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Primary Care Physicians' Attitudes and Practices Regarding Discussing Organ Donation With Their Patients

J. Daryl Thornton, MD, MPH, J. Randall Curtis, MD, MPH, and Margaret D. Allen, MD, DrSC(Hon)

Center for Reducing Health Disparities, Division of Pulmonary and Critical Care, MetroHealth Campus of Case Western Reserve University, Cleveland, Ohio (Dr Thornton); Division of Pulmonary and Critical Care, University of Washington, Seattle, Washington (Dr Curtis); Benaroya Research Institute, Seattle, Washington (Dr Allen)

Abstract

Purpose—Among the general population, discussing organ donation with a primary care provider may be associated with increased willingness to donate. However, the frequency with which primary care providers hold these discussions with their patients has not been reported.

Setting—Cross-sectional mail and an Internet survey of validated questions regarding organ donation were done.

Subjects—A national sample of 831 primary care physicians. black, and Hispanic physicians were oversampled.

Results—Few physicians reported receiving formal training in donation (17%). Only 5% of physicians have donor cards available in their practice, and only 11% have donation information available in their practice. While 30% of physicians reported discussing end-of-life care with their patients, fewer than 4% reported discussing donation with their patients. However, only 36% felt that discussing donation was outside of their scope of practice. In a multivariate regression model, predictors of discussing donation with patients included having received formal education about organ donation (odds ratio [OR], 2.6; $p < .05$) and discussing end-of-life care with patients (OR, 12.8; $p < .001$).

Conclusions—Very few primary care physicians reported discussing organ donation with their patients despite the majority agreeing that it was within their scope of practice. Primary care physicians who had received education on the subject or who regularly discuss end-of-life care with their patients were more likely to discuss donation. Efforts to improve donation in the general population should include a focus on understanding and improving communication about organ donation between providers and their patients.

Keywords

organ donation; transplantation; patient-physician relationship; communication; end-of-life care

BACKGROUND

As the number of persons waiting for an organ transplant surpasses 100 000,¹ finding new ways to increase organ donation becomes more pressing. This issue disproportionately affects people of color who make up more than 50% of those waiting on the national list for an organ transplant. Blacks, for example, continue to represent more than 25% of those waiting despite comprising less than 15% of the population.¹ Due to their higher burden of chronic illness and lower likelihood of receiving a transplant compared to whites,² many will die without receiving a lifesaving transplant. Increasing organ donation among people of all ethnicities is a national priority in order to increase the availability of donated organs and extend the duration and quality of life for all those waiting.³

Obtaining consent for organ donation from families and surrogates at the time of death is fraught with difficulties and is a major factor limiting organ donation and the subsequent availability of donated organs for transplantation.⁴ Only half of the persons who have decided to become a donor make their family aware of their decision. Without that essential information, many family members and surrogates express a general reluctance to make end-of-life decisions regarding their loved ones.⁵ Understandably, families are often completely occupied with the loss of their family member and see donation as being of lesser importance.⁶ Compounding this problem, many critical care physicians find obtaining donation consent from families to be beyond their scope of practice and lack appropriate training to counsel the family.⁷ Not surprisingly, professional organ procurement personnel have been found to be more successful in obtaining consent than inpatient physicians.⁸

Shifting the focus of organ donation consent from family members in the acute inpatient setting to the patient in the ambulatory setting, prior to development of a catastrophic illness, may have a greater impact on donation. Primary care physicians might contribute substantially by directly discussing donation with their patients during routine patient visits and by serving as a source of donation information.^{9,10} However, little is known about how frequently this occurs or what factors might facilitate such discussions. We surveyed a random national sample of primary care physicians and over-sampled Hispanic and black primary care physicians to determine how frequently they discuss donation with their patients and what factors encourage and inhibit these discussions from occurring.

METHODS

Contact information was obtained for a random sample of 1500 general internists and 1500 family physicians from the American Medical Association's Masterfile. One-third of the names were obtained from the general Masterfile, one-third from a subset of Masterfile physicians who designated themselves as black and one-third from a subset of Masterfile physicians who designated themselves as Hispanic. A preletter was sent 1 week prior to the survey alerting the physicians to the study, allowing them to return the enclosed postcard if they chose not to participate, and providing a unique password and Web site address to complete the survey online. A paper copy of the survey was sent to participants 3 times from August to December of 2004 unless they withdrew from or completed the study. Each survey had a unique identification number to ensure the participants completed the survey

only once. A \$2 bill was provided as incentive. The University of Washington Human Subjects Division approved the study.

Questionnaire Content

The anonymous 15-minute, 41-item questionnaire was designed to gather information in 5 categories, including knowledge and personal experience regarding donation and transplantation as well as physician demographics and practice patterns (questionnaire available upon request). Physicians were asked about their own willingness to become deceased and/or living organ donors. The questionnaire was developed using focus groups of physicians, available literature, and prior work by our group.^{11,12} After development, the questionnaire was pilot tested with 25 physicians and modified based on their recommendations and responses.

Donation and Transplantation Training, Education, and Personal Experience

Physicians were asked whether they had received formal donation training regarding during or following medical school and whether they had cared for patients who had received a transplant. Physicians were also asked if they had participated in the care or medical decision making of a deceased family member or loved one. Finally, they were asked if they knew where to obtain answers to patient questions about donation and transplantation.

Assessment of Willingness to Donate Organs

To examine physicians' level of willingness to donate organs, respondents were asked whether they agreed with 3 statements. These statements allowed 4 possible ordinal responses selected to measure the respondents' current stage in the decision-making process using the Transtheoretical Model of Health Behavior Change:^{13,14}

- "I have signed an organ donor card."
- "I would like to become an organ donor but have not signed an organ donor card."
- "I am considering becoming a donor but need more time to think about it."

Discussing Donation With Patients

Primary care physicians were asked if they had talked with more than 50% of their patients about organ donation as well as whether they had talked with more than 50% of their patients about end-of-life issues. They were also asked if they had organ donor cards or information regarding donation available in their practice.

Barriers to Discussing Donation With Patients

Physicians were asked to rate their agreement regarding 9 different potential barriers to discussing donation with their patients. They were given choices ranging from 1, strongly disagree, to 4, strongly agree. Respondents were also given the opportunity to write in additional barriers that they might have encountered.

Characterization of Ethnicity, Gender, and Other Demographic Factors

Physician age, gender, and religious affiliation were collected. Physicians were asked about their race and ethnicity and were encouraged to choose as many options as they felt reflected their ethnic background. Statistical analysis was limited to the 3 most highly represented racial and ethnic groups (black, Hispanic, and white).

Statistical Analysis

Mean values of continuous variables were compared across the three predominant racial and ethnic groups using analysis of variance. The Bonferroni multiple comparison test was used for pairwise comparisons among the 3 groups. Kruskal-Wallis equality of proportions rank test was used to compute medians across the 3 groups. Proportions of categorical variables were compared using χ^2 tests. Ordinal variables were compared using χ^2 test for trend. Logistic regression was used to assess the independent associations of physician race and ethnicity on discussing donation with more than 50% of their patients. Similarly, an ordinal logistic regression model incorporated increasing willingness to donate as the ordinal outcome variable and physician race and ethnicity as the predictors of interest. The approximate test of proportional odds assumption was used to ensure that the ratio of cumulative odds for increasing willingness to donate was constant.¹⁵ Potential confounding variables were determined a priori and included in the multivariate regression models. Statistical significance was defined as a 2-tailed test with $p < .05$. All analyses were performed with Stata 9.2 statistical software (Stata, College Station, Texas).

RESULTS

The survey was mailed to 3000 primary care physicians. Of these, 236 (8%) were returned undelivered because of invalid mail and e-mail addresses. The survey was completed by 831 people, representing a response rate of 30% (831/2764). Physicians self-identified as 35% white, 29% black or African American, 24% Hispanic, 8% Asian, 1% Native American, 1% Pacific Islander, and 1% other. They were also well-distributed with regard to age, gender, religion, and primary care specialty (Table 1).

The average age of all physicians in the cohort was 45 ± 11 years. Black physicians were younger than white physicians (44 ± 11 vs 47 ± 11 years, $p = .001$), but not younger than Hispanic physicians (45 ± 10 years, $p = .8$). Other demographic factors also varied by race and ethnicity.

Donation Support and Willingness

The majority of physicians supported organ donation (97%). More white physicians reported having signed a donor card (79%, vs 61% for Hispanics and 47% for blacks, $p < .001$). Overall, 60% of all physicians in the cohort had signed a donor card.

Donation Training and Knowledge

Few primary care physicians in this cohort had received training on organ donation during (16%) or following (17%) medical school. This did not vary by race or ethnicity (Table 2). A larger proportion of physicians (37%) reported regularly reading donation or

transplantation articles, and the majority reported having cared for patients who had received a transplant (71%). A significant number of physicians also reported knowing someone who had donated or received an organ (79%). Despite these experiences, physician knowledge of donation and transplantation was relatively low. Black physicians had higher knowledge scores than white and Hispanic physicians (68%, vs 64% white and 64% Hispanic, $p = .05$ and $.04$, respectively). Most physicians gauged their knowledge of organ donation and transplantation to be poor, with no statistically significant differences across the 3 groups.

Discussing Donation With Patients

Only 5% of physicians reported having donor cards available, and only 11% reported having donation information available in their practice. Exactly half of the physicians reported knowing where to get donor information should a patient raise questions about it. However, less than 4% of all primary care physicians in this study reported that they had talked with the majority of their patients regarding organ donation. This did not vary by race or ethnicity (Table 3). In contrast, 30% of physicians reported discussing end-of-life care with more than half their patients. Hispanic physicians discussed end-of-life care more frequently than white physicians (36%, vs 23%, $p = .01$) but not more frequently than black physicians (29%, $p = .39$).

In a multivariate logistic regression model identifying independent predictors of physicians discussing donation with their patients, 2 significant predictors emerged: (1) discussing end-of-life care with the majority of their patients (odds ratio [OR], 12.8; $p < .001$) and (2) having received formal donation education (OR, 2.6; $p < .05$). Other variables included in the model but not found to be statistically significant were physician race, ethnicity, gender, age, knowledge level about donation and transplantation, personal willingness to donate, and having donor cards or information available in the office (Table 4).

Barriers to Discussing Donation With Patients

Physicians concurred with several of the available impediments to discussing organ donation with their patients. However, of note, the barriers identified varied by physician race and ethnicity (Table 5). White physicians were more likely to agree with statements that reflected being too busy or having too high of a patient load ($p = .01$ for both). A greater proportion of black physicians indicated that language difficulties prevented them from communicating about donation with their patients ($p = .003$). A higher proportion of black physicians were also more likely to agree with having moral objections to organ donation ($p = .009$). Overall, 64% of physicians expressed not having enough staff to adequately address the issue of donation. While the majority (63%) felt that organ donation was not a high priority in the care of their patients, only 36% felt discussion of donation was outside of their scope of practice.

DISCUSSION

In this nationally representative study, primary care physicians reported receiving little formal education on organ donation and transplantation, having a low level of knowledge about donation and transplantation, and rarely having donor information or donation cards

available in their office for patients. Only a small percentage of these physicians reported regularly discussing organ donation with their patients. This study is the first to report on the paucity of donation discussions among a nationwide sample of primary care physicians and their patients. To our knowledge, it is also the first to report the barriers physicians experience in conducting donation discussions within their practices.

The question then arises regarding the appropriateness of focusing on the primary care physician as a facilitator for these discussions if the physician has little training or knowledge on the subject. First, the gap between the number of persons in need of organs and the number of donated organs has failed to close despite substantial efforts. Additional methods are needed to successfully reduce this gap. Second, in the United States, direct patient consent for organ donation continues to be addressed most commonly at departments of motor vehicles by workers who also are not fully trained to address the topic. It is not surprising that donation conversion rates are so low. The most compelling reason/rationale is that primary care physicians are currently and successfully impacting end-of-life care by addressing the issue directly with patients at an earlier stage in their illness.^{16–18} Adding the topic of organ donation to these end-of-life discussions may have a similarly positive effect on patient attitudes toward donation.¹⁰ However, it is well recognized that primary care physicians are already burdened with the need to address too many issues in an increasingly compressed clinical encounter. Adding the topic of organ donation may be another hurdle many physicians may choose not to cross. Indeed, many physicians in this study felt they had too little time, too much work, and too few ancillary staff to appropriately address the issue of organ donation with their patients. However, the majority of physicians in this study also felt that they lacked suitable training in organ donation and that the subject was difficult to discuss. It may be that with proper training, physicians would feel more comfortable in initiating these discussions and therefore be able to hold them without adding significantly more time to their existing schedules. For example, a randomized controlled trial piloting brief verbal discussions and distributing written materials on organ donation in family medicine office visits was shown to have a significant impact on patient willingness to donate.¹⁹ In addition, if organ donation were to be incorporated into existing discussions of end-of-life care, the discussions might remain brief and effective.

Prior studies that have examined the willingness of physicians to donate their organs have uncovered a similar lack of willingness to donate.^{9,20,21} However, even if so, in this study, personal decisions by physicians on donation were not significantly associated with whether physicians discussed donation with their patients. This suggests that physicians may be able to separate their personal feelings regarding donation from what they recommend to their patients. This finding needs greater exploration, and, if true, further supports the concept of utilizing the ambulatory setting to increase willingness to donate.

Race and ethnicity of primary care physicians may play an important role in improving organ donation, particularly among minorities. Black and Hispanic physicians are more likely to care for patients of similar race and ethnicity. Black patients rate their visits with physicians of their own race as more participatory than with physicians of other races.²² As a result, understanding the practices of minority and white physicians will be important in understanding communication regarding advanced care planning. In this study, the race and

ethnicity of the primary care physicians was not shown to impact the frequency of discussions on organ donation, even though a higher proportion of black physicians expressed moral objections to donation. The relationship between physician and patient race and ethnicity on donation discussions could not be examined here but remains an area that needs further in depth exploration.

Physicians reported having received little donation and transplantation training during or after medical school, and had low perceived and actual donation knowledge. Organ donation education appears not to have significantly increased in medical schools judging by recent studies of Ohio medical students.^{12,23} Several organizations, including the United Network of Organ Sharing, have developed training curricula for medical schools, but it is unclear how often they are implemented. It may be helpful for medical school educators to recognize that training their students may positively impact organ donation among the general population by improving physician competence in discussing donation.²⁴

The findings here should be interpreted in the context of the study limitations. One limitation is that the study relied on physician self-report. Since physicians were not directly observed in their practice to record how often they actually spoke to patients about donation, it is possible that recall bias may have been present, leading physicians to underreport the frequency of their donation discussions. Response bias may also have eliminated participants who infrequently discuss donation with their patients. In spite of this potential, the response rate here is higher than in other studies about end-of-life care conducted using the American Medical Association's Masterfile.²⁵ Finally, given the nature of cross-sectional studies, it is not possible to ascertain whether the barriers selected by survey participants were perceived impediments or whether they actually prevented physicians from discussing donation with their patients.

In conclusion, despite substantial support for organ donation among physicians, as well as the majority of physicians feeling that donation education is within their scope of practice, primary care physicians were found rarely to discuss donation with their patients. Efforts to increase organ donation among the general population should examine ways to educate primary care providers about donation and to encourage them to incorporate discussions of donation into the routine and end-of-life care of their patients.

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Table 1**Physician Characteristics**

	Non-Hispanic Blacks	Hispanics (All Races)	Non-Hispanic Whites	
	N = 233 n (%)	N = 194 n (%)	N = 277 n (%)	P Value
Physician Sociodemographics				
Age, mean ± SD	43.6 ± 11.4	44.8 ± 10.2	47.3 ± 11.3	<.001 ^a
Women	124 (53%)	53 (27%)	95 (34%)	<.001 ^a
Born in United States	143 (61%)	87 (45%)	243 (88%)	<.001 ^a
Physician specialty				<.001 ^a
Family practice	98 (45%)	76 (43%)	161 (61%)	
Internal medicine	122 (55%)	102 (57%)	102 (39%)	
Years since medical school, mean ± SD	18.1 ± 10.3	20.1 ± 10.6	21.7 ± 11.8	<.001 ^a
Religious preference				<.001 ^a
None	19 (8%)	18 (9.5%)	47 (17%)	
Christian	192 (86%)	160 (86%)	196 (72%)	
Jewish	2 (1%)	2 (1%)	21 (7%)	
Muslim	4 (2%)	1 (0.5%)	5 (2%)	
Other	7 (3%)	5 (3%)	5 (2%)	
Region of United States				<.001 ^a
Midwest	41 (18%)	17 (9%)	83 (30%)	
Northeast	70 (30%)	38 (20%)	67 (24%)	
Northwest	5 (2%)	8 (4%)	29 (11%)	
Southeast	96 (41%)	82 (42%)	58 (21%)	
Southwest	21 (9%)	48 (25%)	40 (14%)	
Practice Characteristics				
Urban (ref = rural)	127 (76%)	107 (80%)	123 (59%)	<.001 ^a
Private practice (ref = academic)	68 (61%)	79 (72%)	111 (85%)	<.001 ^a
Outpatient practice only	117 (52%)	84 (44%)	154 (57%)	.07
Percent of time spent in direct patient care	95%	95%	95%	.29
Donation Characteristics				
Support donation	222 (96%)	186 (96%)	272 (99%)	.09
Willingness to donate own organs				<.001 ^a
Unwilling to donate	39 (17%)	21 (11%)	18 (7%)	
Considering donation	38 (16%)	17 (9%)	20 (7%)	
Would like to but have not signed a donor card	47 (20%)	36 (19%)	20 (7%)	
Signed a donor card	108 (47%)	114 (61%)	215 (79%)	

^a $p < .001$.

Table 2

Primary Care Physician Donation Training, Education, and Knowledge

Characteristics	Non-Hispanic Blacks	Hispanics (All Races)	Non-Hispanic Whites	P Value
	N = 233 n (%)	N = 194 n (%)	N = 277 n (%)	
Participated in formal training about organ donation during medical school	39 (17%)	21 (11%)	53 (19%)	.05
Participated in formal training about organ donation after medical school	51 (22%)	35 (19%)	39 (14%)	.08
Read articles about donation or transplantation	83 (36%)	75 (40%)	102 (38%)	.7
Cared for patients who have received transplants	155 (67%)	135 (72%)	200 (73%)	.3
Cared for a loved one at the end of their life	151 (65%)	130 (69%)	201 (74%)	.1
Percent correct on knowledge assessment, mean $\pm$ SD	68 $\pm$ 18%	64 $\pm$ 18%	61 $\pm$ 19%	.02 ^a
Self reported donation knowledge, mean $\pm$ SD	53 $\pm$ 20%	50 $\pm$ 19%	51 $\pm$ 21%	.4

^a $p < .05$.

Table 3

Informing Patients About Donation

Characteristics	Non-Hispanic Blacks	Hispanic (All Races)	Non-Hispanic Whites	P Value
	N = 233	N = 194	N = 277	
	n (%)	n (%)	n (%)	
Talked with >50% of patients about donation	12 (5%)	10 (5%)	6 (2%)	.14
Talked with >50% of patients about end-of-life (DNR, living will, etc)	66 (29%)	68 (36%)	63 (23%)	.01 ^a
Have donation cards available in the physician's office	12 (5%)	10 (5%)	19 (7%)	.65
Have information on donation available in the physician's office	23 (10%)	20 (10%)	35 (13%)	.58
Know where to get donation information if patient asks	115 (51%)	101 (53%)	137 (50%)	.83

^a
 $p < .05$.

Table 4

Predictors of Physicians Discussing Donation With >50% of Their Patients

Predictor	OR (95% CI)	P Value
Physician race/ethnicity (white = referent)		
Women	1.0 (0.4–2.7)	.96
Age	1.0 (1.0–1.0)	.28
Physician willingness to donate own organs	1.6 (0.9–2.8)	.11
Received donation education during or following medical school	2.6 (1.0–6.5)	<.05 ^a
Physician knowledge of donation and transplantation	0.9 (0.8–1.1)	.29
Have information about donation available in the physician's office	2.5 (0.8–7.6)	.11
Have donation cards available in the physician's office	2.0 (0.5–8.1)	.32
Discuss end-of-life care with >50% of patients	12.8 (4.2–39)	<.001 ^b

Abbreviations: CI, confidence interval; OR, odds ratio.

^a $p < .05$.^b $p < .001$.

Table 5**Barriers to Physicians Discussing Donation With Their Patients**

Characteristics	Non-Hispanic Blacks	Hispanic (All Races)	Non-Hispanic Whites	<i>P</i> Value
	N = 233 n (%)	N = 194 n (%)	N = 277 n (%)	
Not enough staff	134 (58%)	118 (61%)	188 (70%)	.06
Too heavy a patient load	144 (63%)	118 (62%)	201 (75%)	.01 ^a
Too busy or too little time	153 (67%)	121 (65%)	208 (78%)	.01 ^a
Organ donation is a difficult subject to discuss.	182 (55%)	110 (57%)	135 (50%)	.22
I lack suitable training in organ donation.	126 (56%)	117 (62%)	148 (55%)	.28
Language difficulties prevent adequate communication about organ donation with my patients.	46 (20%)	25 (13%)	41 (15%)	.003 ^b
Organ donation is outside my scope of practice.	80 (35%)	65 (34%)	95 (36%)	.9
I have moral objections to donation.	18 (8%)	12 (6%)	14 (5%)	.009 ^b
Organ donation is not a high priority in the care of my patients.	182 (68%)	113 (60%)	182 (69%)	.3

^a $p < .05$.

^b $p < .001$.