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Development of a Scale to Measure African American Attitudes toward Organ Donation

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Abstract

African American attitudes toward organ donation differ from other racial and ethnic groups. However, existing measures of organ donation attitudes do not adequately address ethnic identity and cultural factors. We examined the psychometric properties of a new 18-item organ donation scale among 1225 members of 21 African American churches in Southeast Michigan. We identified three factors: (1) Barriers; (2) Family/Race Benefits; and (3) Altruism. More positive donation attitudes on each subscale were observed for individuals who reported being enrolled as a donor. Among individuals not enrolled, higher scores were observed on scales two and three for those with stronger intentions to enroll.

Keywords

beliefs; ethnicity; health education; organ donation; race; randomised controlled trial

Introduction

Transplantation is often required for individuals with end-stage organ failure, most commonly for the kidney, liver, and heart (Organ Procurement and Transplantation Network (OPTN), 2010). Medical advances continue to make transplants safer and more effective. However, the rate of donation has not kept pace with the increasing number of Americans waiting for organs. Over 109,000 Americans are currently awaiting a transplant (OPTN, 2010). African Americans are disproportionately represented among this group. Although comprising around 13 percent of the US population, 31,707 (29%) of those on the waiting list for an organ in the United States are African American (OPTN, 2010). Yet despite this

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Competing Interests

None declared.

need, a 2005 Gallup survey found that whereas 61 percent of Whites had signed their driver's license saying they were willing to donate their organs, only 31 percent of Blacks indicated they had done so. Furthermore, 82.3 percent of Whites were 'very likely' or 'somewhat likely' to have their organs donated after their death compared to 64.1 percent of Blacks, which is the lowest of the four race/ethnicity groups for which data were reported (Gallup Organization, 2005).

African Americans have attitudes toward organ donation that differ from other racial and ethnic groups. Barriers include beliefs regarding religious prohibition against donation, distrust of the medical institutions, and fear of less aggressive medical treatment or premature declaration of death if a donor card has been signed (Arnason, 1991; Davidson and Devney, 1991; Hall et al., 1991; McNamara et al., 1999; Morgan et al., 2003; Siminoff and Arnold, 1999; Spigner et al., 1999; Yancey et al., 1997). Conversely, factors such as religiosity (Morgan, 2006), altruism (Bresnahan et al., 2007; Morgan, 2006; Morgan and Miller, 2002; Skumanich and Kintsfather, 1996), knowledge regarding the allocation system, having experience with friends or family who have received an organ (Jacob Arriola et al., 2005, 2008), and positive attitudes toward donation (Davis et al., 2005; DeJong et al., 1998) are associated with increased likelihood of donation among African Americans. Many education programs, most notably the Minority Organ and Tissue Transplant Education Program (MOTTEP), have focused on increasing organ donation in the African American population (Callender and Miles, 2010; Callender et al., 1995, 1996).

Although measures exist to assess African American attitudes and intentions regarding organ donation, existing measures do not adequately address racial salience or ethnic identity as they relate to donation. Racial salience is defined as 'the extent to which one's race is a relevant part of one's self-concept at a particular moment or in a particular situation' (Sellers et al., 1998: 24). Ethnic identity (EI) has been defined as the extent to which individuals identify with and gravitate to their racial/ethnic group. EI includes elements such as racial/ethnic pride, affinity for in-group culture (e.g. food, media, and language), attitudes toward majority culture, involvement with in-group members, experiences with and attitudes regarding racism, attitudes toward intermarriage, and the importance placed upon preserving one's culture and aiding others of like background. These concepts have been studied in relation to substance abuse prevention (Braithwaite and Resnicow, 2002; Resnicow et al., 1999a, 1999b) and nutrition programs (Resnicow et al., 2009) but not in relation to organ donation. In addition, the potential role of altruism and communal responsibility as they relate to organ donation has not been fully explored.

This study reports the psychometric properties, initial results, and correlates of a measure of organ donation attitudes and practices for African Americans. The study was part of a larger church-based organ donation intervention trial being conducted in Southeast Michigan.

Methods

Survey development

The attitude scale used in this study was adapted from a similar instrument used by our group in a prior organ donation study, funded by the Health Resources and Services

Administration (HRSA), Healthcare Systems Bureau, Division of Transplantation (DoT), among clients of African American hair stylists (Resnicow et al., 2010). The original scale comprised 10 items. For the revised instrument, we deleted some items, revised others, and added new ones in order to further tap the domains of racial salience, altruism, and communal responsibility. These constructs were found to be predictive of other health behaviors in prior studies, but were not adequately addressed in prior organ donation-related surveys (Davis et al., 2010; Resnicow et al., 1999b, 2009). For each of the domains of racial salience, altruism, and communal responsibility, the research team generated a list of potential items which were reviewed and revised iteratively.

The new survey comprised 18 items, which are shown in Table 1. All items were scaled 1 'strongly disagree' to 7 'strongly agree'. We reverse coded seven of the 18 items so that all higher values for all items and subscales are considered more positive, pro-donation attitudes.

To explore the validity of the attitude scale, we compared scale scores with two variables related to donation status: (1) enrollment status in the organ donation registry; and (2) intentions for future enrollment among those not currently enrolled.

We queried all respondents, 'Have you ever signed up to donate your organs?', to determine enrollment status. Respondents who answered 'Yes' were considered to have positive enrollment status. We coded respondents indicating 'No' or 'Don't Know' as having negative enrollment status. We also queried future intentions to donate with a single item with responses ranging from 1–10. We collapsed values into three groups: 1–3 as low intention, 4–7 as moderate intention, and 8–10 as high intention. We analyzed intentions for the subset of respondents who had negative enrollment status.

We determined educational status by asking 'What is the highest grade or degree you have completed?' Response categories were 'less than high school', 'high school graduate or GED', 'some college or two-year degree', 'four-year college graduate', 'Masters Degree', and 'Doctoral or professional degree'. To simplify presentation and interpretation of results, we collapsed this into 'High School or less' and '> High School' in our analysis. To measure household income we queried 'What is your current total yearly household income before taxes from all income sources in your home?' Response categories were 'under \$10,000', '\$10,000–\$19,999', '\$20,000–\$39,999', '\$40,000–\$59,999', '\$60,000–\$79,999', and '\$80,000 or more'. We collapsed these strata into three groups; '< \$20,000', '\$20,000–\$40,000', and '> \$40,000'. We also queried gender and age. We divided age into three groups: < 30, 31–45, and greater than 45 years of age.

Survey administration

The National Kidney Foundation of Michigan (NKFM) received funding from the Health Resources and Services Administration (HRSA), Division of Transplantation (DoT) to implement a culturally tailored organ donation intervention in African American churches in Southeast Michigan. The program aimed to test the effectiveness of using lay health advisers (termed Peer Leaders) to discuss organ donation with their fellow church members in order to increase enrollment in the Michigan Organ Donor Registry.

The NKFM partnered with the University of Michigan, Gift of Life Michigan, and the American Cancer Society on the intervention. Together we identified a list of churches in Southeast Michigan to participate. We pair matched churches by SES (Low – under \$25,000; Medium – between \$25,000 and \$50,000; High – over \$50,000) and size (< 250 members, 250–500 members, >500 members) prior to randomization. SES on the church level was determined by asking the church coordinator ‘What is the average income of your church members?’ or ‘Where does the income of most of your church members fall?’ We used this variable for pair matching. This article reports results from 21 churches that completed baseline data collection between January and August 2009. Because all results were obtained prior to intervention activities, results are reported for the aggregate sample without regard to intervention condition. The study was approved by the institutional review board of the University of Michigan Medical School.

Each church received 150 blank surveys at baseline and each church was asked to recruit 60–100 study participants. Church coordinators received training in survey administration techniques. Churches received \$5 per completed baseline survey, up to the first 100 surveys. The baseline survey was administered prior to implementing any intervention activities. The participants completed the survey on paper forms at their church in groups ranging from five to 50 individuals. Venues for administration varied, including choir practice, a church blood drive, and a special event designed solely to administer the survey.

The survey contains a unique participant code that indicated the church from which the participant was recruited. The participant name and address are associated with the participant identifier but only in a separate database enabling administration of a follow-up survey and linking participants to registration in the Michigan Organ Donor Registry.

Statistical analysis

We began scale construction with exploratory factor analysis, using principal component analysis and Varimax rotation. Factors with Eigen values greater than 1.0 were considered for retention. We then performed a split half confirmatory factor analysis using two random non-overlapping subsamples of the dataset in AMOS 17.0 (PASW/SPSS). Next, internal consistency, that is, coefficient alpha, was computed for each of the three subscales.

Using the three subscales identified we examined the association between scale scores, demographics, self-reported current enrollment, and intention status. Multivariate analyses included age, gender, income, and education as covariates. Because data were collected in churches, we accounted for the potential non-independence of response by individuals in the same church using a mixed effect model. Statistical analyses were performed using Proc Mixed in SAS v 9.1.3. Thus, all *p* values adjust for the intraclass correlation (ICC) due to the design effect of sampling individuals within churches. The ICCs of the three scales identified ranged from .01 to .07.

Results

In total 1307 participants from the 21 churches completed the baseline survey instrument. We excluded the 82 non-African American respondents leaving 1225 participants. The average number of surveys per church was 62 with a range of 13 to 103 surveys.

Sample description

As shown in Table 2, the average age of the sample was 50 years (range 15–94 years). The majority of participants were female (70%). Seventy-two percent had a high school education or above. Fifty-three percent of the sample reported income above \$40,000 whereas 23 percent reported income below \$20,000.

Attitude scale

The Principal Components Analysis (PCA) indicated a three factor solution. In PCA, the three factors accounted for 23.00, 16.75, and 15.20 percent of the variance, respectively. Total variance accounted by the three factors was 54 percent. Next, we used Varimax rotation to generate orthogonal factors. Factor loadings in the rotated solution for each item are presented in Table 1. To verify the factor structure we conducted a split half confirmatory factor analysis. The three factor structure in the two randomly split samples was not significantly different ($\chi^2 = 12.0$ with d.f. = 17, p -value = .80).

The first factor, which we named Barriers, comprised seven items. The second factor, named Family/Race Benefits, comprised nine items. The third factor, named Altruism: Helping Others, comprised four items. Alpha coefficients for the three scales were .77, .87, and .81, respectively.

Association of scale scores and demographics—As shown in Table 3, scores on all three scales were significantly associated with age. For scale one, named Barriers, individuals ages 31–45 had significantly higher prodonation attitudes than those ages greater than 45. Other pairwise contrasts within age groups were non-significant. For scales two (Family/Race Benefits) and three (Altruism: Helping Others), individuals aged 31–45 and greater than 45 years both had significantly higher prodonation attitudes than those younger than 30.

Females had significantly higher scores on scale two (Family/Race Benefits) than males. The two remaining scales did not differ by gender.

Participants with greater than high school education had higher scores on scales one (Barriers) and three (Altruism: Helping Others) than those with high school education or less. Respondents with income above \$20,000 and above \$40,000 had significantly higher scores on the Barriers scale than those with income below \$20,000.

Association of scale scores and enrollment status—Higher scores on all three subscales were observed for individuals with positive enrollment status both in univariate and multivariate analyses. In addition, among individuals not currently enrolled, higher mean scores were observed on scales two (Family/Race Benefits) and three (Altruism:

Helping Others) among those with higher intention to enroll. All pairwise comparisons were significant in both univariate and multivariate analyses across levels of intention.

Discussion

Our study aimed to develop a culturally sensitive organ donation attitude scale for African Americans and to examine correlates of responses with enrollment status among a church-going sample of African Americans in Southeast Michigan. Psychometric analyses indicated our measure tapped three distinct domains of attitudes concerning organ donation. The three subscales identified – Barriers, Family/Race Benefits, and Altruism: Helping Others – had good psychometric properties. Alpha coefficients for the three subscales ranged from .77 to .87. For all three scales higher scores were observed for those who had reported being enrolled as an organ donor. And, among those who had not yet signed up, higher mean scores for Family/Race Benefits and Altruism: Helping Others scales, were observed for those more likely to have future intention to enroll. These findings indicate that the attitudes tapped, at least cross-sectionally, are associated in the expected direction with positive enrollment status, suggesting validity of the measure.

Scale one, named Barriers, addresses many commonly held beliefs about donation that discourage enrollment including that religions prohibit donation and a lack of racial equity within the health care system and donation process. Addressing these fears through educational and social marketing programs may help reduce resistance to donation.

Scale two, named Family/Race Benefits, focused on how the act of donation can impact the donor's family including how people feel their donation decision will positively impact their family's stress and coping after their death. In addition, this scale examines how organ donation may impact other African Americans.

Scale three, named Altruism: Helping Others, looks at the positive ways in which organ donation helps others beyond one's own family and racial group. It is not surprising that altruistic concerns were associated in our sample with a greater likelihood to register as an organ donor. The US system of organ donation allocation is based on an altruistic model (Siminoff and Saunders Sturm, 2000).

Scale responses differed by age, gender, and education. In general, respondents below age 30 had less positive attitudes toward donation. Less positive attitudes may be related to the lower need for organs in this age group and therefore a lower degree of perceived immediacy or relevance. This younger age group may require unique motivational messages to encourage enrollment. Males had less positive attitudes on scale two suggesting these motivational drivers are less salient in their organ donation decisions.

Participants with greater than high school education had higher scores on scales one (Barriers) and three (Altruism: Helping Others) than those with high school education or less. Similarly, respondents with income above \$20,000 had significantly higher, that is, more positive, scores on the Barriers scale than those with income below \$20,000. With regard to the results for the Barriers scale, lower SES individuals may experience and/or perceive more day to day racism in their lives as well as less access to affordable health care,

which may drive higher rates of mistrust toward donation and the health care system in general. Research is needed to understand what may help motivate younger adults, males, and those with lower income and lower educational attainment to enroll in organ donation registries. Targeted interventions could attempt to enhance perceived benefit for domains which are lower among these subgroups, or differentially highlight those areas where these subgroups do not differ.

Limitations and future directions

The study has several limitations. Data were self-reported and we could not validate actual positive enrollment status. The sample was not randomly drawn and therefore, selection bias may be present on the church and individual level. Many of the churches were Baptist (mostly Missionary Baptist Churches) who may have different views than other Christian denominations. Thus our results may not be generalizable to the larger African American population. Moreover, information on exact church membership was not available so we cannot calculate a response rate per church and because we used a quota sampling approach, we cannot determine a true participation rate of the survey. The study was cross-sectional, and therefore caution is required to interpret any causal relationship between attitudes and positive enrollment status. Longitudinal studies examining the association of attitudes and donation behaviors are needed to verify the findings observed here. Finally, researchers and practitioners are encouraged to use the measure presented herein, and adapt it as needed.

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Table 1

Survey questions, subscale grouping, and factor loadings.

	Item	Rotated factor loading
<i>Scale 1</i> Barriers Alpha = .77	1. If a person has signed the organ donor registry, doctors won't try as hard to save that person's life *	.71
	2. Hospitals do not give African Americans the same quality of care that they give to whites *	.63
	3. Organs can be bought and sold in the United States *	.56
	4. If a person has donated his or her organs, it is impossible for that person to have a regular funeral service *	.59
	5. It costs a donor family money to donate organs *	.70
	6. Organ donation is against the rules of my religion *	.60
	7. In general, doctors give preference to white people over black people when deciding who will receive an organ *	.75
<i>Scale 2</i> Family and Racial Responsibility Alpha = .87	8. Organ donation is part of my responsibility to the black community	.70
	9. Signing up to donate my organs will allow my family to carry out my wishes	.70
	10. Signing up now to donate my organs can help my family by removing the stress of making that decision	.71
	11. Donating my organs may provide my family with some comfort	.80
	12. Donating my organs can help my family cope with their grief	.78
	13. If I donate my organs it will help other African Americans in need	.64
	14. Donating my organs is part of the giving tradition in African American culture	.62
<i>Scale 3</i> Altruism: Helping Others Alpha = .81	15. Organ donation is an act of charity	.63
	16. Organ donation allows something positive to come out of a person's death	.73
	17. Signing up to donate my organs is a way I can do something good for others	.63
	18. Donating my organs allows me to help others to live	.71

Note.

* indicates items were reversed coded so that higher scores indicated more pro-donation attitudes.

Table 2Demographics and sample description ($N = 1225$).

Age (mean, range)	50.31 (15–94)
Age group (%)	
30 or less	22.78
31–45	18.61
>45	58.61
Gender (% Female)	70.21
Education (%)	
HS or less	28.25
> High School	71.75
Income (%)	
< 20k	22.64
20–40k	24.23
>40k	53.13
Barriers scale (mean, SD)	5.05 (1.23)
Family and Race scale (mean, SD)	4.65 (1.43)
Help Others scale (mean, SD)	5.63 (1.45)
Rate of positive current organ donation status (%)	20.59
Positive intended organ donation status (%) ^a	
Low (1–3)	22.83
Medium (4–7)	48.09
High (8–10)	29.08

Note.^aPositive intended organ donation status among subjects who reported not currently signed up to donate their organs.

Table 3

Association of three organ donation attitude scales with demographic and organ donation status.

	Barriers ^a scale	Family/Race scale	Help Others scale
Age (<i>N</i> = 1225)			
30 or below	5.03	4.35 ^{1,2}	5.37 ^{1,2}
31–45	5.27 ¹	4.77 ¹	5.78 ¹
>45	4.98 ¹	4.72 ²	5.69 ²
<i>p</i> -value **	.0070	.0086	.0032
Gender			
Male	5.04	4.45	5.56
Female	5.05	4.73	5.67
<i>p</i> -value **	.9394	.0086	.2955
Education			
High school or less	4.60	4.52	5.47
> High School	5.22	4.69	5.70
<i>p</i> -value **	<.0001	.6996	.0203
Income			
<20k	4.66 ^{1,2}	4.51	5.50
20–39,999k	5.05 ¹	4.60	5.56
>40k	5.19 ²	4.72	5.74
<i>p</i> -value **	<.0001	.5099	.0465
Pos current organ donation Status			
Yes	5.40	5.21	6.00
No	5.08	4.46	5.62
<i>p</i> -value **	.0043	<.0001	.0020
<i>p</i> -value ***	.0119	<.0001	.0429
Intended organ donation status among non-current donors			
Low (1–3)	4.92	3.47 ¹	4.90 ¹
Medium (4–7)	4.98	4.50 ¹	5.63 ¹
High (8–10)	5.12	5.43 ¹	6.22 ¹
<i>p</i> -value **	.2621	<.0001	<.0001
<i>p</i> -value ***	.1914	<.0001	<.0001

Notes:

^a Q1–7 are reverse coded so that higher values indicate more positive attitude.** *p*-values based account for correlation of subjects within church.*** *p*-values account for correlation of subjects within church as well as age, gender, race, education and income. Common superscript indicates groups significantly different in pairwise comparison $p < .05$.