



HHS Public Access

Author manuscript

Prog Transplant. Author manuscript; available in PMC 2015 September 01.

Published in final edited form as:

Prog Transplant. 2014 September ; 24(3): 273–283. doi:10.7182/pit2014936.

African American Organ Donor Registration: A Mixed Methods Design using the Theory of Planned Behavior

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Abstract

Context—A large racial disparity exists in organ donation.

Objective—The purpose of this study was to identify factors associated with becoming a registered organ donor in among African Americans in Alabama.

Methods—The study utilized a concurrent mixed methods design guided by the Theory of Planned Behavior to analyze African American's decisions to become a registered organ donor using both qualitative (focus groups) and quantitative (survey) methods.

Results—The sample consisted of 22 registered organ donors (ROD) and 65 non-registered participants (NRP) from six focus groups completed in urban (n=3) and rural (n=3) areas. Participants emphasized the importance of the autonomy to make one's own organ donation decision and have this decision honored posthumously. One novel barrier to becoming a ROD was the perception that organs from African Americans were often unusable due to high prevalence of

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Disclosure: The authors of this manuscript have no conflicts of interest to disclose as described by Progress in Transplantation

chronic medical conditions such as diabetes and hypertension. Another novel theme discussed as an advantage to becoming a ROD was the subsequent motivation to take responsibility for one's health. Family and friends were the most common groups of persons identified as approving and disapproving of the decision to become a ROD. The most common facilitator to becoming a ROD was information, while fear and the lack of information were the most common barriers. In contrast, religious beliefs, mistrust and social justice themes were infrequently referenced as barriers to becoming a ROD.

Discussion—Findings from this study may be useful for prioritizing organ donation community-based educational interventions in campaigns to increase donor registration.

Keywords

Organ Donor Registration; Organ Donation; African American; Theory of Planned Behavior; Mixed Methods Design

Introduction

The need for more organ donors in the United States (U.S.) is well recognized. Currently, more than 105,000 patients are waiting for a solid organ transplant in the U.S., of which, over 6,500 patients will die each year before an organ becomes available.(1) Efforts to increase organ donation via the dissemination of “best practices” in the early 2000s have manifested in a significant increase in deceased organ donation.(2) While significant increases in organ donation have been realized across races, there remains a large disparity in organ donation between Caucasians and African Americans.

African American race is a significant predictor of organ non-donation.(3) At the same time, African Americans are significantly over represented on the transplant waitlist. For example, African Americans make up 26.5% of the Alabama population,(4) yet comprise 67.6% (2244/3320) of the renal transplant waiting list at the University of Alabama at Birmingham (UAB).(5) During 2011, 143 deceased donor kidney transplants were performed at UAB of which African Americans accounted for 59.4% of transplant recipients yet only 16.8% of donor organs originated in African Americans.(5) A recent review of all requests for organ donation in the Alabama donor service area demonstrated a four-fold increase in donor authorization in Caucasians compared to African Americans.(6)

The purpose of this study was to identify factors (beyond those already identified) associated with African Americans choosing to become a registered organ donor. This study adds to existing research by using a theory-based, mixed methods research design intended to reveal factors not tapped by previous research in a sample of African Americans from the Deep South. The dependent variable explored is “being a registered organ donor,” consistent with recommendations from comprehensive reviews of African American organ donation literature which advocate measuring organ donor registration and not attitudes concerning organ donation such as “I would consider becoming an organ donor.”(3)

Methods

Design

The study utilized a concurrent mixed methods design (7–9), which has been previously used in community health research to address health disparities.(10, 11) African Americans' decisions to become a registered organ donor were explored using both qualitative (focus groups) and quantitative (survey) methods. (Figure 1) The results from survey and focus group analysis were compared to produce more consistent and valid conclusions.(12)

Theoretical Framework

This study used the Theory of Planned Behavior (TPB) to explore factors influencing the choice to become a registered organ donor. The TPB, a model used by researchers to predict behavioral intentions(13), has strong empirical support.(14, 15) The theory specifies that people's intentions are the most proximal determinant of their behavior. The model incorporates data from three domains: behavioral beliefs, subjective norm, and behavioral control.

Participant Recruitment

Study participants were recruited via existing UAB partnerships, coalitions, and community networks.(16, 17) Focus group advertisements were distributed through these established channels along with study eligibility requirements (African American race and age 19) and a phone number to call if they were interested in participating. The participants were recruited from areas defined as either urban or rural by the Alabama rural association. (18) The study was approved by the UAB Institutional Review Board (X090325003).

Data Collection

Six focus groups were completed. The number of participants per focus group ranged from 8 to 19. Both registered and not registered organ donors participated in the focus groups jointly. Qualitative and quantitative data were collected concurrently from the 87 focus group participants. Participants were provided with a \$50 Visa gift card as compensation for their time and travel.

Qualitative data—Using the constructs of TPB and the procedures outlined by Morgan (19) and Krueger (20), members of the investigative team developed the qualitative research protocol to guide focus group discussions. The facilitator began each discussion by describing the purpose of the study and discussing the basic ground rules. Each session began by defining the behavior of interest, namely, becoming a registered organ donor, and illustrating the three avenues of becoming an organ donor (registration at the Department of Motorized Vehicles, mail-in brochure and online registration). The focus group moderator then asked specific questions regarding behavioral beliefs (advantages and disadvantages of becoming a registered organ donor), subjective norm (those who would approve or disapprove of becoming a registered organ donor) and behavioral control (facilitators and barriers to becoming a registered organ donor). (Figure 2)

Quantitative data—Following the focus group, participants completed a quantitative questionnaire to assess their awareness and knowledge of organ donation, and attitudes regarding becoming a registered organ donor. The research team developed this preliminary questionnaire using the information from the organ donor literature and a “mock” focus group. An elicitation research “mock” focus group was completed on campus at UAB with 20 African American participants recruited from employees of the Survey Research Unit in Public Health prior to the main study. The mock focus group participants completed the questionnaire and provided feedback including identifying questions that were confusing and words that needed clarification.

The goal was to create a final survey instrument that would have quantitative questions for most qualitative themes that may arise from the focus group discussions. A panel of experts then reviewed the themes that emerged during the mock focus group as well as the answers to the preliminary questionnaire. Thirty-three questions were selected to be in the final instrument and were organized into the following categories: 13 organ donor attitude questions, 14 questions on organ donor awareness and 6 questions designed to measure organ donor knowledge. The validated nine-item Organ Donor Readiness Index (21) and the five-question “Beliefs” section of the National Minority Organ and Tissue Transplant Education Program (MOTTEP) (22) was embedded in the questionnaire. The final tool was rated by Microsoft Word (Redmond, WA) to be composed at a 7th grade level. Data obtained via the mock focus group was only used to inform the development of our final research instrument, and is not included in the statistical analysis in this study.

Data Analysis

Qualitative data—The digitally recorded focus group discussions were transcribed verbatim and analyzed inductively in two stages using a multi-functional software system for qualitative data analysis, NVivo10 (QSR International). First, a standard thematic analysis was conducted to search for common categories and themes in the data. Two qualitative investigators (NI and IH) independently coded the original transcripts by identifying key points and recurring categories and themes that were central to areas of discussion both within and across focus groups. A constant comparative method (23) was used to guide the analytical process. Inter-coder agreement between the two coders reached an acceptable 90% as recommended by Miles and Huberman. (24) Content analysis (25) was also performed on the generated categories and themes using the counts of text references in NVivo 10 to systematically represent consistencies in viewpoints across focus groups. Particular emphasis in the analysis was placed on how the themes interacted with others to explain intentions to become a registered organ donor within the study theoretical framework - TPB. [Table 2]

Quantitative data—Questionnaire results were compared between registered organ donors and non-registered participants. The primary analytic approaches for dichotomous variables utilized Pearson Chi-square and Fisher exact test analyses. To summarize strength and direction of associations, odds ratio and their respective 95% confidence intervals were calculated. Data were expressed in mean \pm standard deviation. The Student t test was used to compare means and the Wilcoxon Rank-Sum test was used to compare median values

between registered organ donors and non-registered participants. Analyses were conducted using the SAS 9.2 (Cary, NC).

Mixed methods data analysis—Mixed methods data analysis and integration of the quantitative and qualitative results were performed at the completion of the separate analyses of the survey and focus group discussion data. Qualitative themes and categories, organized according to the constructs of the TPB, were compared with quantitative survey items in a joint display matrix (Table 3). The number of text references for qualitative categories were compared with the statistical test probability values for quantitative survey items to identify consistency in the participants' viewpoints regarding becoming a registered organ donor.

Results

Demographics (Table 1)

Eighty-seven African American participants completed six focus groups. The mean number of participants was 14.5 (range 8 – 19). The sample consisted of 22 registered organ donors (ROD) and 65 non-registered participants (NRP). Most participants were women (75%) and the mean age was 50 (range 19–88) years. There were no significant differences in baseline measures between the groups. Focus Groups and Survey Findings (Tables 2 & 3).

Behavioral Beliefs: Advantages and disadvantages of becoming a ROD

The opportunity to save someone's life emerged as the dominant qualitative theme about the advantages of becoming a registered organ donor accounting for 51.6% of text references and validated quantitatively to be a more dominant attitude in ROD compared to NRP ($p=0.04$). "Making your own [organ donation] decision" was also commonly referred to as an advantage of becoming a registered organ donor accounting for 20.0% of text references but there was near equivalent agreement between both ROD and NRPs regarding honoring a person's wish to donate organs ($p=0.84$). The concept of "not needing organs when dead" accounted for 8.3% of text references and was a significantly prevalent attitude in ROD compared to NRPs (OR 15.0, 95% CI 1.9 – 121, $p=0.0017$). Two additional advantages to becoming an organ donor that were discussed by the participants were personal factors (6.6% of text references) and taking responsibility for your health (3.3% of text references). However, there were no quantitative questions to measure the association between these two themes and organ donor registration.

The biggest disadvantage to becoming a registered organ donor was fear, accounting for 30.3% of text references. RODs were much less likely to agree with donation fear statements ($p=0.008$). Legal issues and religious/moral beliefs also were brought up as disadvantages to becoming a registered organ donor although there were no significant differences in quantitative responses to questions probing these themes between ROD and NRPs. Organ usability was another disadvantage to becoming a registered organ donor commonly discussed, accounting for 16.6% of text references. Finally, registered donors were significantly less likely to agree with social justice statements regarding transplantation ($p=0.05$), although social justice themes only accounted for 7.6% of text references.

Normative Beliefs: Those who would approve or disapprove of a ROD

The most common groups of persons who were thought to approve of the decision to become a registered organ donor were family and friends accounting for 69.3% of text references. RODs were more likely to have had a conversation with their family about organ donation than NRPs (OR 3.1, 95% CI 1.1 – 8.8, $p=0.035$). Health care providers were also listed as approving of the decision to become a registered organ donor, accounting for 16.3% of text references. RODs were also more likely to have had a conversation with their physician about organ donation than NRPs (OR 9.4, 95% CI 1.7 – 51.6, $p=0.0032$). Community members (8.2% of text references) and those in need of organs (6.1% of text references) were also discussed as groups of persons who would approve of the decision to become a registered organ donor but there were no significant differences in quantitative responses to questions probing these themes between ROD and NRPs.

Family members were also identified as the most common persons to disapprove with becoming a registered organ donor, accounting for 51% of text references. Church and religious groups also were commonly (20.4% of text references) brought up as disapproving of the decision to become a registered organ donor but there were no significant differences in responses to questions probing these themes between ROD and NRPs. Similarly, community (20.4% of text references) was put forth as disapproving with the decision to become a registered organ donor but no differences were measured between ROD and NRPs.

Behavioral Control: Facilitators and barriers to becoming a ROD

The most common facilitating factor discussed in the focus groups was information, accounting for 40% of text references. There was a trend toward increased agreement with the question “I understand the organ donor process” in ROD compared to NRPs, although the difference was not statistically significant ($p=0.068$). The next most common facilitators discussed were family members needing an organ transplant and having a formal process in place for becoming an organ donor, each accounting for 16.4% of text references. Knowing the organ recipient (8.9% of text references) and religious beliefs (6.3% of text references) also were perceived as facilitators but there were no significant differences in quantitative responses to questions probing these themes between ROD and NRPs. RODs were more likely to acknowledge measures of altruism compared to NRPs (OR 5.3, 95% CI 1.3 – 20.4, $p=0.01$), although altruism themes only accounted for 6.3% of text references. Similarly, RODs responded more positively to questions measuring trust compared to NRPs (OR 1.5, 95% CI 1.2 – 7.2, $p=0.018$), although trust themes only accounted for 3.8% of text references.

Many themes emerged when discussing barriers to becoming an organ donor. The lack of information was most commonly referenced (41.2%). In analysis of data from the quantitative questions, mistrust, fear and social justice themes all demonstrated significant differences between ROD and NRPs. Mistrust accounted for 16.5% of text references and was much less prevalent in ROD compared to NRPs ($p=0.002$). Fear accounted for 12.4% of text references and also was much less prevalent in ROD compared to NRPs ($p=0.001$). Similarly, social justice accounted for 6.2% of text references and was less prevalent in

ROD compared to NRPs ($p=0.05$). Personal factors (7.2% of text references) were another significant theme that emerged with differences between ROD and NRPs ($p=0.002$). In contrast, there were no significant differences in quantitative responses to questions probing religious and moral beliefs, which accounted for 8.2% of text references.

Discussion

This study used a mixed methods approach to explore factors associated with choosing to become a registered organ donor in a sample of African Americans from the Deep South. The strength of this study lies in the identification of factors informed by the Theory of Planned Behavior. While previous research has identified factors associated with organ donation (add cites), few have proceeded from a strong theoretical foundation. The current study thus extends the organ donation research paradigm contributing new and novel insights about organ donation in the African American population. One novel finding from this study was the emergence of a self-perception that organs from African Americans are often unusable due to the higher prevalence of health issues compared to other races. Concerns about organ usability were discussed as a disadvantage to becoming an organ donor. One participant said, "...we probably have very little organs to donate with our lifestyle and eating habits." It is important for community-based educational campaigns to emphasize that there often are donation options, even for patients with comorbid illnesses. An analogous theme was that being a registered organ donor might be a healthy stimulus prompting registered donors to take care of their own health, which was discussed as an advantage to being a registered organ donor.

Religious beliefs (5, 26–29), mistrust (2, 4,5, 26, 29–36), and social justice (2, 37–40) are common barriers to organ donation frequently cited in the literature. Interestingly, religious beliefs, mistrust and social justice were infrequently discussed during the focus groups in our study, accounting for few text references. There were no differences in measures of religiosity between the ROD and NRPs. In contrast, mistrust and social justice were statistically different between ROD and NRPs on the quantitative measurements. One issue is the relative importance of religious beliefs, mistrust and social justice barriers in predicting becoming a registered organ donor. Our data suggest that other factors may play a more dominant role in predicting the behavior of becoming a registered organ donor.

Fear and lack of information, in contrast, are commonly cited as barriers to organ donation in the literature and were commonly discussed in our focus groups.(5, 37,41–43) Three common fears cited in the literature are that being a donor will be a financial burden to their family, you will not get a proper burial and your body will be disfigured if you are a donor. (5, 37, 44) Addressing these fear-inducing misconceptions are an important part of informative organ donation educational campaigns. Information was the most common facilitator and lack of information was the most common barrier to becoming a registered organ donor. There were encouraging comments offered about the "younger generation" being informed thus increasing their willingness to become organ donors.

Our study reaffirms the importance of disseminating the decision to become an organ donor to family and friends, as has been frequently documented in the literature. (40, 42,45, 46)

The survey results also confirm that individuals who have had a discussion about organ donation with their family and friends (or health care provider) are more likely to be an organ donor. Efforts to increase organ donor registration need to include mechanisms to ensure familial notification.

This study has several limitations. First, the participants were disproportionately female, older, highly educated and with incomes higher than the average incomes of African Americans in Alabama. Underrepresentation of males may be especially important, as studies have demonstrated that non-donation attitudes in African American males were more likely to be related to medical mistrust than in African American females.(47) Secondly, the quantitative questionnaire contained the nine-question organ donor readiness index (21) and select items from the National Minority Organ and Tissue Transplant Education Program (MOTTEP) (22) without further validity testing in this population. The questionnaire also included items developed specifically for the current study. The self-developed items on the questionnaire were not subjected to construct validity testing due to a small sample size. Third, despite attempts to (prospectively) include items on the questionnaire that would measure each qualitative theme discussed during the mock focus group, some new themes emerged during the focus groups (and thus after the questionnaire was developed) for which there were no matching quantitative items. This is consistent with the inductive nature of qualitative research and its ability to yield more in-depth exploration of the phenomenon of interest, and thus may also be a strength of the study.(48)

In summary, this study measured factors associated with choosing to become a registered organ donor in a sample of African Americans from the Deep South. Using a mixed methods approach helped not only produce more rigorous conclusions, but allowed better capturing of the nuances that may account for differences in the intentions to become or not to become a registered organ donor. Results from this study suggest new content and motivational messages to include in campaigns to increase African American donor registration.

Acknowledgments

Research was supported in part by a Charles Barkley Health Disparities Research Award (D. DuBay) and NIH NIDDK 1 K23 DK091514-01A1 (D. DuBay).

Abbreviations

ROD	Registered Organ Donor
NRP	Non-Registered Participants
MOTTEP	Minority Organ and Tissue Transplant Education Program
TPB	Theory of Planned Behavior
UAB	University of Alabama at Birmingham
OR	Odds Ratio
95% CI	95% Confidence Interval

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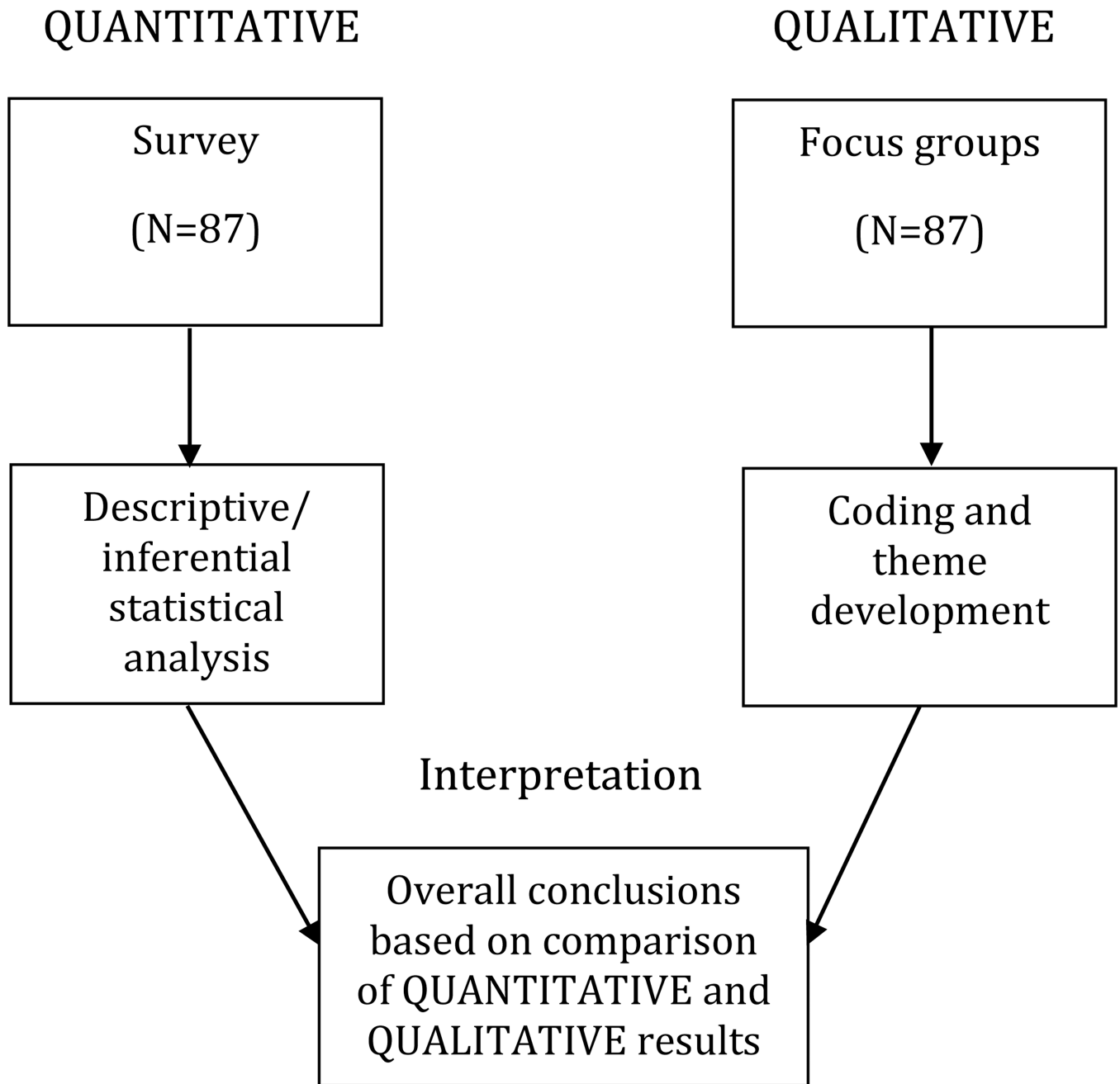


Figure 1. Mixed Methods Concurrent Design Procedures in the Study

THEORY OF PLANNED BEHAVIOR

Behavior Defined: Becoming a registered organ donor
Behavioral Beliefs:
What do you believe are the <u>advantages</u> of you becoming a registered organ donor? What do you believe are the <u>disadvantages</u> of you becoming a registered organ donor?
Subjective Norm:
Are there any individuals who would <u>approve</u> of you becoming a registered organ donor? Are there any individuals who would <u>disapprove</u> of you becoming a registered organ donor?
Facilitators and Barriers:
What factors or circumstances would <u>enable</u> you to become a registered organ donor? What factors or circumstances would <u>make it difficult or impossible</u> for you to become a registered organ donor?

Figure 2.
Focus Group Protocol Guided by Theory of Planned Behavior

Table 1

Characteristics of the Overall Sample and Characteristics by Donor Status

	All	Registered Donors	Non-Registered	p-value
Population	N=87	N=22	N=65	
Age mean (range)	50 (19 – 88)	51.4 ± 20.3	49.2 ± 15.8	0.65
Female gender	65 (75%)	68.4%	80.8%	0.34
Children <18yr in house				0.26
0	55 (63%)	67.7%	50.0%	
1	10 (15%)	10.8%	27.3%	
2	10 (15%)	15.4%	13.6%	
3	5 (6%)	6.2%	9.1%	
Highest Education				0.11
High School or less	26 (30%)	22.7%	32.3%	
Some College	24 (28%)	18.2%	30.8%	
Bachelors	20 (23%)	36.4%	18.5%	
Post-Graduate	11 (16%)	22.7%	13.9%	
Household Income				0.70
<\$20,000	25 (29%)	33.3%	27.0%	
\$20,000 – 40,500	18 (21%)	28.6%	19.1%	
\$40,500 – 60,000	18 (21%)	14.3%	23.8%	
>\$60,000	17 (19%)	19.1%	19.1%	
Marital Status				0.41
Never Married	16 (19.5%)	18.2%	20.0%	
Married/ Common-law	42 (51.2%)	54.6%	50.0%	
Divorced/ Separated	15 (18.3%)	9.1%	21.7%	
Widowed	9 (11.0%)	18.2%	8.3%	
Employment				0.24
Retired	29 (33%)	45.5%	30.5%	
Unemployed	19 (22%)	27.3%	22.0%	
Part-time	7 (8%)	0	11.9%	
Full-time	27 (31%)	27.2%	35.6%	
Religious Person				0.35
No	2 (2%)	3.1%	0	
Yes, somewhat	(40%)	43.1%	31.8%	
Yes, very	(54%)	49.2%	68.2%	
Attend Religious Services				0.44
Less than once/month	11 (13%)	9.1%	13.8%	
2–3 Times/ month	19 (22%)	18.2%	23.1%	
About once/ week	26 (30%)	22.7%	32.3%	

	All	Registered Donors	Non-Registered	p-value
More than once/week	32 (37%)	50.0%	30.8%	

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Table 2

Qualitative Themes, Sub-Themes, Categories and Illustrative Quotes

Themes/ Sub-Themes	Categories	(%)	Illustrative Quotes
Behavioral Beliefs			
Advantages	Saving Someone's Life	51.6%	"It comes up in ways saying like, saving a life, it's a good thing to do."
	Making It Your Own Decision	20.0%	"My mama ...she feel like it's my life so I can do whatever I want to do."
	Not Needing Organs When Dead	18.3%	"When you are an organ donor, I'm dead anyway. I don't need it."
	Personal Factors	6.6%	"...cause it's dealing with your life...it's personal."
	Taking Responsibility for Your Own Health	3.3%	"So if we walk out of this room today and say yes I want to be an organ donor would it not behoove us to say to ourselves we need to make sure that our nutrition is appropriate and we take care of our bodies and since I've made that commitment that I want to be a donor that it would be a healthy donation?"
Disadvantages	Fear	30.3%	"The only disadvantage I think about is that if you become a donor when you're alive, you know you'll have to have surgery ...you are going to have to go under the knife and have that organ removed."
	Legal Issues	21.2%	"... you know you can make one decision and later on down the road, ...there should be a waiver in there if I decide to change my mind I may do so."
	Organ Usability	16.6%	"As a whole, African Americans have more health issues ... That's a disadvantage...high cholesterol, heart disease, and all that, so, we probably have very little organs to donate with our lifestyle and eating habits."
	Religious and Moral Beliefs	10.6%	"Some people have their religious beliefs and some people have moral issues about it. I think that plays a role in it."
	Social Justice	7.6%	"...Sometimes when some people got more money than another person, that kind of up that person to get that organ before the one that really need it...the next in line."
Normative Beliefs			
Approving	Family and Friends	69.3%	"If you had a discussion with family members and significant others ...then they would go along with."
	Health Care Providers	16.3%	"...yes, with a doctor, like if the doctor was to bring it up and explain everything to me, I would probably feel fine about it."
	Community	8.2%	"... like I said, friends, your social surroundings ... you can get positive feedback. I just know the people feel the same thing."
	Those in Need of Organs	6.1	"A person may approve if you were at the point of death."
Disapproving	Family and Friends	51%	"Tell your family that's what your intentions... Sometimes people not on the same page and they still overlook and go against it...it still not fool proof."
	Church and Religious Groups	20.4%	"The leadership of this church...they may be members among the body that might not believe in organ donation...."
	Community	20.4%	"Outside of family, like I said, friends, your social surroundings if it brought up. for the most part I just would say more negative..."
Behavioral Control			
Facilitators	Information	40%	"...if people knew more information then maybe it wouldn't be a thing that's so negative."
	Family Member Needs	16.4%	"if a family member was needing one."
	Formal Process in Place	16.4%	"...maybe when they register to vote? Maybe they need to put it on that."
	Knowing Organ Recipients	8.9%	"I think that's something that's important that you could see that person and know their story that they are ordinary people..."
	Altruism	6.3%	"If it will help somebody else after I'm gone, then that's fine...I can't do anything with it. So, I am an organ donor."

Themes/ Sub-Themes	Categories	(%)	Illustrative Quotes
	Religious Beliefs	6.3%	"I guess it depends on the church. A more modern church, one that's non-denominational a little bit more ...what's going on in the world would be a lot more accepting."
	Trust	3.8%	"I feel that the majority of the doctors take an oath to do their best and to work on you ...I feel like they would try to save me you know if they feel like I could be saved."
Barriers	Lack of Information	41.2%	"...it's the lack of information or whatever."
	Mistrust	16.5%	"I think that goes to the Black community, they think that if it was an accident or whatever happened I think they not gonna work hard on me; I think that's why a lot of them not an organ donor."
	Fear	12.4%	"I just think that the whole organ donor is a scary thing."
	Religious Beliefs	8.2%	"...The Bible always tell you, ashes to ashes, dust to dust...you going back to the ground...This is gone..."
	Personal Factors	7.2%	"...A lot of thinking...well, what I got, I going to take it with me...I isn't giving nobody nothing...cause it's dealing with your life...it's personal..."
	Social Justice	6.2%	"...you really won't know if they are using it for the right reason, giving it to someone really in need."

Table 3

Comparison of Qualitative and Quantitative Results

TPB Constructs/ Qualitative Themes	Related Categories	% Text References	Survey Items	% Yes/True	DV “Registered OD” N=87 (22 registered, 65 not registered)
Behavioral Beliefs					
Advantages	Saving Someone’s Life	51.6%	<ul style="list-style-type: none"> - I believe organ transplantation is an effective treatment (kidney, liver, lungs, heart). - Organ donation allows something positive to come out of a person’s death. 	76% 82%	<p>Donors 5.0 vs. non-Donors 3.9, p=0.04</p> <p>Donors 4.6 vs. non-Donors 3.9, p=0.19</p>
	Making It Your Own Decision	20.0%	<ul style="list-style-type: none"> - A person’s wish to donate organs should be honored under all circumstances. 	77%	Donors 3.4 vs. non-Donors 2.3, p=0.01
	Not Needing Organs When Dead	18.3%	<ul style="list-style-type: none"> - I am willing to donate the organs of my loved ones after their death. 	67%	OR 1.5 (95% CI 1.9 – 121), p=0.0017*
Disadvantages	Fear	30.3%	<ul style="list-style-type: none"> - I am afraid that my body will be mutilated if I donate my organs. 	11%	Donors 3.0 vs. non-Donors 4.5, p=0.008
	Legal Issues	21.2%	<ul style="list-style-type: none"> - A person’s wish to donate organs should be honored under all circumstances. 	77%	Donors 3.4 vs. non-Donors 2.3, p=0.01
	Religious and Moral Beliefs	10.6%	<ul style="list-style-type: none"> - I believe that God wants our bodies whole for the afterlife. - I believe that it is God’s will that those with organ-related diseases are sick so doctors should not intervene. - I cannot have an open casket funeral if I am an organ donor. 	7% 6% 13%	<p>Donors 4% vs. non-Donors 8%, p=0.61</p> <p>Donors 3.7 vs. non-Donors 4.1, p=0.49</p> <p>Donors 3.5 vs. non-Donors 4.5, p=0.09</p>
	Social Justice	7.6%	<ul style="list-style-type: none"> - The process of selecting who gets donated organs discriminates against African Americans. - On average, African Americans wait longer to get an organ transplant than Whites. 	11% 67%	<p>Donors 3.3 vs. non-Donors 4.4, p=0.05</p> <p>Donors 64% vs. non-Donors 68%, p=0.72</p>
Normative Beliefs					

TPB Constructs/Qualitative Themes	Related Categories	% Text References	Survey Items	% Yes/True	DV “Registered OD” N=87 (22 registered, 65 not registered)
Approving	Family and Friends	68.3%	- I have had a discussion about organ donation with my family.	36%	OR 3.1 (95% CI 1.1 – 8.8), p=0.035*
			- The people who are important to me support organ donation.	64%	OR 2.0 (95% CI 0.6– 6.4), p=0.22*
	Health Care Providers	16.3%	- I have had a discussion about organ donation with my physician.	10%	OR 9.4 (95% CI 1.7– 51.6), p=0.0032*
	Community	8.2%	- I know an African American that is an organ donor (signed an organ donor card or registered when they got their driver’s license).	59%	OR 7.1 (95% CI 1.5 – 34.0), p=0.0065*
			- I know an African American who has donated one of their kidneys (living donor).	33%	OR 2.5 (95% CI 0.9 – 7.3), p=0.085*
	Those in Need of Organs	6.1%	- I know an African American who has received an organ transplant (such as kidney, liver, pancreas, heart, lung, etc.).	57%	OR (2.0 95% CI 0.7 – 6.1), p=0.20*
			- I know an African-American who is waiting for an organ transplant (such as kidney, liver, pancreas, heart, lung, etc.).	30%	OR 2.5 (95% CI 0.9 – 7.3), p=0.085*
Disapproving	Family and Friends	51%	- I have had a discussion about organ donation with my family.	36%	OR 3.1 (95% CI 1.1 – 8.8), p=0.035*
	Church and Religious Groups	20.4%	- I believe that God wants our bodies whole for the afterlife.	7%	Donors 4% vs. non-Donors 8%, p=0.61
			- I believe that it is God’s will that those with organ-related diseases are sick so doctors should not intervene.	6%	Donors 3.7 vs. non-Donors 4.1, p=0.49
	Community	20.4%	- The people who are important to me support organ donation.	64%	OR 2.0 (95% CI 0.6– 6.4), p=0.22*
Behavioral Control					
Facilitators	Information	40%	- I understand the organ donation process.	53%	Donors 4.9 vs. non-Donors 3.8, p=0.068
	Knowing Organ Recipients	8.9%	- I know an African-American who is waiting for an organ transplant (such as kidney, liver, pancreas, heart, lung, etc.).	30%	OR 2.5 (95% CI 0.9 – 7.3), p=0.085*

TPB Constructs/ Qualitative Themes	Related Categories	% Text References	Survey Items	% Yes/ True	DV “Registered OD” N=87 (22 registered, 65 not registered)
	Religious Beliefs	6.3%	- My religious beliefs support organ donation.	39%	Donors 4.9 vs. non-Donors 4.1, p= 0.17
	Altruism	6.3%	- I have donated blood in the past. - I regularly volunteer my time	64% 75%	OR 5.3 (95% CI 1.3 – 20.4), p=0.01* OR 0.7 (95% CI 0.2 – 2.5), p=0.6*
	Trust	3.8%	- I would accept an organ transplant if my doctor thought it was necessary. - I would allow my children to receive a transplant if my doctor thought it was necessary.	92% 93%	OR 0.4 (95% CI 0.1 – 3.1), p=0.38* OR 1.5 (95% CI 1.2 – 7.2), p=0.018*
Barriers	Lack of Information	41.2%	- African Americans have better health outcomes if they receive their organs from African American donors (as opposed to donors from other ethnic groups). - More African American organ donors are required to meet the needs of African Americans awaiting transplantation. - Patients can recover from brain death. - On average, African Americans donate organs at a rate greater than Whites.	39% 60% 20% 9%	Donors 41% vs. non-Donors 38%, p=0.84 Donors 59% vs. non-Donors 60%, p=0.94 Donors 23% vs. non-Donors 18%, p=0.66 Donors 14% vs. non-Donors 8%, p=0.40
	Mistrust	16.5%	- I believe my doctors may NOT try as hard to keep me alive if I am a registered organ donor. - I do not trust my doctors so I will not agree to donate the organs of my loved ones.	19% 9%	Donors 2.6 vs. non-Donors 4.8, p=0.0002 Donors 3.1 vs. non-Donors 4.5, p=0.014
	Fear	12.4%	- I am afraid that I will not get a proper burial if I donate my organs.	6%	Donors 2.8 vs. non-Donors 4.6, p=0.001
	Religious and Moral Beliefs	8.2%	- I believe that it is God’s will that those with organ-related diseases are out of harmony with their spirit so doctors should not intervene. - I cannot have an open casket funeral if I am an organ donor.	4% 7%	Donors 4.0 vs. non-Donors 4.2, p=0.71 Donors 23% vs. non-Donors 18%, p=0.66
	Personal Factors	7.2%	- I am afraid that me donating organs will be a financial burden to my family.	7%	Donors 2.8 vs. non-Donors 4.6, p=0.002

TPB Constructs/ Qualitative Themes	Related Categories	% Text References	Survey Items	% Yes/ True	DV “Registered OD” N=87 (22 registered, 65 not registered)
	Social Justice	6.2%	- The process of selecting that gets donated organs discriminates against African Americans. - There is a black market for organ donation in the US.	11% 63%	Donors 3.3 vs. non-Donors 4.4, p=0.05 Donors 59% vs. non-Donors 64%, p=0.64

* Reference groups for all Odds Ratios are the non-registered participants.