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Organ Donation

Organ Donation among Undocumented Hispanic Immigrants: An Assessment of Knowledge and Attitudes

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ABSTRACT

Background

Undocumented immigrants can donate their organs, but lack access to organ transplantation. This challenges foundational principles of organ donation: fairness and informed consent. Little is known about undocumented immigrants' knowledge of barriers to their access to organ transplantation or how this might affect their decision to donate their organs.

Methods

The study was performed in an urban, university-affiliated, safety-net hospital. We interviewed hospitalized patients who self-identified as undocumented immigrants and were unaware of hav-

ing any contraindication to organ donation (for example, cancer). We first recorded their demographic characteristics and knowledge and attitudes regarding organ donation. We then assessed the effects of informing participants about limits to their access to organ transplants on their willingness to donate.

Results

This group of 59 uninsured Hispanic immigrants had adequate knowledge about organ donation. Participants were suspicious about inequality within the medical system, but most were willing to donate their organs (74 percent). Most participants (74 percent) were aware that they would have to pay to receive an organ, but they dramatically underestimated the out-of-pocket expenses. Yet willingness to donate their organs was unaffected by participants being explicitly informed of the low likelihood that they would be able to afford to receive an organ transplant.

Conclusions

Despite being well informed about the organ donation system, undocumented Hispanic immigrants underestimate the costs and overestimate their likelihood of receiving an organ. Even when they are given this information, they remain willing to donate their own organs.

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INTRODUCTION

Undocumented immigrants are able to, and do, donate their organs, but they are effectively barred from receiving organ transplants because of their legal status.¹ This challenges a fundamental principle

of organ donation: fairness. Further, it is not known whether undocumented immigrants appreciate this inequity and, if they did, whether it might affect their decision making about donating their own organs. Not providing potential organ donors with information that might be relevant to their decision undermines another basic ethical principle of organ donation: informed consent.

These questions of fairness and access have not been a significant part of the discourse around organ donation. The conversation has predominantly focused on scarcity and methods to address the paucity of available organs for people in need. The need to increase organ donation is important, but should not come at the expense of the rights of vulnerable groups. The American Medical Association (AMA) and the Organ Procurement and Transplant Network (OPTN) have spoken to this concern. The AMA's "Principles of Medical Ethics" state that potential donors should be fully informed of the consequences of their decisions and free of coercion.²

OPTN Policy 6.2.1 states, "deceased donor organ allocation to candidates for transplantation shall not differ on the basis of a candidate's citizenship or residency status in the U.S."³ Despite this, most undocumented immigrants are excluded from the organ transplantation pool on the basis of their legal status. As Goldberg and colleagues describe, current U.S. legislation makes it difficult for many undocumented immigrants to access needed transplants.⁴ This lack of access is not based on the potential utility of the transplanted organ; it is based on restrictive reimbursement criteria for organ transplants. Undocumented immigrants are uninsurable through plans supported by the federal government.⁵ In order to receive an organ transplant, they would need to cover all expenses independently—an exceedingly rare occurrence.⁶ There are approximately 7.2 million uninsured, undocumented immigrants in the U.S.⁷

Although they are not eligible to receive organ transplants, undocumented immigrants have the capacity to donate their organs. They frequently enter the medical system through emergency and charity care systems.⁸ Once they are in the system, the "required request" policies of the Joint Commission and Medicare insure that undocumented immigrants will be asked about their wishes regarding organ donation.⁹ No stipulations are made regarding their lack of U.S. citizenship.¹⁰

Currently, this information is neither routinely nor explicitly discussed with these patients or their surrogates. Although the attitudes of minority populations such as the African-American, Hispanic, and

Asian communities about organ donation have been studied, little is known about the attitudes of undocumented immigrants toward organ donation or about their knowledge of the barriers to organ transplantation. Previous studies of barriers for the Hispanic community, in particular, emphasized distrust of the medical establishment, language differences, religious issues, and concerns about mutilation of the donor's body.¹¹ Furthermore, little is known about whether this population would consider information about their potential to receive organs relevant to their decision to donate their own organs. To evaluate whether this information would affect their decisions to donate organs, we created a survey in which we provided a sample of undocumented immigrants with information on their limited ability to receive a transplant. We then reassessed their willingness to donate their organs.

METHODS

We conducted this study at Cook County Hospital, a 500-bed public hospital in Chicago, Illinois. Data were collected from December 2009 to September 2011. The study was approved by the hospital's institutional review board.

Eligible patients were general medicine inpatients 18 years or older who spoke English or Spanish and self-identified as undocumented immigrants or legal residents who had lived in the U.S. for less than five years. Legal residents are eligible for Illinois Medicaid after five years of residency. Patients were excluded if they reported having cancer, human immunodeficiency virus (HIV), or chronic viral hepatitis, as these are considered absolute contraindications for organ donation. We reasoned that if patients knew they would not be eligible to donate organs, they would respond to our questions differently. We also excluded patients who were incarcerated or unable to consent.

We used a convenience sample of patients admitted to the general medicine wards. Each morning, attending physician hospitalists on the general medicine service who had admitted new patients the day prior were asked if they had potentially eligible patients for study. The interviewer approached identified patients for enrollment and verbal consent. If consent for participation was obtained, patients were screened. A single interviewer (CM) performed all of the interviews at the bedside on the first hospital day.

After the initial screen, the interview consisted of one open-ended question and 32 closed-list questions. It took about 10 minutes to complete. The in-

terview was developed based on prior research¹² and our consensus opinion. The interview was pilot tested on 15 patients to ensure that the questions were comprehensible; no data from the pilot testing were used in the final analysis.

The survey consisted of three parts: (1) an assessment of knowledge, beliefs, and attitudes about organ donation; (2) an intervention in which participants were informed about the barriers to access for organ transplantation followed by a reassessment of their attitudes; and (3) a collection of demographic characteristics (see the appendix).

To determine their level of knowledge, we asked a single open-ended question about patients' understanding of organ donation and 21 closed-list questions about their exposure to information about donation. We explored beliefs about body disfigurement and beliefs about the presence of an unsanctioned or "black" market for organ transplantation, as these are areas found to be of particular concern in the Hispanic population and are predictive of willingness to donate.¹³ We assessed the participants' willingness to donate their own organs and those of their loved ones, both in the U.S. and in their home country. We asked whether they had discussed end-of-life issues, and organ donation in particular, with family members and friends, as this has been found to be predictive of willingness to donate.¹⁴

The intervention began with an assessment of the patients' insurance status. We then asked whether they understood that, without insurance, they would be responsible for all of the costs incurred by an organ transplant. After asking them to guess how much transplantation of a heart, a liver, and a kidney cost, we gave them the actual estimated cost of each of the procedures.¹⁵ We then reassessed their willingness to donate and asked them whether they believed this information was important. Other than their estimation of the cost of transplantation, all questions were posed in a "yes/no" format.

Statistical Analysis

We judged that, if 10 percent of the participants who had previously agreed to donate their organs decided not to donate them after the intervention, the impact would be considered meaningful. To generate an estimate with 80 percent power for the lower bound of a 90 percent confidence interval (C.I.) to exclude this meaningful impact, we estimated that we would need 60 participants.

We used descriptive statistics to summarize the relevant variables. Given the large number of participants willing to donate organs and the relative homogeneity of the overall population, we did not

estimate associations between demographic variables and participants' willingness to donate organs.

Assessment of the effect of the intervention was made using McNemar's test. The McNemar's test evaluates whether proportions measured before and after an intervention in the same group are significantly different.¹⁶ Data for this test was dichotomized into "yes" responses and "non-yes" responses. "Non-yes" responses included patients who answered "no" and those who answered "don't know." All analyses were performed with Stata 10.1.¹⁷

RESULTS

Of the 60 patients enrolled in the study (see figure 1), 59 completed it. The participants were predominantly uninsured Mexican immigrants with a high school education or less (see table 1). Spanish was the preferred language for every patient except one. Most had family living in the U.S. and family members who were U.S. citizens.

Table 2 provides detailed information about the participants' responses to the survey. Of the 60 participants, 39 (65 percent) had seen information about organ donation within the past year, and 53 (88 percent) did not worry that organ donation would disfigure their body. However, 31 (52 percent) believed that there is a black market for organ donation in the U.S., which suggests that participants had concerns about inequity within the medical system.

Responses to indicators of willingness to donate were mixed. Nearly three-quarters (72 percent) of participants expressed willingness to donate their organs when they die, but only 22 (37 percent) expressed willingness to donate their family members' organs when their family members die. Participants were 19 percent more likely to agree to donate organs of family members if they were living in their home country rather than in the U.S. (95 percent C.I. 5 percent to 33 percent, $p = 0.004$ for the difference). Yet this difference, based on country of residence, was not significant when referring to their own organs (absolute difference 3 percent, 95 percent C.I. -4 percent to 14 percent, $p = 0.18$).

Although rates of reported willingness to donate their organs were high, participants' rates of communication with family and friends about organ donation and death arrangements was low: 22 (37 percent) had discussed organ donation, and 17 (28 percent) had discussed death arrangements with their family.

Regarding the intervention, 74 percent knew that they would have to pay for an organ if they did not have health insurance, but, as a group, the partici-

pants dramatically underestimated the cost of transplants (see table 3). Being informed of this discrepancy between their estimated cost for transplant and the actual cost had no statistically significant impact on the group's willingness to donate organs (95 percent C.I. -8 percent to 14 percent, $p = 0.5$ for the difference) (see table 4). No patients who originally agreed to donate their organs changed their mind after learning this information. Although the information didn't affect their reported willingness to donate their organs, a large majority (49 participants, 82 percent) felt that this was information that their doctor should tell them (see table 2).

DISCUSSION

To our knowledge, this is the first study of the beliefs and attitudes of the undocumented, Hispanic, immigrant population in the U.S. about organ donation. This population is faced with unique barriers to access that might cause their attitudes about organ donation to be very different than people of similar cultural background who are legal residents in the U.S. and, consequently, insurable. We hypothesized that information about this inequity within the organ transplantation system would be relevant for potential donors from the undocumented immigrant community to make a fully informed decision regarding organ donation. This study assesses the opinions of a group of undocumented, Hispanic im-

migrants regarding the relevance of information about their limited access to organ transplants to their decisions about organ donation.

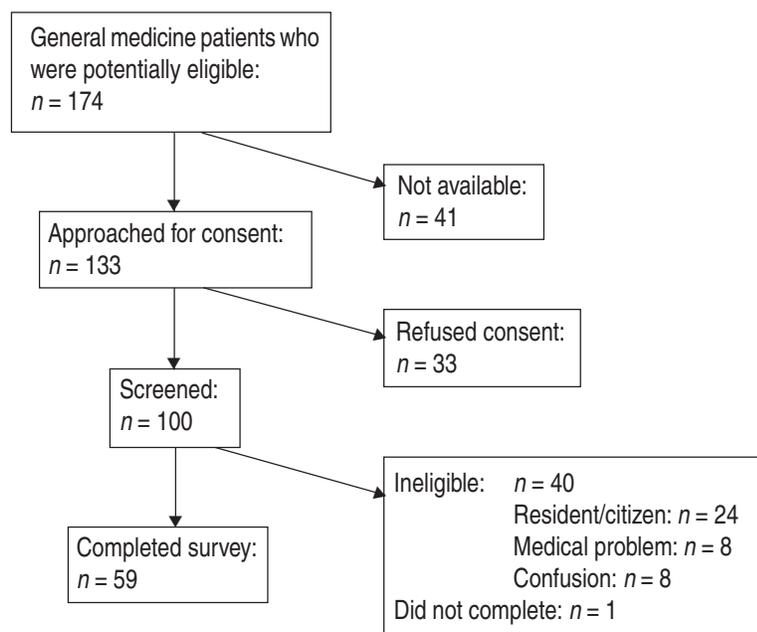
Our study population came from an urban, county-funded hospital. They were predominantly Mexican, and the language preference for the majority was Spanish. This language preference is a marker for limited acculturation.¹⁸ They also had a low educational achievement status and were predominantly uninsured (93 percent). However, the cohort was relatively well informed about organ donation, particularly when compared to other studies of Hispanics. For instance, McNamara and colleagues found that only 46 percent of Hispanic citizens in their study had seen information about organ donation within the prior year, while 65 percent of our participants reported having seen information about organ donation in the prior year.¹⁹

Regarding our primary hypothesis, undocumented immigrants in our study clearly felt that being informed about their barriers to access to organ transplants is important. In our intervention, we gave the study participants two key pieces of information that effectively exclude them from organ transplant lists. We informed them that, if uninsured, they need to pay for organ transplant on their own, and we gave them the true cost of organ transplant procedures; 82 percent felt this was information that doctors should tell their patients who are considering organ donation. It is interesting that this knowl-

edge did not affect their willingness to donate organs. Although our study has limitations, our data suggest that providers might have a robust conversation about organ donation with these patients, including discussion of barriers to access to organ transplantation for their community, without adversely affecting their willingness to donate.

From an ethical standpoint, the need for a robust informed consent process that includes a discussion of inequalities within the organ donation system is clear. However, this obligation for informed consent often conflicts with a countervailing desire to insure that critically ill people have access to life-saving organs.²⁰ This desire to maximize the number of lives saved may cause health professionals to avoid proactively discussing unfairness within the organ donation system; our data undermine this argument. Based on our data, undocumented Hispanic

FIGURE 1. Flow diagram of patient enrollment in the study



immigrants prefer this type of high-information conversation, which suggests that there may be benefits to the relationship between health professionals and patients and families from explicit, proactive discussions of inequities within the system. Although we do not study this outcome here, one might imagine that there could be a positive effect on willingness to donate one's organs as a result of such a robust consent process.

We find this continued willingness to donate organs despite the clarification of barriers to organ transplantation surprising, although reassuring. This suggests to us that an unselfish regard for the welfare of others persists within this community. Although we certainly hope that altruism is what motivates our organ donors, to see it corroborated in this way is encouraging. However, although undocumented immigrants may autonomously choose to donate their organs despite significant limitations to their access to transplantation, this does not mean

that it is acceptable to continue to propagate an unfair system that determines access to organ transplantation based on social criteria.

TABLE 1. Sociodemographic characteristics of 59 participants

	<i>n</i>	%
Female	33	55
Highest level of education		
Less than high school	24	40
High school	28	47
More than high school	7	12
Religion		
Roman Catholic	46	77
Other ¹	13	22
Marital status		
Married	23	38
Unmarried	19	32
Widowed	9	15
Separated	5	8
Divorced	3	5
Have children	52	87
Number of children [mean (SD)]	3	2
Family members living in the U.S.	52	87
Have family members who are U.S. citizens	38	63
Insured	4	7
Country of origin		
Mexico	54	92
Other ²	5	8

NOTES

1. Other religions were: other Christian (*n* = 11), 7th Day Adventism (*n* = 1), and none (*n* = 1).

2. Other countries of origin were: Guatemala (*n* = 2), Chile (*n* = 1), Ecuador (*n* = 1), and Philippines (*n* = 1).

TABLE 2. Participants' attitudes and knowledge related to organ donation

Question	Participants answering "yes"	
	<i>n</i>	%
Knowledge of organ donation		
Aware of need to self-pay if uninsured	41	68
Seen information in the past year	39	65
Known a transplant recipient	14	23
Known an organ donor	8	13
Believe organ donation disfigures body	4	7
Communication about organ donation		
Doctors should tell patients about costs of organ transplant	49	81
Discussed organ donation with family	22	37
Discussed organ donation with friends	20	33
Discussed disposition of dead body with family	17	28
Willingness to donate		
Willing to donate organs to family member	56	93
Willing to donate organs in home country	46	77
Willing to donate organs	43	72
Willing to donate family member's organs in home country	33	55
Willing to donate family member's organs	22	37
Beliefs about organ donation		
There is a black market for organ donation ¹	31	52
Important to have all body parts upon burial	12	20

NOTES

1. 12 participants (20%) answered "don't know."

TABLE 3. Participants' estimated costs for organ transplantation

	Median estimated cost, \$000s (IQR)	Actual cost, \$000s ¹	Difference, \$000s ²
Heart	50 (12.5 to 175)	620	570
Liver	50 (10.0 to 205)	525	475
Kidney	49 (7.5 to 135)	250	201

NOTES

1. R.H. Hauboldt, "2007 Organ and tissue transplant cost estimates," *Milliman USA*, 1 November 2007, <http://www.milliman.com/expertise/healthcare/publications/rr/pdfs/2007-US-Organ-Transplant-RR11-01-07.pdf>, accessed 2 September 2009.

2. Indicates the difference between the median estimated costs and the actual costs.

Our conclusions about altruism, despite limited access within this community, are reinforced by our finding that, whether participants imagined donating their organs in the U.S. or in their home country, they remained equally willing to be an organ donor. The relevance of this evidence is tenuous, as our study was not powered to detect what may have been a subtle difference between willingness to donate in the U.S. and in their home country. Furthermore, participants were significantly more likely to donate their family members' organs if they lived in their home country. This discrepancy between willingness to donate one's own organs and unwillingness to donate a relative's organs has been described elsewhere among Hispanics, so it is likely a cultural phenomenon that is unrelated to our participants' feelings of altruism or engagement in the community in which they live.²¹ They may be less willing to donate their family members' organs in the U.S., however, because they feel more marginalized from the larger community than they do in their home country. We cannot evaluate this hypothesis with this small sample.

Our study revealed several other important insights into the undocumented Hispanic immigrant community regarding organ donation. The proportion of participants willing to donate their organs was very high (72 percent); it exceeded those from

other studies of the Hispanic community and approached those for the population as a whole.²² We can only speculate on the reasons for these discordant findings. They may reflect differences in methodology, unique attitudes among people who make sacrifices to come to this country, or a shift in beliefs in the population as a whole in the recent past. Alternatively, the findings could be explained by the fact that our group is less well informed about organ donation compared with other groups in the literature.²³ Studies indicate that Hispanics who are uninformed about organ donation are more likely to be organ donors.²⁴ Further work needs to be done to examine the attitudes of our population.

We also found evidence of poor communication about organ donation within our immigrant Hispanic cohort. This is not surprising, given the lack of communication within Hispanic communities about end-of-life issues that has been documented in the literature. This literature suggests that Hispanics discuss death arrangements much less frequently and are more uncomfortable with thinking about death than people of other ethnicities.²⁵

Our study has several limitations, and the conclusions should be interpreted as generating hypotheses. Our sample was small and limited to a single institution. Although the numbers are small, this remains the first study of this population's attitudes about organ donation. By using a dichotomous format (yes/no), we did not assess the degree of support that undocumented immigrants give to organ donation. A 2005 Gallup Poll reports that, although people of all races support organ donation in large numbers, the degree of support (strongly support versus support) differs between races.²⁶ Our survey was face-to-face, not self-administered. There may have been a significant social desirability bias to participants' answers. Finally, reported willingness to donate does not correlate well with organ donation, or even key intermediate behaviors such as completing an organ donor card; so the true clinical significance of these results is unclear.²⁷

These results provide insight into the beliefs and values regarding organ donation of a large community within the U.S. whom, to our knowledge, have never been formally studied. Our study empirically addresses the impact of a robust informed consent process on organ donation discussions with undocumented Hispanic immigrants. For this community, the overwhelming majority believe that information about barriers within the system is an important part of the informed consent process. Yet it does not appear to affect their decisions about whether to donate their organs or not. Expanding these conversa-

TABLE 4. Effect of intervention on participants' wishes regarding organ donation

		After intervention ¹		Total (before)
		Wish to donate organs	Do not wish to donate organs or preference unknown	
Before intervention	Wish to donate organs	40	3	43
	Do not wish to donate organs or preference unknown	5	11	16
Total (after)		45	14	

NOTES

1. McNemar's test was performed to evaluate for an effect from the informational intervention. $p = 0.48$. The 95% confidence interval for the proportion of participants who wished to donate organs *before* the intervention but did not *after* the intervention was -8% to 14%.

APPENDIX

[Interviewer: Subjects should only be prompted with “yes” or “no.” Only mark “unsure” if the subject responds with this independently.]

1. Are you a U.S. citizen?
 (0) No
 (1) Yes [If “yes” then stop.]
 (2) Unsure
2. Are you a permanent resident?
 (0) No (1) Yes (2) Unsure
3. If so, how long have you been a resident?
 (0) 0-5 years (1) >5years (2) Unsure

[If greater than 5 years, then stop.]

4. What country are you from, originally?
 (0) Mexico (1) Poland
 (2) India (3) Pakistan
 (4) Other:
5. Other: _____

People know and understand many different things about organ donation. Just so that I know that we’re on the same page, could you briefly tell me what you know and understand about why we do organ donation and how it works?

6. Notes: _____

7. Organs identified by subject: _____
[If incorrect or “no,” then tell them:]

Organ donation is the removal of healthy, internal body parts, or organs, from one person for the purpose of putting them in someone else whose organs aren’t working normally. When someone gets a healthy organ put in their body to replace the organ that isn’t working normally, it is called an organ transplant. Organs that can be transplanted include: kidneys, hearts, livers, lungs, intestines, and pancreas. Some organs, like kidneys, can be given by someone who is still living. Many organs are given by people that have recently died. For these people, their families often make the decision to give their organs away for them. In the U.S., it is illegal to sell organs, they are only given away for free.

8. Do you know about any medical problems you have that would exclude you from donating an organ?
 (0) No (1) Yes (2) Unsure

[If “yes”:] What are those problems? [Mark all that are mentioned:]

9. Infection: (0) No (1) Yes
10. Cancer: (0) No (1) Yes
11. Cardiac: (0) No (1) Yes
12. Pulmonary: (0) No (1) Yes
13. Hepatic: (0) No (1) Yes
14. Alcohol or Drugs: (0) No (1) Yes

15. Other _____

16. [If cancer, HIV, Hepatitis B or C—confirm type of hepatitis—then stop.]

- (0) Cancer (1) HIV
 (2) Hep B (3) Hep C
 (4) Hepatitis—type unknown

17. Other: _____

[If anything else, let them know that they may still be able to donate an organ and proceed.]

18. [If unsure:] For instance, Do you have cancer?
 (0) No (1) Yes (2) Unsure
19. Do you have any chronic infections?
 (0) No (1) Yes (2) Unsure

[If “yes” to any of the above, then stop. If “no” continue on:] Unless I tell you otherwise, all questions can be answered with a “yes” or a “no.”

20. Have you seen information about organ donation in the past year?

- (0) No (1) Yes (2) Unsure

21. Have you ever known anyone who donated an organ?
 (0) No (1) Yes (2) Unsure

22. Have you ever known anyone who received an organ?
 (0) No (1) Yes (2) Unsure

23. Have you ever discussed organ donation with your family?
 (0) No (1) Yes (2) Unsure

24. Have you ever discussed organ donation with your friends?
 (0) No (1) Yes (2) Unsure

25. Some people have thoughts about what they want to happen with their body after they die. Have you ever discussed what you want to happen with your body after you die with your family?

- (0) No (1) Yes (2) Unsure

26. Would you be willing to give your organs away when you die?
 (0) No (1) Yes (2) Unsure

27. If you did not know their wishes, would you be willing to give your family member’s organs away when they die?

- (0) No (1) Yes (2) Unsure

28. Would you be willing to give an organ to your family member, if they needed it?

- (0) No (1) Yes (2) Unsure

29. If you lived in [home country] would you be willing to give your organs away when you die?

- (0) No (1) Yes (2) Unsure

30. If you lived in [home country] would you be willing to give your family member’s organs away when they die?

- (0) No (1) Yes (2) Unsure

31. Many people worry that donating their organs would disfigure their, or their family member’s, body. Is this something that worries you?

- (0) No (1) Yes (2) Unsure

32. Many people feel that it is important for a person’s body to have all of its parts when it is buried. Is this important to you?

- (0) No (1) Yes (2) Unsure

33. A black market is where things are bought and sold illegally. Some countries have black markets for organs. Do you think there’s a black market for organ donation in the U.S.?

- (0) No (1) Yes (2) Unsure

APPENDIX, continued

34. Do you have health insurance?
 (0) No (1) Yes (2) Unsure
35. People without health insurance can only get an organ transplant if they pay for it themselves. Did you know that you would have to pay for an organ yourself if you needed it?
 (0) No (1) Yes (2) Unsure
- I would like to ask you how much you think it costs to get an organ transplant. I will ask you about 3 different organs. Please give me your best guess (in dollars) about how much the surgery would cost.
36. Heart: \$ _____ (1) Don't know
37. Liver: \$ _____ (1) Don't know
38. Kidney: \$ _____ (1) Don't know
- It actually costs about about \$660,000 to get a heart, \$520,000 to get a liver, and about \$250,000 to get a kidney.
39. Knowing this information, would you be willing to give your organs away when you die?
 (0) No (1) Yes (2) Unsure
40. If you lived in [home country] would you be willing to give your organs away when you die?
 (0) No (1) Yes (2) Unsure
41. Do you think that this is information that doctors should tell their patients who are thinking about donating an organ?
 (0) No (1) Yes (2) Unsure
42. Sex
 (0) M (1) F (2) Transgender
43. How far did you go in school?
 (0) <High School (1) High School
 (2) College (3) Graduate
44. What religion were you raised in?
 (0) Baptist (1) Catholic
 (2) Other Christian (3) Muslim
 (4) Hindu (5) Buddhist
 (6) Other
45. What is your current marital status?
 (0) Married (1) Unmarried
 (2) Divorced (3) Separated
 (4) Widowed
46. Do you have any children? If so, how many?
 (0) No (1) Yes
47. If "yes," number: _____
48. Do you have any family in the U.S.?
 (0) No (1) Yes
49. Are your family members U.S. citizens?
 (0) No (1) Yes (2) Unsure
50. What is your language of preference?
 (0) English (1) Spanish (2) Polish
51. Other: _____
52. In the past year, how many times have you been hospitalized?
 (0)#: _____ (1) Unsure

tions is consistent with the goals of an ethically sound organ donation program, and ought to become standard practice.

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