

Attitudes toward Financial Incentives, Donor Authorization, and Presumed Consent among Next-of-Kin Who Consented vs. Refused Organ Donation

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Background. Financial incentives, donor authorization, and presumed consent are strategies designed to increase organ donation rates. Surveys designed to assess attitudes toward these initiatives have been conducted with the general public, transplant patients, and transplant professionals.

Methods. To assess attitudes toward financial incentives, donor authorization, and presumed consent and to identify multivariate predictors of such attitudes, we conducted telephone interviews with 561 family members who had recently been asked for consent to donate the organs of a deceased family member (348 donors, 213 nondonors).

Results. Financial incentives would have made a difference in the donation decision for 54% of nondonors (vs. 46% of donors, $P=0.02$), and a higher percentage of nondonors would themselves become donors if financial incentives were available ($P=0.03$). Donors had significantly more favorable attitudes toward donor authorization ($P<0.0001$) and presumed consent ($P<0.0001$) policies. Overall, 54% of participants thought that family permission for donation was unnecessary when the deceased documented their donation intention, and 24% favored a presumed consent law with an opting out provision.

Conclusions. Of the three initiatives, donor authorization is likely supported by more donor and nondonor families than either financial incentives or presumed consent. Public education efforts should aim to better inform the public regarding existing and proposed donor authorization legislation and its benefits for registered organ donors and their families.

Keywords: Organ donation, Financial incentives, Presumed consent.

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The shortage of donor organs is without question the major impediment to extending the lives of more patients awaiting solid organ transplantation. The gap between the number of patients awaiting transplantation and the number of donor organs procured continues to widen (1, 2). Although most individuals report favorable attitudes toward organ donation (3), next-of-kin consent rates at time of death are approximately 54% (1). This low consent rate has been cited by the Association of Organ Procurement Organizations as the primary reason for the gap between the number of potential organ donors and the number of actual donors (4).

Some strategies designed to close the gap between po-

tential and actual donors have been implemented with little controversy or debate. These include extensive public education campaigns, required request policies, an in-house organ procurement organization (OPO) program, donor authorization or “first-person consent” legislation, the establishment of statewide donor registries, and the Organ Donation Breakthrough Collaborative initiated by the US Secretary of Health and Human Services Tommy G. Thompson in 2003, among others. Despite the apparent success of some of these efforts (5, 6), deceased donation rates have not yet been maximized.

Other proposed strategies appear to be more controversial. For instance, both direct (actual monetary value, e.g., cash payment) and indirect (organs traded for goods or services of cash value, e.g., funeral expense voucher, contribution to charity) financial incentives have been proposed and debated in the literature (7–12) and were the topic of several presentations at the 2005 American Transplant Congress in Seattle, Washington (13). Proponents of financial incentives argue that they are cost-effective and would increase donation rates; whereas opponents counter that such incentives would intrude on altruism by promoting dehumanization and reduce consent rates. Another controversial strategy is the presumption of consent, unless an individual has “opted out” of donation prior to death (14, 15). In such instances, OPOs could proceed with organ removal when the donor’s

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intentions are not known or not documented, even in the absence of family consent. Proponents of presumed consent argue that it is a moral and ethical imperative for the benefit of society and that it has increased donation rates in other countries, whereas opponents counter that it will undermine respect for autonomy and self-determination, which are basic tenets of informed consent.

Several surveys have been conducted to examine the perceptions of the general public (16, 17), transplant patients (18), and the transplant community (19–21) regarding these controversial proposals to increase deceased organ donation. Findings have been mixed, with no clear public imperative to prevent or promote such initiatives. While these cross-sectional opinion surveys have included various segments of the transplant community, they have largely ignored the perspective of those families that have faced the organ donation decision. This study seeks to examine the attitudes and opinions of donor and nondonor families regarding financial incentives, donor authorization, and presumed consent.

MATERIALS AND METHODS

We conducted a nonrandom, cross-sectional survey of adults who had recently been approached about donating a deceased family member's organs. Participants were recruited between July 2001 and December 2004 using three different strategies. First, each next-of-kin or legal surrogate who was approached by coordinators from one Southeastern US organ procurement organization (OPO) were given a laminated card describing the study's purpose, the inclusion criteria and likely time commitment, and how to indicate interest in the study. Second, a message describing the study and inviting participation was posted on three separate occasions on the National Donor Family Council (NDFC) website. Third, a study advertisement was placed in three regional newspapers (Jacksonville Florida Times-Union, Boston Herald, Omaha World-Herald) for three non-consecutive days. Inclusion criteria included: at least 18 years old, primary (preferred) or secondary decision-maker when approached about organ donation, residential telephone service, and ability to complete a telephone interview in English. Monetary reimbursement (\$25 to \$75 US) was provided.

Survey Administration and Content

In all instances, prospective participants who called the research center's toll-free number spoke to a trained research assistant, who ascertained whether the individual met eligibility criteria and provided more information about the study, answered questions, requested study participation, and, for those desiring to participate, scheduled an interview time. Prospective participants were then called at the scheduled time, oral consent was obtained and documented, and the semi-structured interview was conducted. If the individual was not available, we either left a message or called back at another time to reschedule the interview. If a second scheduled appointment was missed, we considered this a passive refusal and made no further attempt to contact the individual. All interviewers were research assistants with specialized education and training in the organ donation request process, grief and bereavement, crisis management, and the protection of human research participants.

The development of the semi-structured interview was guided by theoretical considerations (3), our own pilot studies, prior research with next-of-kin donors and nondonors (22–24), and recommendations of an advisory panel that included OPO and transplant professionals, donor families, and behavioral scientists. The interview comprised 115 questions that gathered information about the sociodemographic characteristics of the deceased and next-of-kin participant, the circumstances surrounding the death and hospitalization of the family member, the donation request and decision-making processes of the next-of-kin, understanding of brain death, current attitudes toward transplantation and organ donation, and organ donation beliefs at the time of the donation request. The University of Florida Institutional Review Board approved all study procedures.

Attitudes about Organ Donation Initiatives

In addition to the content noted above, participants responded to seven questions related to financial incentives, donor authorization, and presumed consent. To measure attitudes about financial incentives, two questions were asked: (1) "Would a cash payment to you or your loved one's estate, paying for your loved one's funeral expenses, or a charitable contribution in your loved one's name have made a difference in deciding whether to donate his/her organs?" Answers were "yes, would have made a difference; no, would not have made a difference." (2) "Would a cash payment to your estate, paying for your funeral expenses, or a charitable contribution in your name make a difference in deciding whether to donate your own organs at time of death?" Answers were "yes, would make a difference; no, would have no effect at all on my decision." For those who indicated that financial incentives would make a difference, we asked whether such incentives would make them *more* or *less* likely to donate their organs.

To assess attitudes toward donor authorization, three statements were read and respondents indicated their level of agreement (1=strongly disagree, 2=disagree, 3=agree, 4=strongly agree): (1) "If a person dies and has documented that they wanted to be an organ donor, then it is not necessary to get the family's permission for organ donation." (2) "If a person dies and has documented that they wanted to be an organ donor, then the organs should be removed even if the family objects to donation." (3) "The family should have the right to overrule a person's documented organ donation decision, at the time of their death."

To assess attitudes toward presumed consent, respondents indicated their level of agreement (1=strongly disagree, 2=disagree, 3=agree, 4=strongly agree) to the following two statements: (1) "If a person dies and has not documented that they wanted to be an organ donor, the organs should be removed without getting the family's permission." (2) "There should be a law that assumes that everyone who dies is a potential organ donor, unless they have documented that they didn't want to be a donor."

We were primarily interested in examining whether donor and nondonor next-of-kin differed in their attitudes toward financial incentives, donor authorization, and presumed consent. However, we also assessed whether other factors were associated with attitudes, including sociodemographic characteristics (sex, age, race, marital status, education, employment status), donor registration status

(documented intention or not), attitudes toward transplantation, and organ donation attitudes. General attitudes toward organ transplantation were measured by responses to four questions (4-point Likert scale), with higher scores (range=4 to 16) reflecting more positive attitudes. Organ donation attitudes were assessed with six questions (4-point Likert scale), with higher scores (range=6 to 24) indicative of more positive attitudes.

Statistical Analysis

Univariate relationships between the financial incentive attitudes and next-of-kin donation decision were examined using the Fisher exact test. For donor authorization attitudes, ratings on the last question were reverse-scored and then the ratings for the three questions were aggregated. This yielded one attitude score that ranged from 3 to 12, with higher scores indicating more favorable attitudes toward donor authorization. Similarly, the individual ratings on the two presumed consent questions were aggregated, yielding one score that ranged from 2 to 8. Higher scores reflected more favorable attitudes toward presumed consent. T-tests were then used to examine whether donor authorization and presumed consent attitude scores varied as a function of next-of-kin donation decision. Chi-square analyses were then conducted for each of the donor authorization and presumed consent questions. Multivariate analyses (logistic regression for financial incentives, multiple regression for donor authorization and presumed consent) were then conducted to

examine the predictive value of sociodemographic characteristics, donor registration status, attitudes toward transplantation, and organ donation attitudes. All data were analyzed using the Statistical Package for the Social Sciences database (SPSS, Version 11, Chicago IL).

RESULTS

Sample Characteristics

Regarding the OPO recruitment strategy, 456 (67%) of those next-of-kin who were approached about donation during the study period received a study information card, 312 (68%) next-of-kin made inquiries about the study, and 285 (147 donors, 138 nondonors) completed telephone interviews. Also, 137 individuals responded to the study advertisement on the NDFC website, and 121 (99 donors, 22 nondonors) completed the interview. Finally, 207 individuals responded to the newspaper advertisements, although 43 of them did not meet eligibility criteria and 9 met eligibility criteria but did not complete the interview. Thus, 155 next-of-kin (102 donors, 53 nondonors) of those recruited via newspaper advertisement completed the interview. Preliminary analyses indicated that participants across the three recruitment groups did not differ significantly on any of the sociodemographic variables ($P>0.05$). Therefore, all subsequent data are based on the total sample of 561 next-of-kin who completed the interview.

Mean age of participants was 47.6 yrs (± 13.9 ; range

TABLE 1. Sociodemographic characteristics, next-of-kin donation decision, and donor registration status (n = 561)

		n (%)	Mean (SD)
Age			47.6 (13.9)
Sex	Female	430 (76.6)	
	Male	131 (23.4)	
Race	White	446 (79.5)	
	Black or African American	92 (16.4)	
	Asian	9 (1.6)	
	More than one race	8 (1.4)	
	Other	6 (1.1)	
Ethnicity	Hispanic or Latino	23 (4.1)	
	Not Hispanic or Latino	538 (95.9)	
Marital status	Married	304 (54.2)	
	Not Married	257 (45.8)	
Employed	Yes ^a	379 (67.6)	
	No	182 (32.4)	
Education	< High school	23 (4.1)	
	High school grad	113 (20.1)	
	> High school	425 (75.8)	
Relationship to deceased	Spouse	193 (34.4)	
	Parent	149 (26.5)	
	Child	119 (21.2)	
	Sibling	52 (9.3)	
	Other	48 (8.6)	
Donation decision ^b	Consented to donation	348 (62.0)	
	Did not consent to donation	213 (38.0)	
Donor registration status	Registered donor ^c	307 (54.7)	
	Not registered	254 (45.3)	

^a Full-time students were considered employed.

^b Refers to the decision made by next-of-kin participant when approached about donating the organs of a deceased family member.

^c Includes those with donor designation on driver's license, signed donor card, and placement of name on donor registration list.

18–85 yrs). The majority of participants was female, white, married, employed, had at least some college education, and had a donor designation on their driver’s license. Relationship to the deceased was as follows: parent (34%), adult child (27%), spouse (21%), sibling (9%), and other (9%). Sixty-seven percent of participants lived in United Network for Organ Sharing’s (UNOS) Region 3 (Alabama, Arkansas, Florida, Georgia, Louisiana, Mississippi, Puerto Rico). Mean interview length was 43.1 min (± 11.6 ; range 31–80 min) (Table 1).

Regarding the demographic characteristics of the prospective donors (i.e., deceased relative of study participant), mean age was 42.4 yrs (± 20.6 ; range, 2–79 yrs), 61% male, 76% white, 39% married, 33% college educated, and 63% employed at time of death. In general, these data mirror those of the regional OPO population during the study (mean age=42 yrs; 59% male; 80% white) as well as national donor-specific data (mean age=41 yrs; 58% male; 77% white).

Attitudes toward Financial Incentives, Donor Authorization, and Presumed Consent

Overall, 91.4% of participants reported that financial incentives would not have influenced their decision to consent or not consent to donation at the time of their family member’s death. Nondonors were more likely than donors to state that financial incentives would have made a difference in their final decision ($P=0.02$). Specifically, 12% of nondonors would have consented to donation had financial incentives been offered; however, 6% of donors would not have consented to donation if approached about financial incentives. Similarly, nondonors were twice as likely to say that financial incentives would influence their donation decision about their own organs ($P<0.0001$), with 66% indicating that such incentives would make them more likely to become an organ donor (vs. 34% for donors, $P=0.03$). (Table 2)

Donors reported significantly more favorable overall attitudes toward donor authorization than did nondonors ($P<0.0001$). When the individual questions are examined categorically, a consistent pattern emerges. Donors were sig-

nificantly more likely than nondonors to agree or strongly agree that when it is known and documented that the deceased wanted to be an organ donor, it is not necessary to get the family’s permission (64% vs. 38%, $P<0.001$) and donation should proceed even if the family objects (73% vs. 40%, $P<0.001$). Also, donors were significantly more likely than nondonors to object (i.e., disagree or strongly disagree) to the family’s right to overrule (or “veto”) a deceased family member’s documented donation intention (83% vs. 40%, $P<0.001$). (Table 3)

Donors had a significantly higher score regarding attitudes toward presumed consent than did nondonors ($P<0.0001$). However, the mean scores for both groups were indicative of generally unfavorable attitudes toward presumed consent. Very few donors (5%) and nondonors (3%) reported agreement or strong agreement with the notion that organs should be removed in the absence of donor documentation and family permission, although donors were less strongly opposed to this than nondonors ($P<0.001$). Similarly, although donors were significantly more favorable toward the idea than nondonors (27% vs. 19%, $P<0.001$), there was generally low support among both groups for a law that assumes that everyone is a potential donor, with the option to opt out. (Table 4)

Multivariate Predictors of Attitudes

Two logistic regression analyses were used to examine the relative contribution of next-of-kin donation decision, demographic characteristics, donor registration status, attitudes toward transplantation, and organ donation attitudes in predicting attitudes toward financial incentives. The following variables predicted favorable attitudes toward financial incentives for both donating their deceased family member’s organs as well as their own: did not consent to donation, younger age, non-working status, less than a college education, not registered as an organ donor, and less favorable organ donation attitudes. Sex, race, ethnicity, marital status, relationship to the deceased, and attitudes toward transplantation were not significant predictors in either model. With

TABLE 2. Attitudes toward financial incentives, by next-of-kin donation decision

		Donation decision ^a		
		Yes (n=348)	No (n=213)	P value
Would cash payment to you or loved one’s estate, paying for loved one’s funeral expenses, or charitable contribution in loved one’s name have made difference in deciding whether to donate his/her organs?	Yes, would have made a difference	22 (6.3)	26 (12.2)	0.02
	No, would not have made a difference	326 (93.7)	187 (87.8)	
Would a cash payment to your estate, paying for your funeral expenses, or a charitable contribution in your name make a difference in deciding whether to donate your own organs at time of death?	Yes, would make a difference	54 (15.5)	69 (32.4)	<0.0001
	No, would have no effect	294 (84.5)	144 (67.6)	
If financial incentives would make a difference (n=123), they would make you . . .	More likely to donate organs	21 (38.9)	41 (59.4)	0.03
	Less likely to donate organs	33 (61.1)	28 (40.6)	

Data are n (%). Percentages reflect percent of respondents endorsing each response item within the respective donor/nondonor category (i.e., column). Only P value is reported because Fisher’s exact test does not yield formal test statistic or critical value.

^a Refers to the decision made by next-of-kin participant when approached about donating the organs of a deceased family member.

TABLE 3. Attitudes toward donor authorization, by next-of-kin donation decision

		Donation decision ^a		Statistical analysis
		Yes (n=348)	No (n=213)	
Donor authorization attitudes, mean (SD) ^b		8.71 (2.2)	7.29 (2.8)	<i>t</i> (549)=6.67, <i>P</i> <0.0001
If person dies and has documented that they wanted to be organ donor, it is not necessary to get family's permission for donation	Strongly Disagree	36 (10.3)	54 (25.4)	$\chi^2(3)=39.7, P<0.001$
	Disagree	91 (26.2)	77 (36.1)	
	Agree	132 (37.9)	42 (19.7)	
	Strongly Agree	89 (25.6)	40 (18.8)	
If person dies and has documented that they wanted to be organ donor, organs should be removed even if family objects to donation	Strongly Disagree	29 (8.3)	58 (27.2)	$\chi^2(3)=66.9, P<0.001$
	Disagree	64 (18.4)	70 (32.9)	
	Agree	181 (52.0)	56 (26.3)	
	Strongly Agree	74 (21.3)	29 (13.6)	
Family should have right to overrule person's documented organ donation decision, at the time of death	Strongly Disagree	89 (25.6)	42 (19.7)	$\chi^2(3)=115.6, P<0.001$
	Disagree	199 (57.2)	44 (20.7)	
	Agree	43 (12.3)	78 (36.6)	
	Strongly Agree	17 (4.9)	49 (23.0)	

Data are n (%) unless noted. Percentages reflect percent of respondents endorsing each response item within the respective donor/nondonor category (i.e., column).

^a Refers to the decision made by next-of-kin participant when approached about donating the organs of a deceased family member.

^b Mean aggregate score for the three questions (strongly disagree=1, disagree=2, agree=3, strongly agree=4; range 3–12), with higher scores reflecting more favorable attitudes toward donor authorization. Ratings on the last question were reverse scored.

TABLE 4. Attitudes toward presumed consent, by next-of-kin donation decision

		Donation decision ^a		Statistical analysis
		Yes (n=348)	No (n=213)	
Presumed consent attitudes, means (SD) ^b		3.91 (1.3)	3.24 (1.4)	<i>t</i> (549)=5.63, <i>P</i> <0.0001
If person dies and has not documented that they wanted to be organ donor, organs should be removed without getting family's permission	Strongly Disagree	141 (40.5)	143 (67.1)	$\chi^2(3)=39.8, P<0.001$
	Disagree	191 (54.9)	64 (30.1)	
	Agree	9 (2.6)	1 (0.5)	
	Strongly Agree	7 (2.0)	5 (2.3)	
There should be law that assumes everyone who dies is potential organ donor, unless documented that they didn't want to be donor	Strongly Disagree	82 (23.6)	110 (51.6)	$\chi^2(3)=47.1, P<0.001$
	Disagree	171 (49.1)	62 (29.1)	
	Agree	69 (19.8)	32 (15.0)	
	Strongly Agree	26 (7.5)	9 (4.2)	

Data are n (%) unless noted. Percentages reflect percent of respondents endorsing each response item within the respective donor/nondonor category (i.e., column).

^a Refers to the decision made by next-of-kin participant when approached about donating the organs of a deceased family member.

^b Mean aggregate score for the two questions (strongly disagree=1, disagree=2, agree=3, strongly agree=4; range 2–8), with higher scores reflecting more favorable attitudes toward presumed consent.

the exception of transplantation attitudes, all steps in both models contributed significantly to the total model. The total model predicted attitudes toward financial incentives for both donating their deceased family member's organs as well as their own in 94.6% and 97.3% of the cases, respectively.

Linear regression analyses were used to examine the degree to which these same variables predicted attitudes toward donor authorization and presumed consent. Demographic characteristics, the next-of-kin donation decision, and organ donation attitudes explained the largest percentage of variance in donor authorization attitudes, followed by donor registration status. For presumed consent attitudes, donation attitudes accounted for the most variance in the model, followed by demographic characteristics and the next-

of-kin donation decision. In both models, transplant attitudes predicted very little variance. Overall, the models explained 43% and 36% of the variation in attitudes toward donor authorization and presumed consent, respectively.

DISCUSSION

This study sought to add new data and perspective to the ongoing debate regarding the use of financial incentives, donor authorization, and presumed consent to increase organ donation. Adults who have personally confronted an organ donation decision at the time of a family member's death offer additional voices that, heretofore, have been relatively silent in the debate. This is the first known examination of the perceptions of both organ donor and nondonor family members regarding these donation initiatives.

The debate regarding financial incentives is occurring largely because of the extreme organ shortage. Direct payment for organs is unlawful under the National Organ Transplant Act (NOTA) of 1984 (25), and is considered unethical by most transplant organizations. However, some transplant professionals consider indirect forms of payment (reimbursing funeral expenses, charitable contribution) to be consistent with NOTA, ethical, and a viable strategy for increasing donation. For instance, an American Society of Transplant Surgeons panel of surgeons, physicians, OPO administrators, and ethicists reported unanimous support for charitable contributions and strong (although not unanimous) support for funeral expense reimbursement following deceased donation (7). Both of these incentives were viewed as preserving altruism and as ethically permissible, while a direct cash payment and an income tax credit were considered ethically objectionable. Similarly, in a recent world-wide survey of members of the International Society for Heart and Lung Transplantation (ISHLT), over half of the 739 respondents believed that indirect compensation would have a positive impact on the organ donation rate (19). Approximately 67% supported indirect compensation while only 34% supported direct compensation for organ donation.

The public may not be as eager to embrace financial incentives. In a 1991 UNOS survey, 52% of 800 respondents indicated support for compensation, with funeral expense reimbursement and a charitable contribution garnering the most support of the specific types of financial incentives surveyed (17). In a 1993 Gallup poll of 6,127 people, only 12% of respondents reported that they would be more likely to donate their own organs or those of a deceased family member in response to financial incentives (26). In both of these polls, younger adults had more favorable attitudes toward financial incentives. Interestingly, even those patients who have the most to gain from an increase in organ donation are not uniformly supportive of using financial incentives (18).

In the current study, the vast majority of donor and nondonor participants (91%) reported that financial incentives would not have influenced their donation decision at the time of their family member's death. Consistent with cognitive dissonance theory, decision justification processes, and confirmation biases (27), it is likely that most donors and nondonors have already justified their donation decision and altering that decision retrospectively on the basis of one additional factor (financial incentive) might be inconsistent with their known behavior. Yet, 12% of nondonors stated that they would have donated had financial incentives been offered. This finding may, on the surface, lend empirical support to proponents of financial incentives. However, this potential gain in organs is partially offset by a concomitant loss in organs – 6% of donors felt so strongly and negatively about financial incentives that they would have chosen not to donate. These data closely parallel those reported in the Gallup survey, in which 12% reported being more likely to donate a deceased family member's organs if some form of compensation was offered (vs. 5% who would be less likely to donate) (26). Collectively, findings from our study and others indicate that financial incentives offered to next-of-kin decision-makers are not likely to lead to increases in deceased donation consent rates.

Interestingly, we found greater support for financial in-

centives when respondents were asked about donating their own organs. Nearly a quarter of respondents said that financial incentives would make a difference in their decision to become an organ donor. Adults who did not consent to donation were considerably more likely to become an organ donor themselves if financial incentives were available. However, of those who stated that financial incentives would have an effect on their own donation decision, there was an even split between those who would be more likely vs. less likely to donate their organs. We also found that younger adults who were less educated and not working were more likely to be influenced by financial incentives (i.e., to consent to donation for a family member or themselves). Furthermore, financial incentives seemed to be viewed more favorably by those who had not already documented their donation intention and who had more negative attitudes toward donation.

Overall, these data suggest that the benefits (i.e., increased number of willing donors) of implementing financial incentives may not outweigh the costs (i.e., deterrence or loss of otherwise altruistic donors), which is a concern expressed by many who have debated the use of financial incentives (7, 9). There is a delicate balance that would be very difficult to achieve in deciding whether to use financial incentives in approaching families about deceased donation. Because our survey questions did not distinguish among the different types of compensation, it is difficult to know what specific direct and indirect financial incentives would contribute more or less favorably (or not at all) to the donation decision-making process. It is entirely possible that some financial incentives carry more negative connotation (e.g., direct payment=bribe, coercion) than others (e.g., charitable contribution=upholds altruism, conveys gratitude for gift). Therefore, further evaluation of donor and nondonor attitudes toward each of these incentives is necessary before conclusions can be adequately drawn regarding the potential benefits or limitations of such incentives.

Donor authorization legislation has now been enacted in 42 states. For the majority of these states, a documented donation decision that has not been revoked by the donor prior to death is irrevocable and does not require the consent of any other person after the donor's death. While the majority of study participants resided in states with such legislation, most were not aware of it and most believed that OPOs were legally required to obtain next-of-kin consent for donation. When a family member's desire to be an organ donor has been documented, 54% of participants thought that family permission for donation was unnecessary and 61% believed that organs should be removed over family objections to donation. Not surprisingly, in both of these scenarios, we found that donor families had more favorable donor authorization attitudes than nondonors. Nondonors were more likely to feel that surviving family members should play a more prominent role in decision-making, while preserving the right to overrule a documented intention to donate. In the ISHLT survey (19), 84% thought that family members should routinely be consulted regarding organ donation, unless the deceased had documented his or her intentions, at which point it was seen as not necessary by the majority of respondents. Interestingly, 22% believed that a family should be permitted to override the donor's wishes and refuse to donate, which is

generally consistent with our finding that 33% of families want to preserve this override capability.

Until recently, signing a donor card, imprinting one's driver's license with a donor authorization, and/or joining a donor registry were expressions of donation intention. In many states, donor authorization legislation now considers such actions to be legally binding. While OPOs are legally authorized to proceed with the donation process without family consent under such circumstances, they are not likely to eschew family consultation for a variety of clinical, ethical, legal, and political reasons. Our interviews suggest that any discussion of donor authorization legislation is likely to be met with some degree of confusion by both donor and nondonor families, who may not have a complete understanding of donor authorization statutes. Nevertheless, for donor authorization legislation to be implemented as intended and received favorably by the general public, a more concerted effort must be undertaken to educate the public about the existence and intent of such state legislation and its potential benefits for both registered donors and their families.

Most transplant professionals favor presumed consent legislation and it is generally seen as the most effective way to increase organ donation (19). Such opinion is not without empirical support, as presumed consent legislation has led to significant increases in organ donation rates in several countries (28–32). Indeed, cogent arguments have been made that presumed consent policies (i.e., where the “default” is to donate) will continue to yield impressive increases in organ donation rates because they allow individuals to not make a choice about a preference that is not yet fully articulated (15, 33). In contrast to the prevailing opinion within the transplant community, we did not find strong support for presumed consent in our survey. In the absence of donor documentation, only 4% believed that organs should be removed without family consent and only 24% favored a presumed consent law with an opting out provision. This latter figure is considerably lower than the 39% in the UNOS survey who felt that physicians should be able to act on the basis of presumed consent for donation (17). We also found that adults who are younger, white, more educated, have a history of consenting to donation, currently registered as donors, and have more favorable organ donation attitudes are more likely to accept presumed consent policies. Collectively, these data suggest that considerable societal change is necessary if efforts to implement presumed consent policies are to be successful in the United States. Recently, some OPOs have begun a presumptive approach to donation, in which it is assumed that families want to donate and communication between the OPO coordinator and family emphasizes donation as the right thing to do after death. On the basis of our interviews and findings, we strongly encourage the inclusion of both donor and nondonor family perspectives in the further development and implementation of this strategy to increase donation rates.

The results of this study should be evaluated within the context of several conceptual and methodological limitations. We employed a passive recruitment strategy in which participants were self-selected. Participants, therefore, likely do not represent a true random sample of the overall population of next-of-kin donors and nondonors. Moreover, the findings should not be generalized beyond the sociodemo-

graphic and regional characteristics of the sample. Our next-of-kin sample was predominantly female, white, employed, and had at least some college education. Another important limitation is the wording of the questions on financial incentives. These questions presented a cluster of both direct and indirect financial incentives and did not allow us to evaluate whether there were differential attitudes toward each individual incentive. We suspect, based on unsolicited comments from participants as well as other survey research, that there are varying opinions about these different financial incentives. Our future research will seek to evaluate this more closely in both donor and nondonor families.

In conclusion, in this study we have attempted to summarize the attitudes of both donor and nondonor families toward various initiatives to increase organ donation rates. We found notable differences in these two groups in their opinions about financial incentives, donor authorization, and presumed consent. Donor families are true ambassadors for organ donation and we must continue to solicit their opinions and guidance in the development of new organ donation initiatives. Additionally, nondonor families represent an opportunity for the transplant community to learn what proposed policy changes might lead them to consider a more favorable decision regarding organ donation, both for themselves and for other family members.

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