American Journal of Transplantation 2009; 9: 2172–2176
Wiley Periodicals Inc.

doi: 10.1111/j.1600-6143.2009.02741.x

Stimulus for Organ Donation: A Survey of the American Society of Transplant Surgeons Membership

J. R. Rodrigue[a,*], K. Crist[b], J. P. Roberts[c], R. B. Freeman Jr.[d], R. M. Merion[e] and A. I. Reed[f]

[a] *The Transplant Center and Department of Psychiatry, Beth Israel Deaconess Medical Center, Boston, MA*
[b] *American Society of Transplant Surgeons, Arlington, VA*
[c] *Department of Surgery, University of California at San Francisco, San Francisco, CA*
[d] *Department of Surgery, Tufts Medical Center, Boston, MA*
[e] *Department of Surgery, University of Michigan, Ann Arbor, MI*
[f] *Department of Surgery, University of Iowa Health Care, Iowa City, IA*
***** *Corresponding author: James R. Rodrigue, jrrodrig@bidmc.harvard.edu*

A copy of the complete survey can be obtained from the American Society of Transplant Surgeons (ASTS) by emailing your request to asts@asts.org.

Federal legislation has been proposed to modify the National Organ Transplant Act in a way that would permit government-regulated strategies, including financial incentives, to be implemented and evaluated. The Council and Ethics Committee of the American Society of Transplant Surgeons conducted a brief web-based survey of its members' (n = 449, 41.6% response rate) views on acceptable or unacceptable strategies to increase organ donation. The majority of the membership supports reimbursement for funeral expenses, an income tax credit on the final return of a deceased donor and an income tax credit for registering as an organ donor as strategies for increasing deceased donation. Payment for lost wages, guaranteed health insurance and an income tax credit are strategies most strongly supported by the membership to increase living donation. For both deceased and living donation, the membership is mostly opposed to cash payments to donors, their estates or to next-of-kin. There is strong support for a government-regulated trial to evaluate the potential benefits and harms of financial incentives for both deceased and living donation. Overall, there is strong support within the ASTS membership for changes to NOTA that would permit the implementation and careful evaluation of indirect, government-regulated strategies to increase organ donation.

Key words: Financial incentives, organ donation, public policy, transplantation

Received 22 February 2009, revised 07 May 2009 and accepted for publication 14 May 2009

Introduction

Numerous strategies to increase the rates of both deceased and living organ donation consent and procurement have been proposed and debated within the transplant community (1–9). These strategies include income tax credits for donor registration and for actual donation, reimbursement for funeral expenses, cash payments to the donor's estate and/or family, a charitable contribution designated by the donor or the next-of-kin, reimbursement for expenses incurred by the next-of-kin secondary to the donor's death, guaranteed health and/or life insurance and payment for lost wages for living donors.

In large parts, dialogue about the relative merits and limitations of these strategies has been theoretical, inferential and anecdotal. One exception is Iran, which substantially reduced its kidney transplant waiting list after implementing a compensated and regulated living-unrelated kidney donor program (10). There are other examples such as Israel (11) and Singapore (12) where recent legislation has specified that it is allowable to compensate donors under certain circumstances but there is no data with which to judge the efficacy of these new efforts for increasing donation rates. Currently, most developed countries prohibit any type of monetary compensation for organ donation. In the United States, for instance, the National Organ Transplant Act (NOTA) prohibits 'any person to knowingly acquire, receive, or otherwise transfer any human organ for valuable consideration for use in human transplantation . . .' (NOTA, Section 274e, 2008) (13). Contemporary interpretations of this clause in NOTA have construed this to mean that it is illegal to implement any of the potential awards mentioned above. Although some recent interpretations suggest that NOTA was never intended to prohibit provision of government-provided compensation for donors, the more rigid interpretation has prevailed and consequently there have been no controlled trials that have specifically

examined the impact of such strategies on organ donation rates.

In 2008, two events led the ASTS Council and Ethics Committee to solicit its membership's views about government-regulated strategies to increase organ donation. First, the Declaration of Istanbul on Organ Trafficking and Transplant Tourism was published (14). Convened by the Transplantation Society and the International Society of Nephrology in Istanbul, Turkey, on April 30–May 2, 2008, this international summit yielded a document that emphasized the need to maximize the use of deceased donor organs, the need for countries with established deceased donor programs (or living donor, for that matter) to share their knowledge with countries without these programs, the need to protect vulnerable populations from abusive acts, the equitable allocation of donor organs based on sound ethical principles and the prevention of organ brokerage and trafficking. While the ASTS supported these and many other aspects of the Declaration, the Society raised concerns about specific areas in the Declaration, including the suggestion that health care insurance be guaranteed to donors and no provisions made for limited, controlled trials of incentives (15). While ASTS supports provision of healthcare coverage to donors, this is not currently a widely applied reality in the United States. Further, the ASTS has been considering support for pilot studies of incentives for donation. Second, while some of the more conservative interpretations of NOTA that have prevented pilot projects of limited donor compensation to move forward at the state level (e.g. Pennsylvania initiative to provide $300 reimbursement toward funeral expenses), a new piece of legislation was being developed for introduction into the US Senate that would amend NOTA in a way that would permit government-regulated trials of donor incentives as a means to increase organ donation (16).

We designed a brief survey, so that the ASTS can more effectively represent the views of its members and to ascertain a broader opinion regarding what are acceptable and unacceptable measures to stimulate organ donation. This survey was initially sent out with the *caveat* that it was intended for data gathering to inform the stance of the ASTS and not for publication. In retrospect, ASTS leadership felt that the opinions expressed in the survey were extremely helpful in formulating the ASTS public stance to this issue and that the membership would benefit from a summary report. In this report, we summarize the findings from the recent ASTS membership survey.

Methods

We designed a brief web-based survey to assess views about government-regulated strategies to increase organ donation. Questions assessed the degree of support/opposition (strongly support, support, neutral/undecided, oppose, strongly oppose) for several government-regulated strategies that have been suggested to stimulate more deceased and living organ donation, and for government-regulated trials to evaluate the effectiveness of financial incentives for deceased and living donation. In addition, we asked open-ended questions to determine (1) whether respondents strongly supported other government-regulated strategies to increase deceased or living donation that were not identified in the survey, and (2) the reasons why respondents did not support the proposed legislation (i.e. Organ Donation Clarification Act of 2008). One of the authors (JR) and a research assistant read each free-text response, identified the major themes, and then categorized each response according to the themes.

In October 2008, ASTS sent an email to 1,080 members, describing the study purpose and providing a secure hyperlink (www.surveymonkey.com) to complete the survey online from October 16 to October 31, 2008. A reminder email with the secure hyperlink was sent every few days to members who had not yet completed the survey. In addition to questions noted above, we asked respondents to provide their UNOS region, number of years in and location (United States, other) of practice, profession and primary organs of practice. No paper copies of the survey were distributed.

Results

During a 1-month period, ASTS collected 449 survey responses (41.6% response rate). The majority of respondents were surgeons, practicing in the United States, had less than 15 years of experience in transplantation and identified abdominal organs as their primary focus of practice. All UNOS regions were represented (Table 1). We were unable to collect data about nonresponders, although the sample appears to be representative of the general ASTS membership based on professional status (86% surgeons, 2% physicians), practice location (89% United States) and geographical representation (i.e. all UNOS regions). The ASTS does not maintain data on years in practice or primary focus of practice.

Most respondents (74.6%) personally support (strongly support or support in the survey) the proposed Organ Donation Clarification Act of 2008 (16) as drafted in October 2008 (35.6% strongly support, 39.0% support, 9.6% neutral/undecided, 10.6% oppose, 5.3% strongly oppose) and believe that ASTS should support this legislation (80.5%). Among those who did not support the legislation as initially proposed, the open-ended comments (n = 55) expressed concerns about the commercialization of an altruistic act (30%), the possibility of exploitation (24%) and the legislation's lack of differentiation between deceased and living donation (13%).

The majority of respondents support one or more government-regulated strategies to stimulate more deceased organ donation (Table 2). However, there is considerable variability in what the respondents consider acceptable strategies. A clear majority support reimbursement for funeral expenses (73.0%), an income tax credit on the final return for donating organs (66.5%) and an income tax credit for registering as an organ donor (64.5%). About half the respondents support a contribution to a charity designated by the deceased or next-of-kin (51.0%)

Table 1: Respondent characteristics

	N	(%)
Profession		
Surgeon	408	(90.9)
Physician	11	(2.5)
Scientist	9	(2.0)
Other[a]	9	(2.0)
Unknown	12	(2.7)
United States practice		
Yes	387	(86.2)
No	32	(7.1)
Unknown	30	(6.7)
Years in practice		
1–5	111	(24.7)
6–10	66	(14.7)
11–15	83	(18.5)
16–20	69	(15.4)
21–25	53	(11.8)
26+	45	(10.0)
Unknown or not applicable	22	(4.9)
UNOS region (US respondents only)		
Region 1	36	(9.4)
Region 2	56	(14.6)
Region 3	41	(10.7)
Region 4	28	(7.3)
Region 5	39	(13.7)
Region 6	11	(2.9)
Region 7	34	(8.8)
Region 8	25	(6.5)
Region 9	41	(10.7)
Region 10	36	(9.4)
Region 11	38	(9.9)
Primary focus of practice[b]		
Kidney	371	(82.6)
Liver	291	(64.8)
Pancreas	275	(61.3)
Intestine	45	(10.0)
Heart	23	(5.1)
Lung	24	(5.4)
Unknown or not applicable	15	(3.3)

[a]'Other' category includes nurse practitioners, physician assistants and allied health professionals.
[b]Column percentages sum is >100% because multiple responses were permitted.

and reimbursement for next-of-kin expenses incurred secondary to a donor's death (56.0%). More direct forms of rewarded gifting are supported only by a minority of respondents (cash payment to the donor's family, 21.9%, or to the donor's estate, 25.8%), with higher rates of strong opposition than those for any other strategy. Additional government-regulated strategies strongly supported and identified by survey respondents in the open-ended question (n = 66) included presumed consent or opting-out legislation (38%), higher transplant priority for those who registered as donors (12%), a national memorial for donors and a Medal of Honor ceremony for family members (9%) and government-mandated organ donation education (8%).

Payment for lost wages (76.8%), payment of health insurance premiums (72.0%) and an income tax credit (64.0%) received the most support as government-regulated strategies to increase living organ donation (Table 3). A slight majority (55.5%) favored payment of life insurance premiums, while cash payment to the donor was least supported by respondents (20.1%). A contribution to a charity designated by the donor received modest support (44.5%), with a quarter of respondents neutral or undecided about this strategy. Comments made by respondents (n = 32) emphasized government-regulated strategies to ensure that donors are fully reimbursed for direct and indirect expenses associated with donation (31%).

Correlational analyses showed that support for any one deceased or living donation strategy was positively correlated with support for all other strategies (all $rs \geq 0.34$, $p < 0.0001$). Also, support for deceased donation strategies was highly correlated with support for living donation strategies (all $rs \geq 0.35$, $p < 0.0001$). Analyses of variance showed that support for deceased donation strategies did not differ by respondent years of practice. However, years of practice were associated with support for guaranteed health insurance ($F = 2.7$, $p = 0.02$) and life insurance ($F = 2.6$, $p = 0.02$) as strategies for increasing living donation. Respondents with 11–25 years of practice were more likely to support these strategies to increase living donation than those with less (1–5 years) or more (26+ years) years of transplant experience ($ps < 0.05$). Finally, Region 4 (Oklahoma, Texas) was significantly less likely to support cash payment to the deceased donor's estate ($F = 3.2$, $p < 0.0001$) or cash payment to the living donor ($F = 2.5$, $p = 0.005$) than the majority of other regions. Relative to all other regions, Region 6 (Alaska, Hawaii, Idaho, Montana, Oregon, Washington) was significantly more likely to support cash payment to living donors.

The majority of respondents personally support a government-regulated trial to evaluate the potential effects of financial incentives for both deceased (74.6%) and living (69.8%) donation, in order to assess the balance between benefit and harm. A similar proportion believes ASTS should support such government-regulated trials (75.5% for deceased donation, 69.6% for living donation). Of those who support such regulated trials, 75.8% said a trial limited to one UNOS region was more acceptable than trials limited to one organ procurement organization (46.0%), one state (41.7%) or one transplant center (14.0%).

Discussion

Worldwide, the demand for transplantable organs continues to outpace the supply. This has served as the catalyst for vigorous debate about both direct (actual monetary compensation, e.g. cash payment) and indirect (organs traded for goods or services of cash value, e.g.

Table 2: Proportion of respondents who support/oppose implementation of specific government-regulated strategies to stimulate more deceased organ donation

	N	Strongly support	Support	Neutral/ undecided	Oppose	Strongly oppose
Income tax credit for registering as an organ donor	444	149 (33.6)	137 (30.9)	65 (14.6)	57 (12.8)	36 (8.1)
Income tax credit (via final return) for donating organs	439	170 (38.7)	122 (27.8)	54 (12.3)	61 (13.9)	32 (7.3)
Reimbursement for funeral expenses	438	185 (42.2)	135 (30.8)	50 (11.4)	45 (10.3)	23 (5.3)
Cash payment to the donor's estate	435	60 (13.8)	52 (12.0)	96 (22.1)	139 (32.0)	88 (20.2)
Cash payment to the donor's family	434	51 (11.8)	44 (10.1)	78 (18.0)	151 (34.8)	110 (25.3)
Contribution to a charity designated by the deceased or legal next-of-kin	439	97 (22.1)	127 (28.9)	106 (24.1)	75 (17.1)	34 (7.7)
Reimbursement of travel and lodging expenses incurred by the family in conjunction with the donor's death	440	123 (28.0)	123 (28.0)	91 (20.7)	65 (14.8)	38 (8.6)

funeral expense voucher, health insurance, contribution to a designated charity) strategies to increase deceased and living organ donation rates. The recent Declaration of Istanbul recognizes that provision of long-term health care for living donors is essential, but it does not provide explicit support for donor incentives. However, ASTS members we surveyed overwhelmingly support legislation that would clarify the NOTA to permit government-regulated trials of donor incentives in the United States. Survey findings highlight a clear preference for certain forms of incentives (funeral expense reimbursement, income tax credits, payment of lost wages) over others (direct cash payments to donors or their surviving family members). This latter finding is generally consistent with an ASTS-convened panel of ethicists, organ donation and transplant professionals, and public policy experts who supported the use of a funeral expense reimbursement as ethically permissible, but who strongly opposed direct cash payments (1). Members of the International Society of Heart and Lung Transplantation and the Foundation for the Advancement of Cardiac Therapies similarly preferred indirect (70%) versus direct (34%) compensation (17).

The debate about whether reward strategies would increase or decrease organ donation rates, or have no effect at all, has been stymied by the lack of any substantial data from controlled trials. While surveys of the general public, transplant patients and providers, other interested parties (policy makers, ethicists) and donor family members shape the debate to some degree (17–22), appropriately controlled and representative trials would provide the systematic data that heretofore have been prohibited by federal statutes. Our survey findings show strong support within the ASTS membership for changes to NOTA that would permit implementation of government-regulated strategies using indirect financial incentives to stimulate both deceased and living donation rates and strong opposition to implementation of direct financial incentives such as cash payments to the live donor or the family of the deceased donor. Additionally, our survey findings show strong support for government-regulated trials for all financial incentives to assess the balance between benefit and harm, using such trials that are inclusive and geographically representative.

One limitation of our findings and their interpretation is the issue of response bias. While survey respondents were generally representative of the ASTS membership, it is possible that those who responded to the survey were those who felt most passionately (pro or con) about donation stimulus. Moreover, the ASTS does not maintain data on its membership in a way that would allow us to compare the study sample to the general membership on all demographic characteristics (e.g. years in practice, primary organ).

Table 3: Proportion of respondents who support/oppose implementation of specific government-regulated strategies to stimulate more living organ donation

	N	Strongly support	Support	Neutral/ undecided	Oppose	Strongly oppose
Income tax credit	437	157 (35.9)	123 (28.1)	51 (11.7)	60 (13.7)	46 (10.5)
Cash payment to the donor	431	45 (10.4)	42 (9.7)	79 (18.3)	140 (32.5)	125 (29.0)
Contribution to a charity designated by the donor	429	79 (18.4)	112 (26.1)	111 (25.9)	78 (18.2)	49 (11.4)
Guaranteed health insurance (premiums paid)	439	172 (39.2)	144 (32.8)	45 (10.3)	48 (10.9)	30 (6.9)
Guaranteed life insurance (premiums paid)	434	132 (30.4)	109 (25.1)	79 (18.2)	78 (18.0)	36 (8.3)
Payment for lost wages	436	188 (43.1)	147 (33.7)	59 (13.5)	20 (4.6)	22 (5.0)

Conflict of Interest Statement

There are no conflicts of interest to report.

References

1. Arnold R, Bartlett S, Bernat J et al. Financial incentives for cadaver organ donation: An ethical reappraisal. Transplantation 2002; 73: 1361–1367.
2. Council on Ethical and Judicial Affairs, American Medical Association. Financial incentives for organ procurement. Ethical aspects of future contracts for cadaveric donors. Arch Intern Med 1995; 155: 581–589.
3. Delmonico FL, Arnold R, Scheper-Hughes N, Siminoff LA, Kahn J, Youngner SJ. Ethical incentives—not payment—for organ donation. N Engl J Med 2002; 346: 2002–2005.
4. Radcliffe-Richards J, Daar AS, Guttmann RD et al. The case for allowing kidney sales. International forum for transplant ethics. Lancet 1998; 2: 1950–1952.
5. Israni AK, Halpern SD, Zink S, Sidhwani SA, Caplan A. Incentive models to increase living kidney donation: Encouraging without coercing. Am J Transplant 2005; 5: 15–20.
6. Friedman EA, Friedman AL. Payment for donor kidneys: Pros and cons. Kidney Int 2006; 69: 960–962.
7. Matas A. Should we pay donors to increase the supply of organs for transplantation? Yes. BMJ 2008; 336: 1342.
8. Chapman J. Should we pay donors to increase the supply of organs for transplantation? No. BMJ 2008; 336: 1343.
9. Hippen BE. In defense of a regulated market in kidneys from living vendors. J Med Philos 2005; 30: 593–626.
10. Ghods AJ, Savaj S. Iranian model of paid and regulated living-unrelated kidney donation. Clin J Am Soc Nephrol 2006; 1: 1136–1145.
11. Jotkowitz A. Notes on the new Israeli organ donation law-2008. Transplant Proc 2008; 40: 3297–3298.
12. Bland B. Singapore legalises compensation payments to kidney donors. BMJ 2008; 337: a2456.
13. National Organ Transplant Act. http://www.unos.org/SharedContentDocuments/NOTA_as_amended_-_Jan_2008.pdf (accessed February 5, 2009).
14. The Declaration of Istanbul on Organ Trafficking and Transplant Tourism. Transplantation 2008; 86: 1013–1018.
15. American Society of Transplant Surgeons. Response from ASTS regarding Declaration of Istanbul. http://www.asts.org/TheSociety/PositionStatements.aspx (accessed February 12, 2009).
16. American Society of Transplant Surgeons. Organ Donation Clarification Act of 2008. http://http://asts.org/Advocacy/Legislative.aspx (accessed February 12, 2009).
17. Oz MC, Kherani AR, Rowe A, et al. How to improve organ donation: results of the ISHLT/FACT poll. J Heart Lung Transplant 2003; 22: 389–410.
18. Evans JH. Commodifying life? A pilot study of opinions regarding financial incentives for organ donation. J Health Polit Policy Law 2003; 28: 1003–1032.
19. Sehgal AR, LeBeau SO, Youngner SJ. Dialysis patient attitudes toward financial incentives for kidney donation. Am J Kidney Dis 1997; 29: 410–418.
20. Jasper JD, Nickerson CA, Ubel PA, Asch DA. Altruism, incentives, and organ donation: Attitudes of the transplant community. Med Care 2004; 42: 378–386.
21. The Gallup Organization, Inc. 2005 National Public Opinion Survey on Organ Donation. http://www.organdonor.gov/survey2005/index.shtm (accessed January 22, 2009).
22. 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.