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Permalink

<https://escholarship.org/uc/item/0jc2q2ww>

Journal

American Journal of Nephrology, 43(6)

ISSN

0250-8095

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Publication Date

2016

DOI

10.1159/000446161

Peer reviewed



Published in final edited form as:

Am J Nephrol. 2016 ; 43(6): 389–396. doi:10.1159/000446161.

Living kidney donors who develop kidney failure: excerpts of their thoughts

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Abstract

Background—Psychosocial data about living kidney donors have been collected for almost five decades. To date, however, no study has provided psychosocial follow-up of donors who develop a serious health problem such as end-stage renal disease (ESRD).

Methods—Donors who developed ESRD were invited to participate in a qualitative interview if they met one or both of the inclusion criteria: 1) developed ESRD within 10 years of donating; and/or 2) lacked health insurance at the time of donation. We contacted 38 individuals who met these criteria, and 22 participated (54%). Two were subsequently excluded from analysis.

Results—Twenty qualitative interviews were analyzed. Five findings are described: 1) donors describe the decision-making process as spontaneous and fast; 2) donors describe a lack of appreciation for the need for post-donation self-care; 3) donors do not regret donating despite the adverse outcome; 4) donors would advise future donors to have in place emotional and physical support post-donation; and 5) donors appreciate the opportunity to tell their story from living donor to living with ESRD which virtually all perceive as two separate unrelated events.

Conclusions—Most donors are positive about their donation decision and experience and would donate again, despite developing ESRD themselves. They propose some important changes to the decision-making and informed consent processes. Our data are reassuring regarding lack of

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CONFLICT OF INTEREST: The authors declare no conflicts of interest.

donor regret, but highlight the need for living donor transplant programs to ensure that living donors understand their long-term risks and receive appropriate life-long follow-up care to minimize these risks.

Keywords

living donor; kidney donor; ethics; adverse outcome; psychosocial; qualitative study

INTRODUCTION

It is estimated that over 150,000 individuals have served as living donors in the United States – *estimated* because for the first 40 years, no systematic data were collected. Since 1996, the Organ Procurement and Transplantation Network (OPTN) has recognized former living donors by awarding them four points if they are listed for a deceased donor kidney. As of May 31, 2015, over 430 candidates have received four points (personal communication E. Beeson, United Network for Organ Sharing, September 11, 2015). However, this remains an underestimation as it does not include those living kidney donors who were listed and transplanted before 1996 nor those living kidney donors who developed ESRD but choose not to be listed for transplant.

Although the OPTN only requires two years of clinical and laboratory follow-up data, data collection compliance is poor.[1] However, recent studies show that when donors are followed over longer observation periods, there is an increased risk of end-stage renal disease (ESRD), reproductive complications, and hypertension.[2-4] There is also a dearth of systematic long-term psychosocial follow-up. In the 1970s, Simmons and colleagues found that donors often decided to donate “spontaneously”. [5] This was confirmed by Fellner and colleagues, who showed that the majority rarely changed their decision, even when given extensive data about risks.[6,7] Simmons and colleagues also found that donors seldom experienced regret, at least in the short-term.[5] In fact, most studies have determined that fewer than 10% of donors regret their decision to donate, and this holds even when there are adverse outcomes, like graft failure and recipient death.[8-14] To date, however, no study has provided psychosocial follow-up of donors who develop a serious health problem like ESRD. In this manuscript, we describe interviews with 20 living donors who subsequently developed ESRD.

METHODS

Design

This project is part of a larger, ongoing study in which one of us (LFR) is recruiting former living donors who developed ESRD to determine whether there are specific biomarkers or genetic risk factors. The Human Resources Services Administration (HRSA), which oversees the OPTN, helped identify participants by providing the names and birthdates of those who had received four points. Nephrologists and other transplant professionals around the country helped locate these candidates as well as candidates not known to HRSA. In June 2014, 165 individuals had been consented to participate in the database and had provided tissue samples. Virtually all agreed to be re-contacted for supplemental projects.

The researchers identified two sub-groups of interest for this study: 1) those who developed ESRD within 10 years of donating [Subgroup Under-Ten]; and 2) those who lacked health insurance at the time of donation [Subgroup Uninsured]. Study participants were restricted to donors who had donated to a first-degree family member, but excluded parents who had donated to a child because of the distinctive emotional dynamics of that relationship.[15,16] The University of Chicago's Institutional Review Board approved the main project and exempted the oral histories from further review.

Recruitment

Twenty-five donors developed ESRD within 10 years of donating and 27 donors lacked health insurance at the time of donation. This double-counts five who both developed ESRD within 10 years and lacked health insurance. Excluding non-first degree relatives and parent donors resulted in 21 participants in Subgroup Under-Ten and 17 potential participants in Subgroup Uninsured. All were sent a one-page information sheet about the qualitative study and an oral consent document. The information sheet explained that they would be contacted within two weeks to determine whether they were interested in participating, or they could contact us in order to set up an interview time. Potential participants were told that the interview would last approximately 60 to 90 minutes and were offered a \$50 gift card in appreciation for their participation.

Interview Scripts

We developed two overlapping scripts of semi-structured questions, one for each subgroup. All scripts began by asking about the participants' decision to donate their kidney. Questions focused on donors' health, interactions with the transplant team, the impact of subsequent kidney problems on the donor and their family, and closed with a discussion of recommendations given their experience of the donation process and their subsequent development of ESRD. The script for Subgroup Under-Ten included additional probes regarding family dynamics surrounding the donor's relatively near-term development of ESRD, while the Subgroup Uninsured script devoted additional probes to the patients' experience with the healthcare system and finances. Interview guides are available from the corresponding author.

Data Collection and Analysis

All participants were interviewed by telephone by either JW or MP, except one who was interviewed in person by MP. All interviews were conducted entirely in English, except one that had Spanish supplementation (LFR), which was translated before coding. A senior researcher (LFR) oversaw the interviews and when salient questions remained, the participants were re-contacted for further questions. Interviews lasted between 40-90 minutes. After 11 interviews in both Subgroups, no new concepts were being expressed. Having reached theoretical saturation, no additional participants were recruited.[17] Researchers transcribed the interviews in Microsoft Word and uploaded transcripts to Atlas.ti (software for qualitative data analysis). All researchers participated in the development of the codebook. Four researchers (CMEH, JK, MCM, and LFR) coded six interviews, making modifications to the coding tree iteratively until there was unanimous agreement about the definitions of each code. Two investigators (CMEH and JK) then

double-coded each transcript; disagreements between the two were reconciled. In this manuscript, participants are identified by gender (F = female, M = male), by subgroup (T = Under-Ten, I = Uninsured), and by a unique number.

All interviews were recorded and transcribed. After reviewing the transcripts, researchers developed 25 coding categories. After further consideration of the categories as they had emerged and the similarity between interview scripts, it was determined that no significant differences in the qualitative findings existed between the two subgroups, and they were merged for analysis.

RESULTS

Participant Characteristics

A total of 22 individuals participated in the interviews, 11 of 21 eligible (52%) from Subgroup Under-Ten and 11 of 17 eligible (65%) from among the Subgroup Uninsured (see flowchart, Figure 1). Two interviews from Subgroup Uninsured were subsequently excluded from analysis because the donation had occurred in the early 1960s when kidney transplantation was still very experimental and would not have been covered even if the donors had insurance.

Overall, 47 individuals met the criteria, being uninsured at time of donation, having developed ESRD within 10 years of donation, or both. Of this group, 27 (57%) were male. Twenty-one of the individuals (45%) self-identified as African American, nine (19%) as Hispanic, 15 (32%) as White, and two (4%) as other. After exclusions, 23 of the 38 potential candidates (61%) were male. Eighteen (47%) potential candidates self-identified as African American, seven (18%) as Hispanic, 12 (32%) as White, and one (3%) as other. These demographic data are not statistically different from those of the actual interviewees (see Table 1).

Thematic Findings

For this study, we describe the findings from five coding categories, four of which have been analyzed in other qualitative research focused on the experiences of living donors and one unique to our project: (1) the decision-making process, (2) instructions for donor self-care after donation, (3) (lack of) regret about having donated, (4) advice for future donors and the donation process, and (5) the impact of the current project on perceptions of their lived experience from donor to recipient.

Decision-Making

Interviewees did not describe becoming a donor as the result of a decision, but rather, as a spontaneous response to their relative's medical condition. "I never lost no sleep over it," one man stated nonchalantly: "I just said, 'Well, that's my brother; that's all'" (FI7). Another woman noted similarly, "I didn't think twice about doing it, 'cause I knew he needed it" (MI6). Likewise, some participants seemed not to have thought retrospectively of their donation as a choice. One participant explained, "I just kind of felt like it was just- that's just

the way it's supposed to be. I never really thought much about it to make a decision” (MT10).

Many participants related this ‘non-decision’ to the perceived rapidity of the donation process. “I'm not saying that I would have said ‘No,’ but I just don't feel like I had a chance to really, really process everything. [...] It went very quickly” (FT8). One participant even went so far as to say, “Everything happened so quickly that it w- there was not time to think” (FI8).

Regret

Throughout the interviews, participants were prompted with questions regarding their feelings toward donation. Did they hesitate during the decision-making? Did the varying success of their donated kidney in the recipient affect their interpretation of its success? Did they regret donating now that they had themselves gone into ESRD?

The interviewees were resoundingly positive about their original decision to donate: “The decision I [made], to me, was the right decision,” stated one man (MI4). “I never regret it,” said a middle-aged woman (FT2). The same interviewee later began to cry while discussing how she found out that her kidney was failing: “I was upset. Yeah, I was upset, but I have no regrets.”

When asked explicitly, all but one participant stated that they – *despite the consequences* – would go back in time and donate all over again. For instance, one man said, “If I had to do it over again, I would do the same thing” (MI3). Another woman responded similarly: “If I knew my kidney wasn't going to work? I would probably still do it” (FT2). One participant described the difficult conversation he had with his recipient-sister when his one remaining kidney began to fail: “She was hurt because she felt like it was her fault, because I donated her a kidney and she felt like it was her fault, but I reassured her that it wasn't. I told her that if I had to do it all over again, I mean, it's a no-brainer; I would do it again” (MT6).

Only one interviewee, when asked outright, stated that she would “probably not” (FI2) have donated knowing that she would subsequently go into ESRD. She explained that she had a complicated post-operative course and a strained relationship with her recipient-sister. Throughout her interview, however, she oscillated between satisfaction and regret, pensively considering the positive and negative results of her donation. At one point she conceded, “I probably would have done it again, who knows?” Later in the same interview, she ruminated: “Had I known that I would be going through this, I don't know. [...] I might've thought a little bit longer.” (It is noteworthy that she characterizes these feelings as “the hardest thing to say” and “a bad thing to say.”) Earlier, however, despite her wavering, she concluded that she is “glad I was able to give her the time that I did.”

Several transplants were relatively unsuccessful clinically (lasting less than a few months), but even this did not sway donors in their steadfast lack of regret. “It wasn't in the cards for my kidney to work for him,” one woman said of her recipient, “but we gave it a shot, because it could have gone either way. It went the wrong way for us, but if need be, I would do it again” (FI6).

Self-care

Participants were asked to recall what their healthcare team told them about self-care after donation. Most responded that they had been told simply to live a 'normal life.' For instance, the interviewer asked one woman, "What did your mom think [about your donating]? Was she concerned like your dad?" The woman responded, "They were very concerned, only because they wanted me to have a full life after I donated. But really the team we were speaking with, they explained everything to us and they said pretty much that I would be able to have a normal life after donation" (FI6). Unlike her parents, she stated, her healthcare team did not focus extensively on the risks of donation. One man noted that he was so trusting of what he recalls his team telling him, that he disregarded what he now knew to be risk factors for developing ESRD:

They told me that I could live a normal life with one kidney. I used to do construction. I never had high blood pressure or diabetes or anything, and I was putting on a lot of weight. I was living a normal life and just working back and forth, and then [...] I started feeling some symptoms, and I didn't know and then I went to the doctor [...] they said it was my kidney. (MT5)

The main fact that individuals remembered from the risk discussion with the transplant team was that one kidney is sufficient. "They told me that you can live with one kidney," one woman explained. "Well, evidently you *can* live off of it, but you have to keep yourself healthy, and nobody explained that to *me*. They told me, 'Go ahead and live your life like you always did'" (FI2).

A few of the donors expressed a certain degree of self-blame for their subsequent ESRD. Participants explained that they did not understand the need to take better care of themselves, as evidenced in this quote:

Somebody should've told me, 'You've got this one kidney. You have to be real careful about your weight. You have to be real careful about eating and doing different things.' I mean, if they had, I don't think that this probably would've happened to me. I just assumed you could go ahead and live your life the way you've always been living with two (FI2).

Another woman lamented, "I think I was careless. I remember in the summer having a sore throat and not going to the doctor because I just- you're a mom; you don't think about that stuff" (FI6).

While some blamed their subsequent kidney failure on "tough luck" (MT12) or "God[']s reasons" (MT5), none explicitly stated that their donation was in part responsible for the development – or even the timing – of their own kidney failure. One respondent, however, offered that his spouse was not certain:

She, I know, in the back of her mind, still feels that maybe some people didn't basically do as thorough a job on the medical side to fully look at my circumstances and maybe would have detected something which would have said, 'Hey, maybe you shouldn't do this because you've got some- some issues looming (MT12).

Advice

Participants were asked how they would change the donation process. Most stated they would not change anything. “I think they did a good job, and I think that hopefully they can continue,” one woman said (FI1). Another respondent responded similarly, “No. [...] They did everything right” (MT4).

Similarly, many individuals gave blanket endorsements for donating a kidney: “I would definitely encourage anybody to be a donor,” declared one woman (MI6). Another woman explained:

I would tell [potential donors] to do it. Don't be scared; just take the test and just, you know, you're doing a good thing. Don't have regrets. Think about it first and, you know, be sure that you don't have any regrets. You're helping someone else (FT2).

However, some provided advice about self-care post-donation. Many stated that they did not seek preventive health care for years or decades after being discharged from follow-up by the transplant team, and that transplant teams need to emphasize the long-term risks with donation: “I wish they don't say to everybody, ‘Oh yeah, you going to be okay, no problem,’ because [it] *can* be a big problem” (MI4). Another man noted the importance of self-observation: “When you think you sick, before you get sick, you should go [to the doctor]. And that's what I do now. I go to the urologist; I go to the cardiologist; I go to the optometrist [...] I go to A through Z now” (MI8).

Several participants advised that prospective donors have a strong community to rely on during and after recovery. One man expressed serious disappointment that his family checked in on the recipient post-operatively but not on him. He advised: “Make sure that [the donors] have a good support group around them [...] at least a couple people that would drop in and see if they're okay” (MT10). Some also recommended that healthcare teams set the donor up with an “advocate [...] like a counselor” (FT9).

Despite their own experience of serious harm (kidney failure), very few comments were directed at the perceived dangers of donation. “Make sure it's something that you really, really are willing to risk your health and life in doing,” one woman exhorted potential donors (FT9). However, some donors stated that the physicians should have been more explicit about the risks. For example, one donor stated:

All the doctors, everybody, said, ‘Oh, you're going to live the same; it's not going to be any problem for you and your kidneys.’ [...] But if somebody at the time [told] me the risks – ‘Maybe you're going to end in renal failure’ – [...] It's not like maybe I don't change the decision to donate, but I wish to at least know. (MI4)

Study Impact

Many of the interviewees valued being asked to tell the story of their trajectory from kidney donor to transplant candidate, although most had not considered any connection between donation and developing ESRD. In several of our interviews, participants mentioned that our study had caused them to reflect on the relationship between these events. One man stated

that he would not have considered a connection between his donation and later development of ESRD from lupus “had you not called me and prompted me to think about [it]” (MT12). That said, he – and almost everyone else – remained very positive about donation.

One participant differed in that he made explicit that he had *intentionally* abstained from thinking about the relationship between his donation and his health. He described initial anger and resentment after donation that he had subsequently worked hard to stifle: “I’ve been suppressing these thoughts, ‘cause I really never told my story. [...] I’m going to put them thoughts- I’m going to close that door and open that file cabinet no more. [...]” (MI10).

DISCUSSION

This is the first study to focus on the attitudes and psychological outcomes of living donors who subsequently developed ESRD. A key and somewhat surprising finding of our study is that despite their universal adverse outcome, our donors’ recollection of their donation experience is mainly positive and mirrors the psychological findings in studies involving living donors who did not have serious adverse health outcomes.[5,18,19] Our donors made spontaneous decisions and for the most part (95%) have no regret despite the adverse outcome. Studies in which donors did not develop ESRD have found parallel results, with no or few participants (<10%) expressing regret for having donated. [8-14]

Most participants recall the donation process as rapid and do not attend to any warnings for modifying behaviors. Our donors interpreted ‘you can live with one kidney’ as meaning they did not need to take precautions regarding their health. Whether this accurately represents the discussion they had with their transplant team is unknown, although one must remember that until very recently, most data were single-center studies that were underpowered to show long-term risks.[21-25] However, even among these small studies, a few authors suggested that there may be some risk to donation and encouraged the establishment of donor registries.[26-28] That said, it has only been in the past five years that large studies over longer observation periods have had the power to show an increased risk of ESRD[3,4] and pregnancy complications in former living kidney donors.[2,29,30] These studies and our data confirm: 1) that the current OPTN requirement of two year living kidney donor follow-up is inadequate as many health complications may not appear for years or decades; and 2) that long-term living donor registries are needed.[31-33] The new risk data also highlight the need for best practices for long-term follow-up care and robust informed consent discussions that focus on both short- and long-term risks. Furthermore, studies are needed to determine: 1) how to ensure that donors understand their need for life-long care; and 2) whether this care should occur at a transplant center, a nephrology clinic, or with a primary care doctor.

Unique to our study is the advice that our participants offered to the transplant community. Like other donors, they support living donor kidney transplants because of the significant benefits they offer both recipients and donors.[5-7,34] However, some of our respondents negatively described the lack of support they received post-operatively because they were presumed healthy, and advised counseling donors to ensure good post operative support. They also recommended that living donors be taught to perceive themselves not as “healthy”

but rather “healthy but at risk” and to seek medical attention for what may seem to be trivial concerns to ensure kidney well-being.

Some respondents stated that the enrollment in the larger project and the subsequent request to interview them made them more aware of the possible link between their donation and their long-term kidney problems. This may be due to a more explicit consent process during the main project that describes the goal of the study to determine risk factors for ESRD after kidney donation. We were careful to explain that it cannot be known in any particular case whether they would have developed ESRD if they had not donated (unless the cause of ESRD was unilateral traumatic injury to the remaining kidney). We further explained that one of the greatest risk factor for developing ESRD is having a family history of ESRD. [35,36]

There are many reasons why donors may not have previously connected donation and ESRD. First, it is only recently that the kidney transplant community has empirical data to show the increased risk of kidney disease in living donors.[3,4] Second, it is possible that the transplant community does not explore the possible link when former donors present with ESRD but rather treats these as separate events.

There are several limitations to our study. First, our participants were quite heterogeneous in the time elapsed since living kidney donation which may influence their recall of events around donation. They are also at different stages of adaptation to living with ESRD—one was pre-dialysis, others are on dialysis or have received a transplant. Current state of health and adaptation to ESRD may also impact the attitudes expressed and the narratives generated about their trajectory from donor to individual in ESRD. Second, donors’ answers regarding regret may reflect cognitive dissonance[37] or a social desirability bias.[38] Third, we limited our data analysis to first-degree relatives other than parents donating to their children. Further research is needed to know whether other donor-recipient relationships elicit the same responses.

Despite these limitations, our study provides unique insight into a population that has not been systematically identified nor well studied. Our data are reassuring in that our donors do not regret their donation, despite the fact that they themselves develop ESRD. This does not mean, however, that we can be complacent about donors’ understanding of the decision-making process or of the risks and consequences of living kidney donation. Ensuring that living donors understand their long-term risks and receive appropriate lifelong follow-up care to minimize these risks should be a priority in living donor kidney transplantation.

Acknowledgements

We would like to thank all of the donors who participated in this study. We would like to thank Sandi Cohen who helped work on the interview guides.

Halverson was funded by the MacLean Center for Clinical Medical Ethics and the Department of Pediatrics at the University of Chicago. Wang was funded by the University of Chicago Summer Research Program and NIH grant number 2T35D062719-26 (PI: Eugene Chang, MD). Poulson and Karlin were funded by the MacLean Center for Clinical Medical Ethics. Ross was funded by the Robert Wood Johnson Investigator Award in Health Policy. The authors have no other funding sources to be declared. The funders had no role in study design or data interpretation.

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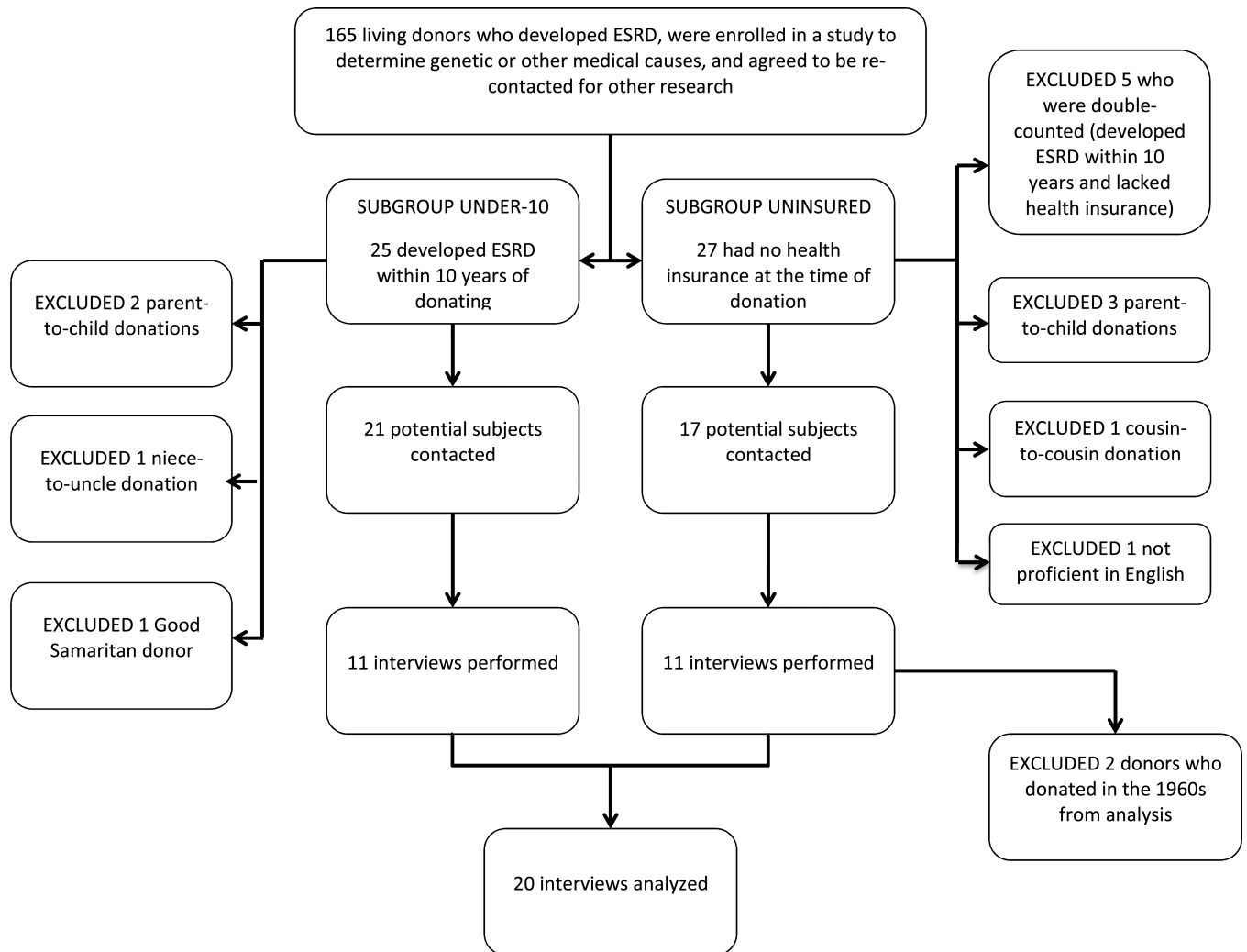


Figure 1.
Flowchart of Living Donor Recruitment and Inclusion for Analysis.

Table 1

Demographics (N =20)

Trait		Total N =20 (%*)	Uninsured N =9 (%*)	Under 10 N =11 (%*)
Race	Black	12 (60)	4 (44)	8 (73)
	Hispanic	4 (20)	4 (44)	0 (0)
	White	4 (20)	1 (11)	3 (27)
Gender	Female	8 (40)	4 (44)	4 (36)
	Male	12 (60)	5 (56)	7 (64)
Relationship to recipient	Child to parent	3 (15)	0 (0)	3 (27)
	Sibling	17 (85)	9 (100)	8 (73)
Age at interview	30s	2 (10)	0 (0)	2 (18)
	40s	5 (25)	1 (11)	4 (36)
	50s	5 (25)	3 (33)	2 (18)
	60s	6 (33)	5 (56)	1 (9)
	70s	2 (10)	0 (0)	2 (18)
Education	Less than high school	1 (5)	1 (11)	0 (0)
	High school or equivalent	7 (35)	2 (22)	5 (45)
	Associates or some college	6 (30)	5 (56)	1 (9)
	Bachelors	3 (15)	0 (0)	3 (27)
	(Some) graduate	3 (15)	1 (11)	2 (18)
Date of donation	1970s	4 (20)	4 (44)	0 (0)
	1980s	5 (25)	4 (44)	1 (9)
	1990s	4 (20)	0 (0)	4 (36)
	2000s	7 (35)	1 (11)	6 (55)
Time from donation to ESRD (years)	10	11 (55)	0 (0)	11 (100)
	> 10 but 20	3 (15)	3 (33)	0 (0)
	> 20 but 30	5 (25)	5 (56)	0 (0)
	>30 but 40	1 (5)	1 (11)	0 (0)
Treatment modality for ESRD at time of interview	First time on waitlist not requiring dialysis	1 (5)	1 (11)	0 (0)
	First time on waitlist, requiring dialysis	2 (10)	0 (0)	2 (18)
	On dialysis after 1 or more deceased donor grafts failed	3 (15)	1 (11)	2 (18)
	Deceased donor graft functioning	14 (70)	7 (78)	7 (64)
	Living donor graft	0 (0)	0 (0)	0 (0)