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Attitudes and acceptance of First Person Authorization: A national comparison of donor and nondonor families

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Abstract

BACKGROUND—First Person Authorization (i.e., donor designation) legislation makes indicating one’s intent to be a posthumous organ donor legally binding, much like a living will or advance directive. Such legislation is the most recent in a long history of organ donation policies in the United States and has received little attention in the literature.

METHODS—This retrospective cohort study recruited nine US organ procurement organizations (OPOs) and their staff who make requests for organ donation as well as family decision makers approached by OPO staff about organ donation. Telephone interviews (N = 1,087) with family decision makers assessed the attitudes, perceptions, and behaviors regarding the request for organ donation of families of designated donors as compared with those of patients who did not formally designate themselves as donors.

RESULTS—Almost two thirds (65.7%) of the families of registered donors were aware of the decedent’s decision to register as a posthumous donor. Family decision makers who authorized donation and those of designated donors exhibited greater knowledge of organ donation and more positive attitudes than decision makers who refused to donate. Families of designated donors had more favorable perceptions of the request for organ donation and were more satisfied with both the time spent discussing donation and the request process; fewer donor designation families were surprised at the request for donation.

CONCLUSION—The enactment of First Person Authorization legislation increases the likelihood of familial authorization and satisfaction with the final donation outcome. As compared with other families approached about the option of organ donation, families of designated donors report having a more positive experience with the organ donation request process overall and greater comfort and satisfaction with the donation decision.

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AUTHORSHIP

Both H.M.T. and L.A.S. contributed equally to the literature search, study design, data collection, data analysis, data interpretation, and writing and revising the article for publication. Both H.M.T. and L.A.S. also had full access to all the data in the study and take responsibility for the integrity of the data and the accuracy of the data analysis. Neither the National Institute of Diabetes and Digestive and Kidney Diseases nor the Health Resources and Services Administration was involved in the design and conduct of the study; collection, management, analysis, and interpretation of the data; or preparation, review, and approval of the article.

DISCLOSURE

The authors declare no conflicts of interest.

LEVEL OF EVIDENCE—Retrospective cohort study, level II.**Keywords**

Organ donation; family authorization; First Person Authorization; donor designation

In the half century since the first successful kidney transplant, only modest progress has been made toward increasing the number of organ donations in the United States. In 1988, when data first became available, organs were recovered from 4,080 deceased Americans. Since then, this figure has doubled, with 8,127 deceased donors recovered in 2011.¹ During this same period, however, the number of critically ill patients awaiting an organ transplant increased exponentially. Whereas 25,000 patients with end-stage organ failure were on the waitlist in 1988, today, there are more than 114,000 waitlisted patients.¹ The marked wait time increases have not only been attributed to improved immunosuppressant therapies and surgical techniques that, in turn, have improved the likelihood of successful transplantation^{2,3} but also to the growing incidence of end-stage renal failure in the United States,⁴ for which transplantation is preferred over prolonged dialysis because of its comparatively lower cost and improved patient survival and quality of life.⁵⁻⁷ Recent data reveal, however, that from 2007 to 2009, the number of living and deceased organ donors dropped substantially.⁸ Although this decrease may be an anomaly, even a small loss of donors equates to the potential loss of eight transplantable organs per donor and the concomitant loss of human life.

First Person Authorization or “donor designation” is the most recent in a long line of regulatory efforts attempting to bridge the ever-increasing divide between the supply of transplantable organs and their demand. First Person Authorization makes the indication of an adult’s intent to donate some or all organs and/or tissue via a driver’s license, a donor card, or other documents legally binding. Enactment of this legislation necessitates changes in the way in which organ procurement organizations (OPOs) approach families of patients whose expressed desire was to become an organ donor at death. Rather than requesting family permission for donation, OPOs must now inform families of the patient’s decision to donate. Currently, all 50 states, the District of Columbia, and the US Virgin Islands have enacted the legislation.⁹

Although First Person Authorization has faced little opposition, unlike legislation that assumes all individuals will be posthumous organ donors unless expressly stated otherwise, that is, presumed consent, or legislation that forces individuals to make and document their donation wishes, that is, mandated choice, we have found few reports as to families’ reactions to the policy. The few evaluation studies conducted are limited to small geographic regions of the United States. One longitudinal study (N = 569) in Virginia found that families of designated donors (n = 162; 28.5%) reported more donation-related communication with the deceased and higher awareness of the decedent’s donation wishes and organ donation in general as compared with other families approached about the option of solid organ donation.¹⁰ Moreover, few designated donor families reported stress surrounding the approach for organ donation, and most were comfortable with the decedent’s decision to donate. Similarly, a 5-year evaluation of an educational campaign

promoting First Person Authorization in Ohio found most respondents stating that donors' wishes should be respected and implemented over family objection.¹¹ Finally, a cross-sectional study of 561 (348 donors, 213 non-donors) Floridians approached about donation reported greater support for the policy and stronger agreement that family permission was not needed among donors as compared with nondonors.¹²

The research reported here extends previous work by examining a nationwide sample of individuals who were approached about the option of deceased organ donation. Our purpose was to compare organ donation knowledge, attitudes, and behaviors of families of designated donors with individuals whose families did not have documentation of the patients' wishes. We also compared the donation process and examined the effectiveness and acceptability of donor designation legislation.

PATIENTS AND METHODS

Study Sites

Nine OPOs representing geographically diverse areas of the United States (i.e., New England, Northeast, Mid-Atlantic, South, Midwest, and West) were invited to participate as study sites. All agreed to the collaboration. OPO staff responsible for approaching families of potential donor-eligible patients and requesting donation were enrolled in the study. After each family contact for which a decision about organ donation was made, participating requesters completed an online survey to collect patient and surrogate decision maker (i.e., family) information. Data collection spanned from January 2009 to June 2011. First Person Authorization legislation was enacted in each region before data collection.

Family Sample

A letter describing the nature and purpose of the study was sent to family decision makers (N = 1,391) approached about the option of donating organs. Each letter also provided instructions for opting out of the research. To allow families time to grieve, the letters were sent 2 months after the death of adult patients and 3 months after the death of pediatric patients, a procedure we have used in past research.^{13,14} Telephone interviews were conducted with 1,090 families agreeing to participate. The sample included 839 families (77.0%) who did not have donor designation (718 families authorized donation, 121 refused donation) and 251 (23.0%) families of designated donors. An overall response rate of 78.4% was obtained for this study. The study received approval from the Virginia Commonwealth University Institutional Review Board. Informed consent was obtained from both OPO request staff and family participants.

Family Interview

Seven research staff were extensively trained to conduct the family interviews during a period of 2 months. The interviews consisted of a series of structured and semistructured questions capturing a variety of aspects of the request for organ donation, including attitudes toward First Person Authorization and satisfaction with the donation request process. The interview, with corresponding measures, has been well validated and used in previous studies examining organ and tissue donation.¹³⁻¹⁵ The specific measures included in the

interview are described in detail below. Higher scores indicate higher levels of each measured variable.

Organ Donation Attitudes

Attitudes toward organ donation were assessed using five-point Likert-type scales drawn from the Attitudes Toward Organ Donation Scale^{16,17} asking respondents to indicate their level of agreement with 17 statements; individual items were summed to compute a global attitude score that ranged from 17 to 85. Internal consistency reliability for the scale was mediocre (Cronbach's $\alpha = 0.44$).

Organ Donation Knowledge

Knowledge of organ donation was measured using four true or false questions; correct responses were summed to create a global knowledge score.

Initial Reaction to the Request

A categoric item assessed initial reactions to the idea of organ donation (favorable/unfavorable/mixed). One dichotomous (yes/no) question gauged families' surprise at the request for organ donation.

Time Discussing Donation

Respondents were also asked to report the total amount of time spent discussing organ donation and donation-related issues; satisfaction with the length of the discussion was measured on a seven-point Likert-type scale.

Perceptions of Requesters' Communication

A shortened version of Burgoon and Hale's Relational Communication Scale¹⁸ was used to capture respondents' perceptions of requesters' relational communication skill during the request for donation along 12 seven-point Likert-type scales of agreement. A single five-point item also asked decision makers to rate the quality of the requesters' communication during the donation discussion. Another seven-point item assessed whether respondents felt pressured or harassed into donating.

Decisional Comfort

Two items assessed respondents' decisional regret. The first, a seven-point Likert-type item, asked participants to indicate their level of comfort with the donation decision. The second asked whether participants would make the same decision about donation (yes/no).

Satisfaction With Request

One seven-point Likert-type item assessed satisfaction with the request process.

First Person Authorization

A series of questions were posed to gauge the families' awareness of and reactions to patients' decisions to donate posthumously. Specifically, three dichotomous (yes/no) items assessed families' awareness of the patient's status as a donor, comfort with the manner in

which this information was given, and stress experienced as a result of being informed about the decision. Two open-ended questions allowed respondents to elaborate on their responses.

Demographic Characteristics

Sociodemographic information, including sex, age, ethnicity, race, and income, was collected from all participants.

Data Analysis

Summary statistics (i.e., means, SDs, frequencies, percentages) were used to characterize the overall sample as well as the three subgroups: family participants who (1) authorized donation, (2) declined donation, and (3) families of designated donors. The appropriate tests of association were performed (e.g., analysis of variance, χ^2) to examine the relationship between the primary outcome variable (i.e., authorization/refusal/donor designation) and the other study variables; Tukey's post hoc comparisons were performed to pinpoint where differences between groups occurred. Analyses were performed using IBM SPSS Statistics 19.

RESULTS

Sample

Overall, the sample was primarily composed of white (77.5%; 16.0% African American, 2.9% multiracial, 2.1% other, 1.5% unknown) females (68.9%) and self-reported Protestant religious affiliation (38.2%) who were raised in the continental United States (91.1%); approximately 15% (14.9%) of the sample self-identified as Hispanic/Latino (a). On average, surrogate family decision makers were aged 48 years (SD, 13.9 years) and had 14 years of education (SD, 2.3 years). Although most participants reported a willingness to donate their own organs at death (86.3%), only one half (50.6%) of those interviewed were registered organ donors. See Table 1 for a complete description of the sample.

Organ Donation Decisions

Family decision makers of patients who had or had not designated themselves as donors differed significantly. As would be expected, designated donors were much more likely to become donors; 97.6% of designated donor families donated compared with 85.6% of other families. This meant that despite the designation, 6 of 251 countermanded the patient's decision to donate. Although First Person Authorization legislation is intended to uphold personal autonomy in the choice to become a posthumous organ donor, there is currently no penalty for families who override patients' decisions and do not donate. Although some OPOs will uphold decedents' wishes in the face of family dissent, others choose not to procure out of habit and/or to prevent negative publicity. The differences between the families of patients who designated themselves as donors (First Person Authorization) and the non-designated families who chose to donate (NDD) and those who refused donation (NDR) will be the focus of the remainder of this article.

Demographic Comparison

Significant differences were found in the demographic characteristics of the three subgroups of families. Specifically, First Person Authorization families were less likely to be of Hispanic/Latino ancestry ($\chi^2_2 = 18.8, p < 0.001$) and more likely to be white ($\chi^2_2 = 36.6, p < 0.001$) as compared with the two other groups. They also reported a greater willingness to become a posthumous organ donor ($\chi^2_4 = 109.4, p < 0.001$) and to be listed on an organ donor registry ($\chi^2_4 = 76.5, p < 0.001$) than families of patients who were not registered organ donors. First Person Authorization families also had more years of education than other families in the sample ($F_{2, 1,087} = 4.4, p = 0.01$) (see Table 1).

Organ Donation Attitudes and Knowledge

Knowledge of organ donation was high, with 1,075 (98.6%) of participants answering at least one half of the items correctly. Overall, families demonstrated the least knowledge regarding the implications of donor designation on organ, tissue, and eye donation (Fig. 1). That is, approximately 20% of families did not understand that designating oneself as an organ donor also committed them to the posthumous donation of tissues (e.g., skin, bone, heart valves, etc.) and eyes (e.g., cornea, sclera, whole eye). NDRs, however, exhibited the highest degree of knowledge about this item. In addition, significant differences were found in the proportion of correct responses for each item and in the global knowledge scores between subgroups ($F_{2, 1,087} = 4.5, p = 0.01$). Specifically, NDDs and designated donor families displayed equally more knowledge of organ donation overall (mean, 3.5; SD, 0.7) than did NDRs (mean, 3.3; SD, 0.9).

On average, respondents expressed positive attitudes toward organ donation (mean, 64.3; SD, 7.1) (see Table 2). However, significant mean differences in global attitude scores were found between subgroups ($F_{2, 1,087} = 12.5, p < 0.001$), with both NDDs and designated donor families exhibiting significantly more favorable attitudes than NDRs (mean, 64.5 and 64.9 vs. 61.3). As compared with families who were faced with making the decision about donation, a larger percentage of designated donor families found solace in organ donation, understood the implications of brain death, and were comfortable with health care providers' knowledge of their willingness to donate organs posthumously. These families, however, were less likely to support monetary payments to donor families, the concept of directed donation, or recovering organs from registered donors without family permission.

Perceptions of the Request for Donation

Table 3 presents respondents' perceptions of a variety of aspects of the request process. Overall, families of designated donors had more favorable perceptions of the request for organ donation. For instance, as compared with other families sampled, significantly fewer designated donor families were surprised at the request for donation ($\chi^2_2 = 30.7, p < 0.001$) or expressed a desire to change the donation decision ($\chi^2_2 = 88.0, p < 0.001$). Conversely, more designated donor families were initially favorable toward the idea of organ donation ($\chi^2_2 = 112.5, p < 0.001$). As compared with NDRs, designated donor families reported significantly less pressure regarding the decision about donation ($F_{2, 1,087} = 57.8, p < 0.001$), greater satisfaction with both the time spent discussing donation ($F_{2, 1,087} = 31.5, p < 0.001$) and the request process ($F_{2, 1,087} = 94.2, p < 0.001$), and more comfort with the decision to

donate ($F_{2, 1,087} = 27.0, p < 0.001$). Significant mean differences were not found between designated donor and NDD families on these variables. Finally, designated donor families rated the overall quality of communication with the OPO request staff ($F_{2, 1,087} = 83.8, p < 0.001$) and the staff member's relational communication skill ($F_{2, 1,087} = 93.0, p < 0.001$) significantly more positively than either NDD or NDR families.

Impact of Donor Designation on Families' Emotional Well-Being

Almost two thirds (65.7%) of the designated donor families were aware of the decedent's decision to register as a posthumous donor. Of the families who were unaware ($n = 86$), 12 (14.0%) were not comfortable with the manner in which they were informed of the patient's status as a registered donor. The most commonly cited complaints were the timing (e.g., being told right after patient was declared brain dead or before being informed of the patient's condition) and mode (e.g., emergency medical technicians) of delivery and requesters' communication of the information. In addition, 12 (14.0%) families noted that the information added to their stress because of lack of family communication regarding the patient's donation wishes, the family's position against organ donation, and the use of life supports to maintain the patient for donation purposes.

A small number (2.4%) of designated donor families refused donation. This figure is considerably lower than the 20% refusal rate found in one single-site study.¹⁹ On request, four were initially favorable toward the idea of organ donation, one was unfavorable, and one was unsure. The reasons offered for refusal included family exhaustion, dissatisfaction with the patient's care, disagreement about donation, and issues surrounding the delay or maintenance of life supports. None stated that they believed the patients had changed their minds about donation or had not designated their wishes accurately.

DISCUSSION

Unlike other regulatory efforts to increase the number of organ donors in the United States and the number of organs available for transplant, the enactment of First Person Authorization legislation was firmly grounded in a body of empirical evidence that knowledge of patients' wishes regarding solid organ donation not only aids families in their decision making but also increases the likelihood of familial authorization and satisfaction with the final donation decision.²⁰⁻²⁵ Our results provide additional support for this legislative approach and offer assurances that this policy does not add additional stress to already bereaved families. Of note are findings that families of designated donors report having a more positive experience with the organ donation request process overall and greater comfort and satisfaction with the donation decision than others.

Although more than one third of the families of registered donors were not aware of the patient's decision to donate posthumously, the donation decision was overwhelmingly accepted. A minority of these families (17%), however, expressed dissatisfaction with the way in which they were notified of the patient's status as a donor. For example, on learning of the patient's decision from an OPO requester and reacting with surprise, one respondent reported being told, "you don't know him too well." Such a response likely caused the family additional distress during a time marked by stress, anxiety, and grief. Clearly, all

health care providers and OPO request staff should be provided training on how to modify their approach with designated donor families. Notification of the patients' decision should be done with tact and sensitivity. Specifically, OPO staff should "provide continuing support and care for the donor family while guiding them toward an understanding of their loved one's wishes."²⁶ Request staff seem to be successful at this, with some notable exceptions. Continued efforts to educate the public about the benefits of organ donation and the critical importance of family communication surrounding the topic, particularly with regard to the act of designating oneself as a donor, are needed as well.

Although this research is the first to examine in-depth the attitudes and behaviors for designated donor families in a national sample, it is not without limitation. Significant differences were found in the demographic characteristics between the three subgroups under examination. Families of registered donors were more likely to be white and to hold more years of education than other families sampled; they were also more willing to donate their own organs and to be a registered organ donor. These findings are consistent with past research documenting positive associations between status as an organ donor and willingness to donate with white race and more years of education.^{27,28} The study's major limitation is the smaller number of families refusing donation. This reflects the myriad of challenges associated with contacting and recruiting families who refused to donate, including incomplete and/or completely missing contact information, transience, and negative experiences with the patient's care and/or the request for donation. Finally, although our participation rate was high (74.3%), we were unable to collect information on families declining participation aside from their donation decision; significantly more NDRs (49.4%) declined participation in the research than NDDs/designated donor families (16.1%; $\chi^2_1 = 128.0, p < 0.001$). As noted above, statistically significant differences between families authorizing to donate and those refusing donation have been documented. Therefore, our findings may contain some degree of nonresponse bias, although very few families who did not donate were those whose loved ones had designated themselves as donors.

This study is the first national examination of the effects of First Person Authorization legislation on the organ donation request process. The study provides strong evidence that this policy can and is being successfully and sensitively implemented. We maintain that, at least in the US context, First Person Authorization, which places a premium on individual autonomy, is ethically and culturally preferable to approaches that fail to acknowledge population diversity (e.g., presumed consent) or commoditize the organ donation process (e.g., monetary incentives for donation).

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References

1. [Accessed June 18, 2012] United Network for Organ Sharing. Available at: <http://www.unos.org/>
2. Veroux P, Giuffrida G, Cappellani A, et al. Two-as-one monolateral dual kidney transplantation. *Urology*. 2011; 77:227–230. [PubMed: 20399490]

3. Khush KK, Hunt SA. Cardiac transplantation—status in 2011. *Eur Cardiol*. 2011; 7:273–279.
4. US Renal Data System. Volume Two: Atlas of end-stage renal disease in the United States. National Institutes of Health, National Institute of Diabetes and Digestive and Kidney Diseases, Division of Kidney, Urologic and Hematologic Diseases; 2011 Annual Data Report.
5. Merion RM, Ashby VB, Wolfe RA, et al. Deceased-donor characteristics and the survival benefit of kidney transplantation. *JAMA*. 2005; 294:2726–2733. [PubMed: 16333008]
6. Wolfe RA, Ashby VB, Milford EL, et al. Comparison of mortality in all patients on dialysis, patients on dialysis awaiting transplantation, and recipients of a first cadaveric transplant. *N Engl J Med*. 1999; 341:1725–1730. [PubMed: 10580071]
7. Abecassis M, Bartlett ST, Collins AJ, et al. Kidney transplantation as primary therapy for end-stage renal disease: a National Kidney Foundation/Kidney Disease Outcomes Quality Initiative (NKF/KDO-QITM) conference. *Clin J Am Soc Nephrol*. 2008; 3:471–480. [PubMed: 18256371]
8. Neumann ME. Transplant updated: UNOS data shows largest drop in organ donations in 20 years. *Nephrol News Issues*. 2010; 24:30. [PubMed: 20196500]
9. Donate Life America. National Donor Designation Report Card. 2011.
10. Dodd-McCue D, Cowherd R, Iveson A, Myer K. Family responses to donor designation in donation cases: a longitudinal study. *Prog Transplant*. 2006; 16:150–154. [PubMed: 16789706]
11. Downing, K.; Jones, L. First-person consent Ohio donor registry: the influence of the first-person consent registry on increasing organ donation. In: Siegel, J.; Alvaro, EM., editors. *Understanding Organ Donation: Applied Behavioral Science Perspectives*. Hoboken, NJ: Wiley-Blackwell; 2009.
12. Rodrigue JR, Cornell DL, Howard RJ. Attitudes toward financial incentives, donor authorization, and presumed consent among next-of-kin who consented vs. refused organ donation. *Transplantation*. 2006; 81:1249–1256. [PubMed: 16699449]
13. Siminoff LA, Gordon N, Hewlett J, Arnold RM. Factors influencing families' consent for donation of solid organs for transplantation. *JAMA*. 2001; 268:71–77. [PubMed: 11434829]
14. Siminoff LA, Traino HM, Gordon N. Determinants of family consent to tissue donation. *J Trauma*. 2010; 69:956–963. [PubMed: 20526212]
15. Siminoff LA, Mercer MB, Graham G, Burant C. The reasons families donate organs for transplantation: implications for policy and practice. *J Trauma*. 2007; 62:969–978. [PubMed: 17426556]
16. Siminoff LA, Arnold RM. Increasing organ donation in the African American community: altruism in the face of an untrustworthy system. *Ann Int Med*. 1999; 130:607–609. [PubMed: 10189333]
17. Siminoff LA, Burant C, Youngner SJ. Death and organ procurement: public beliefs and attitudes. *Soc Sci Med*. 2004; 59:2325–2334. [PubMed: 15450707]
18. Burgoon K, Hale JL. Validation and measurement of the fundamental themes of relational communication. *Commun Monogr*. 1987; 54:19–41.
19. Britton Christmas A, Burris GW, Bogart TA, Sing RF. Organ donation: family members NOT honoring patient wishes. *J Trauma*. 2008; 65:1095–1097. [PubMed: 19001980]
20. Siminoff LA, Lawrence RH. Knowing patients' preferences about organ donation: does it make a difference? *J Trauma*. 2002; 53:754–760. [PubMed: 12394879]
21. Burroughs TE, Hong BA, Kappel DF, Freedman BK. The stability of family decisions to consent or refuse organ donation: would you do it again? *Psychosom Med*. 1998; 60:156–162. [PubMed: 9560863]
22. Radecki CM, Jaccard J. Psychological aspects of organ donation: a critical review and synthesis of individual and next-of-kin donation decisions. *Health Psychol*. 1997; 16:183–195. [PubMed: 9269891]
23. May T, Aulisio MP, DeVita MA. Patients, families, and organ donation: who should decide? *Milbank Q*. 2000; 78:323–326. [PubMed: 10934996]
24. Oz MC, Kherani AR, Rowe A, Roels L, Crandall C, Tomatis L, et al. How to improve organ donation: results of the ISHLT/FACT poll. *J Heart Lung Transplant*. 2003; 22:389–410. [PubMed: 12681417]
25. The Gallup Organization. National Survey of Organ and Tissue Donation Attitudes and Behaviors. Rockville, MD: Health Resources and Services Administration; 2005.

26. Metzger RA, Taylor GJ, McGaw LJ, Weber PG, Prottas JM. Research to practice: a national consensus conference. *Prog Transplant*. 2005; 15:379–384. [PubMed: 16477821]
27. Rodrigue JR, Cornell DL, Howard RJ. Organ donation decision: comparison of donor and nondonor families. *Am J Transplant*. 2006; 6:190–198. [PubMed: 16433774]
28. DeJong W, Granz HG, Wolfe SM, Nathan H, Payne D, Reitsma W, et al. Requesting organ donation: an interview study of donor and nondonor families. *Am J Crit Care*. 1998; 7:13–23. [PubMed: 9429679]

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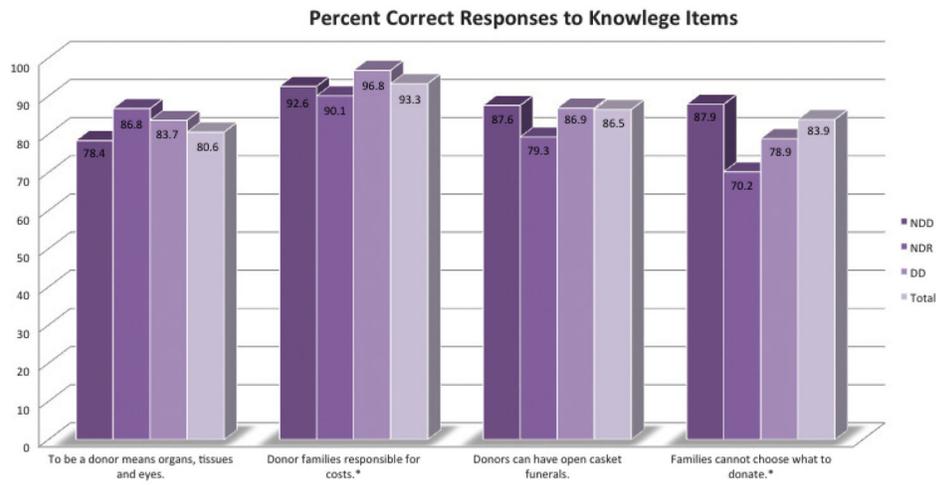


Figure 1. Organ donation knowledge. *Correct response is “false.” *DD*, designated donor; *NDD*, nondesignated donor; *NDR*, nondesignated refuser.

TABLE 1

Sample Demographics

Characteristic	Overall (N = 1,090)	Authorized Donation (n = 718)	Refused Donation (n = 121)	Donor Designation (n = 251)
Sex				
Female	751 (68.9)	497 (69.2)	84 (69.4)	170 (67.7)
Ethnicity*				
Hispanic/Latino	162 (14.9)	127 (17.7)	19 (15.7)	16 (6.4)
Race*				
White	845 (77.5)	548 (76.3)	75 (62.0)	222 (88.4)
Marital status*				
Single/never married	147 (13.5)	104 (14.5)	24 (19.8)	19 (7.6)
Married/cohabit	387 (35.5)	259 (36.1)	39 (32.2)	89 (35.5)
Divorced	154 (14.2)	101 (14.1)	9 (7.4)	44 (17.5)
Widowed	399 (36.6)	252 (35.1)	48 (39.7)	99 (39.4)
Religious affiliation*				
Protestant	416 (38.2)	261 (36.4)	46 (38.0)	109 (43.4)
Catholic	303 (27.8)	207 (28.8)	33 (27.3)	63 (25.1)
Other	254 (23.3)	169 (23.5)	37 (30.6)	48 (19.1)
None	114 (10.5)	78 (10.9)	5 (4.1)	31 (12.4)
Health-related occupation				
Yes	160 (14.7)	100 (13.9)	19 (15.7)	41 (16.3)
Raised in the United States				
Yes	993 (91.1)	645 (89.8)	109 (90.1)	239 (95.2)
Age, y				
Mean (SD)	47.7 (13.9)	47.4 (14.3)	47.1 (12.9)	49.0 (12.8)
Education, y [†]				
Mean (SD)	13.8 (2.3)	13.7 (2.2)	13.9 (2.2)	14.2 (2.4)
Willing to donate own organs*				
Yes	941 (86.3)	643 (89.6)	70 (57.9)	228 (90.8)
Registered organ donor*				
Yes	552 (50.6)	344 (47.9)	30 (24.8)	178 (70.9)

Values are expressed as n (%) unless noted otherwise; counts may not sum to 1,090 (100%) because of missing values.

* χ^2 test statistic significant at $\alpha = 0.05$ level.

[†] Significant mean difference between families authorizing donation and donor designation ($p < 0.01$).

TABLE 2

Organ Donation Attitudes

Attitude Item	Somewhat or Strongly Agree, n (%)			
	Overall (N = 1,090)	Authorized Donation (n = 718)	Refused Donation (n = 121)	Donor Designation (n = 251)
Organ donation helps families grieve. [†]	816 (74.9)	556 (77.4)	55 (45.5)	205 (81.7)
People who have a signed donor card should receive an organ transplant before others do.*	303 (27.8)	203 (28.3)	41 (33.9)	59 (23.5)
I would be more comfortable discussing donation with someone of my own race or ethnic background.* [†]	98 (9.0)	75 (10.4)	13 (10.7)	10 (4.0)
The government should provide money to families who donate organs.*	255 (23.4)	164 (22.8)	34 (28.1)	57 (22.7)
Someone who receives an organ transplant that doesn't work out should have the same chance of getting another organ as someone who is waiting for his or her first one.	724 (66.4)	483 (67.1)	80 (66.1)	161 (64.4)
Organ donation makes something positive come out of death. [†]	1,075 (98.6)	712 (99.2)	117 (96.7)	246 (98.0)
Rich or famous people who need a transplant are more likely to get a transplant than others.* [†]	562 (51.6)	370 (51.5)	76 (62.8)	116 (46.2)
Families who agree to donate organs should be given money to pay for a funeral.* [†]	352 (32.3)	236 (32.9)	49 (40.5)	67 (26.7)
If my doctor told me that I needed a transplant I would want one. [†]	991 (90.9)	665 (92.6)	106 (87.6)	220 (87.6)
People who have organ transplants are able to lead full productive lives.	1,010 (92.7)	662 (92.2)	113 (93.4)	235 (93.6)
Young people should have a chance to get an organ transplant before older people.*	487 (44.7)	326 (45.4)	48 (39.7)	113 (45.0)
A person is dead only when his or her heart stops.* [†]	290 (26.6)	195 (27.2)	47 (38.8)	48 (19.1)
I would be willing to pay higher health insurance premiums to be sure that everyone who needed a transplant gets one.*	592 (54.3)	404 (56.3)	56 (46.3)	131 (52.2)
I worry that if doctors know I am willing to donate organs they won't do as much to save my life.* [†]	253 (23.2)	181 (25.2)	37 (30.6)	35 (13.9)
I think that when families donate, they should be able to ask that the organs go to a particular person. [†]	664 (60.9)	454 (63.2)	77 (63.6)	133 (53.0)
If someone has a donor card, hospitals shouldn't have to ask families for permission to take the organs.*	417 (38.3)	304 (42.3)	45 (37.2)	68 (27.1)
If someone in my family needed one of my kidneys and the doctors said it was possible, then I would do it. [†]	1,058 (97.1)	700 (97.5)	119 (98.3)	239 (95.2)
Global Attitude Score [‡]	64.3 (7.1)	64.5 (7.1)	61.3 (6.6)	64.9 (6.9)

Values are expressed as mean (SD).

* Item was reverse scored to calculate Global Attitude Score.

[†] χ^2 test statistic significant at $\alpha = 0.05$ level.

[‡] Significant mean differences between authorizing and refusing families ($p < 0.001$) and between donor designation and refusing families ($p < 0.001$).

TABLE 3

Perceptions of the Request for Donation

Request Process Variable	Overall (N = 1,090)	Authorized Donation (n = 718)	Refused Donation (n = 121)	Donor Designation (n = 251)
Surprise at request for donation *				
Yes [†]	346 (31.7)	230 (32.0)	61 (50.4)	55 (21.9)
Initial reaction to organ donation *				
Favorable [†]	762 (69.9)	511 (71.2)	38 (31.4)	213 (84.9)
Time spent discussing donation, min [‡]				
Mean	187.8 (531.8)	208.9 (582.9)	56.2 (260.8)	190.6 (463.7)
Median	68.0	75.0	25.0	90.0
Range	0–5,760	0–5,760	1–2,880	5–5,760
Satisfaction with discussion time [§]	6.5 (1.2)	6.5 (1.0)	5.7 (1.8)	6.7 (1.0)
Requesters' relational comm. ^{//}	75.9 (8.5)	76.6 (7.0)	66.9 (13.5)	78.1 (6.6)
Requesters' comm. quality ^{//}	4.5 (0.9)	4.5 (0.8)	3.6 (1.3)	4.7 (0.7)
Pressured/harassed about donation [§]	1.7 (1.6)	1.6 (1.4)	3.1 (2.3)	1.4 (1.3)
Comfort with donation decision [§]	6.5 (1.1)	6.6 (0.9)	5.9 (1.8)	6.7 (0.9)
Would make same decision again * No or unsure [†]	68 (6.2)	30 (4.2)	31 (25.6)	7 (2.8)
Satisfaction with request process [§]	6.3 (1.3)	6.5 (1.1)	4.9 (2.2)	6.6 (1.0)

Values are expressed as mean (SD) unless noted otherwise.

* χ^2 test statistic significant at $\alpha=0.001$ level.

[†] Values are expressed as n (%).

[‡] Significant differences between authorizing and refusing families.

[§] Significant differences between donor designation families and families refusing donation.

^{//} Significant differences between all three subgroups.

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