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Contributing Factors for the Willingness to Donate Organs in the Hispanic American Population

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Abstract

Objective—To identify factors that contribute to intent to donate organs in Hispanic American individuals.

Design—Cross-sectional telephone surveys.

Setting—Four southern California neighborhoods with a high percentage of Hispanic American individuals.

Patients—Respondents 18 years or older were drawn randomly from lists of Hispanic surnames.

Main Outcome Measures—Telephone surveys were conducted that measured demographic and socioeconomic factors, cultural factors, awareness and knowledge, and perception and belief regarding organ donation, as well as the intent to become an organ donor. Logistic regression was performed to identify independent contributing factors to intent to register for organ donation.

Results—Five hundred twenty-four telephone surveys were conducted over a 3-week period. Seventy-three percent of those surveyed were between the ages of 18 and 44 years and the sample was equally divided between men and women. The following independent risk factors contributed to intent to register: low acculturation (adjusted odds ratio [AOR], 0.39; 95% confidence interval [CI], 0.24–0.62; $P<.001$), religion (AOR, 0.33; 95% CI, 0.17–0.60; $P<.001$), perception that the wealthy are more likely to receive organs (AOR, 0.41; 95% CI, 0.25–0.65; $P=.001$), belief that donation disfigures the body and impacts the funeral (AOR, 0.45; 95% CI, 0.22–0.89; $P=.02$), and family influence (AOR, 2.02; 95% CI, 1.28–3.22; $P=.004$).

Conclusions—Among Hispanic American individuals, low acculturation, religion, belief, and family influence affect the intent to register for organ donation. To improve organ donation, these risk factors should be considered using specific, effective educational programs.

Because of a number of medical advances, transplantation has become a preferred treatment for end-stage solid organ failure. The growing demand for organs continues to outpace

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supply, such that the organ shortage is a public health crisis. In 2008, 27 963 transplants were performed from 14 000 donors.[1] Unfortunately, with more than 104 000 people listed, awaiting organs, more than 7000 patients die every year before receiving their organs.[1] This discrepancy is most pronounced in minority populations, who compose more than 40% of the entire organ waiting list.[2]

Hispanic American individuals represent a unique minority in that their population growth outpaces that of all other ethnic groups.[3] Hispanic American individuals accounted for nearly half of the national population growth between 2000 and 2004[3] and it is estimated that they will constitute one-third of the American population by the end of this century.[4] As expected, this population growth parallels a growth in transplant organ need. Over the past decade, the number of Hispanic American individuals added to this organ waiting list has increased by more than 260% while the list involving non-Hispanic individuals has grown by 146%.[4] Despite this growth, His-panic American individuals are still 60% less likely to donate their organs than non-Hispanic white individauls.[4]

There is a paucity of literature to explain why Hispanic American individuals are less willing to become organ donors.[5] As a result, many studies were forced to extrapolate from the successful approach used to increase organ procurement in African American individuals.[6–8] The purpose of this study was to identify unique factors associated with a willingness to donate organs in Hispanic American communities in southern California. This study will serve as a basis for interventions that are designed to increase the organ donation rate in Hispanic American individuals.

METHODS

This research is part of an ongoing project sponsored by the National Institute of Diabetes and Digestive and Kidney Diseases (grant 5RO1DK079667) to help increase organ donation rates in Hispanic American communities in the county of Los Angeles. This study was approved by the institutional review board of the Cedars-Sinai Medical Center.

TARGET NEIGHBORHOODS

Four southern California neighborhoods with high percentages of Hispanic American individuals residing close to a major metropolitan level I trauma center that provides the majority of their care were identified using US census data.[9] Three of the neighborhoods are study communities where future interventions will be implemented, and 1 neighborhood serves as the control community where future interventions will not be implemented. The current study reports the findings of the cross-sectional survey in the 4 neighborhoods conducted in October 2008 prior to the start of any programs or interventions.

SURVEY AND SURVEY INSTRUMENT

The cross-sectional survey (validated by the local organ procurement organization OneLegacy) was designed to measure various factors found to affect organ donation. The specific variables and their corresponding domains are listed in Table 1. With the exception of the level of acculturation, each data element was derived from the direct answer to a question in the survey. The level of acculturation is a composite indicator using the respondent’s generation, percentage of life in the United States, and language preference.

The survey began with 6 demographic questions designed to confirm that the respondents lived in the target zip codes, were Hispanic American individuals, and were older than 18 years. The survey included 21 questions targeting the participant’s thoughts about organ donation. Questions were asked to ascertain the person’s awareness, beliefs, and attitudes about organ donation. Most of these were multiple-choice questions, but some were left

open ended. After the series of questions about organ donation, the participant was then asked basic demographic information. This included 13 questions about education, income, religion, employment, and other demographic data.

Respondents were drawn randomly from lists of Hispanic surnames in the 4 target zip codes. Lists of telephone numbers were purchased from a number registry (SDRSamplingServices). Numbers were then assigned to a calling center by computer randomization. The sample was stratified by zip code so that about one-quarter of the sample came from each of the 4 areas called. Respondents were qualified as self-identified Hispanic American individuals, 18 years or older, who claimed to be one of the heads of their households. The sample included foreign- and US-born Hispanic American individuals and various levels of acculturation.

The survey was conducted over a 3-week period in October 2008 by professionally trained interviewers. Data were collected and coded into a database for each respondent. There were multiple points of termination for participants who did not fulfill the study requirements. Data were collected and coded by technicians blinded to the purpose of this study.

STATISTICAL ANALYSIS

The main outcome measure for this study was the respondent's intent to register to become an organ donor. We defined intent to register as those who answered "already registered" or "very likely to register" to the question "How likely are you to register to become an organ donor?" The contributing factors included demographic and social economic factors, cultural factors, awareness and knowledge, perception, and belief regarding organ donation. Table 1 provides a list of the data elements considered in this study for each domain.

Univariate analysis was performed to identify the differences of each contributing factor between the "intent to register" and the "no intent to register" groups. The 2-sided Fisher exact test was used to analyze categorical factors and the Mann-Whitney rank sum test was used to analyze continuous factors. For all factors, the unadjusted odds ratio for intent to register, with 95% confidence intervals, was derived. Factors with a P value <.20 from the univariate analysis were selected into the stepwise logistic regression model to identify independent contributing factors to intent to register for organ donation. Adjusted odds ratios and their 95% confidence intervals were derived for the significant factors entered in the model.

A sample size of 500 was predetermined to provide us with a 95% confidence interval estimate of at most 5% width for each attitude toward organ donation. This estimation was based on the assumption that each attitude or response was measured as a dichotomous or categorical variable and that the attitudes varied from 10% to 90%. All statistical analysis was performed using SAS Systems for Windows, version 9.1.3 (SAS Institute Inc, Cary, North Carolina).

RESULTS

There were a total of 524 telephone interviews by professionally trained interviewers. Seventy-three percent of the population was between the ages of 18 and 44 years, and 39% were male. Of these respondents, 31% (163) expressed intent to register and 69% (361), no intent to register. A comparison of all contributing factors between the "intent to register" and the "no intent to register" respondents is shown in Table 2. As demonstrated, there was no significant difference in age, sex, income, place of residence (zip code), any of the perception factors, unwillingness to donate to a stranger, and belief that organ donation is cruel, whereas a difference was seen in all other contributing factors between those who expressed a positive or negative intent to register.

Table 3 demonstrates the odds ratio for intent to register for each factor and its 95% confidence interval. Significant differences in the willingness to donate include higher educational level (high school or less), employment, high or medium acculturation, family influence, no religious influence, awareness of organ donation program, awareness of driver license registry, belief that organ donation helps people, and belief that it is a social responsibility.

From the univariate analysis (Table 3), 15 factors with $P<.20$ were entered into the stepwise logistic regression model to identify independent contributing factors. A total of 350 respondents with complete answers to all questions were included in the analysis. Six factors were entered as significant ($P<.05$) independent contributing factors to intent to register. The results are shown in Table 4. Low acculturation, religion, belief that organ donation will disfigure the body and impact the funeral, and perception that wealthy people are likely to receive organ transplants were independent negative factors for intent to register and family influence and awareness of driver license registry were independent positive factors for intent to register. These 6 factors explained 26% of the difference between the “intent to register” and the “no intent to register” respondents.

COMMENT

In the present study, we set out to identify factors that contribute to the willingness to donate organs in the Hispanic American community. These factors could then be addressed in future interventions to help increase consent rates in this minority population. We found that only 31% of the population expressed willingness to become an organ donor. This is far below the 46% intent to register seen in other Hispanic American communities, reinforcing the notion that Hispanic American individuals are not a homogeneous group and different communities may require different interventions.[10] We found that independent contributing factors for the intent to become an organ donor included low acculturation, religion, belief that organ donation will disfigure the body and impact the funeral, perception that wealthy people are likely to receive organ transplants, family influence, and awareness of driver license registry. With the exception of acculturation level, these independent factors can easily be targeted in future campaigns aimed at improving organ donation rates in the Hispanic American community.

While the Hispanic American population is growing rapidly, a disproportionate amount of Hispanic American individuals are on the organ donation waiting list. Although only 16% of the waiting list participants are Hispanic American, this percentage will increase based on current growth rate and disease patterns. Of approximately 35 million Hispanic individuals in America, 1.2 million are diabetic—the leading cause of kidney failure—and Hispanic American individuals are at increased risk for diabetic complications such as pancreas and kidney failure.[10] When compared with the general population, Hispanic American individuals have higher rates of obesity, non–insulin-dependent diabetes mellitus, and end-stage renal disease.[10] For these reasons, dramatic increases in organ need are not at all surprising. Over the past decade, the need for transplanted kidneys increased by 197% and the need for kidney-pancreas transplants increased by 791% in Hispanic American individuals; the corresponding increases in non-Hispanic white individuals were 116% and 184%, respectively.[10] There is clearly an increasing need for transplantable organs in the Hispanic American community. Although the consent rates among Hispanic American individuals are improving, they still are 60% less likely to donate compared with non-Hispanic white individuals.[3]

Interestingly, very little is known about why Hispanic American individuals are less likely to donate compared with non-Hispanic white individuals. In fact, much assumed about

Hispanic American donation rates is extrapolated from African American individuals. Similarities exist in both minority groups, such as distrust of the medical system and misconceptions concerning religion; however, there are other critical issues specific to the Hispanic American community. Important issues identified to affect organ donation rates in Hispanic American individuals include language barrier, involvement of the extended family in decision making, lack of knowledge and/or misconceptions concerning organ donation, religious beliefs and/or cultural viewpoints, and failures of health care professionals to communicate effectively.[3,5,11–15] Also unique to Hispanic American individuals, they are a highly mobile population, with a constant influx of newcomers both from other communities within the United States and their country of origin.[3] This makes promoting organ donation within the Hispanic community a challenging endeavor.

One of the few studies to examine risk factors for organ donation in Hispanic American individuals in Arizona found that family discussions about organ donation and knowing someone willing to be a donor were significant predictors for the willingness to be an organ donor.[11] Similarly, we found that family influence was important and, when present, a participant was 2 times as likely to be an organ donor. The goal of this study was to help identify factors that could later be addressed to improve donation rates. These factors included myths and awareness such as the belief that organ donation will disfigure the body and impact the funeral, the perception that wealthy people are more likely to receive organ transplant, and the awareness of the driver license registry. These beliefs may easily be improved through education. Participants who had a religious influence in their lives were least likely to support organ donation. For this reason, we propose talks and education about organ donation at Hispanic American churches in the target areas. The last factor that influenced our participants was low acculturation. Unfortunately, low acculturation is difficult to control. One target is to educate recent immigrants about donation. The next step is to impact not only the attitudes and beliefs about donation, but also increase the number of Hispanic American individuals who sign up to be organ donors.

There were a number of limitations to the study. The data are derived from cross-sectional surveys, so conclusions that can be made are limited. While the telephone interviews were random, most of the telephone interviews were done during the day, which led to a paucity of men aged 18 to 30 years answering our survey. To adjust for this, we had to slightly weight the responses by this group. We also did not adjust for income. The zip codes used for this study (90031, 90201, and 90011) are all in lower-income and lower-education neighborhoods. For this reason, our results are applicable only to lower-income and less highly educated Hispanic American individuals. Limitations aside, to our knowledge, this is the first study to examine predictors of donation in Hispanic American individuals in California and may serve as a template for increasing the willingness to donate in this population.

In the current study, only 31% of respondents noted a willingness to become organ donors. We found that low acculturation, religion, and belief in inequitable distribution and possible body disfigurement reduced the intent to register for organ donation, while family influence and the awareness of a driver license registry increased this intent. To improve organ donation, these risk factors will be specifically addressed using effective educational programs.

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Table 1

List of Factors Within Each Domain

Demographic	Cultural	Awareness/Knowledge	Perception	Belief
• Age • Sex • Education • Employment • Income • Zip code	• Level of acculturation • Family influence • Religious influence	• General awareness • Aware of driver's license sign-up • Knowledge of how to sign up	• Wealthy people likely to receive organ transplant • Physician may not save an organ donor's life • Increase hospital cost • Brain dead have a chance to survive	• Organ donation helps people • Social responsibility • Willing to donate to stranger • Disfigure the body • It is cruel

Table 2

Comparison of Demographic, Cultural, Awareness, Perception, and Belief Between Respondents With and Without Intent to Register

	No. (%)			
	All Respondents (N=524)	Intent to Register Group (n=163)	No Intent to Register Group (n=361)	*P* Value[a]
Demographic characteristic				
Age, y, mean (SD)	43 (14)	43 (14)	43 (14)	.70
18–34	162 (31)	53 (33)	109 (30)	.61
35–44	165 (31)	53 (33)	112 (31)	.76
45–64	125 (24)	35 (21)	90 (25)	.44
≥65	72 (14)	22 (13)	40 (14)	>.99
Male	202 (39)	63 (39)	139 (39)	>.99
Education, ≤high school	248 (48)	66 (40)	184 (52)	.01
Employed	221 (42)	81 (50)	140 (39)	.02
Income, <$25 000 net	259 (58)	87 (59)	172 (58)	.92
Zip code				
90011	129 (25)	41 (25)	88 (24)	.91
90031	133 (25)	40 (25)	93 (26)	.83
90201	132 (25)	40 (25)	92 (25)	.91
90640	130 (15)	42 (26)	88 (24)	.74
Cultural factor				
Level of acculturation				
Low	232 (44)	56 (34)	176 (49)	.002
Medium	157 (30)	58 (36)	99 (27)	.06
High	134 (26)	49 (30)	85 (24)	.13
Family influence, agree/strongly agree	270 (56)	117 (74)	155 (48)	<.001
Religious influence, agree/strongly agree	129 (26)	24 (15)	104 (30)	<.001
Awareness/knowledge factor				
General awareness, some or more	160 (31)	67 (41)	93 (26)	<.001
Aware of driver's license sign-up	351 (67)	139 (85)	212 (59)	<.001
Knowledge of how to sign up	113 (23)	44 (28)	69 (20)	.07
Perception factor, agree/strongly agree				
Wealthy people likely to receive organ transplant	350 (68)	103 (64)	246 (70)	.23
Physician may not save an organ donor's life	119 (24)	44 (28)	75 (23)	.19
Increase hospital cost	92 (21)	26 (19)	66 (21)	.64
Brain dead have a chance to survive	214 (43)	72 (45)	142 (42)	.51
Belief factor, agree/strongly agree				
Organ donation helps people	451 (87)	151 (93)	299 (84)	.002
Social responsibility	227 (44)	98 (60)	130 (37)	<.001
Unwilling to donate to stranger	164 (32)	52 (32)	112 (32)	>.99
Disfigure the body	78 (16)	18 (12)	1 (186)	.07

	No. (%)			
	All Respondents (N=524)	Intent to Register Group (n=163)	No Intent to Register Group (n=361)	*P* Value[a]
It is cruel	126 (24)	33 (20)	93 (26)	.15

[a]Two-sided Fisher exact test for proportions and Mann-Whitney rank sum test for means.

Table 3

ORs for Intent to Register by Demographic, Cultural, Awareness, Perception, and Belief Factors

	Intent to Register, No./Total No. (%)	OR (95% CI)	*P* Value[a]
Demographic characteristic			
Age, y			
18–34	53/162 (33)	1.11 (0.58–2.10)	.86
35–44	53/165 (33)	1.08 (0.57–2.05)	.93
45–64	35/125 (28)	0.88 (0.45–1.75)	.83
≥65	22/72 (31)	1 [Reference]	
Sex			
M	63/202 (31)	1.01 (0.68–1.50)	.95
F	100/322 (31)	1 [Reference]	
Education			
≤High school	66/254 (26)	0.63 (0.43–0.94)	.02
>High school	92/258 (36)	1 [Reference]	
Employment			
Unemployed	81/297 (27)	0.65 (0.44–0.96)	.03
Employed	81/221 (37)	1 [Reference]	
Income, net $			
<25 000	96/306 (31)	0.77 (0.49–1.20)	.27
≥25 000	51/137 (37)	1 [Reference]	
Zip code			
90011	41/129 (32)	0.98 (0.56–1.70)	.97
90031	40/133 (30)	0.90 (0.52–1.57)	.86
90201	40/132 (30)	0.91 (0.52–1.59)	.83
90640	42/130 (32)	1 [Reference]	
Cultural question			
Level of acculturation			
Low	56/232 (24)	0.55 (0.34–0.90)	.02
Medium	58/157 (37)	1.02 (0.61–1.69)	.96
High	42/130 (37)	1 [Reference]	
Family influence			
Yes (agree or strongly agree)	121/295 (41)	2.76 (1.76–4.34)	<.001
None	37/184 (20)	1 [Reference]	
Religious influence			
Yes (agree or strongly agree)	21/112 (19)	0.42 (0.24–0.72)	.001
None	138/389 (36)	1 [Reference]	
Awareness/knowledge question			
General awareness			
Little or none	96/364 (26)	0.50 (0.33–0.75)	<.001
Some or more	67/160 (42)	1 [Reference]	
Aware of driver's license sign-up			

	Intent to Register, No./Total No. (%)	OR (95% CI)	*P* Value[a]
No	13/97 (13)	0.24 (0.12–0.45)	<.001
Yes	139/351 (40)	1 [Reference]	
Knowledge of how to sign up			
Don't know	113/382 (30)	1.47 (0.93–2.31)	.10
Know	45/118 (38)	1 [Reference]	
Perception question			
Wealthy people likely to receive organ transplant			
Agree or strongly agree	104/355 (29)	0.74 (0.49–1.11)	.15
Do not agree	58/161 (36)	1 [Reference]	
Physician may not save an organ donor's life			
Agree or strongly agree	46/128 (36)	1.29 (0.82–2.01)	.29
Do not agree	109/359 (30)	1 [Reference]	
Increase hospital cost			
Agree or strongly agree	31/108 (29)	0.87 (0.52–1.43)	.65
Do not agree	107/338 (32)	1 [Reference]	
Brain dead have a chance to survive			
Agree or strongly agree	74/226 (33)	1.07 (0.72–1.58)	.82
Do not agree	85/271 (31)	1 [Reference]	
Belief question			
Organ donation helps people			
Agree or strongly agree	152/454 (34)	2.82 (1.35–6.06)	.004
Do not agree	10/66 (15)	1 [Reference]	
Social responsibility			
Agree or strongly agree	98/232 (42)	2.42 (1.62–3.61)	<.001
Do not agree	65/280 (23)	1 [Reference]	
Unwilling to donate to stranger			
Agree or strongly agree	52/167 (31)	0.97 (0.64–1.48)	.98
Do not agree	110/347 (32)	1 [Reference]	
Disfigure the body			
Agree or strongly agree	19/85 (22)	0.57 (0.32–1.03)	.06
Do not agree	133/398 (33)	1 [Reference]	
It is cruel			
Agree or strongly agree	33/128 (26)	0.77 (0.43–1.11)	.13
Do not agree	129/386 (33)	1 [Reference]	

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

[a]Two-sided Fisher exact test for proportions and Mann-Whitney rank sum test for means.

Table 4

Stepwise Logistic Regression to Identify Independent Factors Contributing to Intent to Register[a]

Step	Factor	AOR (95% CI)	*P* Value	Additional R^2	Cumulative R^2
1	Low acculturation	0.39 (0.24–0.62)	<.001	0.1092	0.1092
2	Religion influence	0.33 (0.17–0.60)	<.001	0.0523	0.1615
3	Belief that organ donation will disfigure the body and impact funeral	0.45 (0.22–0.89)	.02	0.0203	0.1818
4	Family influence	2.02 (1.28–3.22)	.004	0.0280	0.2098
5	Perception that wealthy people likely to receive organ transplant	0.41 (0.25–0.65)	.001	0.0338	0.2436
6	Aware of driver's license registry	1.62 (1.03–2.58)	.04	0.0135	0.2571

Abbreviations: AOR, adjusted odds ratio; CI, confidence interval.

[a]Factors in the model (P<.20) included education, employment, acculturation levels, family influence, religious influence, general awareness, aware of driver's license registry, wealthy people likely to receive organ transplant, organ donation helps people, social responsibility, disfigure the body, and it is cruel. The model was based on 350 respondents with complete answers to the questions.