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Donor designation: racial and ethnic differences in US nondesignators' preferred methods for disclosing intent to donate organs

Tanjala S. Purnell,[1,2] Neil R. Powe,[3] Misty U. Troll,[2] Nae-Yuh Wang,[2,4,5] Thomas A. LaVeist[1,6] and L. Ebony Boulware[2,4,7]

1 Department of Health Policy and Management, Johns Hopkins Bloomberg School of Public Health, Baltimore, USA
2 Welch Center for Prevention, Epidemiology, and Clinical Research, Johns Hopkins Medical Institutions, Baltimore, USA
3 Department of Medicine, San Francisco General Hospital and University of California, San Francisco, CA, USA
4 Division of General Internal Medicine, Department of Medicine, Johns Hopkins School of Medicine, Baltimore, USA
5 Department of Biostatistics, Johns Hopkins Bloomberg School of Public Health, Baltimore, USA
6 Hopkins Center for Health Disparities Solutions, Johns Hopkins Bloomberg School of Public Health, Baltimore, USA
7 Department of Epidemiology, Johns Hopkins Bloomberg School of Public Health, Baltimore, USA

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Correspondence
L. Ebony Boulware MD MPH, Associate Professor of Medicine and Epidemiology, Johns Hopkins Medical Institutions, 2024 E. Monument Street, Suite 2-600, Baltimore, MD 21205, USA. Tel.: 443 287 4388; fax: 410 955 0476; e-mail: lboulwa@jhmi.edu

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Summary

Little is known about racial/ethnic differences in preferred methods of disclosing deceased organ donation intentions among persons not previously designating their organ donation preferences publicly or the association of medical mistrust with preferences. We surveyed 307 United States (US) adults who had not yet designated their donation intentions via drivers' licenses or organ donor cards (nondesignators) to identify their preferred disclosure methods (personal discussions with family, physicians, or religious representatives or public registration via mail/telephone/computer, workplace, place of religious worship, or grocery store/bank/post office) and to assess the association of mistrust with preferences. In multivariable models, we assessed racial/ethnic differences in preferences and the influence of medical mistrust on preferences. Nondesignators most preferred discussions with physicians (65%) or family members (63%). After adjustment, African Americans (AAs) were more likely than Whites to prefer discussion with religious representatives. In contrast, AAs and Hispanics were less likely than Whites to prefer registration at a workplace or through mail/telephone/computer. Medical mistrust was common and associated with less willingness to disclose via several methods. Encouraging donation intention disclosure via discussions with physicians, family, and religious representatives and addressing medical mistrust could enhance strategies to improve nondesignators' donation rates.

Introduction

Although many persons in the United States (US) general public may be willing to donate their organs after death, they may not formally disclose their donation intentions to others, contributing to missed opportunities for donation [1–3]. Because of the opt-in nature of the current US system of deceased organ donation, it is imperative that persons wishing to donate their organs disclose these intentions to others, particularly family members, prior to death. In the US, potential donors' family members play a very prominent role in determining whether organs are donated. In most cases, family member consent is required for donation to occur, without which, donation may not occur even if donors have previously declared their organ donor status. Recently, a few states have enacted ‘first-person consent’ or ‘donor designation’ laws that allow OPOs to procure potential donors’ organs as long as they have formally designated their donation through approved means [4].

Nondesignation rates are particularly high among racial/ethnic minorities, who have been shown to be significantly less willing to designate their donation intentions on state drivers’ licenses or organ donor cards and to have lower rates of deceased donor kidney transplants compared to their majority counterparts [1,2,5–7]. Nondesignating potential donors’ mistrust in the medical establishment (including their fears of receiving poor medical treatment with disclosure) may influence their willingness to disclose their organ donation intentions and are more prevalent among racial/ethnic minorities [6,7].

Through its Strengthening Donor Registries Initiative, the US Department of Health and Human Services has recently focused its efforts on identifying strategies to improve donor designation among the US general public [8]. In addition, a growing number of states have implemented novel mechanisms for donation intention disclosure, including internet-based registries maintained by regional organ procurement agencies or state agencies [9]. To date, however, optimal strategies for improving disclosure of donation intentions among nondesignating potential donors are unclear, in part because preferences of nondesignators are not well understood. The extent to which preferences for different methods of disclosure might differ among racial/ethnic groups or might be influenced by mistrust of medical providers or the healthcare industry in general is also unknown. Identification of nondesignators’ preferred strategies for disclosure and ascertainment of potential racial/ethnic differences in preferences could help guide new initiatives to improve deceased organ donation rates overall and to narrow racial/ethnic disparities in donation. Exploration of the potential influence of medical mistrust on disclosure preferences could further aid efforts to improve donation rates by elucidating potential strategies for enhancing disclosure among those who are significantly less likely to designate their donation preferences via conventional methods.

In a national study of US-based adults who had not previously designated their donation intentions, we explored preferred strategies for disclosure of donation intentions, racial/ethnic differences in preferences, and the influence of medical mistrust on preferences. We hypothesized *a priori* that preferences regarding potential methods for disclosing donation intentions would vary according to race/ethnicity. We further hypothesized that the association of medical mistrust with donation disclosure would vary among persons of different races or ethnicities.

Material and methods

Study design and population

As part of a national cross-sectional study of US adults (aged 18–75 years) performed (from May 2004 to August 2005) to study public attitudes about live and deceased organ donation, we assessed preferences for various methods of disclosing their deceased organ donation intentions. As described previously, we randomly selected study participants from households identified using random digit selection of telephone numbers [10]. We performed additional oversampling to enrich responses from African American and Hispanic participants. We performed the oversampling in all four US census divisions. We oversampled African Americans and Hispanics in proportion to the density of households inhabited by African Americans and Hispanics in telephone blocks based on US census data. To assess study participants’ donor designation status, we asked participants whether they had previously designated their donation intentions on a state driver’s license or signed organ donor card. We defined nondesignators as participants who reported that they had not yet designated their donation intentions on a state driver’s license or signed organ donor card. Because we sought to assess disclosure preferences among persons who had not yet disclosed their intentions, we limited our study analysis and assessment of preferences about disclosing intentions to donate organs to the subsample of participants categorized as nondesignators. The Institutional Review Board at the Johns Hopkins Medical Institutions approved the study, and all participants gave their informed consent prior to their inclusion in the study.

Questionnaire administration

The 20-min telephone questionnaire was administered to participants in both English and Spanish and assessed nondesignators’ sociodemographic characteristics and interest in deceased donation, their trust in the medical establishment, and their preferences regarding methods for donation intention disclosure. Questions regarding disclosure preferences and attitudes toward medical mistrust were administered in separate sections of the questionnaire (see Appendix).

Assessment of sociodemographic characteristics and stated interest in deceased donation

We ascertained nondesignators’ self-reported race/ethnicity using categorizations designated by the 2000 US census (White, African American, Hispanic, and other racial/ethnic minority). We also assessed participants’ age, gender, education completed, annual household income, marital status, employment status, health insurance status, and census region of residence. We assessed nondesignators' stated interest in deceased donation by asking them: 'Would you consider donating your organs after death?' Possible answers could be 'no,' 'yes,' or 'not sure.'

Assessment of medical mistrust

We considered nondesignators' mistrustful attitudes regarding the medical establishment to include: (i) their explicitly stated lack of trust in physicians or hospitals, and (ii) their beliefs regarding the likelihood they would receive less than optimal health care if their organ donation preferences were known to health care professionals. We assessed nondesignators' lack of trust in hospitals or physicians by asking them their agreement with the statements, 'I trust hospitals to put my medical needs above all other considerations,' and, 'I trust physicians to put my medical needs above all other consideration.' Possible responses for each question included 'completely agree, mostly agree, somewhat agree, agree a little, or not at all.' We considered persons to trust hospitals or physicians if they answered 'completely agree' or 'mostly agree' (trusting) versus 'somewhat agree', 'agree a little', 'or not at all' (not trusting). We assessed nondesignators' beliefs regarding the likelihood they would receive less than optimal health care if their organ donation preferences were known by asking them their agreement with the statement, 'I believe that when a person who is an organ donor becomes ill, doctors will try everything to save their life before removing their organs for donation.' Possible responses for this question included 'completely agree, mostly agree, somewhat agree, agree a little, or not at all.' We considered people to agree with this statement if they answered 'completely agree' or 'mostly agree' (agree) versus 'somewhat agree', 'agree a little', 'or not at all' (not agree).

Assessment of disclosure preferences

We presented nondesignators with a list of potential avenues through which they might consider disclosing their organ donation intentions and asked them, 'Please tell me if you think any of the following things would make it easier for you to become an organ donor.' The list included people with whom they might have personal discussions about their intentions and public venues through which they might publicly register their intentions. Options for personal discussion of donation included discussions with: (i) family members, (ii) a physician, and (iii) a pastor, rabbi, or other religious representative. Options for avenues through which public registration might occur included registration via: (i) mail, telephone; or computer (offered as one set of options), (ii) a workplace, (iii) a place of religious worship, and (iv) a grocery store, bank, or post office (offered as one set of options). Participants were asked to indicate their preferences for disclosing their intentions via these avenues by indicating an answer of 'yes' versus 'no' for each potential avenue listed.

Statistical analysis

We described nondesignators' demographic characteristics, attitudes of medical mistrust, and preferences regarding avenues through which they might disclose their donation intentions. We assessed differences in nondesignators' characteristics and attitudes according to their race/ethnicity using the chi-squared statistics. In multivariable logistic regression models, we assessed the independent association of race/ethnicity with participants' preferences for personal and nonpersonal disclosure methods, while controlling for age, gender, annual household income, insurance status, and US census region. In additional multivariable models stratified by race/ethnicity, we assessed differences in preferences for disclosure methods according to nondesignators' presence or absence of medical mistrust. We converted adjusted odds ratios from multivariable logistic regression models to adjusted percentages. We considered two-sided *P*-values of <0.05 to be statistically significant. All analyses were performed using STATA version 10.0 for Windows (Stata Corp., College Station, TX, USA).

Results

Response rate and characteristics of study participants

Prior to oversampling, we contacted a total of 847 households who agreed to randomization of participants within the household, and 720 respondents from these households agreed to participate in the study (representing 85% of contacted households). This initial sample consisted of only 44 African Americans and 63 Hispanics. Before oversampling occurred, the total study population consisted of 36.3% nondesignators (77.5% White; 5.9% African American, 8.8% Hispanic). We then identified an additional 125 racial/ethnic minorities (58 African Americans and 67 Hispanics) through oversampling, resulting in 845 total completed telephone interviews. Among those participants oversampled, 75.4% were nondesignators (47.4% African American, 51.6% Hispanic). In the final combined data, a total of 538 (63.6%) participants reported that they had already designated their donation intentions on a state driver's license or signed organ donor card, and a total of 307 (36.3%) participants reported they had not previously declared their donation intentions. We limited our study analysis to this final sample of 307 nondesignators.

A majority of nondesignators were younger than 60 years of age, female, had annual household incomes <$60 000 US dollars, had <2 years college education, were married or living with a partner and reported having health insurance (Table 1). Additionally, a majority of nondesignators reported that they were interested (58%) or possibly interested (19%) in donating their organs after death. Compared to White nondesignators, African American and Hispanic nondesignators were statistically significantly more likely to be female, more likely to have incomes below $60 000 US dollars, and younger than 60 years of age. Whites were more likely to have health insurance than African Americans and Hispanics. Compared to Whites, African American and Hispanic nondesignators in our study were also statistically significantly

Table 1. Characteristics of US nondesignators of deceased organ donation: overall and by race/ethnicity.

		Race/ethnicity			
Characteristic	Overall *N* = 307* *n* (%)†	White *N* = 167 *n* (%)†	African American *N* = 53 *n* (%)†	Hispanic (all races) *N* = 70 *n* (%)†	*P*-value
Age in years					
18–40 years	132 (42)	51 (30)	23 (44)	48 (71)	<0.01
41–59 years	122 (39)	76 (46)	21 (38)	22 (29)	
60–75 years	53 (18)	40 (24)	9 (18)	0 (0)	
Gender					
Female	189 (61)	92 (56)	43 (81)	47 (67)	<0.01
Male	109 (35)	75 (44)	7 (13)	17 (24)	
Education					
High school or less	107 (34)	55 (33)	16 (30)	30 (43)	0.07
2 years college	72 (23)	38 (22)	14 (26)	18 (26)	
College	78 (25)	46 (27)	16 (30)	12 (17)	
Graduate or professional	39 (13)	28 (18)	4 (7)	2 (3)	
Annual household income					
$0–$20 000	56 (18)	19 (11)	13 (24)	22 (31)	<0.01
$20 001–$40 000	74 (24)	45 (27)	14 (26)	12 (17)	
$40 001–$60 000	57 (18)	36 (21)	7 (13)	10 (14)	
$60 001–$100 000	54 (17)	37 (22)	7 (13)	6 (8)	
>$100 000	24 (8)	17 (10)	3 (6)	2 (2)	
Marital status					
Married or living with a partner	156 (51)	89 (53)	18 (34)	40 (57)	0.03
Separated, divorced, widowed	65 (21)	37 (22)	13 (24)	9 (13)	
Never married	74 (24)	40 (24)	19 (36)	13 (18)	
Health insurance status					
Insured	258 (84)	155 (93)	45 (85)	42 (60)	<0.01
Not insured	37 (12)	11 (6)	5 (9)	20 (28)	
Employment					
Full-time or part-time	192 (62)	109 (65)	33 (62)	39 (56)	0.99
Student, homemaker, or retired	80 (26)	46 (28)	12 (23)	18 (26)	
Disabled or unemployed	24 (8)	12 (7)	5 (9)	5 (7)	
Census region					
North east	75 (24)	44 (26)	14 (26)	12 (17)	<0.01
North central	55 (18)	33 (20)	12 (23)	7 (10)	
South	107 (35)	56 (34)	26 (49)	21 (30)	
West	70 (23)	34 (20)	1 (2)	30 (43)	
Interested in donation					
Yes	177 (58)	100 (60)	23 (43)	43 (61)	0.19
No	71 (23)	41 (24)	17 (32)	9 (13)	
Not sure	59 (19)	26 (16)	13 (25)	18 (26)	

*Includes 17 other racial/ethnic minority (American Indian or Alaskan Natives, Native Hawaiian or other Pacific Islanders, Asians, 'two or more races,' and 'others').

†Percentages may not add up to 100% due to missing values.

Table 2. Medical trust among US nondesignators of deceased organ donation: overall and by race/ethnicity.

	Overall	Race/ethnicity			
	Overall *N* = 307* *n* (%)†	White *N* = 167 *n* (%)†	African American *N* = 53 *n* (%)†	Hispanic (all races) *N* = 70 *n* (%)†	*P*-value
Trust my physician to put my medical needs above all other considerations					
Completely agree	126 (41)	78 (47)	19 (36)	21 (30)	0.03
Mostly agree	72 (23)	48 (29)	11 (21)	10 (14)	
Somewhat agree	62 (20)	30 (18)	14 (26)	16 (23)	
Agree a little	16 (5)	5 (3)	1 (2)	9 (13)	
Not agree at all	16 (5)	4 (2)	5 (9)	5 (7)	
Trust hospitals to put my medical needs above all other considerations					
Completely agree	60 (19)	36 (22)	8 (15)	13 (18)	0.48
Mostly agree	59 (19)	41 (25)	6 (11)	9 (13)	
Somewhat agree	108 (35)	54 (32)	20 (38)	29 (41)	
Agree a little	26 (8)	12 (7)	8 (15)	4 (6)	
Not agree at all	40 (13)	21 (13)	8 (15)	7 (10)	
Believe when a person who is an organ donor becomes sick, doctors will try everything to save his/her life					
Completely agree	154 (50)	89 (53)	17 (32)	40 (57)	<0.01
Mostly agree	66 (21)	41 (25)	10 (19)	13 (19)	
Somewhat agree	39 (13)	18 (11)	7 (13)	8 (11)	
Agree a little	15 (5)	7 (4)	5 (9)	3 (4)	
Not agree at all	26 (8)	10 (6)	12 (23)	3 (4)	

*Includes17 other racial/ethnic minority (American Indian or Alaskan Natives, Native Hawaiian or other Pacific Islanders, Asians, 'two or more races,' and 'others').

†Percentages may not add up to 100% due to missing values.

more likely to live in the southern and western US census regions.

Medical mistrust among nondesignators

Nondesignators' medical mistrust varied according to their race and ethnicity. African Americans and Hispanics were statistically significantly less likely than Whites to completely or mostly trust their physicians to put their medical needs above all other considerations (Table 2). Less than half of nondesignators among all racial/ethnic groups reported that they mostly or completely trust hospitals to put their medical needs above all other considerations. African Americans were also statistically significantly less likely than Hispanics and Whites to completely or mostly believe that when a person who is an organ donor becomes sick, doctors will try everything to save his or her life before removing organs.

Preferred disclosure methods among racial/ethnic minority and nonminority nondesignators

Overall, a significant majority of nondesignators reported personal disclosure of organ donation intentions with physicians (65%) and family (63%) would make it easier for them to disclose their intentions (Table 3). Significantly fewer nondesignators reported they preferred disclosure of intentions with a pastor, rabbi, or other religious representative (38%). Among public forms of

Table 3. Unadjusted† and adjusted‡ percentage of nondesignators favoring disclosure of donation intentions via personal discussion or public registration methods.

		Unadjusted† percentage favoring disclosure method by race/ethnicity (95% confidence interval)			Adjusted‡ percentage favoring disclosure method by race/ethnicity (95% confidence interval)		
	Disclosure method	White *N* = 167	African American *N* = 53	Hispanic (all races) *N* = 70	White *N* = 167	African American *N* = 53	Hispanic (all races) *N* = 70
Personal discussion	Family discussion	64 [ref]	72 (54–85)	64 (49–76)	63 [ref]	74 (54–87)	57 (39–73)
	Physician discussion	69 [ref]	56 (39–72)	62 (47–74)	69 [ref]	60 (41–76)	57 (40–73)
	Religious discussion	38 [ref]	55 (37–71)	45 (31–59)	38 [ref]	61 (42–78)*	37 (22–54)
Public registration	Mail, phone, or computer	65 [ref]	44 (28–61)*	54 (40–68)	67 [ref]	44 (27–63)*	59 (38–77)
	Workplace	61 [ref]	34 (20–52)*	41 (28–56)*	64 [ref]	33 (18–53)*	44 (28–62)*
	Place of religious worship	49 [ref]	37 (23–55)	38 (27–53)	52 [ref]	37 (21–57)	30 (17–48)*
	Bank, post office, or store	34 [ref]	28 (15–46)	38 (25–53)	36 [ref]	27 (14–47)	37 (22–56)

*Denotes statistically significant difference compared to White reference group at $P < 0.05$.

†Denotes univariable logistic regression models unadjusted for potential confounders.

‡Denotes multivariable logistic regression models adjusted for age, gender, annual household income, census region, and insurance status.

[ref] Denotes reference group.

( ) Denotes 95% confidence interval.

disclosure, a majority of nondesignators reported registration via mail, phone, or computer (58%) would make disclosure easier, while fewer than half preferred workplace registration (40%), registration at a place of religious worship (36%), or registration at a store, bank, or post office (33%).

In multivariable models adjusting for sociodemographic factors, African Americans were statistically significantly more likely than Whites to prefer discussion with a pastor, rabbi, or other religious representative. In contrast, African Americans and Hispanics were statistically significantly less likely than Whites to favor workplace registration. African Americans were also statistically significantly less likely than Whites to favor registration through mail, phone, or computer-based methods. Hispanics were statistically significantly less likely than Whites to favor registration at a place of religious worship, after adjusting for sociodemographic factors.

Association of medical mistrust with disclosure preferences

In analyses stratified by race/ethnicity, attitudes of medical mistrust were often associated with disclosure preferences, especially among racial/ethnic minorities. Mistrust of physicians was associated with less willingness to disclose via personal discussion with family members (among African Americans), physicians (among African Americans and

Table 4. Adjusted† percentage of nondesignators in favor of disclosure method by race/ethnicity and attitudes about medical mistrust (within racial/ethnic group differences by medical trust levels).

			Completely or mostly trust physician to put medical needs above other considerations		Completely or mostly trust hospitals to put medical needs above all other considerations		Completely or mostly believe when a person who is an organ donor becomes sick, doctorswill try everything to save his/her life	
	% Favoring disclosure method	Race/ethnicity	Yes	No	Yes	No	Yes	No
			Adjusted* percentage (95% confidence interval) favoring disclosure method					
Personal discussion	Family Discussion	White	63 [ref]	59 (38–77)	67 [ref]	58 (44–71)	58 [ref]	81 (57–93)
		African American	94 [ref]	51 (18–82)*	86 [ref]	65 (44–81)*	92 [ref]	60 (24–87)*
		Hispanic	70 [ref]	43 (19–70)	41 [ref]	71 (45–88)*	70 [ref]	11 (1–60)*
	Physician Discussion	White	73 [ref]	59 (37–77)	80 [ref]	59 (45–72)*	67 [ref]	80 (56–92)
		African American	80 [ref]	31 (8–69)*	89 [ref]	48 (24–73)*	82 [ref]	31 (10–67)*
		Hispanic	83 [ref]	28 (10–58)*	58 [ref]	61 (35–82)	75 [ref]	12 (1–67)*
	Religious Discussion	White	35 [ref]	31 (14–53)	30 [ref]	37 (25–52)	30 [ref]	55 (32–77)*
		African American	87 [ref]	47 (12–84)*	79 [ref]	65 (31–88)	83 [ref]	43 (12–81)*
		Hispanic	41 [ref]	18 (4–51)	12 [ref]	44 (20–72)*	37 [ref]	7 (1–57)
Public registration	Mail, phone, computer Registration	White	69 [ref]	62 (41–79)	73 [ref]	61 (47–73)	70 [ref]	55 (32–75)
		African American	46 [ref]	29 (9–62)	51 [ref]	33 (15–59)	36 [ref]	39 (15–70)
		Hispanic	98 [ref]	7 (1–44)*	78 [ref]	52 (29–74)*	75 [ref]	29 (6–71)*
	Workplace Registration	White	51 [ref]	39 (19–63)	57 [ref]	40 (27–57)	55 [ref]	25 (10–50)*
		African American	55 [ref]	12 (2–46)*	38 [ref]	32 (15–56)	26 [ref]	43 (17–73)
		Hispanic	62 [ref]	8 (1–41)*	52 [ref]	31 (13–57)	49 [ref]	13 (2–59)
	Religious Registration	White	41 [ref]	35 (18–57)	48 [ref]	32 (20–46)	39 [ref]	44 (23–67)
		African American	39 [ref]	33 (13–62)	50 [ref]	42 (16–72)	63 [ref]	19 (4–57)*
		Hispanic	39 [ref]	13 (2–43)	29 [ref]	26 (11–51)	32 [ref]	15 (2–62)
	Bank, post office, Store Registration	White	38 [ref]	32 (15–56)	39 [ref]	35 (23–50)	34 [ref]	51 (28–73)
		African American	35 [ref]	18 (4–52)	19 [ref]	29 (12–55)	30 [ref]	23 (7–56)
		Hispanic	61 [ref]	7 (1–35)*	40 [ref]	35 (13–66)	41 [ref]	29 (5–74)

*Denotes statistically significant difference compared to reference group at $P < 0.05$.

†Denotes multivariable regression models adjusted for age, gender, annual household income, census region, and insurance status.

[ref] Denotes reference group.

( ) Denotes 95% confidence interval.

Hispanics), religious representatives (among African Americans) or via public registration via mail, telephone or computer (among Hispanics), public registration at a workplace (among African Americans and Hispanics), and public registration at a bank, post office or store (among Hispanics) (Table 4). Mistrust of hospitals was associated with less willingness to disclose via personal discussion with family members (among African Americans), physicians (among Whites and African Americans) or via public registration via mail, telephone or computer (among Hispanics). Concern about receiving less than optimal medical care with disclosure was associated with less willingness to disclose via personal discussion with family members (among African Americans and Hispanics), physicians (among African Americans), religious representatives, (among African Americans) or via public registration via mail, telephone computer (among Hispanics), at a workplace (among Whites) at a place of religious worship (among African Americans). In some cases, mistrust in hospitals was associated with greater willingness to disclose with family members (among Hispanics) or religious representatives (among Whites and Hispanics).

Discussion

In this national study of US-based adults, a majority of persons who had not previously designated their organ donation intentions on a driver's license or organ donor card expressed interest in donating their organs after death. Most nondesignators reported they more readily preferred to disclose their donation intentions through personal discussions, with greatest preference for discussions with family members and physicians. African Americans were statistically significantly more likely than Whites to prefer disclosure via personal discussions with religious representatives, and both African Americans and Hispanics were less likely than Whites to prefer public registration via mail, phone or computer, at workplace, or at a place of religious worship. Attitudes of medical mistrust were associated with potential donors' lower preference for various methods of disclosure, especially among racial/ethnic minorities.

To our knowledge, this is the first US-based study with a national sample to assess racial/ethnic variation in preferences for disclosure of organ donation intentions among nondesignators and to explore the influence of medical mistrust on preferences. In prior regional studies of disclosure preferences among racial/ethnic minorities, potential donors also demonstrated favorable attitudes toward personal discussion as a means for disclosing organ donation intentions. However these studies did not focus exclusively on nondesignators and may have been influenced by strong opinions expressed by potential donors who had already disclosed their intentions through conventional methods [11–13]. Our findings extend those of prior work by providing public organ donation programs seeking to increase disclosure rates guidance regarding disclosure methods deemed most acceptable to nondesignators as well as factors that may be important to address when working to improve disclosure rates among racial/ethnic minorities.

To date, a majority of efforts to enhance disclosure of donation intentions have focused on improving public forms of disclosure, including disclosure on drivers' licenses and donor cards [14]. Recent programs have devoted significant resources to making public disclosure more convenient (e.g., through registration on the internet) [15]. Our findings suggest that programs emphasizing personal discussion as a means to facilitate disclosure may be better received by nondesignators (especially racial/ethnic minorities with medical mistrust) than programs encouraging disclosure via public registration. Our findings of multiple strong associations between potential donors' medical mistrust and their willingness to disclose preferences in a variety of hypothetical settings emphasize the importance of programs' consideration of ways to directly address potential donors' medical mistrust during program implementation.

Encouragement of personal discussion of organ donation intentions could have several benefits. Potential donor-physician discussions about the need for organ donation may improve potential donors' knowledge about donation procedures and the transplant recipient selection process [19]. Lack of transparency regarding the donation and transplant process has been previously identified as a factor associated with less willingness to donate among the general public (with an even greater impact among racial/ethnic minorities) and may also influence their willingness to disclose donation preferences [16]. Explicit discussions with physicians and other health care providers about how decisions to proceed with donation are approached by health care providers, and about the donation and allocation process could help allay potential donors' mistrust of the donation process, including their concerns about receiving inadequate health care if their donation intentions are known. Regional variation in methods for determining cerebral death in the US likely enhances potential donors' confusion and subsequent mistrust about this aspect of donation [17]. Thus, health care providers' efforts to explain cerebral death and to clarify differences in regional procedures could also help address donors' mistrust. Our finding suggests efforts to directly address medical mistrust within the context of potential donor-physician discussions could be especially important for racial/ethnic minorities, for whom willingness to disclose was more consistently associated with disclosure preferences. Potential donor-family discussions about donation intentions may help potential donors solidify their desires to declare donation. As a result of discussions, family members may also be more receptive to learning about donation when faced with donation decisions and more likely to provide consent for donation. Previous research has demonstrated targeted educational interventions to improve knowledge about the donation process among families prior to organ donation requests may result in increased rates of family consent and deceased donation [1]. Discussions between potential donors and religious representatives may provide a venue through which well-documented concerns, particularly among racial/ethnic minorities, about donation and its potential impact on spiritual well-being after death associated with donation can be addressed and demystified [6,7,18]. Because OPOs play such prominent role in hosting electronic donor registries, their provision of education to potential donors could significantly help to increase the perceived transparency of the donation and allocation process and potentially influence potential donors' mistrust. The value and feasibility of targeted outreach efforts by OPO professionals to identify potential donors and discuss donation and allocation on an in-person basis warrants greater exploration.

Limitations of our study deserve mention. First, we performed a 20-min interview in which we attempted to ascertain some sensitive personal information (such as socioeconomic status) from participants in addition to their attitudes about disclosing their organ donation intentions. It is possible those willing to respond to a lengthy questionnaire with this type of content are systematically different from persons not willing to participate in the study. In addition, participant attitudes assessed at one point in time may not predict future behaviors. Second, our limited sample of nondesignators may have more favorable attitudes toward organ donation than nonparticipating nondesignators. Our study population was diverse in age, gender, income and education, potentially limiting the generalizability of our findings. We also oversampled African Americans and Hispanics and divided our population into smaller subgroups, which could have influenced study results. Further, we did not oversample from other racial/ethnic minority groups known to have disparate rates of organ donation, such as Asian immigrants. Nonetheless, we did draw oversampled minorities from all regions of the US. Third, although we assessed nondesignators' preferences regarding a variety of personal and public avenues for disclosure, we grouped some forms of public disclosure (e.g., presenting bank, post office, or store registration as one category), limiting our ability to determine whether specific subtypes of disclosure might be most preferable within groups. Further, we did not assess nondesignators' specific reasons for preferring certain specific disclosure methods or optimal mechanisms for implementing certain types of disclosure. For example, there might be multiple venues and mechanisms by which computer-based registries could be operationalized (e.g., online registries accessed at home versus computer-based registration at a state department of motor vehicles location). Findings among some subgroups of participants of a positive association between medical mistrust and participants' greater willingness to disclose preferences (for instance, greater willingness to discuss donation intentions with religious representatives among Whites and Hispanics with medical mistrust) warrant further investigation. Some subgroups were small, which could have contributed to variability in estimation of attitudes.

In conclusion, a majority of US nondesignators reported they more readily preferred to disclose their donation intentions through personal discussions, with greatest preference for discussions with family members and physicians. Compared to their White counterparts, racial/ethnic minorities were more likely to prefer personal disclosure with a religious representative and less likely to prefer public registration. Attitudes of medical mistrust were associated with nondesignators' lower preferences for various methods of disclosure, especially among racial/ethnic minorities. Programs seeking to improve nondesignators' disclosure rates may consider encouraging personal forms of disclosure and emphasize the importance of addressing medical mistrust during disclosure opportunities. Further research is needed to elucidate the reasons for nondesignators' preferences and to further elucidate why the influence of medical mistrust on disclosure preferences may differ among racial/ethnic groups.

Authorship

TSP and LEB: were responsible for defining the goals of the manuscript and for writing the manuscript. TSP, NRP, NYW, TAL, and LEB: were responsible for data analysis and interpretation of the results. LEB, NRP, MUT, and NYW: were responsible for developing the survey design, data collection, and data management. NRP, NYW, TAL, and LEB: acted as advisors and contributed to synthesizing the discussion and conclusions.

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Disclosure

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