Class and Race Inequalities in Health and Health Care

INSURANCE STATUS OF U.S. ORGAN DONORS AND TRANSPLANT RECIPIENTS: THE UNINSURED GIVE, BUT RARELY RECEIVE

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Organ transplantation is an expensive, life-saving technology. Previous studies have found that few transplant recipients in the United States lack health insurance (in part because patients may become eligible for special coverage because of their disability and transplant teams vigorously advocate for their patients). Few data are available on the insurance status of U.S. organ donors. The authors analyzed the 2003 National Inpatient Sample (NIS), a nationally representative 20 percent sample of U.S. hospital stays, and identified incident organ donors and recipients using ICD-9-CM diagnosis and procedure codes. The NIS sample included 1,447 organ donors and 4,962 transplant recipients, equivalent after weighting to 6,517 donors and 23,656 recipients nationwide; 16.9 percent of organ donors but only 0.8 percent of transplant recipients were uninsured. In multivariate analysis, compared with other inpatients organ donors were much more likely to be uninsured (OR 3.41, 95% CI 2.81-4.15), whereas transplant recipients were less likely to lack coverage (OR 0.08, 95% CI 0.06-0.12). Many uninsured Americans donate organs, but they rarely receive them.

In September of 2005, one of us (Herring), then a third-year medical student, cared for a previously healthy 25-year-old uninsured day laborer who arrived at the emergency department with rapidly advancing idiopathic dilated cardiomyopathy. The patient was ultimately deemed unsuitable for cardiac transplantation.

The decision on transplantation was driven, in part, by realistic concern about the patient's inability to pay for long-term immunosuppressive therapy and to support himself during recovery. Absent such resources, the likelihood of a

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successful outcome is compromised (1-4). The clinicians caring for him faced a wrenching dilemma: deny the patient a transplant, or use a scarce organ for a patient with a reduced chance of success. He died of heart failure two weeks after his initial presentation. This tragedy inspired us to examine data on the participation of the uninsured in organ transplantation, both as recipients and as donors.

Organ transplantation is a life-saving medical intervention. Advances in surgical technique and immunosuppressive regimens have significantly improved the survival rate and quality of life for transplant recipients (5, 6). Unfortunately, a shortage of donors sharply limits organ transplantation, leaving more than 90,000 patients on waiting lists for solid organ transplantation in the United States as of September 25, 2006 (7, 8).

The U.S. Congress created the United Network of Organ Sharing (UNOS) to ensure fair and equitable procurement and allocation of organs (9, 10). UNOS's mandate requires that each organ be considered a national resource to be used for the public good. Accordingly, individuals and next of kin are solicited to donate organs with the expectation that everyone will have equal access to organs should the need arise (11–14). Transplantation rates differ by race, income, and gender. Among those needing transplants, blacks, women, and the poor are less likely to receive them (15–20), although clinical factors (including disparities in the availability of HLA-matched organs—HLA-matching being a mechanism used to minimize the risk of transplant rejection) may explain some of these differences (2, 21).

Forty-seven million Americans are currently uninsured. Lack of health insurance increases overall mortality, affects surgical decision-making, and limits access to essential care (22–26). Millions of uninsured Americans have diabetes, hypertension, and other conditions that can lead to organ failure, particularly if undertreated (27). In this study we use nationally representative data to explore the participation of uninsured Americans in organ transplantation, both as donors and as recipients.

METHODS

Data Source

We obtained data from the 2003 National Inpatient Sample (NIS) compiled by the Agency for Healthcare Research and Quality (AHRQ). The 2003 NIS includes discharge data for 7,977,729 acute care hospitalizations in the United States from a nationally representative sample of 1,004 hospitals. These hospitals account for 20 percent of all U.S. hospital stays (28). National estimates are obtained with sampling weights provided by the AHRQ.

The NIS contains data commonly available from discharge abstracts, including clinical, demographic, and billing information. Up to 15 International

Classification of Disease, Ninth Revision, Clinical Modification (ICD-9-CM) diagnosis and procedure codes, as well as the expected source of payment for the hospital stay, are available for each patient (29).

Analytical Approach

Cornea, lung, heart, pancreas, liver, and kidney transplant recipients can be identified in the NIS using ICD-9-CM procedure codes (see Appendix tables, p. 650). Organ donors can be identified by ICD-9-CM diagnostic "V" codes that specifically identify kidney, liver, and cornea donors. All other solid organ donors, including heart and/or lung donors, are coded in the ICD-9-CM system as "other/unspecified" organ donors.

Because hospitals do not usually bill the donor or his or her insurer for organ harvest (hospitals bill the organ procurement organization, which then bills the recipient's insurer), some hospitals do not include the diagnostic codes for organ donation in discharge abstracts, and hence in the NIS. As a result, we could identify only a fraction of all organ donors.

We analyzed recipients', donors', and other hospitalized patients' demographic characteristics, the expected source of payment for the hospital stay, as well as hospital characteristics such as size, region, urban/rural location, and teaching status. The NIS categorizes the expected primary source of payment as: Medicare, Medicaid, private insurance, self-pay, no charge, or other. We considered a patient to be uninsured if the expected primary payer was either "self-pay" or "no charge." We also examined the mean length of stay (with stays over 100 days truncated to minimize the distortion of the mean value caused by extreme outliers) and hospital charges for organ donors, recipients, and other hospitalized patients. In instances where the analysis yielded cell sizes of fewer than 10 individuals we censored the results to avoid breach of patient confidentiality, as mandated by the AHRQ. We used SAS (Version 9.1) to calculate 95 percent confidence intervals (95% CI) adjusted for the complex sample design.

We used the SAS Surveylogistic procedure to perform multivariate logistic regression to examine whether insurance status is associated with the likelihood of donating an organ for transplantation after adjusting for differences between donors and other hospitalized patients in sex, age (categorized as 0–17, 18–44, 45–64, and >64 years), race/ethnicity (white, non-Hispanic, black, Hispanic, Asian/Pacific Islander), mean income in ZIP (postal) code of patient's residence, size of the community of the patient's residence (large metropolitan area, small metropolitan area, micropolitan area, non-urban area), and the hospital region (Northeast, Midwest, South, and West). We performed a similar analysis for transplant recipients. For both of these logistic regression analyses we considered patients whose primary payer was listed as "other" to have missing data for their insurance status.

RESULTS

We identified 4,962 solid organ recipients and 1,447 solid organ donors among the 7,977,729 discharge records in the 2003 NIS. These included 2,997 kidney recipients, 1,137 liver recipients, 736 heart and/or lung recipients, 106 pancreas recipients, and 106 cornea recipients. (A few individuals received more than one transplant procedure.) The organ donors included 1,213 kidney donors, 170 liver donors, 47 cornea donors, and 146 other donors. (The data do not allow accurate determination of multiple organ donations by a single individual, although multiple donations by cadaveric donors is the norm.)

Using the NIS weights to extrapolate to the United States as a whole, we found these numbers represent 23,656 solid organ transplant recipients and 6,517 solid organ donors. Hence, our analysis identified approximately 94 percent of all solid organ transplant recipients and 49 percent of all donors in 2003, based on comparison with estimates from the Organ Procurement Transplantation Network (30).

Demographic Characteristics of the Sample

Table 1 shows the demographic and other characteristics of organ donors, recipients, and other inpatients. Most transplant recipients (60.7%) were men, while men accounted for a minority of donors (43.9%) and other inpatients (40.8%). The mean age of organ donors (40.4 years) was younger than that of organ recipients (46.6 years) or other inpatients (47.6 years). Non-Hispanic whites were overrepresented among donors, as were individuals who lived in high-income areas.

As expected, both organ donors and recipients were more likely than other inpatients to be treated at large, urban teaching hospitals and to live in a large metropolitan area.

Strikingly, 16.9 percent of organ donors were uninsured versus only 0.8 percent of transplant recipients and 4.6 percent of other inpatients (Table 2). Private insurance was the most common expected source of payment for organ donors (44.8%). Among recipients, private insurance and Medicare (a government program that covers all elderly and some disabled individuals) were equally common (44.2%). Few donors (14.6%) had Medicare. Medicaid (a government program for the poor) was less common among both recipients (9.0%) and donors (2.6%) than among other inpatients (18.5%).

Over one-fifth (20.4%) of organ donors had "other" listed as their primary payer, versus only 1.8 percent of transplant recipients and 3.1 percent of other inpatients. Among the donors whose primary payer was "other" (and for whom secondary payer information was reported), nearly half (46.3%) of the secondary payers were "self-pay."

In multivariate analysis, organ donors were far more likely to be uninsured (odds ratio (OR) 3.41, 95% CI 2.81–4.15) than were other hospitalized patients (Table 3). Lack of insurance was a stronger predictor of organ donation than was any demographic factor (other than age) or hospital characteristic. Other factors associated with organ donation were being a young or middle-aged adult, male sex, white non-Hispanic race/ethnicity (as compared with blacks and Hispanics), and being cared for at a hospital in the Northeastern United States.

Transplant recipients were markedly less likely to lack health insurance than were other hospitalized patients (OR 0.08, 95% CI 0.06–0.12). As expected, young and middle-aged adults were more likely to be transplant recipients, as were blacks and Asians/Pacific Islanders. Transplant recipients were less likely to live in a low-income ZIP code than were other hospitalized patients. As was the case for organ donors, being cared for at a hospital in the Northeast was associated with a greater likelihood of being a transplant recipient.

DISCUSSION

As in previous studies (1, 31–33), we found few organ recipients who were uninsured at the time of their transplant. This is, at least in part, a success story. Undoubtedly, many patients who were uninsured at the onset of organ failure acquired coverage through programs such as the Medicare End Stage Renal Disease Program, as well as through the concerted efforts of transplant teams' social workers and financial coordinators.

Our finding that uninsured patients frequently serve as organ donors is both new and poignant. The U.S. health care system denies adequate care to many of the uninsured during life. Yet, in death, the uninsured often give strangers the ultimate gift.

We do not believe that this pattern reflects the values or intentions of the transplant community. Indeed, subsequent to caring for the patient described earlier in this report, Herring sought out a clinical clerkship on the transplant service. He was struck by the transplant service staff's evident commitment to equal access for all patients, as well as their extraordinary dedication to furthering this life-saving technology.

The commitment to equitable access to transplantation was emphasized in the 1986 report of the Federal Task Force on Organ Transplantation appointed by Ronald Reagan, which called for an "end to wealth discrimination in heart and liver transplantation." This ethical stance toward fair allocation of donated organs regardless of financial background continues to be reiterated by UNOS and the major organizations of the transplant community (13, 14, 34).

Several caveats apply to our findings. First, some hospitals do not consistently include diagnostic codes identifying organ donors in their discharge abstracts. This may reflect the fact that some hospitals formally discharge brain-dead patients when they are accepted as a potential organ donor by the regional organ

Characteristics of	of organ donors, organ recipie	nts, and all hospital inpatients, 20	003
	Donors	Recipients	All other inpatients
	n = 1,447	n = 4,962	n = 7,971,320
Characteristics	(95% CI)	(95% CI)	(95% CI)
Female sex, %	56.1 (53.2–59.0)	39.3 (37.9–40.7)	59.2 (59.1–59.2)
Mean age, years	40.4(39.8-41.1)	46.6(46.1 - 47.0)	47.6 (47.5–47.6)
Race, %			
White, non-Hispanic	69.4 (66.4–72.4)	63.9 (62.4–65.4)	66.1 (66.0 - 66.1)
Black	13.1(11.0-15.2)	17.4(16.3 - 18.6)	$14.1 \ (14.1 - 14.1)$
Hispanic	11.7 (9.6–13.8)	11.2(10.2 - 12.2)	14.0(14.0-14.0)
Asian or Pacific Islander	3.5 (2.4-4.7)	5.1(4.4-5.8)	2.6 (2.6–2.6)
Native American	0.3 (0.0 - 0.7)	0.2(0.1-0.4)	0.2 (0.2 - 0.2)
Other	2.0(1.1-2.9)	2.2(1.7-2.6)	3.1(3.0-3.1)
Mean income in ZIP code of residence, %			
\$1-\$35,999	22.1 (19.9–24.3)	25.4(24.1-26.6)	27.8 (27.8–27.8)
\$36,000-\$44,999	25.6 (23.3–28.0)	26.9 (25.7–28.2)	26.5 (26.5–26.5)
\$45,000-\$59,999	25.9 (23.6–28.3)	25.3(24.1 - 26.6)	24.8 (24.8–24.8)
60,000+	26.3 (23.9–28.6)	22.4(21.1-23.6)	20.9 (20.9–20.9)
Primary payer, %			
Medicare	14.6(12.8 - 16.4)	44.2 (42.8–45.6)	37.2 (37.2–37.3)
Medicaid	2.6(1.8-3.5)	9.0(8.2 - 9.9)	18.5 (18.4–18.5)
Private insurance	45.8 (43.2–48.4)	44.2 (42.8–45.6)	36.6(36.6-36.7)
No insurance (self-pay or no charge)	16.9 (14.9 - 18.8)	0.8(0.5 - 1.0)	4.6(4.6-4.6)
Other	20.1 (18.0–22.2)	1.8 (1.4–2.1)	3.1(3.1-3.1)

Table 1

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441, 2000 2000 2000 2000 2000 2000 2000 20	charges \$33,367 (\$31,894-\$34,835	\$174,259 (\$169,753-\$178,765)	\$19,634 (\$19,609–\$19,659)

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Insurance Status of Organ Donors and Recipients / 647

Table 2

Insurance status of organ donors and organ recipients by organ

	Percent uninsured	
Organ	Donors (n = 1,447)	Recipients $(n = 4,962)$
All	16.9	0.8
Kidney	17.6	0.4
Liver	13.6	1.5
Heart and/or lung		0.3
Pancreas		0
Cornea	6.7	9.5
Other and unspecified	15.4	

Note: Dash indicates no ICD-9-CM procedure codes are available for these categories.

procurement organization (35). Such brain-dead patients are then "readmitted" under a new medical record number and may not be included in the NIS data. Similar problems precluded our accurate identification of donors' vital status at discharge.

As a result of the incomplete hospital coding of organ donation, our analysis captured only 49 percent of the expected number of organ donors (30). But there is no reason to suspect that the donors we identified differed systematically from other donors, and even if every donor whom we failed to capture were insured, the uninsurance rate among donors would still be twice that of other hospital inpatients. Furthermore, our analysis probably understates the proportion of organ donors who were uninsured. We considered the 20 percent of patients whose payer was listed as "other" to be insured. It seems likely that many of them were, in fact, uninsured, but that an organ procurement organization paid their bill.

Transplantation differs from other expensive medical procedures because it uses a scarce resource that can only come from fellow human beings. Consequently, both U.S. law and the custom of the transplant community explicitly mandate fairness and equality in access to organs. The fact that many organ donors were themselves uninsured highlights the failure of the rest of the U.S. health care system to adhere to such values.

Insurance Status of Organ Donors and Recipients / 649

Table 3

Multivariate odds of being an organ donor (or recipient) relative to other hospitalized patients

	Odds ratio		
Variable (reference group)	Donors (n = 1,447) (95% CI)	Recipients (n = 4,962) (95% CI)	
Age (relative to 0–17)			
18–44	24.13 (13.14-44.34)	4.21 (3.66-4.86)	
45–64	14.79 (8.02-27.29)	6.75 (5.91–7.72)	
>64	0.60 (0.27-1.31)	0.79 (0.67-0.93)	
Female (relative to male)	0.79 (0.66-0.94)	0.42 (0.39-0.45)	
Race (relative to white, non-Hispanic)			
Black	0.62 (0.49-0.79)	1.20 (1.10-1.32)	
Hispanic	0.55 (0.42-0.72)	0.95 (0.85-1.10)	
Asian/Pacific Islander	0.77 (0.45-1.30)	2.18 (1.87-2.56)	
Uninsured (relative to insured)	3.41 (2.81-4.15)	0.08 (0.06-0.12)	
Mean income in ZIP code of residence			
(relative to lowest quartile)			
2nd quartile	1.17 (0.95–1.43)	1.21 (1.10–1.32)	
3rd quartile	1.10 (0.89–1.37)	1.16 (1.05–1.28)	
Highest quartile	0.92 (0.71-1.18)	1.12 (1.00-1.24)	
Patient county of residence (relative to			
large metropolitan area)			
Small metropolitan area	0.85 (0.70-1.03)	0.95 (0.87-1.03)	
Micropolitan area	1.26 (0.97-1.63)	1.18 (1.05–1.33)	
Non-urban area	0.75 (0.50-1.11)	0.86 (0.73-1.01)	
Hospital region (relative to Northeast)			
Midwest	0.47 (0.35-0.62)	0.57 (0.50-0.65)	
South	0.46 (0.39–0.55)	0.83 (0.77-0.90)	
West	0.57 (0.45–0.72)	0.85 (0.77–0.94)	

Note — All three authors participated in the conception, design, analysis, and interpretation of data, statistical analyses, and drafting of the manuscript. Dr. Himmelstein acquired the data. None of the authors has any conflict of interest or any commercial relationships relevant to this manuscript. All authors had full access to all of the data in the study and take responsibility for the integrity of the data and the accuracy of the data analysis.

APPENDIX

Table A.1

ICD-9-CM codes	Diagnosis
V59.4	Donors, kidney
V59.5	Donors, cornea
V59.6	Donors, liver
V59.8	Donors, other specified organ or tissue
V59.9	Donors, other unspecified organ or tissue

Note: The ICD-9-CM does not provide specific V codes or procedure codes for donor cardiectomy or pulmonectomy.

Table A.2

ICD-9-CM V procedure codes used to identify organ transplant recipients

ICD-9-CM codes	Diagnosis	
336	Recipient, combined heart-lung	
375, 3751	Recipient, heart	
116, 1160, 1164, 1169	Recipient, cornea	
505, 5059	Recipient, liver	
528, 5280, 5283	Recipient, pancreas	
556, 5569	Recipient, kidney	
335, 3350, 3351, 3352	Recipient, lung	

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