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## Project ACTS: An Intervention to Increase Organ and Tissue Donation Intentions Among African Americans

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### Abstract

This study sought to evaluate the effectiveness of *Project ACTS: About Choices in Transplantation and Sharing*, which was developed to increase readiness for organ and tissue donation among African American adults. Nine churches ( $N = 425$  participants) were randomly assigned to receive donation education materials currently available to consumers (control group) or *Project ACTS* educational materials (intervention group). The primary outcomes assessed at 1-year follow-up were readiness to express donation intentions via one's driver's license, donor card, and discussion with family. Results indicate a significant interaction between condition and time on readiness to talk to family such that participants in the intervention group were 1.64 times more likely to be in action or maintenance at follow-up than were participants in the control group ( $p = .04$ ). There were no significant effects of condition or condition by time on readiness to be identified as a donor on one's driver's license and by carrying a donor card. *Project ACTS* may be an effective tool for stimulating family discussion of donation intentions among African Americans although additional research is needed to explore how to more effectively affect written intentions.

### Keywords

organ donation; intervention; minority health

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Transplantation has become a preferred therapy for many individuals with end-stage organ failure; however, the gap in the number of organs needed and received continues to increase. This disparity makes the donor shortage the number one problem in transplantation today, and of particular concern is the effect the donor shortage has on racial/ethnic minorities (Callender & Miles, 2001). Whereas ethnic and racial minorities comprise approximately 25% of the U.S. population and 25% of organ donors, they account for more than 40% of the 101,348 persons awaiting transplants on the national transplant waiting list (Organ Procurement and Transplantation Network, n.d.).

African Americans, in particular, are overrepresented on the organ transplant waiting list because they are disproportionately affected by certain health conditions (e.g., diabetes, hypertension, heart disease, hepatitis) that potentially warrant the need for life-saving transplants (Durand, Decker, & Bruder, 2002). This disparity presents a paradox. While the African American need for transplantation is considerably high, organ and tissue donation rates are comparatively low. These low donation rates are likely a result of negative attitudes

toward donation among African Americans as compared to people of other racial and ethnic backgrounds (McNamara et al., 1999). Thus, in the United States, there are expanded educational efforts to increase African Americans' deceased and living donation intentions; this is accomplished through exposure in the national and local media, community interventions, and the dissemination of best practices (National Institute of Diabetes and Digestive Kidney Diseases, 2003).

The church represents a potentially effective mechanism for developing and implementing a community intervention to shape African Americans' views on donation. Although religious objections to donation are often cited (Boulware et al., 2002; Callender, 1987; Durand et al., 2002; Gillman, 1999), almost all major religious organizations support donation; many even have supportive policy statements about organ donation (Gallagher, 1996). Thus, delivering an intervention in a church setting that conveys religious support for donation while addressing nonreligious concerns, such as inequalities in the organ allocation system, has the potential to increase donation intentions among African Americans. With demonstrated effectiveness, such an intervention could affect African American donation rates when taken with other coordinated intervention efforts.

Realizing the critical impact that religious views have on donation intentions, the authors developed an intervention to address many religious objections to donation. *Project ACTS: About Choices in Transplantation and Sharing* is a culturally sensitive organ donation education intervention that targets church-going African American adults. This intervention was designed to address the specific donation concerns of African Americans and encourage individuals to make their donation intentions known by designating their wishes on their driver's licenses, signing donor cards, and talking with their families.

Most donation-related interventions encourage the written expression of donation intentions, but increasing emphasis is being placed on verbally sharing one's wishes with family (Schutte & Kappel, 1997). In the case of deceased donation, family members' awareness of one's donation intentions is one of the most important steps in the process of becoming an organ donor (Callender, 1987). In most states, the family will be asked to consent to the donation of a deceased family member's organs and tissues even in the presence of a signed donor card; therefore, fostering family discussions about donation is critical to closing the gap between the supply and demand imbalances for transplant organs (DeJong et al., 1998; Schutte & Kappel, 1997). Family communication and acceptability are key to donation decisions among African American families because they are oftentimes characterized by strong extended relationships, shared decision making, and strong religious orientation (Kane, 2000). Whereas less than 50% of families have had discussions about organ donation, it is likely that such discussions can serve to increase both positive attitudes and donation intentions (DeJong et al., 1998; Morgan & Miller, 2002).

The purpose of this study is to test the effectiveness of a culturally sensitive, family-focused intervention, *Project ACTS*. Because the act of serving as an organ donor is a rare event, effectiveness was measured by applying the transtheoretical model and stages of change (Prochaska & DiClemente, 1983) to the expression of donation intentions via one's driver's license, donor card, and family discussion. This model has been applied to donation intentions in previous research (Hall et al., 2007; Robbins et al., 2001) and proposes a continuum of behavior change that consists of precontemplation (with no intentions of becoming a donor), contemplation (thoughts of becoming an organ donor), preparation (seeking out information about organ donation), action (expressing donation intentions either verbally or in writing), and maintenance (having expressed donation intentions more than 6 months ago). During each stage, specific processes and techniques are theorized to help individuals advance along the continuum of behavior change. We hypothesize that from

baseline to follow-up individuals receiving the *Project ACTS* intervention materials will demonstrate significantly greater increase in their readiness to express written (via one's driver's license and donor card) and verbal (via talking to one's family) donation intentions as compared to those who receive educational materials that are currently available to consumers.

## MATERIALS AND METHODS

### Design

The primary aim of this longitudinal, randomized, effectiveness trial was to assess whether stage of readiness to express donation intentions among participants who received the *Project ACTS* intervention was significantly different than among participants who did not receive the intervention. Nine churches were randomly assigned to one of two conditions: (a) control (received donation education materials in the form of pamphlets and videotapes that are currently available to consumers) or (b) intervention (received the *Project ACTS* video and written materials). Church size ranged from 100 to 5,000 members, with most churches in the range of 500 to 1000 members. The religious denominations represented are African Methodist Episcopal (two churches), Baptist (five churches), Christian Methodist Episcopal (one church), and Lutheran (one church). Five churches were assigned to the control group and four churches were assigned to the intervention group. Data were collected at two points in time: at baseline and 1-year follow-up during after-church luncheons conducted at each participating church. At baseline, participants in both groups were given self-education materials to take home and review during the 1-year follow-up period. This study was conducted with the approval of the Emory University Institutional Review Board.

### Formative Research

To identify the specific donation-related concerns of this population, we conducted focus groups with African American clergy and parishioners. There were 4 focus groups with clergy ( $n = 26$ ) and 10 focus groups with parishioners ( $n = 42$ ; Arriola, Perryman, & Doldren, 2005; Arriola, Perryman, Doldren, Warren, & Robinson, 2007). Results suggested the need to address concerns that stem from religious beliefs and inequalities in the transplantation system and to provide donation-related statistics that highlight the need among African Americans. Additionally, to maximize the accuracy and currency of our messages as well as the appropriateness of evaluation instruments and analytic strategies, an advisory council (AC) and community advisory board (CAB) were created. The AC included individuals with expertise in donation, transplantation, and mass communication, and the CAB included pastors and administrators from local churches. Both entities were formed to help provide ideas for conveying health messages using religious themes and to review project related materials. Following the synthesis of initial focus groups, a draft video was developed and reviewed by members of the AC/CAB and additional experts in the donation and transplantation field. A rough cut of the video was also shown to focus group participants and their families. Feedback from these sources guided final editing of the *Project ACTS* video.

### Intervention and Control Group Materials

The *Project ACTS* intervention package consisted of the video described above (in the form of a DVD or VHS), an educational pamphlet, a donor card, a National Donor Sabbath pendant, and several additional items embossed with the project name and logo (e.g., pen, notepad, refrigerator magnet, and bookmark). The DVD/VHS was hosted by gospel singing group Trin-i-tee 5:7 and featured excerpts from individual and family conversations about beliefs, attitudes, myths, misconceptions, and fears about the organ donation/transplantation

process. Interspersed throughout the video were biblical and spiritual themes to encourage organ donation (e.g., an excerpt from the biblical book of Acts 20:35, “It is more blessed to give than to receive”). Additionally, the DVD/VHS sought to motivate viewers by including heartfelt, personal stories from individuals who are organ recipients, donor family members, on the waiting list to receive an organ, or living donors. In contrast, the *Project ACTS* educational booklet contained statistical information on the overrepresentation of African Americans on the waiting list, information on how the allocation system works, resources for additional information, and a donor card.

After examining all of the existing donation education materials that were available at the time of this study, we selected the control materials that clearly targeted African Americans. In doing so, we hoped to provide the most rigorous test of the effectiveness of the newly developed *Project ACTS* intervention materials. Thus, control participants received materials that were currently available to all consumers (in other words, standard of care): the African American Health Passport developed by the Department of Health and Human Services, a donor card, and several items from the Donate Life America *Zero Lives Will Be Saved if You Do Nothing* campaign (e.g., pen, bookmark). Additionally, participants were notified that the *Minority Organ Tissue Transplant Education Program (MOTTEP)* video, “How Do I Say Thank You?” was available to be checked out from their church library.

### Data Collection Procedures

Through a process of networking with clergy (via telephone and face-to-face meetings) and colleagues, we identified nine churches to participate in this data collection effort. All of the pastors who agreed to participate in this project were either members of the project’s CAB or nominated a liaison to the board. The authors worked with the pastor of each church to identify a suitable date for data collection, and a liaison was appointed to handle the actual data collection logistics.

Data were collected during project-sponsored luncheons conducted after worship services. Project staff explained what participation in the study entailed and distributed a packet containing the consent form and questionnaire to each interested and eligible participant. Participants were considered eligible if they self-identified as African American, were 18 years of age or older, and did not reside in the same household. Prospective participants read and signed the consent form and completed the questionnaire independently, except in several cases in which participants requested assistance. The questionnaires took approximately 15 minutes to complete. Participants returned completed surveys to project staff and received their monetary incentive, which was either \$10 in cash or a \$10 donation to the church on their behalf. (The method of payment was a church-level decision, made by the pastors prior to data collection, so all participants at the same church were given the same incentive.) During the 1-year study period, participants received postcards, holiday cards, and birthday cards to remind them to review intervention materials and attend the follow-up data collection. At post-test, participants were asked to complete the same 15-minute questionnaire. Those who completed the questionnaire at a scheduled after-church luncheon received a \$15 monetary incentive. Those who did not attend a luncheon were mailed a questionnaire directly, asked to return the questionnaire using a prestamped self-addressed envelope, and offered a \$25 incentive to reflect the additional effort required of them.

### Measures

The primary independent variables of interest are condition (intervention or control) and time (baseline or follow-up). The primary outcome of interest was readiness to engage in deceased donation. Readiness to donate was measured via three items developed by the

authors that represent each stage on the continuum of behavior change theorized by the transtheoretical model and stages of change (Prochaska & DiClemente, 1983; one each for readiness to be designated as a donor on one's license, carry a donor card, and talk to family about one's wishes). Each item asked the respondent to select the statement that best described his or her readiness to be designated as a potential organ donor by means of one of the three mechanisms. For each of the three items (license, card, and discussion with family), there were five response options, one corresponding to each of the five stages of change. For example, the response options for the family discussion item are as follows: (a) I have not talked to my family about organ donation, and I don't plan to do so any time soon (precontemplation); (b) I have not talked to my family about organ donation but I am thinking about talking to them in the next 6 months (contemplation); (c) I have not talked to my family about organ donation but I plan to do it in the next month (preparation); (d) Within the past 6 months I talked with my family about my views on donation for the first time (action); and (e) I talked with my family about my views on donation for the first time more than 6 months ago (maintenance).

The last section of the questionnaire included demographic items (e.g., age, gender, ethnicity, education, income, and marital status).

## Statistical Analysis

**Preliminary Analyses**—First, we computed  $\chi^2$  statistics to determine whether there were any differences in age, gender, marital status, income, highest level of education, monthly church attendance, or prior written intentions to serve as a donor between participants in the two conditions (intervention and control). The purpose of this analysis was 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  $\chi^2$  test to assess which variables remained related to condition. Income was the only variable that remained significantly associated with condition in the logistic regression, thus it was included in the outcome analysis as a covariate. In addition, we computed  $\chi^2$  statistics to determine whether there were any differences in use of the materials by the intervention and control groups.

**Main Outcome Analysis**—The main outcome analysis used generalized estimating equations, specifically logistic models because of the binary dependent variable. The purpose of this analysis was to allow for analysis of repeated measurements (data were collected at two points in time) and the use of nested terms (because participants were nested within church). By including in the model a subject effect that was a church-by-participant interaction, we were able to control for within church variability in participant responses. The model effects that were tested were condition (intervention vs. control), time (baseline vs. follow-up), their interaction, and income (less or more than \$30,000). The three binary outcome variables were created to measure whether participants were in an early (i.e., precontemplation, contemplation, or preparation) or late (i.e., action or maintenance) stage of readiness to be identified as an organ donor on their driver's license, carry a donor card, or talk to their family about their donation intentions at follow-up. All analyses were conducted using SPSS 16.0. An  $\alpha$  level of .05 was used to determine statistical significance.

## Results

### Sample

At baseline, a total of 425 participants were recruited into the study from the nine participating churches. The number of participants per church ranged from 19 to 70 ( $M=47.2$ ,  $SD=2.9$ ). Of the 425 participants, 337 (or 79.3%) completed the 1-year follow-up

survey. There was no significant difference in the rates of follow-up between intervention and control participants (78.5% vs. 80.2%;  $\chi^2 [1] = 0.19, p > .05$ ). Participants tended to be female, married, and relatively well-educated (see Table 1).

With regard to differences in characteristics of participants in the two conditions, intervention participants were slightly younger in age ( $t[314], p < .05$ ) and reported having a lower household income ( $\chi^2 [2] = 16.05, p < .01$ ) and a lower level of educational attainment ( $\chi^2 [3] = 9.10, p = .05$ ) than control participants did. However, no significant differences were seen with respect to donation intentions. When condition was regressed upon age, education, and income together, only income remained significant; thus, income was used as a factor in the generalized estimating equation.

### Use of Materials

In the analysis of use of the intervention materials, intervention participants were more likely than control participants to review a donation-related video (56.6% vs. 23.6%;  $\chi^2 = 37.74, p < .001$ ) and written materials (69.1% vs. 50.9%;  $\chi^2 = 11.63, p < .001$ ).

### Main Outcome Analysis: Donation Intentions

For the first logistic model, the dependent variable was early (i.e., precontemplation, contemplation, or preparation) or late (i.e., action or maintenance) stage of readiness to be identified as a donor on one's driver's license. Results indicate no significant effects of condition, time, condition by time, or income. For the second logistic model, the dependent variable was early or late stage of readiness to be identified as a donor by carrying a donor card. Results indicate no significant effects of condition, condition by time, or income; however, there was a main effect for time such that at follow-up participants were 1.53 times more likely to be in the action or maintenance stage for readiness to carry a donor card than at baseline ( $p = .01$ ). For the third logistic model, the dependent variable was early or late stage of readiness to talk to one's family about one's donation intentions. Results indicate no significant effects of condition, time, or income; however, there was a condition-by-time interaction such that participants in the intervention group were 1.64 times more likely to be in action or maintenance at follow-up than participants in the control group ( $p = .04$ ).

### Discussion

We conducted a randomized effectiveness trial of a culturally sensitive intervention designed to increase organ and tissue donation intentions among African American adults. Not surprisingly, intervention participants were more likely than control group participants were to report watching a donation-related video during the 1-year follow-up period because they were given personal copies of the video to take home. However, both groups were given written materials to review and, indeed, intervention participants were more likely to report reviewing these materials than control participants were.

Regarding the main outcome analyses, results indicate that condition was not significantly associated with having an increased readiness to express donation intentions on a driver's license or by carrying an organ donor card. Additionally, all respondents, regardless of condition, were more likely to be in the action or maintenance stage in their readiness to carry a donor card at follow-up. Finally, intervention participants were significantly more likely to be in the action or maintenance stage in their readiness to talk to family about their donation intentions at follow-up as compared to control participants. The effect sizes are small ( $OR < 2$ ) but significant.

It is unclear why the intervention yielded such small effect sizes; multiple possibilities exist. It might be that the relatively low use of materials attenuated the effect sizes. In the



intervention group alone, just more than half of participants (57%) reported reviewing the video, and 69% of these individuals reported that they reviewed the written materials. Thus, the small effect sizes may be because between one third and one half of intervention participants did not review the intervention materials. We are currently exploring the factors that motivate individuals to review the *Project ACTS* intervention materials so that revisions can be made to the intervention and/or its delivery to maximize uptake.

Another reason for the small effects may be because the *MOTTEP* control group materials are effective as well. One of the few interventions that has addressed donation education with racial and ethnic minority adult populations is *MOTTEP*, and there is evidence that it was effective at increasing positive attitudes and donor consent rates among racial and ethnic minorities (Callender, Hall, & Branch, 2001). The *Project ACTS* intervention is similar to *MOTTEP* in that it is culturally sensitive; however, unlike *MOTTEP*, it was developed with a focus on addressing the religious barriers to donation and encouraging family discussion. The importance of discussing organ donation with family members is underscored in research that finds that donation rates are higher when individual wishes are known within the family (DeJong et al., 1998; Smith, Kopfman, Lindsey, Yoo, & Morrison, 2004). Perhaps this is why *Project ACTS* was most effective for this particular dependent variable (encouraging family discussion).

Both control and intervention group materials included a donor card amongst additional educational information. This may account for the main effect of time from baseline to follow-up and the lack of significance between groups, indicating that the *Project ACTS* intervention performed no better than *MOTTEP* did at increasing readiness to provide written documentation of one's donation intentions. Given that many states are moving toward enacting legislation that would strengthen the ability of the organ procurement agency to recover organs strictly based on the written documentation of donation wishes, the need for family consent may diminish over time (although family consent would always be desirable in the case of deceased donation). Thus, more research is needed to explore how to effectively encourage the written documentation of donation intentions among African Americans.

## Limitations

Limitations of this study relate to the use of a convenience sample of Christian, African American parishioners within the southeastern United States. Moreover, by virtue of their willingness to volunteer, it might be that participants were generally more supportive of donation than were those who did not agree to participate. However, the great variability in donation intentions suggests that this probably was not the case (i.e., the data did not indicate overwhelming support for donation). Additionally, the food and monetary incentives may have helped us recruit individuals with a range of motivations for participating. Moreover, as the first investigation of the effectiveness of *Project ACTS*, this study was designed to place a greater emphasis on internal than external validity. Thus, this study was not designed to generalize findings to African American parishioners in other locales, to those holding non-Christian religious beliefs, or to the non-church-attending population. Additionally, the overrepresentation of women among our sample of parishioners may have affected the findings, although it is notable that this gender disparity is also seen in the churchgoing population more generally (Park, 1998). Thus, the gender distribution reflected in our sample mirrors what exists naturally. Future research is intended to explore the effectiveness of the intervention in a more heterogeneous population of African American adults.

Finally, it was not optimal that control group participants were not given their own personal copies of the *MOTTEP* video. Logistical and financial constraints prevented the project

from supplying all 202 control group participants with this video to take home with them. Moreover, doing so would have undermined our goal to distribute materials that are normally available to consumers. Much like accessing the video would have required a highly motivated consumer who was willing to pay \$10 to \$15 for the video, the highly motivated control group participant in our research study would have had to check the video out from the church library. Nevertheless, the control group written materials could be accessed free of charge at the time the study was conducted, so both groups were given written materials, and significant differences in self-reported review of these materials were still found.

## Conclusion

A considerable amount of research has been conducted over the past two decades to understand the motivators, attitudes, and barriers to organ donation among ethnic minorities. Specifically regarding African Americans, numerous studies have explored knowledge, beliefs, attitudes, and cultural reasons for low donation rates, such as a lack of awareness of the need for transplantable organs, mistrust of the health care system, fear of premature death, racism, and religious misconceptions (Callender, Miles, & Hall, 2002; Davis et al., 2005; Siminoff, Burant, & Ibrahim, 2006). Despite all of this research, educational campaigns and interventions incorporating these results have been slow to materialize, and very few have been systematically evaluated for their effectiveness. *Project ACTS* is a culturally sensitive intervention that was developed out of a desire to address the donation-related concerns of African American adults residing in the southeast region of the United States. The findings of this study can move the field toward a better understanding of successful methods to encourage family discussion of donation intentions among African American adults. *Project ACTS* can be modified and transferred to other populations, contingent on additional research on effectiveness. Given that family discussion is still such a critical mechanism for expressing donation intentions, this study offers new direction for effective donation education efforts targeting African Americans.

## PRACTICE IMPLICATIONS

This intervention study demonstrates the effectiveness of an organ and tissue donation self-education intervention package in encouraging family discussion of donation intentions among African American adults. 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 their target populations to improve consent rates. Additionally, intervention materials could be adapted to fit other racial and ethnic groups in the United States to improve knowledge, attitudes, and beliefs relative to organ and tissue donation.

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**Table 1**Sample Characteristics for Intervention and Control Group Participants ( $N = 337$ )

Characteristic	Intervention ( $n = 175$ )	Control ( $n = 162$ )
Mean age in years*	49.5	52.5
Female (%)	79.4	76.3
Marital status (%)		
Never married	20.7	18.4
Married	46.6	50.6
Divorced, separated, or widowed	32.8	31.0
Educational attainment (%)**		
<High school	2.3	1.9
High school graduate or vocational school	28.2	17.4
Some college	35.1	30.9
College graduate or higher	34.5	49.7
Income categories (%)**		
\$29,000	37.8	18.9
\$30,000 to \$69,000	39.6	42.7
\$70,000 or more	22.6	38.5
Mean monthly attendance at church	5.7	5.1
Action/maintenance at follow-up (%)		
License	46.9	48.8
Donor card	24.0	24.7
Talk to family	37.7	35.2

\*  
 $p < .05$ .\*\*  
 $p < .01$ .