

Factors Perceived to Influence the Decision for African Americans to Become Registered Organ Donors at the Department of Motorized Vehicles

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Abstract: *Background:* African Americans (AA) are a third as likely as Caucasians to become registered organ donors at the Department of Motorized Vehicles (DMV). The Department of Health and Human Services has set the goal that at least 50% of adults in each state are registered donors.

Aims: The purpose of this study was to explore the personal, behavioral and environmental factors associated with AA donor registration decision-making at the DMV.

Methods: Guided by the Social Cognitive Theory, 13 focus groups ($n = 100$ participants) were conducted with AAs within 3 months of visiting a DMV and making a decision regarding whether to become or to not become a registered donor. The data were analyzed using inductive thematic and qualitative content analyses.

Results: Study participants expressed a desire to learn more information while waiting in line at the DMV. Knowing a family member or friend in need of an organ transplant, and the desire to make one's own decision were two salient factors associated with the decision to become a registered organ donor. Several aspects of the DMV environment (e.g., noisy, overcrowded, lacking privacy) were cited as deterrents to becoming a registered donor.

Discussion: This study highlights the personal, behavioral and environmental factors associated with AA organ donor registration decision-making at the DMV.

Conclusion: The DMV is a setting where many adults make a decision about organ donation. Policies that create an environment in the DMV to support informed decision-making (e.g., privacy, informed clerks, available educational materials, etc.) are indicated.

Keywords: Organ donor registration ■ Organ donation ■ Health disparities ■ Social cognitive theory ■ African American ■ Department of motorized vehicles

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INTRODUCTION

There are 122,000 persons waiting for donor organs in the US as of 2015, but only around 30,000 transplants are performed each year.¹ Examination of nationally available data demonstrates a large racial disparity in organ donation.² For example, Caucasians are 4.7 fold more likely than African Americans to consent to organ donation according to a recent study of potential donors in Alabama.³ The disparity in organ donation is a significant public health challenge. In addition to being under represented in the donor pool, African Americans are significantly over represented on the transplant waitlist. In Alabama, for example, African Americans make up 26.7% of the population,⁴ yet comprise 67.6% of the renal transplant waiting list at the University of Alabama at Birmingham (UAB).² Furthermore, in Alabama, 77% of Caucasians are registered organ donors, but only 28% of African Americans are registered organ donors.⁵ With the Department of Health and Human Services mandating that all states have a donor registry and set the goal that at least 50% of adults in each state are registered organ donors, these racial disparities highlight the need for interventions to increase African American organ donor registration.

Although rarely utilized for public health interventions, the ideal setting for these intervention programs may be the Department of Motor Vehicles (DMV). Most organ donor registrations (for all races) occur at the DMV.⁶ However, we know little about the decision making process about donation among adults visiting the DMV. The purpose this study was to begin to address the knowledge gap in the literature regarding the decision-making process of *becoming* a registered organ donor at the DMV.

Guided by Social Cognitive Theory,⁷⁻⁹ this qualitative study identified the personal, behavioral, and environmental factors that influence motivation and result in a decision to become or to not become a registered organ donor among African American adults who visited the Alabama DMV. Two groups were compared: African

Americans who made a first time decision to become a registered organ donor and African Americans who chose not to register as an organ donor.

MATERIALS AND METHODS

Participant recruitment

The study protocol obtained institutional review board approval. Study participants were African American women and men 19 years or older who visited an Alabama Driver's License office and made a decision (yes or no) to become a registered organ donor. A list of potential participants was provided by the Alabama Department of Public Safety on a quarterly basis. Participants were contacted and scheduled to complete the study protocol within 3 months of visiting the DMV. A postcard was mailed to eligible participants that reside in the 22 Birmingham, Alabama area zip codes that are geographically located within a 20-min drive to the University of Alabama at Birmingham (UAB) campus. Interested participants were instructed to call the study office. A telephone screening process excluded persons who had renewed their organ donor registration (i.e. NOT a first-time organ donor registration) by comparing their name to the Alabama Donor Registry. In addition, persons were excluded if they indicated that they were NOT asked if they wanted to be an organ donor while at the Driver's License office (all patrons are supposed to be asked if they want to be a registered organ donor but in practice not all are). The goal was to recruit persons who thought about, and made a voluntary decision (yes or no) about becoming a registered organ donor while at the DMV. There was 5% response rate among eligible participants ($n = 100$) who were mailed a postcard inviting them to participate (Table 1). Newly registered donors were oversampled to reach the recruitment goal of 1/2 registered donors and 1/2 non-registered participants. Ineligible persons ($n = 21$) were a combination of registration renewals (not a first-time yes decision) or longer than 3 months had passed since visiting the DMV.

Data collection

Two experienced African American moderators conducted the focus groups. Semi-structured focus group moderator guides were developed by the research team and organized according to Social Cognitive Theory constructs (Table 2). Thirteen focus groups were then conducted with 100 African Americans with the number of participants ranging from 5 to 8 per focus group. To promote participation and encourage discussion, homogenous focus groups of newly registered organ donors ($n = 7$ groups, $n = 54$ participants) and non-registered participants ($n = 6$ groups, $n = 46$ participants)

were conducted. Audio and video recordings were obtained for each focus group. Participants completed a brief demographic survey upon completion of the focus group. Participants were provided with light refreshments and \$100 cash as compensation for their time and travel.

Data analysis

The digitally recorded focus group discussions were transcribed verbatim and analyzed in two stages using a multi-functional software system for qualitative data analysis, NVivo 10 (QSR International). First, an inductive thematic analysis was conducted to search for common categories and themes in the data.¹⁰ To ensure consistency in data interpretation, two qualitative investigators (NI and IH) independently coded the original transcripts by identifying key points and recurring categories and themes that were central to areas of discussion both within and across focus groups. A constant comparative method¹¹ that involves iterative comparison of new information with the coded data was used to guide the analytical process. Inter-coder agreement between the two coders reached an acceptable 90%.¹² Content analysis¹³ was also performed on the generated categories and themes using the counts of text references in NVivo 10 to systematically represent consistencies in viewpoints across focus groups and participants with different organ donation registration status. Particular emphasis in the analysis was placed on how the themes interacted with each other to explain the decision to become (or not become) a registered organ donor within the study's theoretical framework.

THEORETICAL FRAMEWORK

Focus group questions were organized around the constructs of the Social Cognitive Theory that provided a framework for exploring factors that may be associated with the choice to become a registered organ donor. The Social Cognitive Theory argues that human behavior is shaped by personal, behavioral, and environmental influences, and that the three (behavior, person, and environment) function in a reciprocally determinant manner.⁷ This means that behavior can both shape and be shaped by the environment. In the case of organ donation registration, both social and physical environmental cues can influence what a person believes and how they act on those beliefs about becoming a donor or not. Personal factors addressed by the Social Cognitive Theory include outcome expectations and perceived self-efficacy.⁹ Outcome expectations are the anticipated consequences of a given behavior, and a given behavior can have several anticipated consequences. Perceived self-efficacy is one's confidence to perform a given behavior well enough to achieve the desired outcome.

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