

## PAPER

# Opting out: a single-centre pilot study assessing the reasons for and the psychosocial impact of withdrawing from living kidney donor evaluation

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## ABSTRACT

Understanding why individuals opt out of living donation is crucial to enhancing protections for all living donors and to identify modifiable barriers to donation. We developed an ethical approach to conducting research on individuals who opted out of living kidney donation and applied it in a small-scale qualitative study at one US transplant centre. The seven study participants (64% response rate) had varied reasons for opting out, the most prominent of which was concern about the financial burden from lost wages during the postoperative period. Several reported feeling alone during their decision-making process. Although no participants used an alibi, a centre-provided statement of non-eligibility to donate, all believed that centres should offer alibis to help preserve donor autonomy. Given the complexity of participants' decisions and the emotions they experienced before and after deciding not to donate, we suggest approaches for independent living donor advocates to support this population. This study demonstrates that research on individuals who opt out of donation is feasible and yields valuable insight into methods to improve the evaluation experience for potential living donors.

## INTRODUCTION

Since 1988, 130 000 people have been living kidney donors (LKD) in the USA.<sup>1</sup> However, there is scant information about individuals who begin LKD evaluation but subsequently decide not to donate for non-medical reasons.<sup>2</sup> We refer to this decision to voluntarily withdraw from evaluation as 'opting out'. Studies suggest that 10%–24% of potential donors opt out.<sup>3–5</sup> However, these percentages could be underestimates since transplant centres are not required to collect data on rates of or reasons for opting out.

This paper presents an exploratory study at a single transplant centre to demonstrate that conducting research on individuals who opt out of living kidney donation is feasible and yields valuable insights into their decision-making. Research on opting out may identify avenues to further enhance LKD autonomy, suggest improvements to the LKD education process, reveal risks that are unique to individuals who opt out and facilitate interpretation of trends in living donation rates.<sup>6</sup> A better understanding of the experiences of individuals who opt out may help the transplant community address obstacles to donation.<sup>7</sup>

## METHODS

We conducted a retrospective, qualitative study of English-speaking adults who opted out of living kidney donation at our centre between 1 January 2012 and 31 December 2014. Individuals were excluded if they: only completed a telephone health screen, had a blood type or cross-match that was incompatible with their intended recipient, were deemed ineligible to donate by the transplant centre or had invalid addresses or telephone numbers. Eligible individuals started formal medical and psychosocial donor assessment, but stopped contacting the centre or terminated their donor candidacy for non-medical reasons. We focused on individuals who began in-person evaluation because this is when most donors learn details about the surgery, postdonation risks, recovery and associated financial and logistical considerations. Our urban academic medical centre conducts in-person evaluations of 70–80 potential LKDs per year and performs approximately 50 laparoscopic donor nephrectomies annually.

To minimise potential emotional distress and inadvertent disclosures of an individual's decision to opt out, we employed special protections during recruitment. Our methods adapted Weiss' approach to parents who had withheld permission for their deceased child to become an organ donor.<sup>6 8</sup> The Independent Living Donor Advocate (ILDA) compiled a list of eligible individuals and collected their demographic characteristics via chart review. Potential participants were mailed a cover letter, a factsheet stating that the study aimed to assess the experiences of individuals who started LKD evaluation and an addressed, stamped postcard to return if they did not wish to participate. The ILDA telephoned individuals who did not return the refusal postcard. If contact was achieved, the ILDA indicated that we sought to learn more about individuals who opted out of donation. Contact details for those interested in participating in our study were shared with the research team. We also established a protocol to refer individuals who expressed persistent emotional distress during the interview to the ILDA and/or the transplant psychiatrist.

We developed a semistructured qualitative interview guide based on a literature review. Domains included: reasons for beginning evaluation; perceived risks and benefits of evaluation and donation; the process of deciding to opt out; the impact of opting out; and awareness of and attitudes toward



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alibi offers. The 30–60 min long telephone interviews comprised primarily open-ended questions. Interviews were audio-recorded, transcribed and deidentified. Two researchers independently analysed the data with Dedoose (Los Angeles, California, USA), using an inductive major and minor qualitative coding technique.<sup>9</sup> Coding discrepancies were resolved via discussion. The opt-out reason discussed for the highest percentage of each transcript was considered the *most important*; these labels were independently confirmed by the coders' subjective assessments.

The medical school's institutional review board approved this study. Verbal consent was obtained prior to each telephone interview. Participants received a US\$50 gift card.

## RESULTS

### Study population

During our study period, 220 individuals began in-person donor evaluation (figure 1). Seven people who opted out of donation participated in our study (64% response rate). No one returned the refusal postcard, but four did not respond to ILDA telephone contact and two were unreachable due to outdated information. Table 1 details participant characteristics and their intended recipients. No participant had a history of psychiatric illness prior to evaluation.

### Reasons for opting out

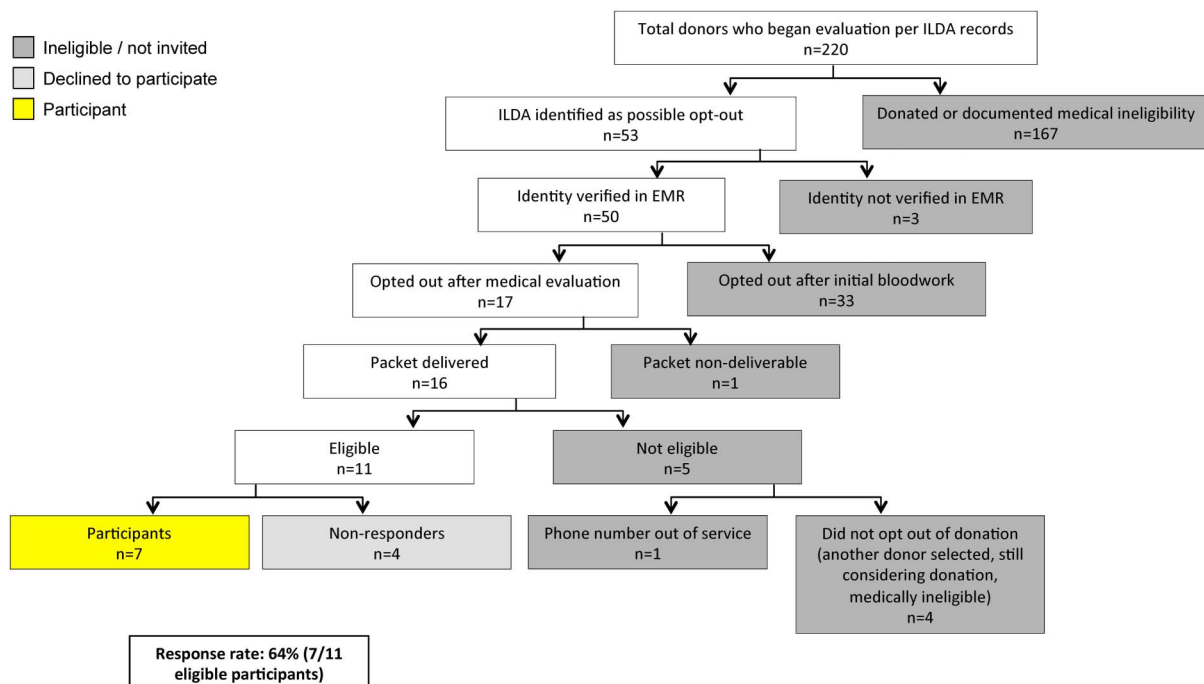
Individuals opted out of donation for a combination of reasons (table 2). Financial concern was the most frequently raised (three of seven participants) *most important* reason for opting out, and was closely tied to fears of a potential postoperative complication and extended recovery. One participant stated: "I was on the verge of really being close to homeless and getting backed up with my financial status and everything. My stress level just became so bad that I started getting anxiety attacks, panic attacks, and the fear kicked in...What happens if I'm going to be out for a few months in recovery?...I might get evicted".

**Table 1** Participant characteristics

Gender	Age at time of evaluation	Intended recipient	Type of donation	Year evaluated
Male	32	Friend	Direct	2012
Female	57	Brother	Direct	2012
Male	71	Friend's son	Exchange	2012
Female	24	Mother	Direct	2013
Male	33	Father	Direct	2013
Male	22	Friend	Exchange	2014
Female	55	Daughter	Direct	2014

Participants who had discussed their financial worries with the ILDA felt that the support provided in response was insufficient. One mentioned that the ILDA told him about a "\$500 grant" and that "other people have done fundraisers. My life was not so that I could take time to do fundraisers". Another potential donor who worked two jobs had been offered a US \$1000 National Living Donor Assistance Center (NLDAC) grant, but calculated that this would not cover her rent and bills during recovery. She thought that centres should "make sure that their [donors'] finances won't suffer. Because that's all I was saying: I can't become homeless in order to help my daughter". Another suggested that centres should say, "we're going to help you and supply you with food, or we're going to pay your heating bill, or something".

Five participants reported the health risks of surgery as contributing to their decisions. Health risks were often considered in conjunction with different concerns rather than the primary reasons for opting out. For example, one participant who opted out due to recipient medication and dietary non-adherence said: "I knew there was risk and if I knew that my dad would be more cautious with his health if I gave him the kidney, I would have gone through it".



**Figure 1** Sample frame. EMR, electronic medical record.

**Table 2** Reasons for opting out with representative quotations

Reason	Participant							Representative quotation
	1	2	3	4	5	6	7	
Perioperative health risks	X	X	X	X	X			"The asthma, even though it's mild...if I had to be intubated, would it trigger bronchospasm and be hard to get me off the vent"?
Potential impact on childbearing						X		"And I kind of felt cheated in a way, because my mother had four children and got to live and have a family....what if something had happened where I wanted a child and I was put in the same position [developing ESRD] as her and I didn't have anyone to help me out"?
Financial issues			X	X	X			"That was, and still is, the only holdback. I'm single and I have one income....I just didn't know how I was going to hold up my finances with surgery and recovery".
Other caretaking responsibilities				X				"The fear of, I didn't live and what happens if I can lose my life in this process, you know what I'm saying? What happens to my daughter?"
Anticipated lack of social support post donation				X				"And it wasn't because I didn't want to [donate]. It was because at the same time I was like I could be screwed at the end too. Nobody's going to be there for me".
Family opposed	X							"[my wife] was worried that everything would go wrong and I would be heading, down a path of poor health because of it [donation].... And she just didn't want any part of it. And I know if I told my three kids, that they would immediately take her side on it, and so I didn't even. They, to this day, have no inkling that this even went on".
Kidney not good enough					X			"...because of my past, drinking and using cocaine...I felt like that my kidney wasn't any good....I just felt like if it was someone younger to step up and donate their kidney to her, she'd probably have a better chance of living a normal and long life".
Recipient non-compliance		X				X		"...when he [the intended recipient] was younger, he would drink a lot and he used to smoke a lot. He used to eat a lot of candy and a lot of sweets and a lot of different things that were unhealthy for him. And that's what led him to the diabetes and the diabetes kept compiling issues after issues. So his kidneys were shot. And so that was my main concern: if I went through this whole process would he actually take care of my kidney?"
Recipient not sick enough						X		"Maybe when she's on dialysis would be more incentive for me to push forward with what needs to be done".
Relationship with recipient complicated						X		"...we didn't have contact for a while and we weren't on good terms, so she had come to me and said that she wasn't doing so well....I went through a bunch of weird feelings".
Relationship with recipient became worse during evaluation						X		"I felt that if you wanted something out of my body, our relationship should have either improved or at least stayed the same. And I felt that our relationship has gotten worse, like we don't speak anymore, we don't see each other, we don't communicate at all. So I just felt that I shouldn't be willing to give you a piece of something that's important to me if you can't even communicate with me".
Not emotionally involved enough	X					X		"This is a friend. It's not like it's somebody in my family....I'm not saying that she's not important in my life....but family vs friend. I mean, anybody would donate something to their family quicker than they would donate for their friend".
Save kidney for family						X		"I have two nieces...I still have my family, my mom, my grandmother are still living, that God forbid if something happened and they need it....I don't want to risk the chance of having to go through not being able to provide it to them because I gave it to someone else".
Concerns about the exchange programme	X		X					"Suppose your kidney's going to a cirrhotic or something, and his guy could care less....I mean I'm sort of getting judgmental about it, and I didn't want [to]...but I suppose there's things that work at anybody's subconscious".

X=reason mentioned.

■ =reason most important for the participant.

### The decision-making process

Most participants described their decision to opt out as a gradual process. In three cases, conversations with or information provided by the transplant team helped shape their decision. For example, one donor said: "I had some reservations or some concerns not because of the operation but more because of my dad....[The ILDA] made me realize that I had those concerns in the back of my head....I told [the ILDA] I think I'm not going to go through this but I'm going to have to think about it a little bit more".

Some participants talked to family and friends when making their decision or in its immediate aftermath. However, three reported a profound sense of loneliness. One said, "I have never just taken my burdens and just said, 'Oh, it's a gloomy day.'... But when it came down to my situation, I felt alone". Another shared, "I was by myself, going through this without anybody actually supporting me....And I was like God, I feel suffocated....My faith started decreasing and I just felt very much alone and sad and a little depressed....there were so many

thoughts, so many questions that I was asking myself, but I wasn't getting any answers. And I felt like, who can I talk to? Who can I tell? Who can help me?"

None of the participants who felt alone contacted the transplant centre for support. One reported, "I didn't talk to anyone....I know that I could have called someone, but I was just so in kind of a strange spot in my life that I really just pushed everything away". Another thought that his problems were outside the centre's purview: "I didn't feel like they could do much for me....They were willing to hear me out and everything, but what could they do?...Their job is probably something else. They don't have to overwhelm themselves with my life issues". He suggested that centres should "reach out a little bit more and investigate...because not everybody's willing to just open up to just complete strangers".

Three participants indicated that they would still consider donation if future circumstances changed. One said she might donate after she had a child or if her intended recipient started dialysis. Another stated that she would donate if she had greater

financial security or when her intended recipient obtained health insurance that would cover her medical expenses: “I was really wanting to do it. I still want to do it. But I don’t know. I just can’t see how”. A third participant reported that her financial status had improved since she had opted out and that ‘when my son gets tested and if he’s not a match, then I have no other choice but to step up....I would do it in a heartbeat. Still to this day’.

### Informing the intended recipient of the opt-out decision

Six participants shared their opt-out decision and reasons with their intended recipient, though one did not do so until the intended recipient had received a transplant from another donor. Most approached the topic matter-of-factly: one said, “I have nothing to lie about. I told her the truth...” and other stated, “It wasn’t that I was going back on my word or anything, but I told them straight up, ‘I’m sorry’”. Others described their discomfort with the conversation: “having that conversation with my dad was a little bit hard just because you know it’s your dad so you don’t want to say ‘Hey, I don’t want to do this anymore’”. Reasons for sharing the opt-out decision varied: “I wanted to be honest with him....and I didn’t want him waiting and wondering with what he’s already dealing with”. One participant told her daughter “because I didn’t want her to feel discouraged about it like I’m not trying to help her in any way”.

Most participants reported that their intended recipients were understanding of their opt-out decision, though they were disappointed. One said that the intended recipient was “pleased that I was honest with her”. Another’s intended recipient told him “it wasn’t fair to me [the potential donor] for me to make a sacrifice because he [the intended recipient] hasn’t taken care of himself....I think he knew that it was a hard decision for me....I think he saw that it’s a burden for me and the future”.

In two cases, the potential donor felt some pressure to reconsider their opt-out decision. One participant reported that her intended recipient and sister “ganged up on me a little bit. And my sister was sending me statistics of pregnant women that have had one kidney before. And I felt really exiled for a little bit”. Another said that his intended recipient was understanding and thanked him. However, the intended recipient’s wife “made me feel like it was just only about them and not me....She was, ‘Well we still need my husband to get this’....And I stepped away from that conversation very heartbroken, very disturbed... It was just, ‘Well just make sure that you don’t go back on your word’”.

A seventh individual had not yet informed his intended recipient about his decision but planned to do so eventually to achieve “closure”. He worried that “maybe she will hate me or resent me. I don’t know. Maybe her kids will never speak to me...I can’t say that I will be upset about it. I can’t blame anybody for it. At this point, nobody’s to blame for it”.

### Impact of opting out

Six participants knew how their intended recipient was doing at the time of the interview. Two intended recipients had received transplants from other donors and were doing well: “[My intended recipient] was very happy. He was very healthy...full of life and everything. And it made me feel good, seeing that he didn’t hold anything against me and he was just very pleased to see me....And I was just very happy that, at the same time, he still got what he wanted”. Two intended recipients were receiving dialysis. In one case, the potential donor helped care for the intended recipient after her dialysis sessions. The second

potential donor noted that she could see the intended recipient “getting depressed at some points”. Two intended recipients still had not required dialysis. The final participant had not talked directly to his intended recipient, but had been told that another potential donor was being evaluated.

None of the six participants who had informed their intended recipient about their decision to opt out thought their relationship had suffered subsequent long-term harm. One described a transition period during which the intended recipient was “a little upset by that at first” before accepting her decision to opt out. Another three participants perceived no change in their relationship with their intended recipient. Two others thought their relationship had become better, with “more in depth conversations” or increased interaction.

When asked how they felt about their decision to opt out, most participants reported complex emotions. This was the case even for those who believed that opting out was the right decision at the time. One said: “I feel good and I feel bad. I feel good because like I said I’m still young and I still need to go through my life. And I feel bad because my dad sooner or later is going to go through more complications”. Another stated, “It [opting out] wasn’t a selfish act...[LKD evaluation] came at the right time, but at the wrong time on top of it”. A third wished that circumstances were different: “I can potentially save her life. I can give her extra time on this earth for her children, but for the simple fact of me saying no. It does hurt me because what if that was me?...I wish things were different and we had that communication and I still was willing to go through with it”. Other donors seemed more ambivalent about their decision to opt out: “I feel, honestly, confused. Because I’ve always, always wanted to do this [donate], but just I don’t know if right now is the best time for me. But maybe there isn’t a good time. Maybe I’m just still confused”. Another participant felt comfortable with his decision, noting that he had developed a new medical condition after opting out and that “all of these things happen for a reason. You know, it’s probably better I didn’t do it”.

### Alibis

Six participants definitely thought that centres should offer alibis, written or verbal statements of unsuitability for donation provided to the potential donor to share with their intended recipient. The seventh participant initially stated that she preferred honesty, but after a moment’s reflection added, “I suppose that if they don’t want to, that makes them unsuitable”. Participants thought of an alibi as a way of ensuring that “in times of stress or confusion, you don’t feel alone”. One reflected that it removes the “onus off the potential donor from feeling that they personally let down [the intended recipient] or were irresponsible....It’s not judgmental....It’s a nice way of not saying, ‘Oh Joe Smith just chickened out or something.’ It’s better to say he’s not a suitable donor. It covers it and doesn’t make him look like a bad person”.

While all participants reported that they were told multiple times that they could opt out, only one definitely remembered being informed that the transplant centre would provide an alibi. A second participant said she was sure such a statement was available but could not recall the offer. No one had used an alibi, although some said they would have wanted to do so: “I think having a letter or something just saying that I’m not qualified because of whatever reason, I think that it would have been easier. I think that it would have helped my dad and I communicate better...”. In contrast, another would not use an alibi due to the worry that the intended recipient would find out: “Because God forbid the truth gets out, she goes back to

somebody that I know and is like, 'He's got this and this was the letter I got', and they'd be like, 'Well he didn't tell me that'. Then if I was in her shoes, I would be hurt too".

### Transplant centre support

All of the participants felt that they received adequate support from the transplant centre. The support was manifested as prompt answers to the donor's questions, accommodating the donor's schedule, assistance with paperwork, conversations with the ILDA and a sense that the transplant team members "really do care on both parts, about the donor and the recipient". Participants described the evaluation as "non-judgmental" and said that "everybody was trying to encourage me, but at the same time, no pressure...And just trying to make me [think], is this the right decision? If this is really what I want?" One potential donor thought the team was "compassionate", but felt that they were occasionally overly "involved in the excitement of the surgeries".

### Participants' emotional status and attitudes toward the research

Two participants became emotional, with altered tenor and intensity of speech, when describing the stresses and anxieties they felt during and after opting out. However, neither of them expressed a desire to terminate or pause the interview. At the conclusion of that segment of the conversation, both participants rapidly recovered their equilibrium. Multiple participants volunteered that they appreciated that someone was following up with them.

## DISCUSSION

This is the first in-depth study of US potential LKDs' reasons for and experiences with opting out of donation. This is a small-scale study, but has important implications. It serves as a proof of concept that well-designed and carefully implemented research can be effectively and ethically conducted with individuals who opt out of donation. Moreover, this study highlights strengths and weaknesses of the current living donor evaluation and support systems at our centre.

Our results underscore the significance of financial concerns as a barrier to living kidney donation. For some individuals at our centre, the expenses associated with a standard recovery period of 6–8 weeks<sup>10–11</sup> were unaffordable. Others worried about the possibility of postnephrectomy complications and prolonged inability to work. NLDAC funding was inadequate for the two participants who were eligible to receive it. Our participants' experiences support the extant consensus in favour of removing financial disincentives to donation.<sup>12</sup> Their comments indicate that making donors 'whole' by reimbursing them for their forgone wages might eliminate a major source of anxiety for potential donors and could increase the number of LKDs in the USA, even in the absence of further financial incentives or offers of medical insurance.<sup>7–13–16</sup>

Participants' comments reinforce the importance of ILDA's, while also revealing areas where the ILDA's role may merit further expansion.<sup>17</sup> While potential donors at our centre reported being adequately supported by the transplant team, many still felt alone while making their decision to opt out. This suggests that ILDA's should routinely renew offers of support to potential donors who have not continued their evaluation after a designated period of time. Moreover, ILDA's should follow up with individuals after their opt-out decision: assistance could include role-playing disclosure of the opt-out decision, facilitating a meeting between the potential donor and

intended recipient to discuss the opt-out decision, and debriefing those who opted out to help them process their feelings and their intended recipients' responses.

While ethicists have debated the use and types of alibis<sup>18–21</sup> and written offers of alibis are uncommon,<sup>22</sup> our study participants unanimously believed that centres should offer alibis to all potential donors. Our centre's evaluation consent form details the availability of an alibi; the ILDA and other transplant team members verbally reiterate this option during the donor evaluation process. Yet, most of our participants could not recall these offers. This finding could be due to the retrospective nature of our study. However, since some participants reported that they would have wanted to use an alibi but did not do so, it is likely that some were not aware that they could receive an alibi at the time they opted out. Donors may overlook alibi offers given at the start of the evaluation process, when they receive an overwhelming amount of information and documentation. We therefore suggest that ILDA's repeat alibi offers at the time that individuals notify the transplant centre of their decisions to opt out. In addition, the fact that several participants indicated that they might consider donation in the future suggests that transplant centres should provide alibis that do not exclude future donor candidacy.

The generalisability of our results is limited by small sample size at a single institution, our retrospective approach, the exclusion of individuals who opted out before in-person evaluation and the absence of potential living liver donors in our sample. Participants had opted out between several months to 2.5 years prior to our study, which may have resulted in varying degrees of recall bias.

While the number of individuals who opt out of donation is relatively small, continued research will highlight additional ways in which they perceive a lack of information, resources or support during their decision-making process. Addressing these shortcomings will improve our ability to protect the autonomy and ensure the welfare of all potential living donors. Moreover, qualitative research that offers potential donors a direct narrative voice<sup>23</sup> may enhance transplant professionals' empathy for and awareness of the complexity of potential donors' experiences and decisions.

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