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Demographic factors affect willingness to register as an organ donor more than a personal relationship with a transplant candidate

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Abstract

Background—Transplant candidate caregivers (TCCs) are an under-utilized but potentially devoted pool of advocates who themselves may be recruited to register for deceased organ donation.

Aim—To assess and compare recruitment barriers to deceased donor registration efforts in TCCs and health fair attendees (HFAs).

Methods—A 42-item questionnaire assessing willingness to register as an organ donor and perceptions and knowledge about organ donation was administered to 452 participants (174 in Denver, 278 in San Francisco). Logistic regression, stratified by study site, was used to assess associations between explanatory variables and willingness to register as an organ donor.

Results—In Denver, 83% of TCCs vs 68% of HFAs indicated a willingness to register ($p = 0.03$). Controlling for study group (TCC vs HFA), predictors of willingness to register were female gender (OR 2.4), Caucasian race (OR 2.3), college graduate (OR 11.1), married (OR 2.4) and higher positive perception of organ donation (OR 1.2), each $p < 0.05$. In San Francisco, 58% of TCCs vs 70% of HFAs indicated a willingness to register ($p = 0.03$). Controlling for study group (TCC vs HFA), predictors of willingness to register were Caucasian race (OR 3.5), college graduate (OR 2.2), married (OR 1.9), higher knowledge (OR 1.6) and higher positive perception of organ donation (OR 1.2), each $p < 0.05$. In both locales, Caucasians were more likely to have positive perceptions about organ donation and were more willing to register.

Conclusions—Demographic characteristics, not personal connection to a transplant candidate, explain willingness to register as an organ donor.

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Conflicts of Interest

The authors have no conflicts of interest to disclose.

Keywords

organ donation; transplantation; recruitment; survey

Introduction

Organ transplantation is a life-saving intervention for patients suffering from end-stage solid organ failure. Despite recent increases in organ donation rates, the current supply of donor organs fails to meet the demand. As need outstrips supply, the number of patients waiting and dying on the organ transplant list is progressively increasing.¹⁻³ The number of patients waiting for solid organ transplantation has increased 70% in the past decade.¹ As of March 2013, The United Network for Organ Sharing (UNOS) reported that there were approximately 22,517 individuals waiting for an organ transplant in the United States.⁴ The vast majority of available organs are from deceased donors, which in the United States is greatly facilitated by an *a priori* decision to donate posthumously.^{1, 5} It is therefore crucial to increase peoples' willingness to register for deceased organ donation.⁶

Identification of groups of individuals receptive to becoming potential organ donors can increase the success of organ donation registration recruitment efforts. While altruism is often stated as the ultimate driving force behind self-registered organ donation,⁷⁻⁹ other factors, namely demographic (including race, gender, education status, and religion) and knowledge about organ donation also appear to play a role.¹⁰⁻¹⁵ Understanding what barriers dissuade certain groups from registering to become deceased organ donors can facilitate the design of targeted marketing campaigns aimed at increasing donor registration rates.^{8, 12, 16-19} The family members and support persons of patients in need of organ transplant represent a potentially receptive group of individuals to target organ donation registration recruiting efforts. We previously hypothesized that persons with personal relationships to potential organ transplant recipients would be more willing to register as organ donors than those without a personal connection to a transplant recipient candidate. Yet, in a prior study, we demonstrated that transplant candidate caregivers (TCCs) accompanying potential transplant candidates to clinic visits were surprisingly more difficult to recruit using standard donor registration materials than were community health fair attendees (HFAs) in the San Francisco Bay area.²⁰

In the current study, our goal was to assess if the lower willingness to register as a deceased organ donor among TCCs could be explained by socioeconomic or geographic factors. Herein, we assess the influence of these factors as well as knowledge and perceptions about organ donation of TCCs and HFAs in San Francisco, California and Denver, Colorado on their willingness to be an organ donor.

Methods

Study Population and Survey Administration

The survey was piloted in 30 volunteers at the University of California, San Francisco (UCSF) Health Science campus. Feedback was elicited regarding the question content and

the survey was modified accordingly. Study participants were recruited in two distinct geographic locations: 1) San Francisco, California and 2) Denver, Colorado. In each geographic location, subjects were recruited between August 2009 and October 2011 from the two target populations: TCCs and HFAs. The TCC group at each site included family members and support persons who accompanied potential transplant candidates to clinic visits at UCSF and University of Colorado Denver (UCD) organ transplant educational classes. The HFA group at each location included community health fair attendees at local health fairs in the San Francisco and Denver metropolitan areas. Participants were eligible to take the survey if they volunteered to do so, were at least 16 years of age, and could read and write in English. The Institutional Review Boards at UCSF and UCD approved this study.

Questionnaire Content

We designed and piloted a 42-item Likert scale based questionnaire. (Supplemental Table 1) The questionnaire incorporated items from two previously validated surveys on student perceptions of posthumous organ donation.^{14, 15} Respondents were asked about their current organ donor status and their willingness to register to become a deceased organ donor. Information was collected regarding their transplant-specific knowledge by true/false questions. Respondents' perceptions of the organ donation and transplantation process were assessed by 5-level Likert scale questions with answer responses ranging from "strongly disagree" to "strongly agree". Additionally, we collected demographic information including age, race/ethnicity, education level, marital status, family size, and religious preferences.

Statistical Analysis

Logistic regression, stratified by study site, was used to assess associations between explanatory variables and willingness to register as an organ donor. All models included study group (TCC and HFA) and location (San Francisco and Denver). Interaction terms between location and all other explanatory variables permitted analysis of separate effects for each location. Over-dispersion was tested for and a scale parameter was included when needed. Models investigated each explanatory variable individually, aside from study group and location, and the estimated effect of study group for each location was compared with the study group effects estimated from a crude model consisting only of study group and location. For each explanatory variable available, case data were used and the corresponding crude model was fit using the same sample. A crude model was also fit using all of the data. For each location, odds ratios, 95% confidence intervals, and p-values were obtained for the study group effect and for the specified explanatory variable.

Results

Denver Metropolitan Area

In the Denver metropolitan area, 174 participants completed the survey, 86 of whom were TCCs accompanying liver transplant candidates to clinic visits at UCD and 88 of whom were HFAs. Respondents' characteristics are shown in Table 1. Compared to HFAs, TCCs more commonly were older (51 years old vs. 46 years old; $p = 0.02$), female (72% vs. 51%; OR 2.5; $p = 0.004$), married (86% vs. 52%; OR 5.5; $p < 0.0001$), had children (79% vs. 54%; OR 3.2; $p = 0.0006$), and were less educated (41% college graduates vs. 62% college

graduates; $p = 0.02$). Additionally, TCCs had higher organ donation knowledge scores (5.5/6 vs. 5.1/6; $p = 0.006$) and had higher positive perception of organ donation scores (54.5/65 vs. 51.4/65; $p = 0.007$) than did HFAs (Figures 1 and 2). TCCs more commonly were organ donors than were HFAs (83% vs. 68% respectively; OR 2.2; $p = 0.03$) (Figure 3). Several independent predictors of donor registration were found after controlling for study group (TCC and HFA). (Table 2). Variables associated with an increased likelihood to donate were female gender (OR 2.36; $p = 0.025$), Caucasian race (OR 2.33; $p = 0.024$), college graduate (OR 11.07; $p < 0.0001$), higher positive perception of organ donation score (OR 1.23; $p < 0.0001$, per scale unit), and being married (OR 2.40; $p = 0.029$). Older age, higher organ donation knowledge scores, regular attendance of religious services, and having children were characteristics that did not significantly affect likelihood of organ donation (each $p > 0.05$).

College graduates had higher positive perception of organ donation scores than respondents with high school degrees or less ($p = 0.0006$) or only some college ($p < 0.05$). However, they did not achieve higher knowledge of organ donation scores ($p = 0.66$). Caucasian participants had significantly higher positive perception of organ donation scores ($p = 0.013$) compared to non-Caucasians, however they did not have different organ donation knowledge scores ($p = 0.48$). Mean knowledge and perception scores were not significantly different for those who were married compared to those who were single (each $p > 0.05$).

San Francisco Metropolitan Area

In the San Francisco metropolitan area, 278 participants completed the survey, 111 of whom were TCCs at UCSF and 167 of whom were HFAs. Compared to HFAs, TCCs more commonly were older (50 years old vs. 45 years old; $p = 0.003$), non-Caucasian (54% vs. 31%; OR 2.6; $p = 0.0002$), married (74% vs. 46%; OR 3.4; $p < 0.0001$), and had children (68% vs. 53%; OR 1.9; $p = 0.011$) (Tables 1). Additionally, TCCs had lower perception of organ donation scores (50.6/65 vs. 52.4/65; $p = 0.05$) than HFAs and similar knowledge scores (5.2/6 vs. 5.2/6; $p = 0.94$) (Figures 1 and 2). TCCs were less commonly organ donors than were HFAs (58% vs. 70% respectively; OR 0.58; $p = 0.03$) (Figure 3).

Controlling for study group (TCC and HFA), Caucasian race (OR 3.47; $p < 0.0001$), college graduate vs. high school or less (OR 2.24; $p = 0.025$), higher knowledge of organ donation score (OR 1.64; $p = 0.003$, per scale unit), higher positive perception of organ donation score (OR 1.18; $p < 0.0001$, per scale unit), and being married (OR 1.86; $p = 0.028$) were characteristics associated with an increase likelihood to donate. (Table 2) Yet, older age, gender, regular attendance of religious services, and having children were characteristics that did not significantly affect likelihood of organ donation (each $p > 0.05$).

College graduates had higher positive perceptions of organ donation scores than those with high school degree or less ($p = 0.0007$) or only some college ($p = 0.01$) but education level had no association with knowledge of organ donation scores ($p = 0.11$). Caucasians had significantly higher positive perception of organ donation scores ($p < 0.0001$) and organ donation knowledge scores ($p < 0.0001$), compared to non-Caucasians. Mean knowledge and perception scores were not significantly different for those who were married compared to those who were single (each $p > 0.05$).

Discussion

In this study, we found that demographic characteristics and perceptions of organ donation, rather than personal connection to transplant candidate, explain willingness to register as an organ donor. Interestingly, in Denver, TCCs were more willing to donate than were HFAs (OR 2.2; $p = 0.03$). Yet several demographic characteristics of the TCCs were also independent predictors of increased willingness to donate. TCCs were more commonly female, married, and had higher positive perception of organ donation scores, each of which was independently associated with increased willingness to donate. Both Caucasians and those with higher levels of education had significantly higher mean organ donation perception scores; however they did not have higher knowledge scores. Having an overall positive perception of organ donation appears to be more predictive of organ donation registration than does having more transplant-specific knowledge.

In San Francisco, HFAs were more likely to donate than were TCCs (OR 1.7; $p = 0.03$). This finding corroborates the findings of our previous study, in that TCCs appeared to be a more difficult group to recruit for organ donation registration than were the HFAs.²⁰ The TCCs were more commonly non-Caucasian and had more negative organ donation perception scores, which likely explains the challenges met when recruiting them for organ donor registration.

These findings suggest that demographic characteristics and perceptions of organ donation, rather than personal relationships to a transplant candidate, motivate deceased organ donor self-registration. After controlling for relationship with a transplant candidate, we found that Caucasians, college graduates, those who were married, and those who had higher organ donation perception scores were significantly more willing to register for deceased organ donation. Additionally, Caucasians and those with higher education had more positive perceptions of organ donation. This implies that overall perceptions of the organ donation and transplantation process may be the most influential factors in the decision to sign posthumous organ donation pledges (Figure 4). This finding has important implications for deceased organ recruitment efforts; that is, population-specific recruitment materials are more likely to be effective than more general materials.

Previous studies in other populations have identified organ donation registration disparities among specific racial and ethnic groups. Compared to Caucasians, African Americans are less willing to donate their own organs and reported greater mistrust in the equity of the donation system and concerns about the trustworthiness of the health care system.^{10, 11, 21–23} Asian Americans have been found to have more negative attitudes toward organ donation and participate less in organ donor programs compared to European Americans.²⁴ A study by Breitkopf revealed that Hispanic Americans are less willing to donate their organs but, while their attitude toward donation is favorable, mistrust of the medical profession and perceptions of inequity in the distribution of donated organs are barriers to donating their own organs for transplantation.²⁵

Although we studied people from two large metropolitan areas, our sample reflects the demographic diversity of people living specifically in the Denver and San Francisco

metropolitan areas. Thus, our results may not be generalizable to other geographic areas or non-metropolitan segments of the United States. Further survey of other locations or with more granular demographic and/or socioeconomic data may improve the generalizability of our findings. As with any voluntary survey study, there is risk for response bias, in that the results may over-represent individuals with strong opinions. Additionally, our results may overestimate the true incidence of organ donation registration as the donor registration status of respondents could not be verified. Despite these limitations, we believe that our findings are valid and could impact recruitment efforts for deceased organ donation.

In conclusion, we conducted a study in both the San Francisco and Denver metropolitan areas in two distinct populations (TCCs and HFAs) in order to characterize the barriers to deceased organ donation registration recruitment efforts. Contrary to our hypothesis, we found that a personal relationship to a potential solid organ transplant recipient was not necessarily associated with an increased willingness to personally register as a deceased organ donor. Donor registration barriers appear to involve mainly cultural and socioeconomic differences, and are not overcome by personal relationships to potential organ transplant recipients in need. To increase the availability of life-saving organ transplants, these barriers need to be deconstructed. Future targeted donor registration recruitment campaigns should focus on dispelling misconceptions of the transplantation process among non-Caucasians and the less educated via culturally sensitive, directive messages.^{13, 18} Addressing the misconceptions that exist across this cultural divide is paramount to the success of our organ donation registries and can help save lives.

Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

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Figure 1.

Knowledge scores (total score out of 6) among survey participants.

Vertical bars represent 95% confidence intervals.

Horizontal bars represent groups tested for displayed p-values.

HFA, health care fair attendees. TCC, transplant recipient caregivers.

Figure 2.

Perception scores (total score out of 65) among survey participants.

Vertical bars represent 95% confidence intervals.

Horizontal bars represent groups tested for displayed p-values.

HFA, health care fair attendees. TCC, transplant recipient caregivers.

Figure 3.
Willingness to donate among HFAs and TCCs in Denver and San Francisco.
HFA, health care fair attendees. TCC, transplant recipient caregivers.

Figure 4. Schematic representation of variables associated with increased willingness to donate both in Denver and San Francisco.

Table 1

Participant characteristics.

	Denver		San Francisco	
	HFAs	TCCs	HFAs	TCCs
Sample size	88	86	167	111
Average age	46	51	45	50
Female	51%	72%	63%	69%
Caucasian	69%	72%	69%	46%
Highest education level				
High school or less	12%	22%	12%	20%
Some college	26%	37%	27%	28%
College graduate	62%	41%	61%	52%
Regularly attends religious services	31%	44%	27%	38%
Married	52%	86%	46%	74%
Has children	54%	79%	53%	69%

HFAs = Health fair attendees; TCCs = Transplant candidate caregivers

Table 2

Willingness to register as a deceased organ donor*

	Denver			San Francisco		
	OR	95% CI	p-value	OR	95% CI	p-value
Older age	0.98	0.96–1.01	0.24	1.01	0.99–1.03	0.15
Female	2.36	1.12–5.01	0.025	1.58	0.93–2.69	0.092
Caucasian	2.33	1.12–4.83	0.024	3.47	2.05–5.88	<0.0001
College graduate	11.07	3.62–33.88	<0.0001	2.24	1.11–4.54	0.025
Higher knowledge score	1.23	0.79–1.92	0.35	1.64	1.18–2.27	0.003
Higher perception score	1.23	1.14–1.33	<0.0001	1.18	1.13–1.24	<0.0001
Regularly attends religious services	0.81	0.38–1.69	0.58	0.66	0.38–0.93	0.14
Married	2.40	1.09–5.26	0.029	1.86	1.07–3.22	0.028
Has children	0.49	0.21–1.12	0.090	1.32	0.78–2.22	0.30

* Controlling for study group (TCC and HFA).

OR = Odds ratio; 95% CI = 95% confidence interval