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Assessing Living Donor Priorities through Nominal Group Technique

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Introduction

The need for donated kidneys surpasses the number available for transplant,¹ and the number of living donors has declined over the past ten years.² Living donors are most often close relatives of recipients and often report being motivated to donate in order to improve or save the lives of their loved ones, to fulfill family expectations, or for their own personal benefit.^{3,4} As the number of related donors has decreased over the past decade, organ transplant programs have increasingly been open to accepting living donations of unrelated donors, which includes both those who are connected to the recipient via social networks as well as those who donate to an unspecified recipient.⁵ Unrelated and unspecified donors appear to have many of the same altruistic motives for donation as related donors and experience similar positive psychological outcomes and high satisfaction with the donation decision.⁶

Studies of knowledge and attitudes towards living donation in community samples find that most participants are aware of and support the idea of living kidney donation.⁷ Most would be willing to donate to a known recipient, and a sizable minority report that they would even consider donating to an unknown recipient.⁷ However, despite their stated awareness of the need for donation and support for the idea of donation, few go on to donate. It remains unclear what motivates or deters individuals who are aware, knowledgeable, and in support of donation from donating, though some have suggested that removing financial disincentives or even offering incentives could increase the rate of donation.^{8,9}

In order to effectively tailor programs to increase the number of living donors, we must first determine the factors most salient to the donation decision. While past studies have

examined the public's opinions on barriers and facilitators to living donation,^{7,10} it is not known which factors most heavily impact on the decision to donate. The purpose of the current study was to examine potential barriers and facilitators to living kidney donation, as well as factors perceived to be most salient to the donation decision.

Methods/Approach

Nominal Group Technique (NGT) is a focused, structured, facilitated small-group discussion that generates ideas around a specific topic and determines ideas that are most salient among group members. This technique generates a rank ordering of ideas, thereby providing both qualitative and quantitative data. Additional benefits include the evocation of participation from all group members and equal weighing of all participants' priorities through the ranking process contributing to an unbiased group consensus.

Informed consent was obtained from all participants included in the study. This project was approved by the Yale Institutional Review Board.

Setting and Sampling

Participants were recruited via flyers posted in the dialysis units and transplant clinic in a large academic medical center. Flyers stated "Do you know someone with kidney disease and are interested in giving your opinions on transplant?" In addition, potential living donors who had previously contacted the medical center to discuss the option of donation but were deemed ineligible to donate were contacted to ask if they would be interested in participating in a focus group about donation. Individuals with end-stage renal disease and transplant recipients were excluded. Forty individuals expressed interest in participating and were sent a confirmation letter.

Information Collection and Analysis

Participants were oriented to the NGT process and told that the goal was to learn about their perspectives on two specific issues related to living kidney donation. The facilitator (LD) presented participants with the first question for consideration – "What things make it harder for people to donate a kidney?" Participants were asked to work silently and independently to generate a list of ideas. After completing their independent lists, the facilitator elicited responses one by one until all items on all participants' lists had been read aloud. Each item was then reviewed, discussed, and clarified as needed. Items that were determined by the group to be extremely similar or identical were combined. A final list comprised of the remaining items was created.

The facilitator asked participants to think about what they considered to be the three most important factors when answering the question: "What things make it harder for people to donate a kidney?" Participants were given cards and asked to rank and write down what they perceived to be the three most important factors (1 = most important, 2 = second most important, 3 = third most important). Participants were given a short break before repeating the process with the second question for consideration – "What things make it easier for people to donate a kidney?" Each round lasted for approximately one hour. Detailed notes,

including quotes from group participants, were taken during each group. Participants were thanked for their time and provided with a \$100 gift card.

We followed previously published strategies for analyzing NGT data across multiple groups.^{11,12} Initially, responses were analyzed by NGT group. Each item generated within each group and question was entered in a spreadsheet along with the scores given by each participant. For example, if a participant ranked an item as the “most important” item discussed within that group, that translated into a score of 3. If a participant ranked an item as the “second most important” item discussed within that group, that translated into a score of 2, and if a participant ranked an item as the “third most important” item discussed within that group, that translated into a score of 1. If a participant did not rank an item as one of the three most important items, it received a score of 0. Item scores from each participant within each NGT group were then summed to calculate a total score for each item. Items with higher scores were therefore considered most salient, as scores reflected both the number of participants who ranked the item, as well as how important the item was perceived to be compared to other potential barriers and facilitators.

Consistent with the NGT method for data analysis, rather than determining themes a priori two authors (LD, LF) independently conducted a content analysis of items to group them into themes. The two authors met to discuss their independent lists and a consensus was reached that items could best be classified into nine themes. The content analysis was verified by re-categorizing items into the nine agreed-upon themes; through this process, all items could be categorized into one of the nine themes and each fit only in one category (i.e., categories were exhaustive and mutually exclusive). In order to prioritize themes, we calculated the average score of items within that theme.

Results

Participant demographics are presented in Table 1. Thirty subjects participated in four NGT sessions. Women were more likely to respond to recruitment and scheduling efforts, and therefore the first two groups consisted of seven women each. We recruited specifically for male participants, and conducted two additional groups with eight men participating in each group. Most participants were Caucasian (70%) and married (67%). There was wide variation in age, education, and income. Participants commonly knew someone waiting for a transplant and/or knew a living donor. Two female participants previously served as a living donor: one donated to a family member in the past, and another served as an altruistic donor.

A total of 156 responses were generated across groups, consisting of 71 barriers and 85 facilitators. Of the 156 responses, 93 (59.61%) were selected and ranked as one of the three most important by at least one participant. All 156 responses were categorized into nine themes. The nine themes, in order of greatest to least importance to respondents, were: 1) altruism, 2) relationship to the recipient, 3) knowledge, 4) personal risk/impact, 5) convenience/access, 6) cost, 7) support, 8) personal benefit, and 9) religion.

Altruism

Participants most commonly ranked altruism as the most important factor that would lead someone to donate a kidney. Of note, this did not relate specifically to known recipients, but rather to helping others more generally. Participants most commonly endorsed “saving someone's life” and “giving to others” as particularly important factors driving the donation decision. Some viewed it as a way to give back to the community, and others noted the value of being able to “put yourself in someone else's shoes – you would want someone to donate to you.”

Relationship to the recipient

Participants frequently described wanting to save or improve the lives of family members and other loved ones, and noted that other family members would also benefit from the improved quality of life and survival of the recipient (e.g., “you could help to extend time for the family to be with their loved one”). Participants discussed the potential value of developing or feeling a personal connection with the recipient and his or her family; for example, one participant stated that people would be more motivated to donate “if there was a face to the need, knowing a real person as opposed to a general concept.” They suggested that family members could advocate on behalf of the recipient (e.g., “Social media is a great way to share stories”). Several noted the importance of “personalizing the need” and reported that they had begun researching donation after hearing of someone in their broader social network, such as someone from their town, who was in need of donation. As another stated, “it's not going to work by saying that we need 1000 donors... [it's about] putting a face that we can identify with.”

Knowledge

Participants commonly reported that additional knowledge about eligibility criteria, evaluation of potential donors, and the procedure and recovery would all serve as facilitators to donation. Several mentioned that the awareness of donor exchange chains would make people more likely to donate given that donors would know that multiple recipients would benefit as a result of their willingness to donate. Several also mentioned the potential value of speaking with someone who has donated and learning from their experience.

Personal risk/impact

Participants cited potential concerns about the surgery itself, including risks of anesthesia, time spent in the operating room, possible infections, and pain (e.g., “I am just worried, you know, about something unexpected happening while I am in the surgery. What if something goes wrong?”). They also spoke of the uncertainty about how living with one kidney might affect them medically in the future, or whether they would be at greater risk for future kidney problems themselves. Similarly, several participants expressed concern that donation would later result in a shortened life span: “...maybe having a shorter life, I don't know if it is true, but maybe it will shave ten years off of my life.” One female participant wondered: “Can I have a baby someday if I give up a kidney? Could something happen to me or the baby?” Participants wondered how living with one kidney would impact other lifestyle factors such as physical activity (“I like to work out and play sports – is that limited if I give

up a kidney?") and whether they would still be able to consume alcohol after donating. Some participants wondered if they might feel depressed after donating, if they might experience regret, or if they might feel like an "incomplete person" who has "lost a piece" of themselves.

Convenience/access

Participants reported that having transplant facilities and testing centers closer to home, better coordination/streamlining of appointments pre-donation, and better communication among providers, transplant teams, and transplant centers would all make donation easier. One participant lamented "I wish the process could be quicker, there are people dying and it shouldn't take so long to get checked out as a donor." Regarding barriers, some felt that the medical testing as part of the workup was inconvenient, with one person saying "my primary care was laughing at the process" and another suggesting "doing some pre-testing to help the process along, maybe some of the testing is done as routine care." Others said they felt the donor criteria were too stringent, and one participant who was interested in donating but was found medically ineligible for a reason he perceived as trivial noted that "[his] internist laughed at the reason for exclusion."

Cost

Participants cited two distinct barriers related to cost: 1) direct or indirect costs to donors, such as increased healthcare costs post-donation or the cost of travel to and from the transplant center, and 2) lost wages related to time off of work. They also reported a lack of knowledge related to how long the recovery process would be, and therefore how long they would be out of work, which served as a barrier. For example, one participant stated, "I am concerned about what happens if I can't get back to work right away... I am the only one who can work. It's a big fear to not be able to afford to live if I can't get back to work in time, if there is a complication... or something goes wrong." Only two of the 30 participants voted for items relating to some type of direct compensation or financial incentive for donation serving as a facilitator to donation, and both participants ranked it last on their lists of their top three votes.

Social support

Participants initially reported that having good social support could serve as a facilitator to donation, and that a lack of social support could serve as a barrier to donation. However, only four of the 30 participants ultimately voted for items in this theme.

Personal benefit

The potential for personal benefit was discussed in three of the four groups, and a total of six items were generated within this theme. Some participants noted that donation may lead to feeling recognized and appreciated by others, or might facilitate personal reflection or increase motivation for self-care. However, only one out of the 30 participants voted for any of these six items.

Religion

While religious beliefs were mentioned as a potential barrier to donation in each of the groups, none of the participants voted for this item, thus resulting in it being the factor deemed to be of lowest relative importance by participants.

Conclusions

In this study, through the use of NGT methodology, we were able to determine factors that were perceived to be most salient to the donation decision and are thereby most important to target in efforts to increase rates of living kidney donation. Consistent with the literature on blood donation,^{13,14} our findings suggest that that altruism and relationships are the primary drivers in the donation decision. Participants reported a strong desire to help others, and frequently discussed not only the benefit to recipients who could have longer lives with an improved quality of life post-donation, but also to the recipient's family and friends who would indirectly benefit through the longer life, and improved quality of life, of the recipient. Participants discussed how "personalizing" and "giving a face to the need" could serve as strong motivators for donation, and several mentioned becoming interested in donation after seeing stories on social media. Thus, a greater focus on campaigns that tell the personal story of individuals in need of donation, as well as their families who would also benefit indirectly via donation, could encourage potentially interested donors to take the first step towards seeking additional information about donation to determine whether it is the right choice for them. Campaigns that specifically focus on educating the public about donor chains, in which multiple recipients can ultimately benefit from one altruistic donation, could further leverage public interest in learning more about, and potentially pursuing, donation.

Some participants reported that being able to meet or learn about recipients could increase rates of altruistic donation. However, many donation centers and professionals in the transplant community, and even the lay public, remain conflicted about whether the potential benefits of removing anonymity outweigh the potential costs.¹⁵ Recipients also report mixed feelings about altruistic donors, both reporting appreciation for the altruistic act, yet also desire for information about the donor.¹⁶ Thus, while it seems that there may be potential benefit to providing information about donors and recipients in altruistic donation, concerns and possible negative consequences also remain.

Findings from the NGT sessions suggest that increasing public knowledge about the donation process and the impact (or lack thereof) of donation on lifestyle factors and future health could increase rates of living donation. Participants reported limited knowledge of how donation would affect their own health and wellbeing, as well as if donation would impact their day-to-day life. They also reported limited knowledge about how and where to find the answers to these questions, and how and where to learn about donation more broadly. These findings are consistent with consensus within the field that increasing awareness and education are key to increasing the pool of potential living donors.^{17,18} Participants also commonly reported that the process of being evaluated as a potential donor could be long and cumbersome, and cited this as a barrier to donation; therefore,

transplant centers could explore options for further streamlining the process to enhance convenience for potential donors.

Participants reported that costs, specifically out-of-pocket costs related to medical care post-donation, travel costs, or lost wages, could serve as barriers to donation. These findings are consistent with past studies suggesting that most people support the idea of removing financial disincentives, rather than introducing financial incentives, to help increase the number of living donors,^{3,7} and is also consistent with expert consensus on best practices for living donation.¹⁷ However, while compensation and incentives for living donors is a frequently discussed and hotly debated topic in the literature and studies have shown that donors commonly incur costs both before and after donation,^{8,19-21} our findings suggest that costs and compensation may be less salient to the donation decision compared with other factors. Therefore, public education or policy changes related to costs and incentives may be less influential in increasing public interest in living donation compared with strategies that appeal to altruism and that address concerns related to health risks.

We did not find strong support for the roles of social support, religious beliefs, or personal benefit in either increasing or decreasing the likelihood of becoming a living donor. During the brainstorming stage of the NGT sessions, participants noted that having a strong social support network could help facilitate donation, while family opposition could serve as a barrier to donation; however, these factors were rarely endorsed as one of the top three factors that would influence the donation decision. While participants acknowledged that some individuals may have religious beliefs that would preclude donation, this was not a salient factor for the participants in our NGT sessions. Similarly, participants recognized that serving as a living kidney donor could make someone feel good about or proud of himself, and potentially would lead to recognition or appreciation from others; however, only one of the thirty participants ranked one of these factors as one of the top three factors that would influence the donation decision. This last finding is in contrast with other studies reporting that living donors commonly cite perceived personal benefit as a significant motivator for donation^{22,23} and differences in findings may be partly related to the nature of the samples (i.e., individuals who have donated compared to those who could potentially donate). It is unclear whether perceived personal benefit increases the likelihood of actually becoming a living donor, or whether the act of donation facilitates perceived personal benefit. Future studies could examine the impact of campaigns emphasizing personal benefit compared to those emphasizing altruism to try to determine which factor might have a greater influence on increasing donation rates.

We were interested in examining factors that could potentially convert individuals who support and are knowledgeable about and interested in donation into actual donors. Therefore, we purposefully recruited a sample of participants who were likely to be at least somewhat familiar with and favorable towards donation by recruiting from dialysis clinics, the transplant center, and a pool of individuals who had previously expressed preliminary interest in donation. Consequently, findings may not be generalizable to the broader pool of potential donors, and future studies could use the same methodology to examine factors most salient to the general public and not just those who are likely already somewhat personally invested in the practice of kidney donation. No data were available about

participants who declined participation, which also limits generalizability. Participants were primarily Caucasian, and therefore future studies could examine perspectives of individuals from other racial and ethnic groups. Further, the sample included two previous donors, whose contributions during item generation as well as rankings may have differentially influenced findings compared to those who had not donated. Study findings may also be influenced by social desirability bias; however, because the process includes anonymous voting, the potential impact of the social desirability bias is likely reduced. Limitations also include the small sample size and the fact that all participants were recruited from a single center.

In summary, we found that while subjects are able to list numerous factors that influence the decision on whether or not to donate, a relatively small number of factors are consistently ranked as highly important. These data underscore the value of public campaign efforts seeking to increase the rate of living kidney donation that are tailored to appeal to altruism, improve outreach to increase awareness and increase knowledge, and facilitate both the selection process and actual donation to maximize convenience and minimize burden on potential donors.

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Table 1
Participant characteristics

	Overall	Female groups	Male groups
Gender			
Female	14 (47%)	14	n/a
Male	16 (53%)	n/a	16
Hispanic or Latino	4 (13%)	3	1
Race			
White or Caucasian	21 (70%)	9	12
Black or African American	4 (13%)	1	3
Other	5 (17%)	4	1
Age			
25-44	14 (47%)	7	7
45-64	11 (37%)	7	4
65	4 (13%)	0	4
Missing	1 (3%)	0	1
Marital status			
Married	20 (67%)	8	12
Never married	10 (33%)	6	4
Education			
Less than high school	1 (3%)	0	1
High school, GED, or equivalent	13 (43%)	5	8
Associate degree	3 (10%)	2	1
Bachelor's degree	10 (33%)	6	4
Master's degree	3 (10%)	1	2
Income			
10,000-50,000	16 (53%)	8	8
50,000-100,000	9 (30%)	5	4
>100,000	5 (17%)	1	4
Self-rated health			
Excellent	5 (17%)	4	1
Very good	17 (57%)	6	11
Good	6 (20%)	4	2
Fair	2 (7%)	0	2
Organized religious activity			
More than once a week	8 (27%)	2	6
Several times a month	1 (3%)	0	1
Rarely	15 (50%)	10	5
Never	6 (20%)	2	4
Know someone on a waiting list to receive a kidney transplant	19 (63%)	11	8

	Overall	Female groups	Male groups
Know a living donor	17 (57%)	10	7
Know a deceased donor	3 (10%)	3	0
Evaluated as a living kidney donor	11 (37%)	7	4
Registered bone marrow donor	4 (13%)	3	1
Registered deceased organ donor	19 (63%)	8	11

Table 2
Themes by rank and score, with sample statements

Theme	Rank	Mean item score	Sample statements
Altruism	1	5.63	Saving someone's life
			Helping someone in need
			Put yourself in someone else's shoes – you would want someone to donate to you
			It's a way of giving back to the community
Relationship to the recipient	2	4	Donating to family member or other loved one
			It's not going to work by saying that we need 1000 donors... [it's about] putting a face that we can identify with
			Making amends, or building or helping a relationship
			You don't want your kidney going to person who isn't deserving
Knowledge	3	2.59	There should be more information about donation, everybody should know about it
			No one told me exactly what I would need to do, there wasn't enough information regarding the stuff we needed to get done
			Knowledge about donor chains
			Knowledge of eligibility criteria
Personal risk/impact	4	2.33	I am just worried, you know, about something unexpected happening while I am in the surgery. What if something goes wrong?
			Not knowing what to expect, uncertainty
			Losing a piece of myself or feeling like an incomplete person
			Can I have a baby someday if I give up the kidney? Could something happen to me of the baby?
Convenience/access	5	1.17	I wish the process could be quicker, there are people dying and it shouldn't take so long to get checked out as a donor
			Testing closer to home
			Maybe the transplant team could come to us to evaluate us instead of coming to the transplant center for everything
			Doing some pre-testing to help the process along, maybe some of the testing is done as routine care
Cost	6	1.16	Financial burden of things not covered by insurance
			Being out of work - whether you're permitted to take time off
			It's a big fear to not be able to afford to live if I can't get back to work in time, if there is a complication... or something goes wrong
			Having all costs covered
Social support	7	0.8	Having a good support system
			Family pressure to not donate. Sometimes families don't want you to do it
			Support post-transplant from transplant facility
			Good support network to help take care of you after surgery
Personal benefit	8	0.33	Feel good about yourself
			Feeling of being appreciated by others
			Learn about yourself. It might encourage personal reflection about priorities

Theme	Rank	Mean item score	Sample statements
			More motivated after to take better care of yourself and your health
Religion	9	0	You might not want to donate for religious reasons
			Religious beliefs of you or your family