

# Relationship of exposure to organ donation information to attitudes, beliefs, and donation decisions of next of kin

**Context**—Public education campaigns about organ donation are common, but their association to actual attitudes, beliefs, and decisions about organ donation among family members of donation-eligible individuals is unknown.

**Objective**—To examine the sources of organ donation information identified by donor and nondonor families who participated in a large-scale study to examine factors that influence organ donation decisions.

**Design**—Semistructured telephone survey conducted after a passive recruitment strategy.

**Setting and Participants**—Participants were 285 next of kin of donor-eligible individuals (147 donors, 138 nondonors) from one organ procurement organization.

**Results**—Most (85.6%) of next of kin were exposed to at least 1 source of donation information that was important to them, although the types of donation information they were exposed to varied widely. White and educated adults were more likely to have been exposed to more donation information than had minorities and persons with less education. Favorable attitudes and beliefs about organ donation, donor designation, and sharing donation intentions with others were all associated with more exposure to different types of donation information. Donation consent was more likely when next of kin had been exposed to more donation information in the months preceding the family member's death.

**Conclusions**—When examined in the context of other recent research, these findings argue for continued development and implementation of public education campaigns for organ donation, with an emphasis on repeated exposure over time. (*Progress in Transplantation*. 2009;19:173-179)

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Public education campaigns continue to be a common strategy for enhancing awareness about the need for more transplantable organs. Organ procurement organizations, independently or in partnership with private and public organizations and businesses, have implemented innovative strategies to inform the public about organ donation and to encourage individuals to register as donors. A variety of public education venues have been implemented and evaluated, including motor vehicle offices, driver's education classes, community events, worksites, hospitals, and media.<sup>1-10</sup> Moreover, some education campaigns have targeted specific audiences known to have less favorable attitudes toward organ donation (eg, minorities).<sup>1,7-9</sup>

Few published studies have addressed the impact of exposure to favorable organ donation and transplantation messages on public attitudes and behaviors (ie, donor registrations, donation consent). A 2005 Gallup Survey<sup>11</sup> indicated that most of the 2500 respondents identified general news media coverage (75%), local

news coverage (68%), and a public service announcement on television (58%) as important sources of information about organ and tissue donation. In a smaller study, Haustein and Sellers<sup>12</sup> found that adults attending a community medical clinic were more willing to donate their own organs at the time of death if they had recently been exposed to donation information. One segment of the public that is missing from these studies is the family member who is being approached about organ donation at the time of a loved one's death. Examining the exposure to organ donation information among these next of kin most likely provides some insight into whether such exposure is associated with actual consent decisions being made at the time of a family member's death.

Therefore, this study was done to examine the sources of information on organ donation identified by donor and nondonor families. In addition, we assessed the relationship between exposure to donation messages and several personal and contextual next-of-kin

variables. Specifically, we hypothesized that organ donation education from any source would be associated with next of kin having more favorable donation attitudes and beliefs, being registered as an organ donor, having shared their organ donation decision with others, and having consented to donate the organs of their deceased loved one. Data reported in this study are part of a larger study that examined multivariate predictors of organ donation decisions among next of kin.<sup>13</sup>

## Methods

### Study Design and Recruitment

The study design and recruitment details have been described previously.<sup>13</sup> Briefly, this was a non-random, cross-sectional survey of next of kin who were approached about donating the organs of a family member. Next of kin who had been approached about donation within one organ procurement organization during a 4-year period were invited to participate in a semistructured telephone interview that used a passive recruitment strategy. Families approached about donation were given a study information card and directed to a toll-free number to call if they wanted to complete the telephone interview.

### Telephone Interview

When a potential participant called into our research center, they were screened for eligibility by a trained research assistant, and verbal consent was then obtained to conduct the interview at a time convenient to the participant. The telephone interview comprised 115 questions and was guided by theoretical considerations, pilot work in our research center, published studies, and feedback from our advisory panel (organ procurement organization and transplant professionals, donor family members, behavioral scientists). Interview questions were designed to solicit sociodemographic information about the deceased and next of kin, contextual factors associated with the donation request, organ donation attitudes and beliefs among next of kin, and various communication processes. Of particular relevance to the present study, we provided participants with a list of possible sources for donation information and asked them to indicate if they were “important sources of information” for organ donation within the 6 months preceding their loved one’s death. We also asked them to identify any additional sources of organ donation information not included on our list.

Organ donation attitudes were measured with 6 questions by using a 4-point Likert scale (range, 6-24), with higher scores reflecting more positive attitudes. Sample items included the following: “A person willing to be an organ donor is a hero” and “Deciding to donate organs at the time of death adds extra meaning to life.” Organ donation beliefs were assessed with 22

questions by using a 4-point Likert scale (range, 22-88), with higher scores reflecting more positive beliefs. Sample items included the following: “I believed that donating my loved one’s organs would allow something positive to come out of his/her death” and “I believed that organ donation would negatively affect my loved one in the afterlife.”

Most (76%) of the interviews were completed within 1 month of the family member’s death. Participants were paid \$75 for study participation. The University of Florida’s institutional review board approved all study procedures.

### Statistical Analysis

All data were entered and analyzed by using the Statistical Package for the Social Sciences database (SPSS, Version 11, Chicago, Illinois). First, simple proportions for each source of donation information were calculated. Second, an “information dose” was determined by calculating how many sources of donation information were endorsed by individual participants. Third, univariate relationships between the donation information sources and next-of-kin sociodemographic characteristics, attitudes, beliefs, donor designation status, and donation decision (donation or refusal) were examined by using *t* tests for continuous variables, the Fisher exact test for variables with 2 categories, or a 2-tailed  $\chi^2$  test for variables with 3 or more categories.

## Results

### Sample Characteristics

Participants were 147 donor and 138 nondonor next of kin (63% participation rate). Most study participants (78%) were white (16% were black), female (80%), married (55%), employed (59%), and either the spouse (36%) or parent (26%) of the deceased. Mean (SD) age was 49.3 (13.2) years. Most (77%) had some college education. Slightly more than half (52%) identified themselves as a registered organ donor.

### Exposure to Organ Donation Information

Table 1 summarizes the proportion of participants who endorsed each item as an important source of organ donation information in the 6 months preceding the family member’s death. The only donation source identified as important for more than half of the participants was a newspaper or magazine article (52.6%). The other top sources of information were discussion with a family member (39.6%), public service announcement (36.1%), and a movie or television show (32.3%). The most common “other” sources of organ donation information were Web sites (*n* = 12), driver’s license offices (*n* = 7), and church services or bulletin (*n* = 5). Regarding “information dose” (ie, the number of donation sources identified by participants), 41 participants

Table 1 Important sources of organ donation information (N = 285)

Information source	No. (%)
Newspaper or magazine article	150 (52.6)
Discussion with a family member	113 (39.6)
Public service announcement on TV or radio	103 (36.1)
Movie or TV show	92 (32.3)
Information from a health care provider	88 (30.9)
Personal experience with organ donation	74 (26.0)
Discussion with a friend	66 (23.2)
Community activity or event	48 (16.8)
Other	37 (13.0)

(14.4%) did not identify any donation information sources in the past 6 months, 49 (17.2%) identified 1 source, 110 (38.6%) identified 2 or 3 sources, and 85 (29.8%) identified 4 or more sources.

**Exposure and Sociodemographic Characteristics**

White adults were more likely to have been exposed to any donation information (89.6% vs 71.9%,  $P < .001$ ), as were those with some college education (91.3% vs 66.7%,  $P < .001$ ). Also, whites and the college educated had been exposed to more sources of information in the past 6 months than had nonwhites and those with less formal education (mean [SD], 3.7 [2.4] vs 1.4 [1.8],  $t = 7.3$ ,  $P < .001$  and 3.0 [2.0] vs 1.9

[2.0],  $t = 3.7$ ,  $P < .001$ , respectively). Age, sex, marital status, and occupational status were not significantly associated with exposure to donation information or information dose ( $P < .05$ ).

Table 2 displays the relationship between socio-demographic characteristics and specific sources of donation information. White adults were more likely to have been exposed to organ donation information in a newspaper or magazine article ( $P = .05$ ) and through discussions with family members ( $P = .02$ ) than were nonwhites. Relative to those with less education, adults with a college education were more likely to endorse exposure to the following information sources: newspaper or magazine article ( $P < .001$ ), discussion with family members ( $P = .03$ ) or friends ( $P = .02$ ), health care provider ( $P = .03$ ), and personal experience with organ donation ( $P = .05$ ). Married adults were more likely than nonmarried adults to endorse personal experiences with organ donation as an important source of donation information ( $P = .03$ ).

**Exposure and Donation Attitudes and Beliefs**

Organ donation attitudes and beliefs were positively correlated with donation information dose ( $r = 0.34$ ,  $P < .001$  and  $r = .35$ ,  $P < .001$ , respectively). Table 3 presents the relationship between donation attitudes and beliefs and exposure to specific sources of donation information in the 6 months preceding the family member's death. With the exception of movies or TV shows (attitudes, beliefs) and community activities (beliefs), adults who were exposed to all other donation

Table 2 Significant associations between sociodemographic characteristics and exposure type

Information source and characteristic(s)	Percentage endorsing exposure type during past 6 months	$P^a$
Newspaper or magazine article		
Race	White, 55.3%; nonwhite, 39.6%	.05
Education	College, 58.0%; no college, 34.8%	<.001
Discussion with a family member		
Race	White, 46.2%; nonwhite, 29.7%	.02
Education	College, 45.2%; no college, 30.3%	.03
Public service announcement on TV or radio		NS
Movie or TV show		
Employment status	Employed, 27.8%; not employed, 38.8%	.05
Information from a health care provider		
Education	College, 34.2%; no college, 19.7%	.03
Personal experience with organ donation		
Education	College, 28.8%; no college, 16.7%	.05
Marital status	Married, 31.5%; not married, 20.1%	.03
Discussion with a friend		
Education	College, 26.5%; no college, 12.1%	.02
Community activity or event		NS

Abbreviation: NS, not significant.  
<sup>a</sup> From Fisher exact test.

Table 3 Mean (SD) donation attitudes and beliefs broken down by exposure type

Attitude or belief	Endorsed exposure type?		<i>t</i>	<i>P</i>
	Yes	No		
<b>Donation attitudes<sup>a</sup></b>				
Newspaper or magazine article	16.0 (3.2)	14.4 (4.4)	3.7	.001
Discussion with a family member	16.5 (3.3)	14.4 (4.0)	4.6	.001
Public service announcement on TV or radio	16.4 (2.9)	14.6 (4.2)	4.0	.001
Movie or TV show	15.4 (3.9)	15.2 (3.9)	0.5	.70
Information from a health care provider	16.2 (3.5)	14.8 (4.0)	2.8	.005
Personal experience with organ donation	16.9 (2.7)	14.7 (4.1)	4.3	.001
Discussion with a friend	16.7 (2.8)	14.8 (4.1)	3.5	.001
Community activity or event	16.8 (2.3)	14.9 (4.1)	3.1	.002
<b>Donation beliefs<sup>b</sup></b>				
Newspaper or magazine article	67.2 (9.7)	62.1 (12.4)	3.9	.001
Discussion with a family member	69.0 (9.6)	62.1 (11.6)	5.3	.001
Public service announcement on TV or radio	68.2 (8.8)	62.9 (12.1)	3.9	.001
Movie or TV show	65.8 (10.8)	64.3 (11.5)	1.0	.24
Information from a health care provider	66.8 (8.7)	63.9 (12.2)	2.0	.05
Personal experience with organ donation	70.3 (8.8)	62.9 (11.5)	5.0	.001
Discussion with a friend	69.0 (10.0)	63.5 (11.4)	3.5	.001
Community activity or event	67.0 (9.1)	64.4 (11.7)	1.5	.11

Abbreviation: NS, not significant.

<sup>a</sup> Measured by using 4-point Likert scale. Range = 6-24, with higher scores reflecting more positive attitudes toward organ donation.

<sup>b</sup> Measured by using 4-point Likert scale. Range = 22-88, with higher scores reflecting more positive beliefs about organ donation.

information sources had higher organ donation attitudes and beliefs when compared with those without such exposure.

### Exposure and Organ Donation Actions

Exposure to more donation information sources was associated with being a registered organ donor (mean [SD], 2.9 [2.1] vs 2.4 [2.0],  $t=2.0$ ,  $P=.05$ ), having shared one's donation intentions with others (3.1 [2.1] vs 1.9 [1.6],  $t=5.2$ ,  $P<.001$ ), and having consented to donate the organs of their deceased loved one (3.0 [2.1] vs 2.5 [2.0],  $t=2.0$ ,  $P=.05$ ). Regarding the last finding, the likelihood of donation consent increased with each incremental dose of donation information (see Figure).

Registered organ donors were more likely than nonregistrants to have had discussions with a friend (29.5% vs 16.0%,  $P=.01$ ), a personal experience with organ donation (31.5% vs 19.1%,  $P=.02$ ), and read a newspaper or magazine article on donation (60.4% vs 42.7%,  $P=.004$ ). Those who shared their donation intentions with others were more likely to have had discussions with family members (47.5% vs 26.3%,  $P=.001$ ) and friends (28.2% vs 14.1%,  $P=.008$ ), a personal experience with organ donation (32.2% vs 14.1%,  $P=.001$ ), read a newspaper or magazine article on donation (60.5% vs 38.4%,  $P=.001$ ), and heard a public service announcement on TV or radio (44.1% vs 20.2%,  $P<.001$ ). Finally, those who consented to donate their loved one's organs were more likely than those who refused consent to have had discussions with a family member (47.6% vs 31.2%,  $P=.005$ ) and

a personal experience with organ donation (32.0% vs 19.6%,  $P=.02$ ).

### Discussion

This study is the first to examine the types of donation information that next of kin were exposed to in the 6 months preceding making a donation decision about a deceased family member, and the relationship between this exposure and their organ donation attitudes, beliefs, and actions. The study had 5 main findings: (1) the

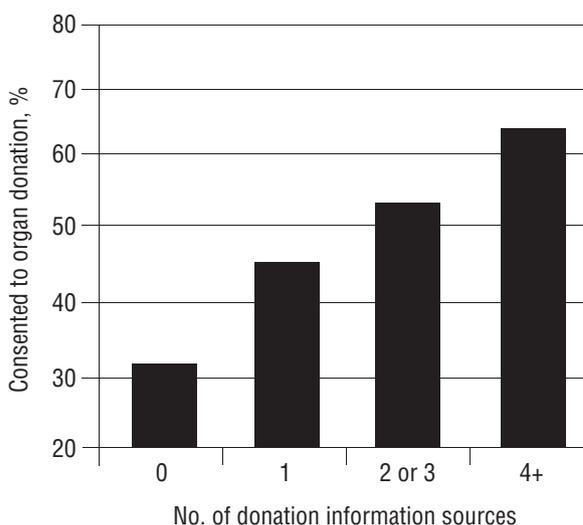


Figure Relationship between donation consent and exposure to donation information sources in the 6 months preceding loved one's death.

vast majority (85.6%) of next of kin were exposed to at least 1 donation information source that was considered important to them; (2) the types of donation information to which next of kin were exposed varied widely; (3) white, educated adults were more likely to have been exposed to more donation information than were minorities and persons with less education; (4) favorable attitudes and beliefs about organ donation, donor designation, and sharing donation intentions with others were all associated with more exposure to different types of donation information; and (5) next of kin were more likely to consent to donation when they had been exposed to more donation information in the months preceding a family member's death.

The finding that most participants had been exposed to some organ donation information that they considered helpful is encouraging. By far, the most common source of information for next of kin in this study was from a newspaper or magazine article on organ donation or transplantation. Print media can be very influential in shaping public opinions about organ donation. For instance, Feeley and Vincent<sup>4</sup> conducted a content analysis of 20 major newspapers in the United States and found that more than half (57%) of the published articles on organ donation were positive, with a primary focus on profiling the welfare of transplant recipients and the heroism of living donors. Also, findings from the Gallup survey<sup>10</sup> a few years ago found that general and local news media coverage (newspaper, TV, radio) was the most common source of organ donation information, with local news media stories being most influential in organ donation attitudes and behaviors. It is important to emphasize, however, that not all media messages about organ donation are favorable, and some most likely perpetuate certain myths by highlighting images of moral corruption in organ transplantation.<sup>14-16</sup>

Regardless of the public education strategies used, organ donation outreach in mainstream media markets is less likely to reach minorities and persons with less formal education. Minorities are more likely to report mistrust of the health care system and misunderstanding about organ donation, so it is imperative that organ donation outreach efforts address these barriers specifically. Additionally, members of minority groups may be underexposed to positive messages about organ donation and may not know how to document their organ donation intentions. For instance, Siegel et al<sup>17</sup> found that more than half of the Hispanic Americans surveyed did not know how to sign up as an organ donor and more than one-third of them stated that they would sign a donor card if asked. Also, the print media contain very little coverage of minority-specific organ donation and transplantation issues.<sup>14</sup> As demonstrated by several researchers to date, enhancing awareness of the need for organ donation in minorities requires more

targeted public education campaigns that are culturally sensitive, use ambassadors that are known within the community, and use culturally similar community outreach educators.<sup>1,7,9,18</sup> In light of the disproportionate representation of minorities on transplant waiting lists in the United States<sup>19</sup> and the less favorable attitudes among minorities toward organ donation,<sup>11</sup> effective strategies for disseminating culturally appropriate organ donation education must be urgently identified and evaluated.

An important finding, something we did not specifically examine in our primary study,<sup>13</sup> is that consent to organ donation was much more likely when the next of kin had a higher dose of organ donation exposure in the 6 months preceding the family member's death. This finding highlights the potential importance of repeated exposure to favorable messages about organ donation. One criticism of public education campaigns is that it is difficult to assess whether such campaigns actually lead to organ donation at the time of death, since it may be years between the intervention (ie, a workplace educational program) and the desired behavior (ie, the next of kin's consent to donation).<sup>20,21</sup> Moreover, some transplant professionals attribute the relatively stagnant rate of organ donation to the failure of public education campaigns and, therefore, report little enthusiasm for public education as a primary strategy for increasing organ donation worldwide.<sup>22</sup> However, such conclusions may be premature and the case for more public education can be made on at least 3 grounds.

First, research has consistently demonstrated that favorable organ donation attitudes, beliefs, and family discussions are strong predictors of family consent to organ donation.<sup>13,23,24</sup> That some organ donation campaigns are effective at increasing favorable attitudes and beliefs about organ donation and promoting family discussions about donation underscores the importance of public education. Second, our current study found a significant relationship between exposure to organ donation information and actual consent rates by next of kin. Third, recent research highlights the relationship between TV coverage of organ donation and actual organ transplant rates. Specifically, Quick et al<sup>25</sup> conducted an analysis of organ donation content in mainstream TV programming in the United States (ABC, CBS, NBC) during a 16-year period and found that as donation coverage increased, so too did the rate of organ transplantation. This association was particularly noteworthy for kidney transplantation, which might be explained by the more pervasive coverage of live donor transplantation by media outlets.<sup>14</sup> In light of the correlational nature of these findings, more prospective research is needed to properly examine whether (and how much) public education influences donation decisions by the general public, but these

findings collectively suggest that the organ donation and transplant communities can ill afford to abandon public education.

Findings from our study should be considered within the context of a few methodological limitations. First, this study involved only 1 organ procurement organization, and the degree to which these data can be generalized beyond the southeastern United States is unknown. Second, we used a passive recruitment strategy, which may have contributed to a self-selection bias in which those more favorable toward organ donation chose to participate. Indeed, we found that more favorable organ donation attitudes and beliefs, as well as the likelihood of being a registered organ donor, were associated with having been exposed to organ donation messages in the past several months. It is entirely possible that those with favorable donation attitudes are more likely to seek out or attend to organ donation messages that support these views. Third, while we asked participants to identify sources of organ donation information in the 6 months preceding their loved one's death, we did not ask them to specify when this exposure occurred. Therefore, we were unable to assess for any proximal effects of exposure, for example, whether those exposed to organ donation information in the days or weeks preceding the death were more or less likely to consent to donation. Fourth, because this study was not a randomized controlled trial, our findings must be considered correlational in nature and caution should be exercised to not infer causality between exposure to organ donation information and donation attitudes, beliefs, and actions.

Despite these shortcomings, this study is the first to examine exposure to organ donation information among next of kin who were recently approached about donating the organs of a loved one. When examined in the context of other recent research, our findings suggest that organ procurement organizations and transplant centers should continue to develop and implement organ donation public education campaigns. Emphasis should be placed on repeatedly exposing the public to favorable donation messages. Greater collaboration with media outlets may be the most efficient way in which to do this. In addition, more research is needed to systematically evaluate the effectiveness of public education efforts in increasing actual donation and transplantation rates.

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