

Identification of Strategies to Facilitate Organ Donation among African Americans using the Nominal Group Technique

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Abstract

Background and objectives

African Americans are disproportionately affected by ESRD, but few receive a living donor kidney transplant. Surveys assessing attitudes toward donation have shown that African Americans are less likely to express a willingness to donate their own organs. Studies aimed at understanding factors that may facilitate the willingness of African Americans to become organ donors are needed.

Design, setting, participants, & measurements

A novel formative research method was used (the nominal group technique) to identify and prioritize strategies for facilitating increases in organ donation among church-attending African Americans. Four nominal group technique panel interviews were convened (three community and one clergy). Each community panel represented a distinct local church; the clergy panel represented five distinct faith-based denominations. Before nominal group technique interviews, participants completed a questionnaire that assessed willingness to become a donor; 28 African-American adults (≥ 19 years old) participated in the study.

Results

In total, 66.7% of participants identified knowledge- or education-related strategies as most important strategies in facilitating willingness to become an organ donor, a view that was even more pronounced among clergy. Three of four nominal group technique panels rated a knowledge-based strategy as the most important and included strategies, such as information on donor involvement and donation-related risks; 29.6% of participants indicated that they disagreed with deceased donation, and 37% of participants disagreed with living donation. Community participants' reservations about becoming an organ donor were similar for living (38.1%) and deceased (33.4%) donation; in contrast, clergy participants were more likely to express reservations about living donation (33.3% versus 16.7%).

Conclusions

These data indicate a greater opposition to living donation compared with donation after one's death among African Americans and suggest that improving knowledge about organ donation, particularly with regard to donor involvement and donation-related risks, may facilitate increases in organ donation. Existing educational campaigns may fall short of meeting information needs of African Americans.

Keywords: kidney donation, organ transplant, renal transplantation

Introduction

Over 100,000 patients are currently waiting for a deceased donor kidney transplant, but each year, only 11,000 patients receive a transplant (1). Many waitlisted patients (5%–15%) die before receiving a transplant (1). As a result, the topic of organ donation has taken center stage as an important public health issue, and there is an increased emphasis on living kidney donation (2,3). Against this backdrop is the disproportionate number of African Americans affected by ESRD in need of transplantation; however, African Americans are less likely than other ethnic groups to receive a kidney (4–8).

Data have shown that individuals awaiting transplant have a better chance of finding a compatible kidney when there are larger numbers of donors from their same ethnic/racial background, with racial concordance between donor-recipient pairs >95% (9). Surveys assessing attitudes toward donation have shown that African Americans are 20% less likely to express a willingness to donate their own organs compared with Caucasian Americans (10,11). Not surprisingly, African Americans comprise 34% of waitlisted patients but only 11% of recipients of living donor kidney transplants (8,12).

Prior studies have shown mistrust of the medical community and religious/cultural beliefs to be major predisposing factors for the lower organ donation rates among African Americans (10,13–16). Given the prominent role of the church in shaping African-American community life, some have suggested church-based interventions to overcome these concerns (17,18). Studies incorporating organizational constructs known to influence beliefs and priorities, such as the church, are needed to identify factors that may facilitate the willingness of African Americans to become organ donors, particularly living kidney donors. Herein, we report findings from a formative research study that uses the nominal group technique (NGT) to identify and prioritize strategies for promoting organ donation among church-attending African Americans.

Materials and Methods

Ethical Approval and Participant Reimbursement

Approval from the Institutional Review Board of the University of Alabama at Birmingham was secured before proceeding with the research. Informed consent was received from each participant. An honorarium of United States \$25 was paid to participants. The research activities being reported are consistent with the Principles of the Declaration of Istanbul as outlined in the "Declaration of Istanbul on Organ Trafficking and Transplant Tourism."

NGT

The NGT is a well established, highly structured, multistep facilitated group meeting that uses informant panels to elicit and prioritize responses to a specific question (19–23). To be an effective data collection activity, the NGT structured meetings include (1) silent written generation of responses to a single study question, (2) round robin presentation and recording of responses, (3) nonevaluative discussion of responses for clarification, and (4) anonymous voting on response importance (24,25). The initial tabulation of the prioritized responses is reviewed with participants for task completion and to obtain additional response clarity. The NGT meetings are structured to effectively minimize the process loss that occurs when group participants directly interact, which often occurs with brainstorming and focus groups (26). This structure promotes even rates of participation and equally weights the input from all participants, and as such, the anonymously ranked responses provide a valid reflection of the collective views held by group participants (27).

Formulation of the NGT Question

The success of the NGT as a formative research method is dependent on designing a question that both clarifies the objective of the meeting and elicits the desired responses. To accomplish this task, the research team prepared several candidate questions intended to elicit facilitative strategies for increasing the willingness of African Americans to become organ donors. We elected to focus on facilitative strategies as opposed to barriers, because a thorough review of the literature indicated this area to be an area in need of more focused attention. The candidate questions were evaluated through an informal cognitive interviewing process, which involved a panel of seven individuals (not enrolled in the study), to determine how the questions were understood and whether they elicited the information as intended. Each candidate question was assessed for level of (1) accuracy or the level of abstraction of responses and (2) clarity or the scope of responses. The question that elicited the greatest accuracy and clarity in terms of responses was chosen and used in the NGT panel meetings: "What would make it easier for people to decide to become organ donors?"

Questionnaire

A brief questionnaire was constructed to assess willingness to donate one's organs after death and willingness to be a living kidney donor. Each question was associated with a four-point Likert scale ranging from strongly disagree to disagree to agree to strongly agree. The questionnaire also contained basic demographic questions and was administered at the beginning of the NGT session.

Participant Selection and Recruitment

Adult (≥ 19 years old) church-attending African Americans in the local Birmingham area were recruited to participate in the NGT meetings. To the extent possible, we sought to maximize participation from individuals representing varied faith-based denominations. Three NGT panels consisted of churchgoing community members, and each of the panels represented a different faith-based denomination. Individual participants were recruited from three distinct local African-American churches and contacted directly by research team members by telephone and in-person interactions. The fourth NGT panel consisted of church clergy recruited from local African-American churches. Five distinct faith-based denominations were represented in this final NGT panel.

Panel Participation

Each NGT meeting was structured to promote equal involvement of all participants, with each session lasting approximately 90 minutes. Participants in each meeting group were informed that the purpose of the meeting was to tap into their unique insights, knowledge, and experiences to identify a comprehensive list of varying strategies that may help African Americans in making the decision to become an organ donor. Group members were informed of the ground rules for the meeting and asked to work independently and develop their own lists of concise statements/phrases in response to the NGT question. To help ensure that a wide array of responses would be generated, participants were encouraged to think broadly about the different types of strategies that members of their community would find helpful. Each participant was then given an opportunity to present their responses to the group. To promote open disclosure, increase response volume, and ensure that all participants had an equal opportunity to contribute to the generation of responses, a round robin format was used. This format involved having each participant in turn articulate a single response to the question without providing any rationale, justification, or explanation. The facilitators immediately recorded each response verbatim. The nomination process continued until all responses were exhausted.

Participants from each panel were given an opportunity to briefly discuss the responses (strategies) that they generated for the purposes of clarification (not evaluation) to ensure that every response was understood from a common perspective. During these discussion phases, there was some response elaboration, and a small number of responses were added to the lists.

The final phase of each meeting consisted of a structured prioritization exercise that involved having participants anonymously selecting from the group list what they individually perceived as the three most important strategies that might facilitate increases in organ donation among the African-American community. Participants could select any three strategies from the group list and were not limited to strategies that they themselves nominated. Each participant was then asked to rank each of their three chosen strategies by weighting the strategies from most to least important. To accomplish this task, each participant was given a total of six votes and asked to assign three votes to the strategy that they considered most important, two votes to the second most important strategy, and one vote to the third most important strategy. The individual rank orderings were aggregated across participants to tabulate a group level result, which was then presented to the group for comments. Thus, each individual panel generated a unique set of responses.

Results

Study Population

Twenty-eight church-attending African-American adults enrolled in the study; 21 community participants completed the questionnaire, and 20 participants completed the NGT exercise. Seven clergy participants completed the NGT exercise, and six clergy participants completed the questionnaire. In total, 60.7% of participants were women, with a mean age of 52 (± 11) years; 33.3% of community participants and 42.9% of clergy participants reported an income above the median state (Alabama) and federal household income levels, and 71.4% of participants had an education at or above the college level (community=66.6%; clergy=85.8%) (Table 1).

Demographic	Community (n=21)	Clergy (n=7)
Female	13 (61.9%)	3 (42.9%)
Male	8 (38.1%)	4 (57.1%)
Age (Mean \pm SD)	52 \pm 11	52 \pm 11
Income above median	7 (33.3%)	3 (42.9%)
Education at or above college level	14 (66.7%)	6 (85.7%)

Identified Strategies

Individually, 66.7% (18 of 27) of participants indicated that knowledge about organ donation was the most important facilitator for increasing organ donation rates (living and deceased) among African Americans by awarding their highest weighted vote (three points) to knowledge- or education-based strategies. This was slightly more pronounced among clergy compared with community participants (71.4% versus 65.0%). Among four convened NGT panels, three of four (community: two of three panels; clergy: one of one) panels rated knowledge about organ donation as the most important facilitating factor. Collated NGT group responses that used terms such as knowledge, understand, or telling were defined as knowledge or education based (Table 2).

Strategy	Community (n=21)	Clergy (n=7)
Provide more information about organ donation	10 (47.6%)	3 (42.9%)
Better publicize the need for organ donation	8 (38.1%)	2 (28.6%)
Simplify the organ donation process to make it easier to become an organ donor	5 (23.8%)	2 (28.6%)

Community Panel 1—Nondenominational (n=8). In total, 29 strategies were elicited, and 13 strategies were assigned votes. Five strategies were endorsed as relatively more important than others, accounting for 77% of 48 total available weighted votes (Table 3). Three strategies received 50% more votes than the other identified strategies: (1) provide more information about organ donation, (2) better publicize the need for organ donation, and (3) simplify the organ donation process to make it easier to become an organ donor.

Strategy	Community (n=21)	Clergy (n=7)
Provide more information about organ donation	10 (47.6%)	3 (42.9%)
Better publicize the need for organ donation	8 (38.1%)	2 (28.6%)
Simplify the organ donation process to make it easier to become an organ donor	5 (23.8%)	2 (28.6%)

Community Panel 2—Baptist Denomination (n=7). In total, 27 strategies were elicited, and 11 strategies were assigned votes by six participants (one participant elected not to complete the study) (Table 3). Five strategies were endorsed as relatively more important than others, accounting for 80% of 36 total available weighted votes: (1) show more television advertisements and commercials about the need and importance of organ donation, (2) provide potential donors information about what actually is involved, (3) help people recognize that organ donation can help someone in need, (4) provide payment to donors, and (5) help potential donors understand how big the need for organ donation is.

Community Panel 3—Pentecostal Denomination (n=6). In total, 27 strategies were identified, and 12 strategies were assigned votes. Six strategies were endorsed as relatively more important than others, accounting for 72% of 36 total available weighted votes (Table 3). Two strategies received 50% more votes than the other identified strategies: (1) provide seminars at work or at school to educate and inform people about organ donation and (2) help people to understand that the decision to become an organ donor may help someone to maintain a productive life.

Church Clergy Panel (n=7). Five faith-based denominations were represented: nondenominational (n=1), Baptist (n=2), Methodist (n=1), Seventh Day Adventist (n=1), and Pentecostal (n=2). In total, 31 strategies were elicited; 14 strategies were assigned votes, and five strategies were endorsed as relatively more important than others, accounting for 64.3% of 42 total available weighted votes (Table 3). Two strategies received 50% more votes than the other identified strategies: (1) help people become more knowledgeable about organ donation and (2) help overcome the lack of trust in the medical community.

Willingness to Donate

In total, 29.6% of participants indicated that they disagreed with deceased donation, and 37% of participants indicated that they disagreed with living donation (deceased: eight of 27; living: 10 of 27). Community participants' reservations about becoming an organ donor were similar for living and deceased donation (disagree: living, 38.1% versus deceased, 33.4%). In contrast, clergy participants were more likely to express reservations about living donation (disagree: living, 33.3% versus deceased, 16.7%) (Table 4).

Response	Community (n=21)	Clergy (n=7)
Agree	14 (66.7%)	4 (57.1%)
Disagree	7 (33.3%)	3 (42.9%)

Discussion

In this novel formative research study, African Americans identified knowledge acquisition as the most important factor for facilitating willingness to become an organ donor. Uniquely, participants primarily focused on acquiring knowledge specific to potential donors, such as helping potential donors better understand the donation process and donation-related risks, particularly in the context of a potential living donor's existing health status. Overall,

approximately one third of study participants disagreed with being an organ donor. Moreover, there seemed to be greater opposition to living donation compared with donation after one's death, and this finding was most pronounced among clergy compared with community participants.

With substantial potential to promote health, partnerships between faith organizations and the health system are not new. In fact, it has been shown that individuals who attend church services regularly are more likely to have continuity with a health provider than those who do not attend (28). Moreover, studies have shown that regular church attendance is linked with improved health and wellbeing, suggesting that regular church attendance is associated with more medical community interactions and improved health-related knowledge (29,30). It follows then that church-attending African Americans may be exposed to more educational opportunities on topics such as organ donation. Recruitment of churchgoing participants afforded us the greatest opportunity to identify facilitating factors that may extend beyond knowledge acquisition. Interestingly, our study found that knowledge acquisition remains a key determinant in the willingness of African Americans to donate. Uniquely, however, the need for knowledge now seems to be centered on donor-related issues, particularly with regard to living kidney donation. Previous studies have correlated low socioeconomic status with lack of knowledge (31–33); however, our data indicate that the problem may be more related to information gaps about risks and benefits specific to African-American donors as opposed to lack of understanding of existing data, suggesting a need for refinements to current educational programming on organ donation.

Prior studies have highlighted the importance that knowledge plays in improving deceased organ donation consent rates, but almost universally, these studies have identified lack of knowledge about recipient benefit as the primary motivator (34,35). Although our study suggests that knowledge remains a key determinant in the willingness of African Americans to donate, this investigation has yielded novel findings. Specifically, stakeholders in the African-American community achieved consensus that the key to increasing organ donation is the provision of additional information on donor-related issues, particularly living kidney donation. It is not surprising that African Americans cite lack of knowledge as a deterrent to organ donation. In fact, a 2010 United States consensus conference entitled "Living Kidney Donor Follow-up: State-of-the-Art and Future Direction" concluded that more information is needed on postdonation outcomes, including hypertension and CKD (36). African-American living donors were identified as a leading subgroup in need of focused attention because of poor understanding of donation-related risks.

In addition to these novel findings, our study is the first of its kind in the United States to use the NGT, a technique considered highly valid and widely applicable, to assess willingness to become an organ donor. The NGT is a highly structured formative research tool that minimizes the process loss that occurs when group participants directly interact, allowing robust data collection to occur, despite smaller sample sizes. The use of the NGT allowed us to understand specific needs, preferences, and culture in relation to organ donation willingness among African Americans. Results from this study indicate that a tailored educational program that addresses these factors, particularly donation-related involvement and risks, is needed to facilitate organ donation within the African-American community. These findings will be used as the foundation for a cognitive mapping study and development of a Delphi questionnaire on organ donation, affording the opportunity for more widespread participation, assessment of the generalizability of our findings, and ultimately, development of educational programming.

Although there are strengths associated with NGT-based formative research, we must acknowledge several study limitations. Our study involved only 28 participants, all of whom live in the Deep South and attended church, potentially limiting the validity and generalizability of our findings in the broader United States African-American population. A major goal of our study, however, was to assess willingness to be an organ donor among a subset of African Americans most likely to have been exposed to the medical community on a consistent basis, and therefore, have the greatest likelihood of having discussed organ donation. Prior studies have shown that church-attending individuals have more continuity with the medical community, supporting the decision to limit the study population to church-attending African Americans (28). Moreover, it is well known that the church plays a key role in African-American community life (37). Involvement of key stakeholders early during the formative research stages has been shown to be critical for effective educational program development, implementation, and adoption within the priority community (38). In addition, we did not assess the influence of the *a priori* knowledge of the participants of end stage disease, organ donation, and transplantation on their willingness to donate, and as such, it is possible that the prior experiences of participants may have biased our results. However, recruitment materials and strategies that involved leading phrasing/terminology that may have encouraged only individuals with experience in organ donation and/or transplantation to participate were avoided. Furthermore, the NGT panels comprise a select group of individuals, but our experience suggests that only a few meetings are necessary and usually sufficient to identify a full array of responses to a particular question and achieve idea saturation. (26) Although small sample size is often associated with weak study design, in the context of formative research using the NGT, smaller sample sizes actually enhance and facilitate robust research subject participation and granularity of data collection (38). Specifically, the NGT minimizes normative pressures for conformity prevalent in conventional large-group discussions, hidden agendas, and overt group dynamics, and in so doing, it ensures that minority ideas and opinions are expressed (20,39). Finally, although it is possible that interpretation bias occurred, it is unlikely given that the written verbatim responses of participants were recorded in real time (20,39).

At a population level, African Americans have high rates of ESRD and substantial need for organ donors (particularly living kidney donors), but less access to transplantation (4,5,7,8,40). It is well established that African Americans have significantly lower organ donation rates (12,41,42). Our data suggest that improving knowledge about organ donation, particularly with regard to donor involvement and donation-related risks, may facilitate increases in organ donation among the African-American community. Moreover, our findings suggest that existing educational campaigns may fall short of meeting the information needs of this population and that efforts should be directed to expanding the educational content to balance both risks and benefits to the organ recipient and donor. These data represent the first step in a formative research process designed to identify the most salient facilitating factor for promoting willingness to be an organ donor among the African-American community, and they will serve as the foundation for development of educational interventions focused on improving knowledge of donor-related risks and outcomes.

Disclosures

None.

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