

Does Donor Status, Race, and Biological Sex Predict Organ Donor Registration Barriers?

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Abstract: Purpose: The purpose of the current study was to examine differences among bodily integrity, disgust, medical mistrust, and superstition among African Americans, Caucasians, and Latinos; females and males; and registered organ donors and non-registered potential donors.

Methods: A random digit dialing phone survey was utilized to garner information pertaining to organ donation beliefs among African American ($n = 200$), Caucasian ($n = 200$), and Latino ($n = 200$) Chicago residents. More specifically, participants responded to measures of bodily integrity, disgust, medical mistrust, and superstition, organ donor registration status, among others.

Results: The results indicated that African American and Latino participants were less likely to be registered organ donors than Caucasians ($p < .001$). In general, females maintained fewer barriers than males with respect to bodily integrity ($p < .05$), disgust ($p = .01$), and superstition ($p = .01$). With respect to organ donation barriers, bodily integrity ($p < .0001$) emerged as a central concern among those surveyed.

Conclusion: This study highlights the significance of audience segmentation when promoting posthumous organ and tissue donation. Specifically, the results stress the importance of constructing distinct messages to non-registered potential donors compared to messages delivered to registered donors. Moreover, different barriers surfaced among females and males as well as among African American, Caucasian, and Latino residents. It is clear that a one size fits all approach will likely not work when promoting organ and tissue donation.

Keywords: Organ donation status ■ Race ■ Biological sex ■ Barriers

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INTRODUCTION

The need for more posthumous organ donors in the United States is the greatest obstacle to increasing organ transplantation rates. To date, over 121,000 individuals find themselves on the national waiting list for an organ transplant.¹ Yet, despite near unanimous public support for organ donation,² less than half of American adults

are registered organ donors in their respective state registries.¹ In an attempt to better understand this attitude-behavior discrepancy, a growing literature seeks to identify profiles of individuals who are more or less willing to register as organ donors (for a recent review, see Falomir-Pichastor, Berent, & Pereira³). In this same spirit, in the current investigation we recruited a diverse sample of young adults to examine organ donor status, race, and biological sex as antecedents of four commonly known barriers organ donor registration: bodily integrity, disgust, medical mistrust, and superstition.⁴

In doing so, the current study stands to move the literature forward in two important ways. First, the current study adds to a burgeoning literature examining racial differences in predictors of organ donation behaviors among African Americans, Caucasians, and Latinos.^{5–12} This is particularly consequential as African Americans and Latinos are more likely to suffer from end-stage renal disease than Caucasians,¹³ and are disproportionately represented on the national transplant waiting list.¹⁴ Further elevating the need for more organ donors among African Americans and Latinos is the low consent rates. For instance, in a recent national survey conducted by Gallup,² only 18.6% of African Americans and 25.4% of Latinos had registered in their state donor registry, compared to 31.6% of Caucasians. This reluctance to register as organ donors directly translates to fewer eligible African American and Latino organ donors.¹⁵ Although race is not used as a determining factor in matching organ donors with transplant recipients — and individuals from different racial backgrounds commonly match with one another — compatible blood types and tissue markers more often are found among those with concordant racial backgrounds.¹³

Second, the current investigation seeks to examine potential main effects and interactions among participant organ donor status, race, and biological sex on well-known registration barriers. To date, the role of biological sex differences in antecedents to donor registration has received rather scant attention,^{16–18} and to our knowledge no work has investigated interactions between organ donor status, race, and biological sex. In the current study, we focus on a sample of young adults, as young adults are a prime population for

targeted registration enrollment.^{10–12} Furthermore, as research recruiting from a representative statewide population is rare, and thus deserving of greater attention, the current investigation moves the literature forward by examining a racially diverse, yet an understudied sample.

In the current investigation we pay special attention to what Morgan, Stephenson, Harrison, Afifi, and Long⁴ refer to as ‘noncognitive’ factors. Historically, much of the scholarship on organ donor registration antecedents has predominantly relied on rational-based models.³ Morgan and colleagues, however, argue that in addition to these cognitively oriented predictors (e.g., attitude, knowledge), several ‘noncognitive’ factors are key determinants of registration behavior. By noncognitive, Morgan et al⁴ refer not necessarily to irrational thoughts or ideas, but rather to more visceral beliefs and reactions to the topic of organ donation. These include: (a) *bodily integrity*, the desire to keep the body intact following death (e.g., the belief that the body must be left whole postmortem in order to reach the afterlife), (b) *disgust*, discomfort at the thought of transplantation procedures (e.g., feeling squeamish about having your body cut open to have your organs removed), (c) *medical mistrust*, representing concerns about self-serving goals of doctors and institutionalized practices that may harm patient well-being (e.g., the belief that doctors prematurely let patients die in order to harvest their organs), and (d) *superstition*, including fears, anxieties, and myths associated with organ donation registration (e.g., the belief that registering as an organ donor may make death happen sooner). A growing body of work has supported these noncognitive factors as consequential predictors of donor status.^{4,7,11,12,19} Missing from the literature, however, is a broader understanding of how these barriers differ by participant organ donor status, race, and biological sex. With the goals of the current investigation articulated, we put forth the following research questions:

H1: Non-registered potential organ donors will maintain less concerns regarding bodily integrity, disgust, medical mistrust, and superstition than registered organ donors.

RQ1: Do African Americans, Caucasians, and Latinos differ in bodily integrity, disgust, medical mistrust, and superstition?

RQ2: Do males and females differ in bodily integrity, disgust, medical mistrust, and superstition?

RQ3: Does race and biological sex interact in accounting for differences in bodily integrity, disgust, medical mistrust, and superstition?

RQ4: Among bodily integrity, disgust, medical mistrust, and superstition, which account for the most variance in organ donation status?

METHODS

Participants and procedures

Utilizing a quota sample, young adults ($N = 600$) residing in Illinois between the ages of 18 and 24 ($M = 21.01$, $SD = 2.14$) completed a telephone survey with an even distribution across race: African American ($n = 200$), Caucasian ($n = 200$), and Latino ($n = 200$). Most participants were female ($n = 367$). Additionally, the sample was well represented with respect to parent income with no more than 10% of the sample falling into any income category, which ranged from under \$10,000 to greater than \$100,000 with \$10,000 increments separating each category. 51.2% of participants were registered organ donors.

Phone lists were purchased with these age and race qualifications in mind. After the phone lists were purchased, random digit dialing was performed until 200 surveys were completed by each racial group. If an individual was not reached at first, five additional callbacks followed at various times throughout weekday and weekends. Individuals were invited to participate if they identified as African American, Caucasian, or Latino, were between the age of 18 and 24, and were fluent in English. Of those reached, 18% of African Americans, 21% of Caucasians, and 19% of Latinos qualified to participate in the study. Of the African Americans, Caucasians, and Latinos reached that met the racial and age qualifications, 89%, 92%, and 95% completed the phone survey, respectively. Participants received a \$25 gift card to Wal-Mart for their participation in the 15-min survey.

Measures

All items were measured on a 7-point scale with 1 = *strongly disagree* to 7 = *strongly agree*. Each of the noncognitive factors was measured with items taken from Morgan et al (2008). Four items were used to comprise the *bodily integrity* scale (e.g., Removing organs from the body just isn't right) ($\alpha = .83$; $M = 2.25$, $SD = 1.49$). Three items assessed *disgust* (e.g., The idea of organ donation is somewhat disgusting) ($\alpha = .73$; $M = 2.02$, $SD = 1.40$). Four items measured *superstition* (e.g., Joining the organ donor registry might make death happen more quickly) ($\alpha = .79$; $M = 1.81$, $SD = 1.22$). Two items assessed *medical mistrust* (e.g., You don't feel like you can trust doctors) ($\alpha = .60$, $p < .01$; $M = 2.51$, $SD = 1.43$).

RESULTS

To ensure that medical mistrust, superstition, disgust, and bodily integrity could be measured as distinct constructs, a

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