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A Quantitative Appraisal of African Americans' Decisions to Become Registered Organ Donors at the Driver's License Office

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Abstract

African American (AA) organ donation registration rates fall short of national objectives. The goal of the present study was to utilize data acquired from a quantitative telephone survey to provide information for a future Department of Motorized Vehicles (DMV) intervention to increase AA organ donor registration at the DMV. AAs (n = 20,177) that had visited an Alabama DMV office within a 3-month period were recruited via direct mailing to participate in a quantitative phone survey. Data from 155 respondents that participated in the survey were analyzed. Of those respondents deciding to become a registered organ donor (ROD; n=122) 1/3 made that decision at the time of visiting the DMV. Of those who chose not to become a ROD (n=33), 1/3 made the decision during the DMV visit.

Almost 85% of all participants wanted to learn more about organ donation while waiting at the DMV, preferably via TV messaging (digital signage), with the messaging delivered from organ donors, transplant recipients, and health care experts. Altruism, accurate organ donation information and encouragement from family and friends were the most important educational topics to support AAs becoming a ROD. These data provide a platform to inform future interventions designed to increase AAs becoming a ROD at the DMV.

Keywords

Organ Donor; African Americans; Telephone Interview

INTRODUCTION

There are over 120,000 patients waiting for an organ to become available for transplant⁽¹⁾. Organ transplantation needs cross all races and ethnicities with approximately 30% of those on organ donation waiting lists being African Americans (AAs). In contrast, AAs comprise only 13% of organ donors⁽¹⁾.

In response to the significant need for organ donation, the United States Health and Human Services department has set the goal that at least 50% of all adults should be registered organ donors⁽²⁾. As of 2016, approximately 54% (> 130 million) of the US population were registered organ donors⁽³⁾. These goals are mostly being met in Caucasians, although there remains a disparity in achieving these goals in AAs⁽⁴⁾. There have been multiple studies conducted identifying barriers to AAs becoming registered organ donors (ROD); including mistrust in hospitals, influence of religious beliefs and spirituality, and lack of accurate information about the donation process and the associated financial aspects⁽⁵⁻⁷⁾. While there is a paucity of data regarding the factors associated with AAs positive decision to become RODs, studies have suggested that a desire to learn more about the donation process may be of benefit to RODs^(8, 9). Previously, we conducted a qualitative study based upon social cognitive theory utilizing 13 focus groups of AAs who had frequented a DMV in the past 3 months and made a ROD decision⁽⁸⁾. The goal of that study was to determine key indicators of AA DMV patrons' decision whether to become a ROD or to not become a ROD. From these data it was determined that positive influences for registering as an organ donor included altruism, familiarity with a registered donor, a deceased donor family or someone

in need of an organ donation, and self-determination over the donation process. Factors adversely affecting registration included components of the DMV environment including noise, overcrowding, and lack of privacy⁽⁸⁾

Currently, the most common mechanism to become a ROD (for all races) is at the Department of Motorized Vehicles (DMV) during the process of obtaining/renewing a Driver's License^(10–12). Health behavior change studies demonstrate the greatest positive effect when the interventional materials utilized are close to the location of the behavioral decision (i.e. promoting use of stairs as opposed to the elevator is more effective when promotional items are located close to the stairs)^(13–15). Thus, interventions promoting ROD are likely to be most effective at the DMV where the organ donation decision is made. There remains a knowledge gap in the literature, however, as far as identifying effective and pragmatic approaches at the DMV to increase AA ROD^(16, 17).

The purpose of this investigation was to develop formative data to inform a DMV intervention to increase AA ROD at the DMV by measuring if sentinel qualitative themes were quantitatively associated with a positive ROD decision. A secondary objective was to have participants rank-order identified organ donation educational topics, potential types of individuals to present this information, and best modality to deliver the messaging.

MATERIALS AND METHODS:

Study population and survey administration.

The target population included in this study was derived from Alabama DMV patrons and included English-speaking African American men and women aged 19 or older. In Alabama, an individual must be 19 or older to independently consent for research studies. Residents of Alabama may register to be an organ donor through on-line applications, by mail or at the DMV when obtaining or renewing their driver's license. The objective was to recruit AA participants within 3-months of their visit to the DMV that had made a decision regarding organ donation registration. A data file containing AA Alabama residents who visited DMV offices located throughout the state of Alabama for the purpose of obtaining/renewing their driver's license and making a decision on becoming a ROD within a three-month time frame was obtained from the Alabama DMV. This file contained 20,177 AA residents, including registered organ donors (5,468–27.1%) and non-registered donors (14,709–72.9%). Based upon an agreement with the Alabama DMV, potential participants could only be contacted via mail and “opt in” for research studies. The AA residents in this file were mailed a post-card between October 6, 2015 and July 15, 2016, asking if they would like to participate in a phone call survey in which they would be asked questions regarding their decision about becoming a ROD. The sample was not stratified by ROD status, although the telephone interviewer could verify ROD status, race, date of birth, and that the respondent did in fact frequent a DMV within 3 months. 198 residents responded (0.98% response rate) to the post card by calling the 1 800 number (141 females). Of these 198 respondents, 159 met eligibility requirements (i.e. AA race, aged 19 or older, visited a DMV within 3 months) and agreed to consent to the phone survey (115 females). All respondents determined to be ineligible had not frequented a DMV and made a ROD decision in the past 3 months. Participants were stratified into those that became a ROD and those that chose to not become

a ROD. The percentage of RODs vs. non-RODs was not determined until performance of the telephone survey, therefore the comparison to non-respondents is not possible. In the current study, 78% of the participants were or chose to become a ROD, compared to 28% of AA being RODs in Alabama overall.

Participants provided verbal informed consent over the phone prior to the survey. The University of Alabama at Birmingham (UAB) Institutional Review Board approved this study.

Survey Development and testing.

Our previous qualitative study using focus groups of AAs that had recently visited a DMV and that made a decision regarding registering as an organ donor, identified themes that influenced decision making⁽⁸⁾. Questions for the current telephone survey were generated from these themes⁽⁸⁾. In addition to general demographic questions, queries regarding visiting the DMV and DMV environment were also posed including; wait time, availability of organ donation informational brochures, DMV staff, noise, overcrowding, and privacy. The balance of the survey focused upon 1) factors that were associated with becoming a ROD, 2) factors that were associated with the decision to not become a ROD, 3) options to present organ donation education at the DMV, 4) possible organ donation education topics, and 5) which types of individuals should present the organ donation education (Supplemental Table 3). In consideration of the small number of responses in certain questions (i.e. 10 and 11), responses of 'somewhat' were combined with 'yes' when analyzed in comparison with those who responded 'no'. The survey was administered to AAs within 3 months of visiting a DMV and making a ROD decision. All participants reviewed a list of factors (identified from the previous qualitative study), endorsed all that applied, and then rank ordered the top three factors that were most important to their decision making. The questions were worded at a 6th grade education level. Two preliminary focus groups (n=7 ROD and n=5 non-ROD) were conducted to ensure understanding of the questions and solicit suggestions for potential rewording and additional questions for inclusion on the survey^(18, 19). The questions were loaded into Redcap computer platform and administered via the UAB Recruitment and Retention Shared Facility by trained research personnel. Several practice runs were conducted with UAB employees to ensure appropriate computer programming and for feedback regarding clarity of presentation.

Statistical Analysis:

Demographic information was summarized using measures of mean (with standard deviation) and proportion. Depending on the variable structure, ANOVA, Chi-square, Fisher's exact, and ordinal logistic regression were used to determine the significant differences between non-RODs and RODs with a p-value of < 0.05 indicating significance. Rank orders determined as a consequence of the percentage of non-RODs or RODs indicating that a particular factor was 'most important' in their decision. SAS version 9.4 (Cary, NC) was used to conduct the statistical analysis.

RESULTS

Demographics.

A total of 198 participants responded to the postcard invitation. There were 155 eligible participants who completed the telephone survey and were included in the final analysis yielding a 0.98% response rate and 78% participation rate⁽²⁰⁾. Participants had the option of identifying themselves as a non-ROD, previously a ROD and renewing their registration or as a first-time ROD. As a consequence of the limited responses, and because newly RODs (n=47) and renewed RODs (n=75) had similar demographics, these groups were combined (ROD n = 122 vs. non-ROD n = 33). RODs were younger than non-RODs (35.9 yrs. $\pm$ 13.5 yrs. vs. 41.9 yrs. $\pm$ 13.1 yrs., $p=0.022$, t-test). There were no differences in gender, education or marital status. RODs were more likely to be students ($p=0.047$, Fisher's exact), and tended to be working full time whereas non-RODs tended to be working full time or unemployed. Despite differences in employment, there were no differences in annual household income. Measures of religiosity and frequency of attending religious services were not different between RODs and non-RODs (Table 1).

Factors related to the decision to become a ROD.

Many participants made their registered organ donor decision prior to the visit to the DMV (61.7% ROD vs. 69.7% non-ROD, $p=0.341$, Chi-square). Only 4.9% of RODs and 6.1% of non-RODs had a conversation about organ donation while waiting at the DMV ($p=0.565$, Fisher's exact). Similarly, only 9.2% of RODs and 6.1% of non-RODs made their registered organ donor decision while waiting in line at the DMV. In Alabama, driver's license applicants are asked by DMV staff at the time of application, if they wish to register as an organ donor. A similar percentage of ROD and of non-ROD patrons (95.8% vs 97.0%; respectively) were asked if they wanted to become a registered organ donor. There was no significant differences in the proportion of RODs that made their registered organ donor decision only when asked by the DMV clerk compared to non-RODs (28.7% vs. 18.2%, $p=0.225$, Chi-square). Only 24.6% of RODs and 28.1% of non-RODs recalled viewing organ donation promotional items at the DMV.

RODs were asked to rank factors that most influenced their decision to become a ROD. The most mentioned theme was 'desire to help someone' (67.2% of RODs indicated this theme as most influential), followed by 'family member in need of a transplant' (16.4%), 'knowing someone who received a transplant' (7.4%), 'knowing a donor' (4.1%), and lastly 'encouragement from persons most important to me' (2.5%), and 'information about organ donation' (2.5%) Non-RODs were asked to rank their perceived barriers to becoming a ROD. The highest ranked barrier mentioned by non-RODs was 'lack of information' (24.2% of non-RODs ranked as highest barrier), followed by 'organ not useable' (21.2%), 'distrust of provider' (18.2%), 'not able to direct organ donation' (9.1%), 'religious beliefs' (9.1%), 'organs used on black market' (6.1%), and finally 'family influence' (3.1%).

DMV Environment/Experience.

Questions examining patrons' impressions of the local DMV offices indicated there were no differences in travel time (to the DMV) or in-house DMV waiting time between RODs and

non-RODs (Supplement Table 1). Appraisal of DMV staff was also balanced across ROD and non-RODs as measured by questions pertaining to DMV staff providing additional information, enough information, and enthusiasm towards organ donation. Furthermore, both RODs and non-RODs similarly assessed DMV noise, crowdedness, and lack of privacy.

Best Modality to Promote Organ Donation at the DMV.

The majority of RODs and non-RODs expressed a desire to learn more about organ donation while waiting at the DMV. The most preferred modality to promote organ donation at the DMV was considered to be via flat screen TV monitors (Figure 1). Participants, both RODs and non-RODs, rank ordered the individuals whom they considered the most important to least important to provide organ donation education and promotional messaging. Transplant recipients, registered donors/deceased donor families, and health care experts were identified as the top 3 most important types of people to deliver organ donation messages (Table 2).

Relationship with someone who is a registered organ donor or transplant recipient.

Questions probing the association between knowing a donor or transplant recipient and becoming a ROD indicated knowing someone who is a registered organ donor was significantly associated with the decision to become a ROD (65.8% ROD vs. 45.5% non-ROD, $p=0.033$, Chi-square). Conversely, knowing a transplant recipient was not associated with becoming a ROD (51.6% ROD vs. 60.6% non-ROD, $p=0.359$; Chi-square).

DISCUSSION

The present study provided the following surprising findings: Almost 1/3 of AA DMV patrons who became a ROD made the decision on the spur of the moment, only when asked by the DMV clerk, and at least 1/3 of the AA DMV patrons who chose not to become a ROD had not made the decision prior to visiting the DMV. Collectively, these data suggest that potential interventions might influence the ROD decision in up to 1/3 of all AA patrons. Furthermore, almost 85% of all the participants (ROD and non-ROD) wanted to learn more about organ donation while waiting at the DMV. They identified flat screen TV monitors (digital signage marketing) as the best promotional modality (Figure 1) and rank-ordered both the ideal candidates to present organ donation material and the most important topics promoting a positive ROD decision.

Contrary to the findings from our qualitative study, impressions of the DMV environment were not

quantitatively associated with a positive ROD decision⁽⁸⁾. Additionally, many non-ROD indicated that they had made their decision not to become a ROD prior to visiting the DMV and that lack of knowledge regarding organ donation contributed significantly to their decisions. We previously studied homogenous groups of AA who did not decide to become a ROD who associated excessive travel distance, waiting time, noise and lack of privacy at the DMV with their negative decision⁽⁸⁾. The health behavior literature strongly supports the environment as significantly influencing decision-making^(21–23). Similarly, religiosity has been strongly associated with non-donation attitudes in epidemiologic studies^(24–26), especially in older AA⁽²⁷⁾. Our qualitative study also suggested that religiosity significantly

affected the ROD decision. This quantitative survey, however, did not demonstrate differences in ROD decision as measured by self-assessment of religiosity, or religious service attendance frequency, with 90% to 94% of the participants considering themselves' religious. Religious leaders had one of the lowest rank-order for individuals to promote organ donation. Furthermore, religious concerns had the lowest rank order of the barriers to organ donation as defined by AA who did not become a ROD. Although interesting, these seemingly contradictory findings (DMV environment, religiosity) may be a result of the participant sampling approaches ("opt-in" recruitment), rank-order methodologies employed in this study, and small non-ROD sample. Further research is required to determine if these findings are representative of the AA community.

This study found that becoming a ROD is more common in younger AA than older AA. However, a recent study in which a numerical scale was developed and utilized to examine AAs attitudes towards becoming a ROD indicated that younger AAs' reticence regarding becoming a ROD may be a consequence of being more susceptible to traditional perceived barriers, (i.e.) medical mistrust, black market fears, costs, norms of burial and religiosity, as well as being less altruistic⁽²⁸⁾. Susceptibility to the traditional barriers could be overcome with targeted educational interventions as proposed in a study by Locke et al⁽²⁹⁾. Education may contribute to our findings on younger AA being more likely to be a ROD. Knowledge specific to donation and transplantation is relevant for increasing the number of RODs, and the overall level of education of an individual contributes to their willingness to be a ROD. In general, individuals with college education or greater are more likely to be a ROD^(28, 30, 31). In a national survey conducted in 2012 of AAs that indicated that they were RODs on their driver's license, 58.3% were a college or post-college graduate, a much higher education level than that observed in the general AA community⁽³⁰⁾. Participants in this study similarly were highly educated (65.2% of our survey participants indicated an educational level of college and above while nationally, 31.7% of AAs attained a similar level of education⁽³²⁾).

Transplantation and organ donor educational interventions utilizing materials developed by Callender et al (National Minority Organ Tissue Transplant Education Program; MOTTEP) have demonstrated success at increasing the donor rates of AAs⁽³³⁾. Follow-up studies by Arriola et al utilizing the similar donor educational materials targeted at adult AAs have also proven to enhance participation in ROD programs when the intervention occurs in group settings vs. utilization of these same materials in a 'take-home' program^(34, 35).

This study focused upon AAs becoming a ROD at state DMVs. We chose DMVs because these agencies are required to inquire of applicants about becoming a ROD and the majority of donor registrations occur at DMVs^(3, 10, 11, 36). A similar study was performed probing the attitudes of New York state licensed drivers about choices regarding ROD⁽¹²⁾. Although the study of New York licensed drivers failed to provide demographic information regarding the race of the participants, their results for those surveyed, similar to the results in our current study, indicated altruism as a major factor for becoming a ROD (34.9% of newly RODs and 38.1% of previously RODs). For non-RODs in the New York study, the indeterminate choices of being "unsure" or "having no specific reason" was reported to be the number one reason for not choosing to become a ROD (29.6% of those surveyed)⁽¹²⁾. In

contrast, for the AAs surveyed in our present study the specific concept of lacking knowledge of organ donation was cited as the reason for not choosing to be a ROD.

According to the U.S. Department of Transportation, 87% of driving age population are licensed drivers, indicating that DMVs provide a prime location for targeting potential donor organ registrants. Interestingly, the participants in our study indicated that DMV staff would be one of the least preferred individuals to provide additional information regarding organ donation. Yet, successful interventions utilizing DMV staff have been reported. In a study conducted in West Virginia DMVs, offices in which customer service representatives took a web-based organ donation training session saw a 7.5% increase in RODs compared to control DMV offices in which no training occurred⁽³⁷⁾. Similarly, Harrison et al demonstrated a 14% increase in RODs in DMVs at which the staff received a 1-hour training intervention on organ donation registry and organ donation information⁽¹⁰⁾. A follow-up study by this group, utilizing a three-prong intervention approach (mass media, point-of-decision, interpersonal components), demonstrated a significant increase in RODs⁽³⁸⁾. Development of newer personal devices has allowed the utilization of iPod videos as an intervention to specifically target donation concerns of minorities visiting Ohio DMVs. Participants viewed an iPod video with ear bud-audio prior to entering the DMV, resulting in a significant increase in RODs across all ethnicities; 84% of participants who watched the video became RODs vs 72% who did not. This effect was shown to be even more significant among AAs; 76% vs 54%, respectively⁽¹⁷⁾. Further, Rodrigue et al,⁽³⁹⁾ and more recently Thornton et al⁽⁴⁰⁾ demonstrated the usefulness of video presentations on TVs or on iPads, to enhance donor registrations at DMVs and primary care physician offices. Our respondents in the current study indicated by a large proportion, a need to learn more about organ donation. The success of these newer means of personal communications at increasing RODs suggests that the more traditional pamphlets and brochures available at most DMVs, may be obsolete at presenting the requested donor information. However, the obvious limitation of these more progressive interventions was that they were resource intensive and impractical for sustained implementation. Thus, from the data described above and the current data, it would seem reasonable to propose that a video intervention designed to provide organ donation information tailored to minorities visiting DMV offices would be an appropriate intervention for generating additional organ donor registrants.

This study had several limitations inherent to telephone surveys. Telephone survey response rates have been on the decline, reaching a low of 9% over the last few years^(41, 42). These low response rates have been attributed to many causes including, lack of perceived benefit, the demographic targeted and telemarketing and political over-surveying^(20, 41, 43) and are considered to be unavoidable⁽²⁰⁾. As a consequence of low response rates, participation bias becomes a serious concern, yet not necessarily inherent to the study⁽²⁰⁾. In fact, although high response rates can reduce the risk of bias, significant variability exists in assessing response-bias and rate of non-response does not predict level of bias magnitude⁽⁴⁴⁾. Telephone surveys initiated by a participant ("opt-in" participation) as a consequence of a mailed solicitation are also known to suffer from low response rate biases^(45, 46). While political, religious, demographic and lifestyle telephone response rates may compare favorably with federal benchmarks and in-person surveys, civic and social engagement surveys suggest response bias may still exist⁽⁴¹⁾. Those responding to the mailed solicitation

may have had more favorable attitudes towards organ donation and thus more willing to participate in the survey, as a consequence of their more intrinsic altruistic attitudes. Another concern could conceivably be recall bias. Respondents may have had difficulty in remembering events that they experienced during their visit to the DMV. To control for this possibility, certain survey questions included a “don’t remember” response. A strength of the study population was that, participants were surveyed within only 3 months of having visited the DMV. Targeting AAs who recently visited an Alabama DMV and subsequently made a decision regarding organ donation registration allowed for obtaining valuable quantitative information reflective of this minority cohort but limited true random selection. Furthermore, the respondents in our survey appeared to reflect a bias towards female and more well educated participants than seen in the general AA population. Due to these selection biases this study population was not completely representative of the broader African American community. And lastly, it should be noted that the survey utilized in this study was a non-validated, homemade survey designed to probe and quantitate AAs’ opinions on registering to become an organ donor at the Alabama DMVs. As such, it was a unique quantitative survey to answer specific questions developed by previous qualitative research by our group.

Conclusions

This quantitative telephone survey measuring factors associated with AAs’ becoming ROD at the DMV identified several key factors that may inform future interventions. Almost 85% of all participants desired more organ donation information while at the DMV and flat screen TV (digital signage) approaches were identified as the optimal delivery modality. Participants rank ordered educational topics and types of individuals that may be best suited to present organ donation information to AAs. Collectively, the information garnered from this study can inform future interventions aimed at increasing RODs at DMVs. Such interventions can be developed which would utilize appropriate individuals, i.e. donors, recipients, famous people or health care experts to provide educational information through video presentations directed towards enhancing the knowledge of potential organ donor registrants visiting the DMV.

Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

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ABBREVIATIONS PAGE:

ROD	Registered Organ Donor
AA	African American

DMV

Department of Motorized Vehicles

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Figure 1:
Choice of modality for organ donation information. Participants were asked to choose their preferred choice of technology to receive educational material regarding becoming a registered organ donor while waiting at the DMV. ROD, registered organ donor. Not ROD, n=33; ROD, n=75.

Table 1.

Participant Demographics (values indicated are frequencies and percentages unless otherwise noted).

Characteristic	Non-ROD (N = 33)	ROD (N = 122)	Statistical Test	DF	Test Statistic	Significance (p value)
Age (yrs) (mean $\pm$ SD)	41.9 $\pm$ 13.1	35.9 $\pm$ 13.5	T-test	153	2.310	0.022
Gender			Chi-Square	1	0.137	0.711
Female	23 (69.7%)	89 (73.0%)				
Male	10 (30.3%)	33 (27.0%)				
Education			Chi-Square	1	0.042	0.838
High School and less	11 (33.3%)	43 (35.2%)				
College and above	22 (66.7%)	79 (64.8%)				
Marital Status			Chi-Square	1	3.210	0.073
Married	13 (39.4%)	29 (23.8%)				
Not Married	20 (60.6%)	93 (76.2%)				
Employment						
Student	1 (3%)	21 (17.2%)	Fisher's Exact			0.047
Full-time	10 (30.3%)	56 (45.9%)	Chi-Square	1	2.585	0.108
Unemployed	8 (24.2%)	15 (12.3%)	Fisher's Exact			0.101
Annual Income			Ordinal Logistic	1	1.443	0.230
<\$20,000	18 (56.3%)	47 (41.6%)	(Wald Chi-Square)			
\$20,000 – \$40,000	7 (21.9%)	41 (36.3%)				
\$40,001 – \$60,000	4 (12.5%)	9 (8.0%)				
>\$60,000	3 (9.4%)	16 (14.2%)				
Religious person			Fisher's Exact			0.445
Yes	30 (90.9%)	115 (94.3%)				
No	3 (9.1%)	7 (5.7%)				
Religious attendance			Chi-Square	1	0.300	0.584
~ or >1/week	18 (54.5%)	73 (59.8%)				
< 1/week	15 (45.5%)	49 (40.2%)				

ROD-Registered Organ Donor; yrs-years

Table 2.

Rank-order preferences for individuals to Promote Organ Donation Registration. Rank-order #1 most popular individual to #6 least popular individual. Percentage of Non-ROD or ROD indicating that the individual was ‘Very Important’ vs ‘Somewhat Important’ or ‘Not Important’.

Rank-Order	Non-ROD	ROD
1	Donor/Donor Family (100%)	Transplant Recipient (95.1%)
2	Transplant Recipient (97%)	Donor/Donor Family (89.3%)
3	Health Care Expert (69.7%)	Health Care Expert (86.6%)
4	Famous People (33.3%)	Famous People (38.8%)
5	Religious Leader (24.2%)	Religious Leader (32.2%)
6	DMV Staff (21.2%)	DMV Staff (32.0%)