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Spirituality and Religiosity of Non-Directed (Altruistic) Living Kidney Donors

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Abstract

Aims and objectives: To describe the spirituality and religiosity (S&R) of 30 non-directed (altruistic) living kidney donors (NDDs) in the United States (U.S.) and explore how they may have affected their motivations to donate and donation process experiences.

Background: The rise in NDDs and their ability to initiate kidney chains offers a novel approach to help alleviate the overextended kidney transplant waitlist in the U.S. However, little is known about the NDDs' motivations, characteristics, and experiences.

Design: We conducted a qualitative-dominant study and used a grounded theory approach to analyze data.

Methods: Thirty participants completed in-depth interviews between April 2013 and April 2015. Three analysts independently read and coded interview transcripts. Grounded theory techniques were used to develop descriptive categories and identify topics related to the NDD donation experience.

Results: Sixteen of the 30 NDDs discussed the topic of S&R when describing their donation experiences, regardless of whether they were actively practicing a religion at the time of donation. Specifically, three themes were identified within S&R: motivation to donate, support in the process, and justification of their donation decisions post-donation.

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Conclusions: Findings from this study are the first to describe how S&R influenced the experiences of U.S. NDDs and may help improve NDD educational resources for future spiritual or religious NDDs, and the overall NDD donation experience in efforts to increase the living donor pool.

Relevance to clinical practice: Spirituality and religiosity are often overlooked yet potentially influential factors in Western medicine, as demonstrated through the experiences of Jehovah's Witnesses and their religious restrictions while undergoing surgery and the beliefs of Christian Scientists against taking medications and receiving medical procedures. Understanding needs of NDDs specifically with S&R can better position kidney transplant centers and teams to improve pre-donation screening of NDD candidates and provide support services during the donation process.

Keywords

Decision-making; transplantation; qualitative study; grounded theory; beliefs; health services research

INTRODUCTION

Non-directed donors (NDDs) donate their kidney to strangers in need and assist in resolving common biological incompatibility challenges facing predetermined, incompatible donor-recipient pairs (Melcher et al., 2013). Moreover, NDDs are able to initiate kidney donation chains (Melcher et al., 2013; Rees et al., 2009), the largest of which has resulted in 51 transplants triggered by a single donation (Greer, 2015). Despite the potential impact NDDs have to help meet the substantial demand for kidney transplants, the current literature on the characteristics and donation processes of U.S. NDDs remains limited (Jacobs et al., 2004; Roth et al., 2006).

Research exploring the influence of spirituality and religiosity (S&R) on the experiences of NDDs in the U.S. has not yet been closely studied (Jacobs et al., 2004; Faber et al., 2016). This paper describes the spirituality and religiosity of NDDs and its influence on their motivations to donate and overall donation experiences. Further investigation and understanding on how cultural characteristics such as spirituality and religiosity may influence the kidney donation experiences of NDDs can help inform future interventions aiming to improve NDD screening, education, and outreach and can be beneficial in improving cultural competency in healthcare delivery to meet the needs of S&R NDDs. Altogether, research focused on understanding the characteristics of NDDs can have larger implications toward increasing the availability of living kidney for transplantation, providing end-stage renal disease patients with their preferred treatment choice and an improved quality of life (Fadem et al., 2011)

This study aimed to describe the spirituality and religiosity of NDDs and its influence on their motivations to donate and overall donation experiences. We defined spirituality as: a personal quest to understand answers about life, meaning, and relationship to the sacred or transcendent, which might or might not lead to or arise from the development of religious rituals and community formation (King et al., 2009). We defined religiosity as: a strong

religious feeling or belief. Although spirituality and religiosity are distinguishable, they share underlying principles and for this reason were kept as one topic for this analysis. This study is also ancillary to a larger, descriptive, qualitative-dominant, mixed methods study, Understanding Donor Choice (UDC). The UDC study aims to provide a description of NDDs to provide the foundation upon which to develop education and decision-making tools for individuals contemplating living kidney donation.

BACKGROUND

One systematic review on qualitative studies that explored population attitudes towards living and deceased organ donation in the U.S., United Kingdom, Canada, South Africa, Malta, and Australia found that religious faith could positively influence willingness to consider organ donation (Irving et al., 2011). Meanwhile, another review found that religious concerns may inhibit individuals' willingness to donate and is likely to be an under-reported barrier to organ donation (Oliver et al., 2011).

Religious leaders are recognized as having an educational and influential role in the living kidney donation process (Ismail et al., 2011). Previous research has addressed the impact of S&R values on the willingness to donate organs; however, findings were limited to Chinese-American church attendees from minority groups (Lam et al., 2000). While religions such as Judaism and Islam may waver on whether or not to endorse organ donation, other religions such as Christianity have been more open to accept donation (Oliver et al., 2011; Coad et al., 2013). Current literature has a limited understanding of the role of spirituality and religiosity in the living kidney donation process, particularly among U.S. NDDs.

Aim

The purpose of this study was to explore the spirituality and religiosity of NDDs in the U.S. The experiences of non-directed (altruistic) living kidney donors are currently poorly understood. Understanding the attitudes, motives and decision-making processes behind NDDs may benefit strategies aimed to reduce barriers to living organ donation, improve the NDD donation experience, develop educational materials to heighten non-directed donation awareness, and help guide improvements in clinical care during the donation process.

METHODS

Study Design

This study examines the themes and sub-themes of spirituality and religiosity in the donation experience of 30 NDDs in the U.S. The study incorporates concurrent qualitative and quantitative data collection and analysis techniques consistent with constructivist grounded theory (Charmaz, 2006; Thorne, 2016).

The UDC employed in-depth interviews and grounded theory techniques to develop descriptive topics relevant to NDDs' kidney donation experiences (Charmaz, 2006). Grounded theory techniques, including open coding (inductive), focused coding, and constant comparison method, were used to analyze the data because qualitative methods are best suited to areas about which there is little currently known. The COREQ 32-item criteria

checklist for comprehensive reporting of qualitative studies was adopted as the primary guide for the procedure and report process for this study (Tong et al., 2007).

Through our initial analysis of the NDDs' donation experiences, we identified spirituality and religiosity as an important topic discussed during interviews of 16 of the 30 participants. We conducted the current study to explore the themes and sub-themes of S&R present during the 16 participants' donation experiences.

The multidisciplinary research team with kidney transplantation, urology, nursing, and public health backgrounds had experience conducting qualitative and quantitative research studies with clinical populations before this study. No one from the research team had any prior communication or relationship with the study participants.

Participants

We defined an NDD as a living donor who donates a kidney to an unspecified recipient (Melcher et al., 2013). The inclusion criteria required participants to have non-directly donated their kidney in the U.S., be at least 21 years old, and read and speak English. We excluded donors who were directed donors miscategorized as non-directed donors and people who were still on the waitlist as a non-directed donor and had not yet donated.

After obtaining Institutional Review Board (IRB) approval, we received lists of potential participants from three databases. We stratified the lists by race/ethnicity (non-Hispanic White vs non-White), sex, and age groups, and randomly selected individuals within each strata to be contacted. However, men and racial-ethnic minorities are historically underrepresented in the kidney population (Faber et al., 2016; Zimmerman et al., 2000; Siminoff et al., 2006), therefore we purposively sampled for males and non-Hispanic Whites.

A letter from the directors of each recruitment source providing information about the research study was mailed to the selected potential participants. Individuals were asked to contact the study coordinator by either email or telephone if they were interested in enrolling into the study. Individuals who contacted the study coordinator were screened for eligibility and given the opportunity to ask questions about the study. After completing the screening questions and successfully meeting the eligibility requirements, individuals who agreed to participate were verbally consented into the study and scheduled for an appointment date/time to complete their telephone interview with one of the trained qualitative interviewers. Each study participant was mailed a copy of the consent form along with a letter confirming their interview appointment.

The sample size was limited to 30 NDD participants and study enrollment was conducted on a first come, first to enroll basis. Sample size for the NDD group was determined according to grounded theory practice, which indicates between 20–30 interviews to reach category saturation (Charmaz, 2006; Creswell, 2013).

Data collection

The in-depth, semi-structured telephone interview consisted of two sections; the first section consisted of the qualitative questions and the second section consisted of the demographic questions.

The interview guide (Appendix A) was developed by the research team with the support of the study's community advisory committee, composed of stakeholders from the kidney transplant community which included past donors and recipients, family members of past donors and recipients, and organ donation organization administrators. The interview included open-ended questions that probed topics surrounding the factors that initially interested participants in a non-directed kidney donation, the experience of their decisions to donate, and the effects their decisions had on their lives. In grounded theory, data collection and analysis are done concurrently; thus, during the data collection process, we continued to expand on arising themes that had not yet reached saturation. All participants were interviewed with the same questions from the developed interview guide.

While the interview guide did not specifically probe questions on the topic of spirituality and religiosity, or religious affiliation and practices, interview prompts such as, "How did you decide to donate a kidney?"; "How did you understand the pros and cons of kidney donation?" and "During the process of getting to donate, what was helpful?" elicited responses regarding S&R.

Interviewers were trained in qualitative interviewing techniques and supervised by the study co-investigator, a qualitative methods expert. Interviews were audio-recorded and lasted between 15 to 90 minutes. Participants received a \$15 gift card for their participation. After each interview, interviewers summarized their observations about the participant and their responses, such as tone of voice. All audio recordings were transcribed verbatim by a professional transcription company. Interview transcripts were double-checked by comparing the audio to the transcription text to ensure quality rigor. Any identifiable information was removed from the transcripts to maintain confidentiality. Finally, all interview transcripts were uploaded into ATLAS.ti version 7 (Hardenbergstr, Berlin) to undergo coding and analysis; the demographic data was analyzed using SAS 9.4 (Carey, NC).

Data Analysis

Analysts applied grounded theory techniques to analyze the text. The NDD interview transcripts were analyzed using the following steps. Initially, four transcripts were chosen to be read in their entirety by four qualitative team members to become familiarized with the narratives, withholding from any coding of the text. Next, the team completed the open coding process of the transcripts. The team then met to discuss the initial coding and inductive categories emerging in the text to develop the codebook. Following this discussion, three analysts carried out the focused coding of all 30 interview transcripts using the newly developed codebook and ATLAS.ti. The qualitative team continued to meet regularly during the open coding process in order to discuss the transcripts, further refine the codes in the codebook, and fully expand on and define the emerging categories and themes.

To minimize any potential bias or influences from the analysts' coding, the interview transcripts, audio recordings, and interviewer notes underwent constant comparison throughout the analysis. During group meetings, the analysts reached a consensus on the major topics discussed by participants. Rigor in the qualitative analysis was strengthened through maintaining memos on the discussion of coding discrepancies and refining of codes during the weekly meetings until an agreement was reached.

Regular discussions of the data and codes revealed spirituality and religiosity as a major theme in the donation experiences of 16 participants. Analysts re-read interview transcripts and met regularly to expand on S&R as a major theme and identify its sub-themes. Analysts compared their coding and interpretations to determine if any discrepancies were present in their analysis of S&R. Analysts did not undertake additional analysis of transcripts in which S&R was not identified for this study.

Demographic information of the 14 NDDs who did not mention spirituality and religiosity were included in the summaries of the demographic measures. We compared demographic characteristics between the 16 S&R NDDs and 14 non-S&R NDDs.

Ethical Considerations

The University of California, Los Angeles (UCLA) Office for Protection of Research Subjects Institutional Review Board approved all study protocols (#11-003253).

Study participants were informed that they may feel discomfort when answering certain questions during the telephone interview, however, that they could choose to skip any question(s) that they did not feel comfortable answering as well as discontinue their study participation at any time and for any reason. The risks associated with participating in the study were deemed minimal by the UCLA IRB. Moreover, the potential knowledge gained from the study is expected to have an impact at the national level. Information gained for this study may be used to better understand the psycho-social insights of transplant patients and provide an opportunity to improve practice methods in the entire field of kidney transplantation.

RESULTS

A total of 76 NDDs from the three recruitment sources were identified as eligible and invited to participate. Of the 76, 31 enrolled and completed interviews; 16 were waitlisted once the sample size was met; and 29 never responded, were lost to follow-up or had incorrect contact information. One of the 31 interviews was not available at the time of this analysis and was excluded, resulting in a sample of 30 NDDs. None of the participants skipped any questions or discontinued the interview.

Table 1 summarizes the demographic information of all NDD participants. The majority of the 30 participants were non-Hispanic White (97%), female (57%), under the age of 50 (53%), married (77%), college graduates (86%), and had an annual income greater than \$100,000 (60%). Our analysis revealed that 16 participants mentioned spirituality and religiosity during their interviews. There were no differences between the 16 S&R and the

14 non-S&R NDDs. As seen in Table 2, participants were geographically distributed across eleven different United Network for Organ Sharing regions (United Network for Organ Sharing [UNOS], 2015), with the majority being from Region 5 (Arizona, California, Nevada, New Mexico, Utah).

Of the 16 S&R NDDs, religious affiliations included eight Christians, two Buddhists, one Atheist, two Agnostic, one Unitarian Universalist, and two did not self-identify their affiliations. We divided spirituality and religiosity into three themes: motivation for donation, faith in the process, and post-donation experiences. Ten participants discussed how their religious upbringings and beliefs motivated them to donate their kidney. Five participants discussed their faith in their God when making decisions via prayer and consultations with religious leaders. Three NDDs discussed how their S&R enhanced their post-donation experiences, specifically with the relationships with their recipients.

Theme 1: Motivation to Donate

This theme was defined as a factor influencing the pursuit of becoming a NDD and was divided into three sub-themes: religious upbringing, religious opportunity, and collecting merit. Religious upbringing was defined as the influence of a participant's childhood exposure to religious values, beliefs and ideals. Religious opportunity was defined as a participant's outlook on their ability to donate in a religious context. Collecting merit was the participant's accumulation of good deeds, benefits, and karma from the donation.

Sub-theme 1: Religious Upbringing—Participants raised in a religious environment regardless of active participation at the time of donation revealed that their exposure to spirituality and religiosity contributed to their decision to donate.

One donor described his Christian faith: "As a Christian, it just became sort of a calling I just sort of came to a natural kind of a realization that this was the thing I should do." Two NDDs described how their Christian upbringing helped shape their values. Specifically, one NDD explained, "I'm agnostic, but I was raised in a very fundamental evangelical Christian family... And the religion didn't stick, but the 'be a good person' part did." and another NDD stated, "And in the Bible it says if you have two coats and your neighbor doesn't have any, give him one of your coats... Well we have two kidneys. We were taught the golden rule and that we should be living for God and for other people, not just for yourself Donating a kidney just seemed like a natural thing to do."

Irrespective of their current religious observance at the time of the interview, religious upbringing helped influence participants' motivation to donate.

Sub-theme 2: Religious Opportunity—Some participants viewed the donation opportunity as a "gift" from God or as a sign of being chosen by God to help their recipient.

One donor described, "God obviously picked me to do it or he wouldn't have put her in my path of life." Another donor referenced a Bible verse to describe his donation as an opportunity: "There's a Bible verse that says '...As we have the opportunity, let us do good

to all people.’ And to me, this was an opportunity.” This participant felt that he was called by God to donate his kidney.

Sub-theme 3: Collecting Merit—Participants discussed their donations as a means to obtain merit or help them achieve the afterlife. Specifically, two participants referred to their Buddhist principles:

“I studied Buddhism And I just believed that we all should try to help one another since we’re all going through this together and we’ll all end up in the same end. Buddhism would very much encourage donating organs. Buddhists are very big about as they say collecting merit”

These participants also viewed the act of donating a kidney as serving humanity.

One participant stated that his donation was rooted in his faith and was part of a pathway to heaven: “This is a faith-based kind of journey We’re supposed to live our life to achieve the afterlife in heaven one day. To me that’s the kind of thing you’re supposed to do.”

Theme 2: Donation Process

The theme of spirituality and religiosity during the donation process was defined as a participant’s mention of their S&R values, beliefs or ideals as a source of support in their donation journey. S&R during the donation process was divided into two sub-themes: acceptance of the donation risks and religious/spiritual confirmation. Accepting donation risks was defined as a participant’s mention to their S&R beliefs to help them overcome concerns associated with the donation. Religious/spiritual confirmation was defined as a participant’s engagement in S&R activities, such as prayer, to help reassure them of their donation decision.

Sub-theme 1: Acceptance of Donation Risks—Participants used their S&R by placing their trust in God and reaching out to religious leaders as a means of support to help cope with donation fears and assess the potential health risks. One participant discussed the role of God in ensuring his and his family’s future well-being: “Giving my kidney away to a stranger meant that someone else in my family or friends wouldn’t get it later. I just got reassurance from [God] that there were lots of other donors out there that if I couldn’t give a kidney, somebody else could.”

Another participant described that her belief in God provided reassurance for her daughter’s future health: “I really do have a high belief in God that I thought, okay, if something ever happened and my daughter needed a kidney, I just have a feeling that it would all work out.” These participants utilized their trust in God to help alleviate fears of future risks associated with the donation.

Participants also mentioned their interaction with a specific Catholic priest who had written articles online about his own kidney donation and helped counsel them through their own donation experience. One participant mentioned that speaking to a religious leader had provided him with a faith-based support during his donation experience: “Father [Catholic

priest name] initially at the beginning, he was a support. It's nice to know that he's a faith-based support."

This experience with a religious leader highlights the theme of religiosity as a support mechanism during the donation process.

Sub-theme 2: Religious/Spiritual Confirmation—Participants engaged in S&R-related activities such as prayer, when in need of clarity and guidance throughout the donation process. One donor expressed his participation in prayer:

"I was wondering, should I follow through with this? What should I do? Pray about it and I ran into someone from my church. He was just talking about the fact that he donated a kidney...So I just thought 'wow! well [God] brought me that story right when I'm praying about it'...So I just thought that was the confirmation that I should look into it." Engaging in prayer helped the participant gain a greater level of reassurance and confirmation about his decision to continue with the donation process.

Theme 3: Post-Donation Experience

We defined the post-donation experience as the emotional and physical aspects (e.g., pain, overall health and quality of life) of an NDD after the donation. We divided this theme into two sub-themes: relationship with recipient and outlook on donation.

Relationship with recipient was the presence of spirituality and religiosity in a participant's positive or negative experience with their recipient after the donation. Outlook on donation was a participant's mention to S&R in the context of being appreciative for having the opportunity to donate.

Sub-theme 1: Relationship with Recipient—Participants noted that the decision to interact with their recipient post-donation was often difficult, and some utilized faith as a source of support. The NDDs did not know the individuals that they were donating to, until after the donation.

One participant discussed prayer as a form of guidance to decide whether to meet his recipient: "Shortly after the transplant, I got two or three cards with my recipient's contact information. I was thinking, 'Should I respond? Shouldn't I respond?' I kind of prayed about it and I said, 'Yes, okay.'" During this challenging stage in the process, this participant was able to gain reassurance to contact his recipient by engaging in prayer.

Sub-theme 2: Outlook on Donation—Donors shared their thoughts about what they had gained through their donation experience. One donor referred to a religious verse in accordance with his feelings of giving to others: "Of course it's extended his [recipient's] life, but I really have learned that when Jesus says it's more [a] blessing to give than to receive; I'll just say it's been a great blessing to be able to do it." Participants felt grateful for having the opportunity to successfully complete the donation process while helping their kidney recipient.

DISCUSSION

This study analyzed and described the topic of spirituality and religiosity and its themes associated with the experiences of 16 NDDs in motivating their decision to donate, providing support during the donation process, and improving their post-donation experiences. We found no significant differences in marital status and income and education levels between the 16 S&R donors and the 14 non-S&R donors.

Our findings suggest that spirituality and religiosity are important to some donors relative to their decision to donate, their donation process, and post-donation life. Our findings on the theme of S&R throughout the donation process, as mentioned by one in every two NDDs in our study, may help shed greater insight on the potential role of transplant centers in raising greater awareness about kidney donation through collaborations with faith-based organizations. Transplant centers should consider collaborating with faith-based organizations to help educate members on risks and benefits of donating that are not widely known (Arriola et al., 2007; DeHaven et al., 2004; Roth, 2015; Saad et al., 2016).

Transplant centers can also assess the importance and observance levels of spirituality and religiosity of their NDDs to help develop support services based on their specific S&R needs. Our findings on NDDs utilizing support from religious leaders during the donation process are consistent with previous research citing the influential role of faith leaders during the donation experience (Ismail et al., 2011).

The majority of the S&R NDDs in our study self-identified as Christian. Christianity has been noted to view donation as an action indicating dedication to God (Oliver et al., 2011; Oliver et al., 2012). The NDDs raised in a religious environment stated that their initial exposure to their S&R beliefs motivated them to pursue kidney donation, regardless of their S&R observance at the time of donation.

Although spirituality and religiosity is commonly uncoupled from the practice of western medicine, the integration of S&R has been noted through the experiences of Jehovah's Witnesses and Christian Scientists (Pauls, 2002; Puchalski, 2001; Koenig, 2004; Detry et al., 2005). Liver transplantation patients who utilized religious coping mechanisms, similar to how our participants received support from their religious leaders, have been found to have better long-term health outcomes than non-Jehovah's Witness patients (Detry et al., 2005). This finding is consistent with research on patients using religious coping to promote better adjustment during and after the kidney transplant surgery (Tix et al., 1998), and elucidates how spirituality and religiosity affects health-related outcomes. Another example of the role of spirituality and religiosity in healthcare delivery is observed through the experiences of Christian Scientists, a religious group who may refuse medical treatments due to their beliefs concerning death and disease (Pauls, 2002).

Our findings may help improve pre-donation screening processes for transplant teams by maintaining awareness of the spirituality and religiosity observance of each NDD candidate. The S&R NDDs in our study were more likely to report being registered organ donors and registered bone marrow donors. Therefore, the inclusion of spirituality and religiosity in

psychosocial assessments may assist in assessing that an NDD's decision was well informed.

Limitations

There are limitations to our study. Conducting telephone interviews limited our ability to see body language, facial expressions, or the environment. We had to rely on tone of voice for nonverbal communication; however, previous studies show that telephone interviews provide the depth of information needed for qualitative analysis and allows researchers to access geographically distant individuals (Maliski et al., 2008; Maliski et al., 2010). Our sample was not racially-ethnically diverse, as all but one participant were non-Hispanic Whites. Although we attempted to purposively sample for racial-ethnic minorities during the recruitment phase, our sample was representative of current trends in non-directed donation that the majority of U.S. NDDs are non-Hispanic Whites (Faber et al., 2016). However, our sample consisted of a broad distribution of U.S. regions from which our participants were enrolled), providing diversity to the sample. Our ability to eliminate self-selection bias was limited by our study design; we recruited participants via mail and email and only NDDs who were willing to discuss their experience may have contacted the study. Lastly, our interview guide did not probe questions about spirituality and religiosity directly, but spirituality and religiosity emerged as a major topic discussed by 16 participants in the analysis process.

Conclusion

Our findings may improve understanding of spirituality and religiosity among the NDD donation experience in the U.S. and encourage transplant teams to support religious practice as a coping mechanism for NDDs with high S&R observance. The positive donation experiences and high levels of satisfaction of NDDs observed among those spirituality and religiosity NDDs in our study suggests that living kidney donation organizations and advocates ought to work closely with faith-based leaders and organizations in future efforts to increase non-directed donation awareness. Future research on the topic of spirituality and religiosity within the donation processes comparing the experiences of NDDs and unsuccessful NDD candidates is warranted. Similarly, research exploring the various degrees of influence spirituality and religiosity may have on NDD candidates when assessing the risks involved also remains not widely understood in the literature and is critical to help transplant teams ensure individuals are adequately understanding and accepting risks free of pressure or coercion.

Although 14 NDD participants did not mention spirituality and religiosity during their interviews, it is possible that spirituality and religiosity did not exhibit any distinct role in their donation experiences. These individuals may have utilized other resources for their decision-making and support during the donation process. From our findings, we encourage transplant teams to increase collaboration with faith-based organizations to help improve the NDD donation experience and bring greater awareness to living kidney donation (DeHaven et al., 2004).

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Appendices

Appendix A: Kidney Donor Qualitative Interview Guide

Study ID# _____

Date administered: ____/____/____

Interviewer: _____

Hello Mr./Mrs/Ms _____, we are very interested in hearing about your experience as a kidney donor and your participation in the Donation Chain. We hope to learn how to attract and best facilitate potential donors. Please remember that your participation in this interview is voluntary and that we can stop anytime you wish. Also, you can skip any questions you wish. Your transcript will be assigned an ID number and separated from your contact information and the recording will be destroyed after transcription. I will turn on the recorder now.

To start, I'd like to hear your story. How did you decide to donate a kidney?

PROMPTS: What first prompted you to think about donating?

What were your thoughts?

How did you weigh the pros and cons?

What concerns did you have about your personal health?

Tell me about the kinds of things or people who influenced your thinking?

Could you describe what your life was like in that period? CONTRAST PRE-TRANSPLANT

How did you hear about the Donation Chain?

PROMPTS: How did you learn about it?

Who was influential for you?

Please tell me what your conversation was like with him/her.

How did you feel about someone else getting your kidney?

What terminology do you use to describe the donation chain?

How did your family react to the Donation Chain opportunity?

PROMPTS: What did you say to them?

What do they think now?

When you talk to someone about it what message do you try to get across?

How did your friends react to the Donation Chain opportunity?

PROMPTS: What did you say to them?

What do they think now?

When you talk to someone about it what message do you try to get across?

What do you know about the person who received your kidney?

PROMPTS: Have you met the person who received your kidney? Why or why not?

What expectations did you have about meeting the person who received your kidney?

How did you feel?

Have you felt appreciated through this process?

Has being part of a chain been meaningful? How?

**Ask for anecdotes*

Describe your life now. What has changed since kidney donation? CONTRAST POST-TRANSPLANT. **Ask for specifics, e.g. travel, sports, interaction with children...*

What was helpful during your journey to donate a kidney?

PROMPTS: Have you felt supported throughout this experience?

After transplant how did you feel?

Is there something that could have facilitated your experience?

What was difficult?

What advice would you give to someone who finds themselves in a position similar to yours?

Was there anything that surprised you about this experience?

**Ask for anecdotes*

Finally, is there anything that you feel is important for us to know that we have not already covered?

PROMPTS: What would you like to ask other donors or recipients?

Thank you so much for your time and insights

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Relevance to clinical practice

Our findings provide greater support for hospitals to invest in assessment tools to screen spirituality and religiosity observance levels during the pre-donation screening period. Recognizing the spirituality and religiosity levels of NDDs can help guide transplant centers to provide more accessible S&R support services and resources for patients who identify as spiritual or religious during the donation process.

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What does this paper contribute to the wider global clinical community?

* The findings from this study provide more knowledge on the non-directed donor experience and recommendations for improving the quality of care for donors identifying as spiritual or religious.

* This study describes how non-directed donors used their spirituality and religiosity to help reach their decisions on whether to donate, provide support during their donation processes, and contribute meaning to their decisions.

* The findings from this study can help provide recommendations for healthcare professionals, including nurses to implement practices and support services for spiritual and religious NDDs.

Table 1.

Demographic information

Characteristic	Total (n=30)	S&R NDDs (n=16)	Non-S&R NDDs (n=14)
Recruitment Source			
1	6 (20%)	4 (25%)	2 (14%)
2	21 (70%)	11 (69%)	10 (71%)
3	3 (10%)	1 (6%)	2 (14%)
Sex			
Male	13 (43%)	8 (50%)	5 (36%)
Female	17 (57%)	8 (50%)	9 (64%)
Age at Interview			
50 years	16 (53%)	9 (56%)	7 (50%)
>50 years	14 (47%)	7 (44%)	7 (50%)
Race/Ethnicity			
Non-Hispanic White	29 (97%)	15 (94%)	14 (100%)
Asian Pacific Islander/Alaskan Native	1 (3%)	1 (6%)	0 (0%)
Education			
Some college or less	4 (13%)	2 (12%)	2 (14%)
College degree	26 (87%)	14 (88%)	12 (86%)
Annual Income			
<\$25,000	1 (3%)	0 (0%)	1 (7%)
\$25,001-\$50,000	3 (10%)	2 (13%)	1 (7%)
\$50,001-\$100,000	6 (20%)	4 (25%)	2 (14%)
>\$100,000	18 (60%)	8 (50%)	10 (71%)
Refused	2 (7%)	2 (13%)	0 (0%)
Marital Status			
Single	3 (10%)	1 (6%)	2 (14%)
Married	23 (77%)	12 (75%)	11 (79%)
Divorced	4 (13%)	3 (10%)	1 (7%)
Other Altruistic Behaviors			
Blood donor	21 (70%)	10 (63%)	11 (79%)
Registered organ donor	28 (93%)	15 (94%)	13 (93%)
Registered bone marrow donor	21 (70%)	12 (75%)	9 (64%)
Current volunteer for an organization	23 (77%)	14 (88%)	9 (64%)
Past volunteer for an organization	27 (90%)	14 (88%)	13 (93%)

Table 2.

UNOS Region Distribution

Region Number (states comprised)	Total (n=30)
1 (Connecticut, Maine, New Hampshire, Rhode Island, Eastern Vermont)	3 (10%)
2 (Delaware, District of Columbia, Maryland, New Jersey, Pennsylvania, West Virginia, Northern Virginia)	4 (13%)
3 (Alabama, Arkansas, Florida, Georgia, Louisiana, Mississippi, Puerto Rico)	2 (7%)
4 (Oklahoma, Texas)	2 (7%)
5 (Arizona, California, Nevada, New Mexico, Utah)	10 (33%)
6 (Alaska, Hawaii, Idaho, Montana, Oregon, Washington)	2 (7%)
7 (Illinois, Minnesota, North Dakota, South Dakota, Wisconsin)	1 (3%)
8 (Colorado, Iowa, Kansas, Missouri, Nebraska, Wyoming)	2 (7%)
9 (New York, Western Vermont)	3 (10%)
10 (Indiana, Michigan, Ohio)	1 (3%)
11 (Kentucky, North Carolina, South Carolina, Tennessee, Virginia)	0 (0%)