ORIGINAL REPORTS: ORGAN TRANSPLANTATION

PROJECT ACTS II: ORGAN DONATION EDUCATION FOR AFRICAN AMERICAN ADULTS

Objective: Project ACTS "About Choices in Transplantation and Sharing" is a culturally sensitive intervention designed to address organ donation concerns among African American adults. Our study sought to evaluate the efficacy of two versions of the Project ACTS intervention and to determine whether reviewing materials in a group setting would be more effective at increasing participants' interest in organ and tissue donation than allowing participants to review the materials at home with friends and family.

Design: A pre-post simple factorial experimental design was used to assess differences between intervention package (Project ACTS I vs II) and mode of delivery (group vs take home).

Methods: Participants completed a baseline and 1-year follow-up assessment of donation-related knowledge, attitudes, and interest.

Main Outcome Measures: A summed score that represents participants' interest in being recognized as an organ donor on their driver's license, via donor card, and by talking to family.

Results: From baseline to follow-up, participants increased their knowledge, attitudes, and interest in being recognized as an organ donor regardless of intervention package (Ps<.05). Regarding setting, participants who reviewed materials in a group setting demonstrated greater increase from baseline to follow-up in interest in organ donation ($\beta=.22$, P<.01) and positive attitudes toward donation ($\beta=.22$, P<.05) than those who were allowed to review materials at home with friends and family.

Conclusion: Project ACTS I and II are equally efficacious; reviewing the intervention in a group setting may be necessary for low vested interest/high ambivalence health behaviors such as organ donation. (*Ethn Dis.* 2013; 23[2]:230–237)

Key Words: Organ Donation, Transplantation, Intervention Research, Minority Health, African American

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Introduction

Transplantation continues to be the therapy of choice for many individuals with end-stage organ failure. While the need for transplantation among racial/ ethnic minorities is considerably high, organ and tissue donation is comparatively low. Racial/ethnic minorities comprise approximately 28% of the US population¹ and 31% of organ donors. However, they account for nearly 55% of the 111,647 persons awaiting transplants on the national transplant waiting list and 60% of those on the national kidney waiting list.² African Americans (AAs), in particular, are overrepresented on the kidney transplant waiting list. As of June 2012, while they represented 34% of candidates waiting for a kidney, they only represented 16% of deceased and 11% of living donors.² The reasons for the overrepresentation of AAs in need of kidneys are complex, but they relate to them being disproportionately impacted by certain health conditions (eg, diabetes, hypertension, heart disease) that potentially warrant the need for life saving transplants.³ It is for this reason there has been increasing attention to the need to increase AA commitment to organ and tissue donation.

The barriers to donation among AAs are profound. Research suggests that lack of knowledge and awareness, 4-7 concerns that being recognized as an

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organ donor might hasten one's death, 8-10 and religious beliefs about needing the body to remain whole to enter heaven^{11–13} serve as impediments to donation among AAs. Beliefs about inequalities in the health care system and the treatment of AA patients serve as barriers to donation. ^{9,14,15} Concerns about the fairness of the allocation of organs are central to the donation decision-making process among AAs.^{6,9} While there have been public education campaigns, legislation and other policies to improve organ donation conversion rates, interventions designed to increase donation among AAs have been slow to materialize.

Project ACTS (About Choices in Transplantation and Sharing) is a selfadministered donation education intervention targeting AA adults that was developed with a focus on addressing religious barriers to donation and encouraging family discussion. It was developed based on formative research and a deep structure model of cultural sensitivity¹⁶ by seeking to address the specific cultural, environmental and historical barriers to organ donation among AAs. 14-16 Among churchrecruited AAs, data support the efficacy of the intervention but suggest that additional work is needed to improve its uptake.¹⁷ Thus, additional formative research was conducted to determine how to enhance the intervention (herein referred to as Project ACTS II) and to determine how to deliver it in a way that improves uptake thereby maximizing efficacy. Moreover, additional research is needed to determine the extent to which the interventions are efficacious among non church-recruited AA adults.

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The purpose of the current study was to evaluate the efficacy of the revised Project ACTS intervention materials (Project ACTS II) as compared to the original Project ACTS (Project ACTS I) materials and to determine whether reviewing materials in a group setting would be more effective at increasing participants' interest in organ and tissue donation than allowing participants to take materials home for later viewing. Each of these delivery modes offers unique advantages. The group setting ensures that participants have watched the DVD at least once in keeping with the need for focused engagement on the issue of donation, 18 but allowing participants to take the DVD home gives them multiple opportunities to watch the DVD with family thereby increasing the possibility that rich and meaningful family discussion will ensue as opposed to merely a group discussion with strangers. We hypothesized that from baseline to follow-up, individuals receiving the Project ACTS II intervention materials would demonstrate significantly greater increase in their desire to be recognized as an organ donor than those who received Project ACTS I materials. We further hypothesized that those who reviewed the intervention DVD in a group setting would demonstrate significantly greater increase in their desire to be recognized as an organ donor than those who were allowed to take the DVD home for viewing with family.

METHODS

Our study used a pre-post simple factorial experimental design to assess: 1) whether the Project ACTS II intervention materials were more effective at improving intentions to be recognized as an organ donor than Project ACTS I intervention materials; and 2) whether delivering the intervention in a group setting was more effective than allowing participants to review materials at home. Secondary outcomes explored change in donation-related knowledge and beliefs and attitudes. This research design allowed us to assess the independent effect of intervention package (revised vs original) and mode of delivery (group setting vs take-home) on the desired outcomes. Data were collected at two points in time: at baseline (April 2009 - December 2009) and 1-year follow-up (April 2010 - February 2011). This study was conducted with the approval of the Emory University Institutional Review Board.

Intervention

The Project ACTS I intervention package consisted of a DVD and educational booklet. The DVD was hosted by the gospel singing group Trin-i-tee 5:7, and featured excerpts from family conversations about attitudes, beliefs, myths, and fears about organ donation and transplantation. Interspersed throughout the DVD were biblical and spiritual themes to encourage organ donation (eg, an excerpt from the biblical book of Acts 20:35, "It is more blessed to give than to receive"). Additionally, the DVD included heartfelt, personal stories from individuals who are organ recipients, donor family members, patients on the waiting list to receive an organ, and living donors. The Project ACTS I educational booklet contained factual information on the

overrepresentation of AAs on the waiting list, information on the organ allocation system, resources for additional information, and a donor card. Those participants who received the Project ACTS II intervention materials received a revised DVD and educational pamphlet. Based on eight focus groups with 5–10 individuals (n=59; data not shown), the Project ACTS II DVD had a new host with a personal connection to the topic of donation, a youth perspective on donation, the presence of a physician, shortened family discussions, and additional information about living donation. The Project ACTS II booklet was also restructured to improve readability and included additional information about living donation per participant suggestion.

Recruitment and Data Collection

To assist in recruitment and delivery of the intervention, we trained and hired a heterogeneous group of 19 African American community outreach workers (15 female and 4 male). They were tasked with recruiting up to 32 individuals from their social, neighborhood, and professional networks. The outreach workers were selected based on their demographic similarity to our target population outreach and their relatively large social networks. 19 All persons agreeing to serve as community outreach workers were required to attend a mandatory group or one-onone training that described the project, the study protocol, how to recruit participants, and how to facilitate a group discussion. For participant recruitment, each outreach worker was provided with talking points, personalized fliers, and tailored form letters that detailed the study. They were each asked to schedule four data collection group sessions with 5-12 participants.

Using an online randomization tool, the project coordinator assigned each outreach worker to one of four conditions. Outreach workers were told which group they would be assigned so they would be prepared to facilitate the subsequent group discussion. Within each condition, participants watched a 30-minute educational DVD. After viewing the educational information, individuals participated in a 30-45 minute group discussion facilitated by the outreach worker: 1) Group 1 (revised intervention - group setting) viewed the Project ACTS II DVD and educational booklet in a group setting followed by group discussion; 2) Group 2 (revised intervention - take home) viewed an unrelated DVD (on the social determinants of health) in the group setting followed by group discussion and took the Project ACTS II materials home; 3) Group 3 (original intervention - group setting) viewed the Project ACTS I DVD and educational booklet in the group setting followed by group discussion; and 4) Group 4 (original intervention - take home) viewed the unrelated DVD in a group setting followed by group discussion and took home the Project ACTS I intervention materials.

At each session, project staff explained what participation entailed and distributed consent forms explaining the longitudinal nature of the study. Participants were considered eligible if they self-identified as Black or AA (for the purpose of this study, the term Black included people of African descent regardless of cultural identification) and were aged ≥18 years. Participants then completed a baseline self-administered questionnaire. Next, participants watched a 30-minute DVD (depending on the group their outreach worker was randomized to) and participated in a group discussion about their respective DVDs that was facilitated by the outreach worker. They received a \$15 monetary incentive.

Approximately one year later, participants were contacted by the outreach worker and scheduled to attend a group session. At follow-up, participants did not watch a video nor did they participate in a group discussion. The

follow-up group session only entailed the completion of a questionnaire that was very similar to the baseline assessment. Participants were provided with light snacks and upon completion of the questionnaire, a \$20 monetary incentive was offered. Those who were unable to attend the group session at follow-up could mail their completed questionnaires directly to project staff and receive a \$30 incentive.

Measures

The baseline and follow-up instrument included measures of knowledge of the donation/transplantation system, attitudes and beliefs regarding donation and transplantation, expression of donation wishes, and demographic characteristics. Each scale included in this study is described below.

Knowledge of the donation/transplantation system was assessed with 14 true/false items adapted from other scales. 20,21 The scale captured different dimensions of knowledge including: general donation-related statistics, AA donation-related statistics, and knowledge of the donation process. We created a knowledge index by totaling the number of items each participant answered correctly. Scores ranged from 4–13 at baseline (M=9.5, SD=1.7) and from 4 to 14 at follow-up (M=9.8, SD=1.6).

Drawing from existing measures in the research literature, ^{8,13,20} we created a 20-item scale that captured attitudes and beliefs about donation and transplantation. These included items that measured willingness to donate to people of other racial/ethnic groups, religious objections to donation, concerns that donation might hasten death, trust in the donation and transplantation system, and perceptions of equality in the transplant system. Response options for these items ranged from 1 (strongly disagree) to 5 (strongly agree), where higher scores indicated more positive attitudes towards organ/tissue donation. Total scores ranged from 43 to 100 at baseline (M=77.9, SD=9.5; α =.85) and from 41–100 at follow-up (M=81.3, SD=9.9, α =.87).

Expression of donation wishes was measured via three author-developed items that have been used successfully across multiple health behaviors. 22,23 Each item includes response options representing each stage of readiness (to be designated as a donor on one's license, carry a donor card, and talk to family about one's wishes) on the continuum of behavior change theorized by the Transtheoretical Model and Stages of Change.²⁴ This scale, used in previous research,^{6,25} asked the respondent to select the statement that best described his/her readiness to be designated as a potential organ donor by means of one of three mechanisms (license, card, and discussion with family), with five response options, each corresponding to the five stages of change. A total "expression of donation wishes" score was computed by summing across the three items. This total score could range from 3 to 15 where higher scores indicate stronger willingness to be recognized as an organ donor (baseline M=8.8, SD=3.7; α =.76; follow-up M=7.8, SD=3.7; $\alpha=.73$). Although individuals with an interest in being recognized as organ donors do not have to use all three mechanisms for expressing their intentions, this scale was created recognizing that individuals with a stronger desire to be recognized as an organ donor may be more interested in communicating this desire via multiple mechanisms to ensure that it is carried out. The last section of the questionnaire measured demographic characteristics.

Statistical Analyses

Analyses were conducted using SPSS 19.0. First, we computed frequencies for each demographic characteristic separately by intervention package and delivery setting. Next, we conducted a drop-out analysis to determine the extent to which those who were retained

in the study at 12-month follow-up significantly differed from those who dropped out.

The next series of analyses assessed differences in demographic characteristics, separately by intervention package (ACTS I vs ACTS II) and delivery setting (group vs take home). We computed χ^2 statistics to determine whether any potentially confounding variables differed by condition. Using logistic regression, we then regressed condition upon all variables for which there was a significant difference on the χ^2 test, to assess which variables remained related to condition. These analyses indicated that educational attainment, employment status, and income were associated with intervention package. However, because they are highly intercorrelated (r values range from .23 to .35) we opted to only include one variable in the multivariable analyses to minimize the problem of multicollinearity.²⁶ Employment status was the variable most strongly related to intervention package in a subsequent logistic regression model (with intervention package as the dependent variable), so it was included as a covariate in all multivariate analyses involving intervention package.

Regarding the analyses for delivery setting (group vs take home), selfidentifying as AA, being married, employed, and having a higher income were significantly associated with delivery setting. As before, because employment status and income were so highly correlated (r = .30), we opted to retain employment status because its effects were the largest when entered into a regression model with delivery setting as the dependent variable. Thus, multivariable models testing the effect of delivery setting included cultural identification, marital status, and employment status as covariates.

Main Outcome Analysis

The main outcome analysis used generalized estimating equations, which

allowed for analysis of repeated measurements (baseline and follow-up) and the use of nested terms (because participants were nested within outreach worker). By including in the model a subject effect that was an outreach worker-by-participant interaction, we controlled for withinoutreach worker variability in participant responses. Because generalized estimating equations do not generate standardized regression coefficients (which are easier to interpret and compare across multiple predictors than unstandardized regression coefficients) we standardized all variables prior to running the models. Two sets of models were created. The model effects tested intervention package (revised vs original), time (baseline vs follow-up), and their interaction while controlling for employment status. The second model tested delivery setting (group vs take home), time (baseline vs follow-up), and their interaction while controlling for cultural identification, marital status, and employment status. These two models were run separately to maximize our ability to understand the independent effects of intervention package and setting on the outcomes of interest and out of appreciation for differences in the covariates across the two effects. The primary outcome was expression of donation wishes, which was created by summing across three behaviors: recognition of donor status on one's driver's license, carrying a donor card, and talking to family about one's wishes. A combined measure of expression of one's donation intentions that sums across three methods of expression provides more information than any single measure of the expression of one's donation intentions because of the measurement error associated with each individual item.²⁷ It is expected that higher scores on such a comprehensive measure would be associated with stronger intentions to express donation wishes. We ran the same models using donationrelated knowledge and beliefs and attitudes as the outcomes for secondary analyses. An alpha of .05 was used to establish statistical significance.

RESULTS

Sample Description

At baseline, a total of 585 participants were recruited into the study by the 19 outreach workers. The number of participants each individual recruited into the study ranged from 7 to 73. Of the 585 participants, 509 (87%) completed the 1year follow-up survey (ranging from 76%-95% across the four study conditions). Participants with incorrect contact numbers and addresses did not complete the follow-up survey and were considered lost to follow-up. Participants ranged in age from 19 to 96 years (M=46.3; SD=14.6). They were predominantly female, unmarried, employed, and college graduates. Next we examined demographic characteristics separately by intervention package (Project ACTS I or II) and setting in which they watched the DVD (group or at home). Participants who watched the Project ACTS II DVD were more likely to have graduated college, be employed, and make \$30-\$69k per year than those who watched the Project ACTS I DVD. Additionally, those who watched the DVD in a group setting tended to be younger and more likely to make \$30-\$69k per year than those who were allowed to take the DVD home (Table 1). There were no group differences in expression of donation wishes at baseline.

We performed an attrition analysis to compare the demographic characteristics of those who were retained in the study at 1-year follow-up to those who were lost to follow-up. We found that those who were retained in the study tended to be older, female, married, and of higher socioeconomic status (as evidenced by their work status, highest level of educational attainment, and income; data not shown).

Main Outcome Analysis: Donation Intentions

The first set of outcome analyses explored expression of donation wishes as the outcome with separate analyses

Table 1. Baseline sample characteristics, N=585

— Characteristic	Intervention Package			Delivery Setting		
	Project ACTS I (n=302)	Project ACTS II (n=283)	P	Group Take Home (n=288) (n=297)		P
Mean age, years (range)	46.3 (19–96)	46.2 (20–79)		44.9 (19–94)	47.6 (20–96)	<i>P</i> ≤.05
Female, %	67.5	70.7		70.1	68.0	
Black/African American, %	89.7	84.3		83.8	90.3	
Married, %	35.9	43.0		47.3	31.6	
Educational attainment, %			<i>P</i> ≤.01			
<high school<="" td=""><td>8.0</td><td>2.1</td><td></td><td>3.2</td><td>7.0</td><td></td></high>	8.0	2.1		3.2	7.0	
High school graduate/GED	44.6	33.9		40.1	38.6	
Completed college	35.3	48.2		44.4	38.9	
Professional degree	12.1	15.7		12.3	15.4	
Employed (full/part-time), %	55.8	71.2	<i>P</i> ≤.01	68.2	58.5	
ncome categories, %			<i>P</i> ≤.05			P≤.05
Up to \$29,000	41.0	28.4		29.3	40.0	
\$30,000 to \$69,000	40.0	52.9		52.9	40.7	
\$70,000 or more	19.2	17.8		17.8	18.5	
Mean stages of change donation intentions score (SD)	7.6 (3.6)	8.0 (3.8)		7.8 (3.6)	7.7 (3.8)	

for intervention package and delivery setting. Regarding intervention package, results indicated no effect of condition or a condition by time interaction (see Table 2). However, there was a significant effect of time such that at baseline, participants tended to have lower donation expression scores than at follow-up (regardless of intervention package), β =.27, P<.001. Regarding setting, results indicate a significant main effect of condition and time as well as a condition by time interaction, β =.22, P<.01. The

interaction indicates that participants in the group condition had a larger increase in expression of donation wishes from baseline to follow-up (baseline=7.6, follow-up=8.9) compared to participants in the take home condition (baseline=7.6, follow-up=8.1).

Secondary Outcomes Analysis: Knowledge and Beliefs/Attitudes

The second set of analyses explored knowledge as a secondary outcome. Regarding intervention package, results indicate no significant main effect of condition on knowledge. However, there was a significant effect of time; from baseline to follow up, participants (regardless of what intervention package they received) increased in their donation-related knowledge, β =.22, P<.05. There were no significant effects for setting (see Table 2).

The final set of analyses explored donation-related beliefs and attitudes. Regarding intervention package, results indicate no significant main effect of

Table 2. Repeated measures regression analyses with expression of donation intentions as the dependent variable using generalized estimating equations, N=509

	Donation Intentions Total		Donation-related Knowledge		Donation-related Beliefs & Attitudes	
	Intervention Package	Setting	Intervention Package	Setting	Intervention Package	Setting
Study variables						
Condition	.06	.21 ^a	.17	.14	.21	.29 ^b
Time	.27 ^c	.14 ^a	.22 ^a	.09	.26°	.22 ^b
Condition \times time	.05	.22 ^b	.10	.14	.16	.22 ^a
Control variables						
Employment status	.08	.10	16	12	.20 ^a	.22 ^b
Cultural identification	N/A	.18	N/A	.11	N/A	.17
Marital status	N/A	.09	N/A	.06	N/A	.12

Standardized regression coefficients are presented.

^a *P*≤.05.

^b *P*≤.01.

^c *P*≤.001.

condition on beliefs and attitudes. However, there was a significant effect of time such that at baseline, participants tended to have lower donation intentions scores than at follow-up (regardless of intervention package), β =.26, P<.001. Regarding setting, there was a significant condition by time interaction such that at follow up, participants who watched the DVD in a group setting (baseline=77.4, follow-up=81.9) had a significantly greater increase in positive attitudes toward donation and beliefs than those who were given the DVD to take home (baseline=76.8, followup=79.0), β =.22, P<.05.

DISCUSSION

The purpose of our study was to determine whether the Project ACTS II intervention was more effective at increasing interest in expressing donation wishes than the Project ACTS I materials and whether reviewing the intervention in a group setting was more effective than allowing participants to take the intervention materials home to watch with friends and family. Results indicate no significant difference between Project ACTS I and Project ACTS II materials with respect to the expression of donation wishes. From baseline to follow-up, respondents, regardless of intervention package, reported increased interest in expressing donation wishes, donation-related knowledge, and more positive beliefs

Results indicate no significant difference between Project ACTS I and Project ACTS II materials with respect to the expression of donation wishes. and attitudes about donation. It might be that because the fundamental attributes of the Project ACTS II intervention stayed the same, the two intervention packages were too similar to generate different findings. Thus, these data support the utility of both intervention packages. Collapsed across intervention package, participants viewing the intervention in a group setting demonstrated a greater increase in readiness to express donation wishes and beliefs and attitudes about donation from baseline to follow-up, than those who were allowed to review the intervention DVD at home with friends and family.

For some AAs, discussions about death are taboo, and for some there is a fear that speaking of death may actually bring death to fruition. 14,28 Given the sensitive nature of the topic of donation and its relation to death and dying, it is not easily discussed.²⁹ Thus, we sought to create an intervention that demonstrated AA families having healthy debates about the advantages and potential disadvantages of donation (in both the revised and original intervention DVDs). Our intervention DVDs showed real families having light-hearted discussion in a manner that was non-threatening, non-judgmental, and respectful. It was expected that the DVD could be used as a vehicle for stimulating family discussion of donation wishes for people who took it home. However, organ donation is a health behavior that is different from others in many ways. First, there may be little personal benefit derived from agreeing to serve as a deceased donor. Certainly living donors may derive deep personal satisfaction from seeing how their decision positively impacts a loved one, but that satisfaction is more abstract in the case of deceased donation when the beneficiaries are unknown and the benefits to their lives cannot be seen because the donor has passed. Second, there is generally a low level of knowledge

and awareness about donation, particularly among communities of color.4 For these reasons, vested interest in deceased donation may be low.18 Furthermore, in the context of historical injustices,30 concerns about inequalities in the health care system, and concerns about inequalities in organ allocation more specifically, AAs attitudes towards donation oftentimes range from ambivalence to aversion unless one has personal experience related to donation.³¹ Thus, it may be unreasonable to expect participants to watch a DVD at home under these circumstances. Ensuring their attention to the topic at hand by sharing the intervention materials in a group setting appears to be the best way to address these barriers. The group dynamic not only provides an opportunity for active contemplation of donation related beliefs, attitudes, and the act of registration(referred to as focused engagement)¹⁸ but overall engages people in a way that cannot be attained by reviewing materials individually at home. The group setting also provided a relatively homogenous and safe environment allowing for open dialog about the topic and the ability to exchange ideas and express support for or apprehensions about donation.

LIMITATIONS

This study suffers from several noteworthy limitations just as any other. It utilized a convenience sample of AA participants within the Southeastern United States. Because participants were recruited by outreach workers, we were unable to accurately describe the participants who did not enroll in the study, as we did not track the number of contacts each representative made. Therefore selection bias may be a concern. Additionally, our sample had an overrepresentation of women, which may have also impacted the findings. Participants who dropped out of the

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study tended to be younger, male, married, and had lower levels of education and employment, thus potentially increasing bias of the sample; however, their donation intentions did not differ from those who remained in the study.

CONCLUSION

Project ACTS was developed out of a desire to increase donation-related knowledge and interest and improve positive attitudes among AAs. This selfeducation intervention package has utility for AAs recruited from different settings. However, organ donation is a health behavior that may be characterized by high attitudinal ambivalence. When taken together with low vested interest it might be critically important to ensure active engagement in thinking about the topic of organ and tissue donation in order for interventions like Project ACTS to be effective. This study offers new direction for the development and delivery of effective donation education efforts targeting AAs. With continued evidence of its effectiveness, organ procurement organizations, civic organizations, churches, and public health departments that are targeting African Americans may distribute this intervention to members of its target populations in order to improve consent rates. Additionally, intervention materials could be adapted to fit other racial/ ethnic groups in the United States to improve knowledge, attitudes, and beliefs relative to organ and tissue donation.

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Design and concept of study: Jacob Arriola, Robinson, Perryman, Thompson, Russell Acquisition of data: Jacob Arriola, Robinson Data analysis and interpretation: Jacob Arriola, Perryman, Thompson, Russell Manuscript draft: Jacob Arriola, Robinson, Russell

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