2.
All Benefits Identified by Interview Participants

Tangible Benefits	Nontangible Benefits
Health and well-being benefits	Help or save recipient
Donor more proactive about health	Sense of life purpose
Reduced stress/worry postdonation	Emotional or mental health benefits
Improved donor quality of life	Sense of pride, satisfaction
Waitlist priority for donor	Learn about organ donation and kidney disease
Reduced dietary restrictions	Gratefulness, perspective
Time and financial benefits	Donor as a role model to children
Reduced caregiving burden	Recipient avoided dialysis (preemptive transplant)
Ability to travel	Contributing to research
Return to normalcy	Fulfill familial duty
Recipient's return to work	Recipient discontinued dialysis
Career benefits	Return favor to parents
Increased donor's free time	Receive/expect high quality healthcare
Financial benefits	Appreciation of support system
Interpersonal benefits	Belief in karma
Closer relationships with recipient and family	Legacy of donation
Involvement in donation advocacy	Regain control of situation
Spiritual/religious benefits	Relationship with exchange recipient family
Preserve family unit	
Recognition or appreciation	
Sense of courage/confidence/resilience	
Avoiding guilt of not donating	
Increased independence	
Community of other living donors	
Improved household dynamics	
Improved marital quality	
Recipient or donor able to see children grow/age	
Improve donor's social life	
Donor and recipient ability to have children	

Many participants also described the spillover effect of the recipient's renal-dietary restrictions. Before donation, participants experienced daily challenges in shopping and meal preparation that impacted the entire family. Following donation—and cessation of the dietary restrictions associated with dialysis—participants reported their families could eat “basically whatever we want now” (Participant 27: parent to child, interdependent).

Other health and well-being benefits reported by donors included reduced stress/worry postdonation, improved donor quality of life, and waitlist priority for the donor (Table 3).

Time and Financial Benefits and a Return to Normalcy

Many participants emphasized their idea of life “before transplant,” when life was organized around the recipient's clinic visits and dialysis. Achieving a return to normalcy was defined by participants as resuming life as it existed before their recipient became ill. They noted that following transplantation, donors and recipients could “do everything ... life just kind of resumed back to normal” (Participant 26: spouse, interdependent). Others noted that aside from immunosuppressant medication and follow-up appointments, the donor and recipient “live the same life that we used to have before things went downhill” (Participant 49: spouse, interdependent) with a greater ability to participate in activities such as entertaining friends or going out for the evening.

Donors, especially those in interdependent relationships with their recipients, emphasized the reduced caregiving burden they experienced following donation as recipients regained independence. Donors felt their donation allowed recipients to become active participants in their own medical care. After transplantation, recipients often managed their own caregiving responsibilities such as arranging appointments and preparing medications, which, in the case of spousal donation, allowed them to be more helpful partners. Many participants expressed relief at the time they regained postdonation, for example, “just time not having to drive him to dialysis” (Participant 27: parent to child, interdependent). One donor stated that postdonation, “He [the recipient] could do more for himself. I still did the shopping, but he could do his own medication. He could get around better. He could

be more beneficial to me as far as responsibilities were concerned” (Participant 43: spouse, interdependent). Similarly, another donor highlighted the contrast in caregiving burden before and following donation: “[following LKD] I didn't have all the responsibilities for, you know, finding the care, negotiating the care, doing all the meds ... she was able to independently manage that herself. So that's very helpful” (Participant 56: parent to child, interdependent).

As recipients returned to work full-time following transplantation, many donors disclosed relief of termination in their role as the sole financial provider in the household, describing a “tremendous load off me” (Participant 5: spouse, interdependent). These financial benefits following LKD positively impacted both the donor and the recipient: “It improved our social economic standing drastically ... it was a life changer ... we can afford to go on vacations” (Participant 51: spouse, interdependent).

In addition to the financial benefits associated with increased time and recipient productivity, several career benefits were reported by participants who work in healthcare. They reported gaining “additional credibility” (Participant 52: child to parent, noninterdependent) or empathy from the experience: “It's a benefit for me as a nurse to talk to [patients about] my experiences ... [Patients] feel that they're being taken care of by somebody who really understands what they're going through” (Participant 27: parent to child, interdependent). Another participant expressed their ability to focus on work: “I'm not as distracted and I'm able to take care of my clients” (Participant 51: spouse, interdependent).

Other time and financial benefits reported by donors included increased free time, the recipient's ability to return to work, and the ability of the donor and recipient to travel (Table 4).

Interpersonal Benefits

Several participants who donated to their spouse or partner described improved marital/relationship quality as a result of LKD. Participants felt closer to their partners and reported LKD made their relationship stronger “knowing that we have a longer life together” (Participant 26: spouse, interdependent) than they would have had together without LKD. Participants also felt that LKD strengthened their marriage,

TABLE 3.
Health and Well-being Benefits of Living Kidney Donation

Benefit	Representative Quote
Donor more proactive about health	I got very healthy. I got a personal trainer. I needed to lose a few pounds ... I quit smoking as soon as I heard so about a year before [donating] (Participant 35: child to parent, interdependent). I am much more conscious of food. I don't drink. When you look at it long term, it's probably extended my life (Participant 55: child to parent, noninterdependent).
Reduced stress/worry postdonation	Stress, now, I don't think it's anything compared to when somebody's going through a health issue. I think when you're going through a health issue, almost everything revolves around that issue. Stress now is just a fraction of what it used to be (Participant 5: spouse, interdependent). After the transplant was successful and he was getting healthy, the stress just, it wasn't as stressful I guess. He was getting better. I didn't have to worry about the worst happening (Participant 9: spouse, interdependent).
Improved donor quality of life	My husband wasn't sick anymore. So we had a better quality of life (Participant 48: spouse, interdependent). You have improved mental health and improved physical health then your quality of life goes up (Participant 55: child to parent, noninterdependent).
Waitlist priority for donor	This kind of sounds selfish, when I donated this wasn't the reason just an after-effect, they said oh hey if I ever needed a donation, because I was a live donor it would increase my places on the list (Participant 35: child to parent, interdependent).
Reduced dietary restrictions	Before that, if there were foods he couldn't eat, I just didn't buy them. We just didn't eat them, even if other people liked them, because I didn't want to have things in front of him that he couldn't have. So just ... eating basically whatever we want now. I think that we noticed that right away, the whole family (Participant 27: parent to child, interdependent).

saying: “There was a greater appreciation for the relationship that we have and it made our relationship stronger ... we modeled the fact that as a couple you’re close and care for each other” (Participant 45: spouse, interdependent). Others simply expressed that it was “easier to be happy” when their partner was healthy again following LKD, allowing the donor and recipient to go on dates together and participate in activities as partners (Participant 51: spouse, interdependent).

Among participants who shared a household with their recipient, many reported positive changes in household dynamics following LKD. These benefits extended beyond just the donor and recipient to the entire family. As 1 participant said: “[The transplant] was a tremendous benefit to our family after my husband was well ... We went from a family that revolved around his dialysis schedule and his wellness and his health to a family that could do normal things as far as planning a vacation, and at the drop of the hat, going and doing something together, instead of hoping that he was well enough to participate. That definitely changed our free time” (Participant 5: spouse, interdependent).

Many participants described the preservation of their family unit as a tangible benefit of LKD. For example, participants were grateful to have the recipient present at major life milestones: “I was young, I wasn’t married yet. And it was definitely important to me that I have my dad around to [pause] oh my gosh, I’m getting emotional, um, to walk me down the aisle, be there when I had children, and I can happily say now that um, he did walk me down the aisle and he has been around for my son and another baby on the way” (Participant 14: child to parent, interdependent). Likewise, participants described the benefits of having the recipient present and engaged in the care and upbringing of younger generations: “I’m just so, so thankful for that. That he’s [the recipient] well and my kids are able to do the things that they want with their dad. I have my husband back and they have their daddy back!” (Participant 5: spouse, interdependent).

One participant reported that without LKD, she would not have been able to have a biological child with her partner: “We never would have been able to have a baby ... I have

a child. That’s brought me a lot of happiness. We had one together” (Participant 51: spouse, interdependent).

Other interpersonal tangible benefits reported by donors included recognition or appreciation, avoidance of guilt for not donation, sense of courage/confidence/resilience, benefits to spiritual/religious beliefs, closer relationships with recipient and family, ability of donor or recipient to see children grow/age, finding a community of other living donors, involvement in donation advocacy, increased independence, and improvement in donor’s social life (Table 5).

Extent of Potential Benefits as Motivating Factors

Participants varied in their consideration of potential tangible benefits as motivating factors for donation. Some participants acknowledged a “selfish” aspect of their decision to donate. As 1 participant explained: “In a way I did it [donated] for myself because I wanted to save him and give him a better quality of life, and because I love him, so that’s an indirect benefit to me. Because we share children, and households, and responsibilities” (Participant 45: spouse, interdependent). Another described their decision to donate as personally motivated, saying: “it’s just that [donation] was the quickest option to get what I needed and what I wanted in life” (Participant 51: spouse, interdependent).

Others said the benefits they experienced were not motivating factors: “I wasn’t looking to get anything out of it myself. So even though I ended up getting a lot out of it, it wasn’t like, ‘hey let me feel good about myself, let me put something on my résumé’” (Participant 34: sibling via paired exchange, noninterdependent). Another said they were entirely motivated by helping the recipient, and they had not considered any personal motivations: “I just was looking forward to being able to do something for her. I mean, it’s not often you get a chance to be completely selfless about something” (Participant 20: other relative, noninterdependent).

Benefits of Donation Outweigh Risks

All participants acknowledged that the benefits of donation, whether experienced by themselves or the recipient, outweighed the peri- and postoperative risks as they understood

TABLE 4.

Time and Financial Benefits of Living Kidney Donation

Benefit	Representative Quote
Ability to travel	It was tremendously liberating and you know we just got back from a family trip to Europe and I guarantee that would not have been a possibility if we didn’t have a successful kidney transplant (Participant 31: parent to child, interdependent). As a family group, we do small 2-day vacations ... We feel freer to do that. We’re not worried that, oh, what if—we used to check what hospitals were nearby if we were going to do an overnight someplace, and we don’t do that now (Participant 27: parent to child, interdependent).
Reduced caregiving burden	[My caregiving responsibilities now are] minimal, just normal, I do the grocery shopping, I do the cooking and the food planning. So just the regular stuff I did beforehand, I’m just doing it the same now. As opposed to, you know, it was longer, more arduous process leading up to transplantation (Participant 49: spouse, interdependent).
Return to normalcy	We were able to do a little bit more ... going out for the evening, having friends over, we probably did a few vacations, just you know life was more back to normal not totally, but more back to normal than what it was before all this happened (Participant 16: spouse, interdependent).
Career benefits	I actually work in pharmaceuticals and it kind of got me working in transplant cases, so I do work on some pharmaceuticals for that kind of stuff and there is some additional credibility gained from that experience (Participant 52: child to parent, noninterdependent).
Recipient return to work	I didn’t really think this kidney would work as well as it has. You know, that he could get back into the work force and work was nice (Participant 51: spouse, interdependent).
Financial benefits	Financially and overall, if you’re married to someone, you are partners so can you imagine if I lost him, how that would have looked, how that would have impacted me in the most negative way (Participant 45: spouse, interdependent). Financially he was able to go back to work full-time, which took a tremendous load off me. Also, helped us out financially to know that the bills would be paid and that we would be fine! Emotionally too (Participant 5: spouse, interdependent).
Increased donor’s free time	We definitely got a lot more free time but then we had a baby who takes it. But yeah, it’s definitely freed up time for us (Participant 51: spouse, interdependent).

TABLE 5.
Interpersonal Benefits of Living Kidney Donation

Benefit	Representative Quote
Closer relationships with recipient and family	I think it just made him [the recipient] appreciate the sacrifice I was willing to make a little more. I think it made him respect me and appreciate me a little bit more than he did previously (Participant 44: child to parent, noninterdependent). [The donation] sort of changed my perspective that I, my family was more important than living off of ramen in the city and now I live next door to my mom and dad, in between my sister and my mom and dad (Participant 13: child to parent, interdependent).
Involvement in donation advocacy	We did the kidney walk and we were much more outspoken and much more involved in organ donation and that kind of thing and like I said dad wasn't even an organ donor before, so it definitely makes you more aware of the cause and need for organ donation (Participant 13: child to parent, interdependent). I guess it made me feel much more strongly—not that I wasn't before—but much more strongly about organ donation ... I would tell my story as much as I could ... that made me feel good that I could come back and be an advocate for that (Participant 16: spouse, interdependent).
Spiritual and/or religious benefits	I think it made me a stronger person. My belief was stronger, my faith and trust in the lord, it just ... It made me stronger in the way that I could see what I did (Participant 7: parent to child, interdependent).
Preserve family unit	I watch my dad with my kids and I mean like, cause I live next to my sister too, so it's like a circus 24 h a day. She has 2 kids, I have 2 kids, and when my dad pulls up at 4 o'clock every day, they all like rush and he can't even get out of his truck ... he can't go into his garage to work on anything without the boys like driving him insane and he loves it ... He just stops and does whatever and does all these crazy things for the grandkids and like I look at him, I'm like I'm so blessed to be able to provide him with that ... And, it's such a great feeling, you know. I was able to do that, me and you know the team of [laughs], but that's pretty incredible (Participant 13: child to parent, interdependent).
Recognition or appreciation	As far as elevating the status, like the people that are aware of what we've been through ... from the church and the community, they put us you know, they looked at us in a different way. So, we enjoyed some privileges (Participant 13: child to parent, interdependent).
Sense of courage, confidence, and resilience	Well, I figured if I could do that, I can do anything. It gave me a sense of confidence, Like wow if I can do that I can pretty much tackle anything (Participant 28: parent to child, noninterdependent).
Avoiding guilt of not donating	If I hadn't been able to [donate], or no one was able to, I can't imagine the torment that that would cause if [the recipient] hadn't had a chance. I just can't even imagine that. The gift of being given the opportunity, just is really invaluable (Participant 56: parent to child, interdependent).
Increased independence	Tonight I'm going to have to work late. I mean, we're able to do that because I don't have to rush home to put him on a machine (Participant 51: spouse, interdependent).
Community of other living donors	With the people who ... may have family members who are going through something like that and I mentioned there's kind of a bond or a trust. People who have gone through it before (Participant 52: child to parent, interdependent).
Improved household dynamics	He was able to help me around the house, just to be a partner, you know. My life improved when—it's, you know, marriage is a partnership and we were a team and he was sick and once he got better, you know, it was, our lives were better (Participant 51: spouse, interdependent).
Improved marital quality	I don't think we—Who knows if we'd still be married had we not donated and done the surgery... It was stressful. He, you know, he was far more volatile ... He was scared he was going to die ... And, I mean, it was tough. There was one time I brought him the wrong brand of chicken nuggets ... But the home hemo was definitely a lifestyle improvement and the kidney was the best improvement ... [It improved our relationship] drastically
Recipient or donor able to see children grow, age	Oh [if I hadn't donated] it would've been terrible ... he would have been more sickly ... my daughter had a baby, he got to see his grandchildren, um you know we had holidays and birthdays and celebrations for the next 10 y (Participant 41: spouse, interdependent).
Improve donor's social life	Yeah, we can do a lot more. You know, with my husband being healthy and just dealing with his mental health at the moment at home that really helps me with work so then we can go out and have fun (Participant 51: spouse, interdependent).
Donor and recipient able to have children	We never would have been able to have a baby ... I have a child. That's brought me a lot of happiness. We had one together (Participant 51: spouse, interdependent).

them. As 1 participant described: “I was very hopeful and I was willing to take that chance ... Because the outcome could be just like it is, you know, that he actually was able to get his life back” (Participant 12: child to parent, noninterdependent). Another described their decision-making process, saying: “You're sort of weighing the pros and the cons, and every step that I went, there was never a deal-breaker con, and the goal of improving my mom's life was the end goal, and there was nothing, there was nothing presented to change that plan” (Participant 55: child to parent, noninterdependent).

Among participants who acknowledged personal motivations when deciding to donate, all believed those potential benefits outweighed the risks. One participant described the interdependency of their and their husband's health and explained that the benefits of donation, especially with regards to their marriage, were worth the potential risks of donation:

I remember saying to the transplant coordinator to tell them that “I don't want to live my life well into my 90s alone without my husband because you won't let me give my kidney when I'm willing” ... if you're telling [me],

“We're concerned about your long-term health,” my statement back was “I'm concerned about my long-term health and my husband's long-term health, and I want us both to have long-term health together” (Participant 49, spouse, interdependent).

Despite the overall belief that the benefits of donation outweighed the risks, a few participants believed they did not experience any tangible benefits of donation: “I don't think of it as something that benefited me ... for me it was just I had the ability to help him out with something that was life saving for him” (Participant 2: friend, noninterdependent). Some harms of donation were also identified, although far fewer and less prevalent than benefits. Those included increased worry/stress about recipient well-being, concerns about donor health, lifestyle/medication restrictions, and a strained relationship with the recipient.

DISCUSSION

In this qualitative study of living kidney donors, we identified 44 unique benefits of LKD, of which 26 were classified

as “tangible.” Among the tangible benefits, 5 were related to health and well-being, 7 to time and finances, and 14 to interpersonal relationships. Participants varied in the extent to which they were motivated to donate by tangible benefits; however, some participants explicitly described potential tangible benefits as factors that motivated them to donate.

We have previously argued for a donor evaluation and selection framework that does not just consider acceptable levels of risks but one that assesses and balances the potential tangible benefits with the risks of donation.⁹ Under such a framework, it is important to distinguish those tangible benefits that are experienced directly by the donor from those that are experienced by the recipient or by society more broadly. The tangible benefits identified in this study may be used in a more balanced framework for donor screening and evaluation. In the current risk-acceptance paradigm for living kidney donors, it is assumed there is no tangible benefit expected for LKD as a result of donation. If indeed there were no tangible benefits of donation and LKD assumed only risk, then it follows that the ethical responsibility of the transplant center is to minimize the risk of donation. Now with evidence of tangible benefits received by LKD as a direct result of donation, we argue that LKD may accept higher levels of donation risk commensurate with these tangible benefits. As a result, donor candidates previously precluded from donation in the current risk-acceptance paradigm due to their slightly elevated medical risk profile may be allowed to proceed with donation if they are likely to experience tangible benefits.⁷

Prior studies of potential benefits expected by potential living kidney donors found that donors, especially spouses, expected improvements in household and family life.^{13,14,27-30} Our study lends credence to these expectations because many donors in our study also experienced benefits in these areas. In addition, a 1997 quantitative survey of 176 spousal living kidney donors found that 47% experienced improvements in marital quality and 25% experienced improvements in their relationship with their children.¹⁵ Our study supports and adds context to these findings by describing the nature of these interpersonal benefits. By contrast, a 2017 qualitative, semistructured interview study with 16 living kidney donors in Norway found that some donors experienced increased family tensions, even years after donation.³¹ This did not emerge as a common theme among our participants, which may be due to cultural differences or the different focus of the study; our study focused on the benefits of donation while the Norwegian study sought to more broadly understand overall donation experience. Furthermore, the interview guide for the Norwegian study was not provided so we are unable to determine what questioning led participants to discuss family tensions. A longitudinal, single-center study of 93 living kidney donors in the United Kingdom found no changes in psychosocial well-being up to 12 months postdonation.³² Likewise, a Dutch prospective study of 135 living kidney donors and matched general population controls did not find any significant changes in overall mental health (psychological complaints and well-being) between LKD and the controls in the short term. They also did not find any change for psychological complaints and well-being over time for LKD.³³ However, although these findings contradict the benefits of decreased stress and quality-of-life benefits experienced by participants in our study, these studies did not assess changes or differences in other tangible benefits common in our participants, such as time and financial benefits.

This study adds to the recent conversation surrounding donor-centered evaluation and selection, as well as how risks and benefits should be discussed with donor candidates.^{34,35} A donor-centered approach to donor evaluation would involve donor candidates in decision-making processes and would consider the donor’s long-term medical risks, their personal level of risk-tolerance, and their motivations for donation.³⁴ It has also been suggested that the evaluation process should consider the potential risks of turning down donor candidates who may otherwise benefit from donation.^{8,17,18} The extent to which centers already employ a donor-centered evaluation, or even consider the potential benefits of donation or interdependency of their donor and recipient candidates, may vary among centers. Considering the benefits of donation would require centers to vary risk thresholds for each individual donor based on their unique risk-benefit profile, rather than applying the same threshold to all donors. For instance, a center could establish a universal “net risk threshold” that considers how much risk is offset by the tangible benefit (eg, no more than 5% lifetime risk); if a donor candidate’s individual lifetime risk is 6%, but the potential tangible benefits offsets 1% of those risks, then they would meet the center’s 5% net risk threshold.

This study should be interpreted in light of several limitations. First, as a single-center study, the experiences of participants may not be generalizable. That said, our study population was purposefully sampled to include the same percentage of non-Caucasian donors as the distribution among living donors nationally (75% white/Caucasian versus 70% white/Caucasian, respectively), and we reached thematic saturation, which suggests that most possible themes were identified.³⁶ Despite this, the practices regarding how donor benefits are considered in the evaluation process may vary among centers; we hope these data help encourage the consideration of benefits across all centers. Second, all studies that rely on participant-reported data are subject to recall bias; this is of concern in this study, given that the median years since transplant among participants was 9. Although recovery and adjustment to life postdonation may influence our findings, we interviewed donors at various stages in this process (interquartile range, 6.4–12.4 y postdonation). Further, this longer follow-up allowed time for long-term benefits to emerge. The findings of this study may also be limited by a social desirability bias, especially with regards to the health and behavioral changes resulting from donation. Participants were also prompted to consider the benefits of donation, which may have biased their responses in favor of reporting benefits. Third, we were unable to link participant responses to their recipients’ transplant outcomes. Donors whose recipients had good outcomes may be more likely to participate in research studies such as this, and a prior study found that donation experience was associated with recipient outcomes.³⁷ However, donors whose recipients passed away or experienced graft loss were not excluded, and several participants mentioned that their recipient experienced a negative outcome. Fourth, we did not specifically ask participants regarding negative experiences with or following donation; prior work has found that although rare, some donors do experience negative mental health outcomes following donation.^{37,38} Future work should assess the negative consequences of donation to further expand our understanding of the risks and benefits of donation. Fifth, a participation rate was not captured for this study. Finally, the goal of qualitative studies

is to obtain rich, narrative data to provide a deeper understanding of individual and interpersonal experiences.^{20,39} These data can subsequently be used to generate hypotheses, and the benefits identified here may be used to inform future quantitative work, expanding on existing work into psychosocial experiences postdonation^{32,33} and exploring new areas, such as assessing the trajectory of benefits over time after donation, or differences in benefits by demographic factors, as these questions were outside the scope of this study.

In conclusion, living kidney donors reported they were motivated to donate based on a more nuanced understanding of the benefits of donation than accounted for by the current donor evaluation paradigm. Some tangible benefits identified by donors are currently overlooked in living donor evaluation including reduced caregiving burden, increased wage earnings, and improved donor independence. These qualitative findings should inform quantitative research on the tangible benefits of donation, as these additional benefits may alter present living donor risk-benefit calculations. This shift from an “acceptable risk” framework to one that also considers the potential benefits to the donor could motivate a greater threshold of acceptable donor risk, particularly for interdependent donors.

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