Published in final edited form as:

Clin Transplant. 2012 November ; 26(6): E634–E640. doi:10.1111/ctr.12036.

A Focused Educational Program after Religious Services to Improve Organ Donation in Hispanic Americans

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Abstract

Religion is an important determinant in Hispanic Americans (HA) becoming organ donors as HA often believe religion forbids donation. We investigated the effect of an educational program targeting HA organ donation in places of worship. A prospective observational study was conducted at four Catholic churches with a high percentage of HA. A 45 minute ‘culturally sensitive’ educational program, conducted in Spanish, was implemented. Organ donation awareness, knowledge, perception and beliefs, as well as the intent to become an organ donor, were measured before and after the intervention. Differences between before and after the intervention were analyzed. A total of 182 surveys were collected before and 159 surveys were collected after the educational program. A significant increase was observed in organ donation knowledge (54% vs. 70%, $p<0.0001$), perception (43% vs. 58%, $p<0.0001$) and beliefs (50% vs. 60%, $p=0.0001$). However, no significant difference was found in the willingness to discuss donation with family, intent-to-donate, or registering to donate after the intervention. This study demonstrates that a focused educational program in places of worship can significantly improve HA knowledge, perceptions, and beliefs regarding organ donation. Further work is needed to understand why intent-to-donate does not increase despite the increase in organ donation awareness.

Keywords

organ donation; Hispanic; church; religion; transplantation

Introduction

The success of organ transplantation has led to a demand for organs that significantly outpace supply. As a result, both the number of patients added to organ transplantation waiting lists and the number of patients dying while on these lists, continues to increase (1). This discrepancy is most pronounced among ethnic minority populations, who currently

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The authors have no conflict of interest to report and have received no financial or material support related to this manuscript

Authors' contributions: Concept/design—Salim, Chan, Navarro

Data analysis/interpretation—Salim, Ley, Chan, Zheng

Drafting article—Salim, Berry, Ley, Schulman, Chan

Critical revision of article—Salim, Berry, Ley, Chan

Approval of article—Salim, Berry, Ley, Schulman, Navarro, Chan, Zheng

Statistics—Chan, Zheng

Data collection—Schulman, Navarro, Berry

account for 54% of those on the waiting list but only 40% of the transplants performed in 2010 (1). Hispanic Americans are the nation's fastest growing minority and are projected to account for 24% of the population by 2050 (2). While the need for an organ transplant has increased 260% among Hispanic Americans, they are 60% less likely to donate their organs compared to non-Hispanic whites (2). Important issues identified that affect organ donation rates in Hispanic Americans 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 (3-9).

Religion is an important determinant in the decision for Hispanic Americans to become organ donors as they often believe that their religion forbids donation (10, 11). We recently published on the factors that were independently associated with a willingness to donate organs in Hispanic American adults (12) and high school students (13) in Southern California. In both populations, participants who had a religious influence in their lives were less likely to support organ donation. The purpose of this study was to investigate the effect of an educational program targeting Hispanic Americans organ donation in places of worship. Our hypothesis was that a culturally sensitive educational program targeting places of worship in the Hispanic American community would have a positive effect on organ donation outcomes.

Patients and Methods

This research is part of an ongoing project sponsored by the National Institute of Diabetes and Digestive and Kidney Diseases (Grant number 5R01DK079667) 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,

The Target Neighborhoods

As described previously (12-14), four Southern California neighborhoods with high percentages of Hispanic Americans, residing in close proximity to a major metropolitan Level 1 Trauma Center that provides the majority of their care, were identified using United States Census data. Four neighborhoods defined by zip codes with high concentration of Hispanic Americans were identified as our study areas. Four Catholic churches in these neighborhoods were involved with this education program. Permission to conduct the study within each church was granted by the presiding Catholic Bishop of the San Gabriel Region.

Intervention

The intervention was administered to four churches in the four area codes described above. The educational program was administered by the local organ procurement organization, OneLegacy, and involved a 45-60 minute presentation created specifically for religious organizations, and was conducted in both English and Spanish. It involved factual information about the need for organ and tissue transplantation, how the organ donation and allocation process serves this critical social need, and discussed religious misconceptions regarding organ donation.

The Survey and Survey Instrument

A cross-sectional survey was administered to participants before and after conducting the educational program. The survey was intended to assess demographics, awareness, knowledge, perception and beliefs regarding organ donation as well as the intent to become an organ donor. The survey included one general question on awareness and 18 other questions measuring different aspects for awareness/knowledge (four questions), perception

(ten questions) and belief (four questions). Awareness was derived from the question on the source(s) of information on organ donation. Any mention of a source was considered as “aware” and no mention of any sources was considered as “not aware”. For knowledge, perception and belief, we derived a composite score defined as the percent of correct answers to the questions in the domain to the total number of possible answers. The “intent-to-donate” outcome measure was defined as a positive answer to the questions: “Have you ever discussed any issues regarding organ donation with family members?” and/or “Are you a registered donor?”

Statistical Analysis

The endpoints of interest in this paper are organ donation awareness, perceptions and beliefs, and the likelihood of organ donation. The independent factors and outcome measures are listed in Table 1. Univariate analysis was performed to assess the significance of the differences. Categorical variables were analyzed by the Chi Square Test and Continuous variables were analyzed by the two-group Student t test. Differences were considered significant if the p-value was <0.05. Stepwise logistic regression analysis was performed to identify independent predictors for intent-to-donate. All statistical analysis was performed using SAS Systems for Windows, version 9.1.3 (SAS Institute, Inc., Cary, NC).

Results

A total of 182 pre-intervention surveys and 159 post-intervention surveys were collected from four churches over a four-month period. Table 2 provides a comparison of the demographic and cultural factors between the pre-intervention and post-intervention groups. No significant differences were identified except that there was a significantly higher percentage of participants with family support to donate (69% pre vs. 81% post, $p=0.009$). The participants were mostly female, between the ages of 40 to 65 years, and primarily Hispanic. Most were not born in the United States and spoke Spanish at home.

Table 3 provides the analysis for the differences in awareness, knowledge, perception, belief, and intent-to-donate between pre- and post-intervention respondents. The post-intervention survey showed a significant increase in correct answers describing organ donation knowledge (54% vs. 70%, $p<0.0001$), perceptions regarding organ donation (43% vs. 58%, $p<0.0001$), and organ donation beliefs (50% vs. 60%, $p=0.0001$), when compared to the pre-intervention group. Despite these significant increases, there was no significant difference between the two groups in the intent-to-donate. During the pre-intervention survey, 62% expressed intent-to-donate when there was family support but only 26% did so when there was no family support. During the post-intervention survey, the percentages were similar (61% vs. 27% respectively).

We used the responses in the post-intervention survey to conduct a stepwise logistic regression analysis in order to identify independent predictors for intent-to-donate in the study population. Factors with $p<0.20$ in all domains were included in the model. Three factors were identified as significant independent predictors for the intent-to-donate and two factors were identified as significant negative independent predictors for the intent-to-donate (Table 4). Family support (AOR 4.53; 95%CI: 1.67-12.33; $p=0.003$), not perceiving that wealthy people are more likely to receive a transplant (AOR 5.39; 95%CI: 2.02-14.37; $p=0.0008$), and knowing that there is a national matching program (AOR 3.36; 95%CI: 1.43-7.88; $p=0.005$) were all positive predictors for the intent-to-donate. Interestingly, the belief that Hispanics were more likely to need a transplant (AOR 0.3; 95%CI: 0.14-0.65; $p=0.002$) and not believing that most religions prohibit organ donation (AOR 0.28; 95%CI: 0.1-0.76; $p=0.013$) were negative predictors for the intent-to-donate.

Discussion

Religion is often cited as a reason to avoid donation, particularly in minority populations (15-17). How religious an individual views him or herself correlates with his or her attitudes toward organ donation (15). Our previous research efforts identified religion as an independent risk factor for the intent-to-donate organs both in adults (12) and high school students (13) among Hispanic Americans. This persists despite the fact that no religion formally forbids donation or receipt of organs or is against transplantation from living or deceased donors (18). In the current study, we sought to investigate the effect of a culturally sensitive education intervention that targets church going Hispanic Americans. We found that among Hispanic Americans, a focused educational program after religious services can significantly improve organ donation knowledge (54% vs. 70%, $p<0.0001$), perceptions regarding organ donation (43% vs. 58%, $p<0.0001$), and organ donation beliefs (50% vs. 60%, $p=0.0001$). Although there was no significant difference in the intent-to-donate, we were able to identify several independent predictors that could be later targeted for education.

Religious obstacles to organ removal cited among minorities include; fears that organ donation precludes an open casket funeral; fears that it may delay funeral proceedings; fear that organ donation mutilates the body; wanting to remain whole for the transition to heaven; and fears that the absence of certain organs at the end of life will have deleterious effects in the afterlife (19-21). Specific to Hispanic Americans, presumed religious obstacles include: the belief that a miracle may occur, thus delaying death (11); the belief that discussing death may cause death to occur prematurely (10, 11, 22); and that organ donation will disfigure the body and interfere with the funeral (12). Research performed in African American communities demonstrated that overcoming these religious myths and concerns could improve donation rates in minority populations (21, 23, 24). Furthermore, guiding clergy and other religious leaders about what stance their religious organizations take and how to talk to parishioners about organ and tissue donation could be a useful intervention in overcoming religious obstacles (20, 21).

The majority of Hispanic Americans are Roman Catholic, who once viewed organ donations from live donors as a form of mutilation (15). This changed after the formal endorsement of organ donation by the Vatican (9). Pope Benedict XVI registered as an organ donor and stated that organ donation is the purest form of altruism (25). Despite this, many Hispanic Americans still believe that the Catholic Church forbids organ donation (10, 11, 25). This may be in part due to the fact that many people are unaware of their religion's stance on organ donation and transplantation (19, 25). Or it may be in part due to the lack of discussion of organ donation in the church. We found that only 5.5% of pre-intervention respondents learned about organ donation at church. Studies suggest that people are more willing to donate organs if they anticipate the support of their religious community and a religious leader (15). A potential barrier specific to our population was the fear of government surveillance. We found 32% of the pre-intervention group, and 53% of post-intervention respondents believed that they would be placed on other government lists if they signed up to be an organ donor. Thus, dispelling myths and subsequently breaking down barriers to organ donation through targeted educational programs is an important approach among Hispanic Americans. Religious leaders are in a powerful position to convey the theologically based support of organ donation while also dispelling inaccurate religious assumptions (15).

We identified three factors (Table 3) that positively affect the intent-to-donate: Family support (AOR 4.53; 95%CI: 1.67-12.33; $p=0.003$), not believing that wealthy people are more likely to receive a transplant (AOR 5.39; 95%CI: 2.02-14.37; $p=0.0008$), and believing

in a national matching program (AOR 3.36; 95%CI: 1.43-7.88; $p=0.005$). These factors will help guide future interventions to increase organ donation rates among this minority population. The negative predictors identified were unusual: believing that Hispanics were more likely to need a transplant (AOR 0.3; 95%CI: 0.14-0.65; $p=0.002$) and not believing that most religions prohibit organ donation (AOR 0.28; 95%CI: 0.1-0.76; $p=0.013$). These results conflict with our recent findings in evaluating knowledge, perception, and beliefs regarding organ donation among Hispanic American teenagers (13). We believe that the high rate of illiteracy in our study population may have explained this, in part. Many of the participants were unable to read in English or Spanish and relied on study volunteers to read each question of the survey to them. An interesting, yet unsurprising finding was that 62% in the pre and 61% in the post intervention survey expressed an intent-to-donate when there was family support present, whereas only 26% in the pre and 27% in the post intervention survey did so when there was no family support. Family awareness of one's donation intentions is one of the most important steps in becoming a donor (20, 26). For this reason, most interventions are designed to foster family discussion about donation (20).

There are several limitations to the study. Despite our best efforts, we were only able to complete 182 pre and 159 post intervention surveys. Even with offering incentives such as complimentary food, attracting participants to stay after religious services was challenging. Many cited time constraints as the primary reason for not participating in the study. This small sample size limits the conclusions that we can make. The population studied included only lower income and lower education neighborhoods. For this reason, our results are applicable primarily to lower-income and less highly educated adult Hispanic Americans. Our education intervention was administered by our local OPO. Data in the African American community suggests that clergy may be useful in helping parishioners work through religious issues regarding organ donation by clarifying religious misconceptions (20, 21). Finally, since the surveys did not include any specific identifiers, we were unable to ensure that the post survey questionnaires were completed by individuals who filled out a pre-survey questionnaire. This undoubtedly would have made our results more methodologically sound.

Despite these limitations, to our knowledge, this is the first study to date demonstrating that a targeted educational program after religious services can increase knowledge, perception, and beliefs regarding organ donation among Hispanic Americans. The church represents a potentially effective mechanism for developing and implementing a community intervention that could shape views on organ donation and increase donation intentions among minority populations (20). Further studies involving church interventions are needed to promote organ donation among Hispanic Americans.

Acknowledgments

Supported by the National Institute of Diabetes and Digestive and Kidney Diseases grant Number 5R01DK079667

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Table 1
List of factors within each domain of the survey

(A) Predisposing Factors	
Demographic	<ul style="list-style-type: none"> • Age • Gender • Ethnicity • Born in U.S. • Spanish spoken at home • English spoken at home • Source of knowledge • Religion
Cultural	<ul style="list-style-type: none"> • Family influence • Religious influence
(B) Outcome Measures	
Awareness	<ul style="list-style-type: none"> • General awareness
Knowledge	<ul style="list-style-type: none"> • Must have a driver's license in order to be an organ donor (False) • Everyone who dies can be an organ donor (False) • There is a national matching system for donors and recipients (True) • People on waiting list dies daily because not enough organs (True)
Perception	<ul style="list-style-type: none"> • Organ transplants are rarely successful (False) • Doctors will less likely to save my life if I am a donor (False) • Costs money to register for organ donation (False) • Wealthy people are more likely to receive a transplant (False) • There is a chance that a person who is brain dead will survive (False) • Individuals can choose which organ(s) to donate (True) • U.S. is the only country where organ transplants are performed (False) • If I register through DMV or online I will be put on government lists (False) • Registering as a living donor is same as registering as a donor after I die (False) • Hispanics are more likely to need organ transplants (True)
Belief	<ul style="list-style-type: none"> • Organ donation can save lives and help people (True) • Organ donor cannot have an open casket at funeral (False) • Most religions prohibit organ donation (False) • It is a social responsibility to donate organs (True)
Intent-to-donate	<ul style="list-style-type: none"> • Had discussed with family regarding organ donation • Had registered as an organ donor

Table 2
Comparison of Baseline Demographic and Cultural Characteristics Between Participants
in Churches With and Without the Educational Intervention

Characteristic	Group	Pre-Intervention Group (n=182)	Post-Intervention Group (n=159)	p-value
		% (number)	% (number)	
Gender	Male	34.6%(63)	35.8% (57)	0.79
	Female	63.2%(115)	62.9% (100)	
	Unknown	2.2%(4)	1.3% (2)	
Age group in years	18-25	8.8%(16)	11.9% (19)	0.59
	26-39	18.7%(34)	17.6% (28)	
	40-65	46.2%(84)	49.7% (79)	
	65+	13.7%(25)	8.8% (14)	
	Unknown	12.6%(23)	11.9% (19)	
Born in U.S.	Yes	22.5%(41)	24.5% (39)	0.16
Hispanic	Yes	93.4%(170)	94.3% (150)	0.72
Spanish spoken at home	Yes	94%(171)	90.6% (144)	0.24
English spoken at home	Yes	43.4%(79)	39.6% (63)	0.48
	Newspaper	18.7%(34)	18.9% (30)	0.96
	Radio	22.5%(41)	29.6% (47)	0.14
	TV	61.5%(112)	57.9% (92)	0.49
	Doctor	15.9%(29)	16.4% (26)	0.92
	Class	14.3%(26)	17.6% (28)	0.40
	Friend	22.5%(41)	23.9% (38)	0.76
	Church	5.5%(10)	8.2% (13)	0.32
Source of Knowledge(Can be multiple)	Other	4.9%(9)	3.8% (6)	0.60
Catholic	Yes	96.7%(176)	95% (151)	0.42
Religion has effect on decision to donate	Yes	20.3%(37)	20.1% (32)	0.96
Family would support decision to donate	Yes	68.7%(125)	81.1% (129)	0.009

Table 3
Differences in Awareness, Knowledge, Perception, and Intent-to-Donate Between
Participants in Churches With and Without the Educational Intervention

Outcome Measure	Group	Pre-Intervention Group (n=182)	Post-Intervention Group (n=159)	p-value
General Awareness	Any mention of a knowledge source	86% (157)	91% (144)	0.22
Knowledge	Composite score of the following 4 questions:	54% (396/728)	70% (448/636)	<0.0001
	Must have a license in order to be Organ donor	68% (123)	79% (126)	0.015
	Everyone who dies can be an organ donor	26% (48)	49% (78)	<0.0001
	There is a national matching system for donors and recipients	50% (91)	72% (114)	<0.0001
	People on waiting list dies daily because not enough organs	74% (134)	82% (130)	0.07
Perception	Composite score of the following 10 questions:	43% (778/1820)	58% (929/1590)	<0.0001
	Organ transplants are rarely successful	31.9% (58)	42.8% (68)	0.038
	Doctors will less likely to save my life if I am a donor	49.5% (90)	67.3% (107)	0.0009
	Costs money to register for organ donation	63.2% (115)	79.2% (126)	0.001
	Wealthy people are more likely to receive a transplant	40.7% (74)	68.6% (109)	<0.0001
	There is a chance that a person who is brain dead will survive	30.2% (55)	54.7% (87)	<0.0001
	Individuals can choose which organ(s) to donate	61% (111)	68.6% (109)	0.15
	U.S. is the only country where organ transplants are performed	62.6% (114)	62.9% (100)	0.96
	If I register through DMV or online I will be put on government lists	32.4% (59)	53.5% (85)	<0.0001
	Registering as a living donor is same as registering as a donor after I die	26.4% (48)	44% (70)	0.0006
Belief	Hispanics are more likely to need organ transplants	29.7% (54)	42.8% (68)	0.012
	Composite score of the following 4 questions:	49.5% (360/728)	59.9% (381/636)	0.0001
	Organ donation can save lives and help people	83.5% (152)	84.3% (134)	0.85
	Organ donor cannot have an open casket at funeral	32.4% (59)	40.3% (64)	0.13
	Most religions prohibit organ donation	43.4% (79)	66.7% (106)	<0.0001
Intent-to-donate	It is a social responsibility to donate organs	38.5% (70)	48.4% (77)	0.06
	Any mention of the following 2 questions:	51.1% (93)	54.7% (87)	0.50

Outcome Measure	Group	Pre-Intervention Group (n=182)	Post-Intervention Group (n=159)	p-value
	Had discussed with family regarding organ donation	47.3% (86)	52.8% (84)	0.30
	A registered donor	19.2%(35)	25.2% (40)	0.19

Table 4
Stepwise Logistic Regression to Identify Independent Factors for Intent-to-donate Among Post-intervention Subjects (N=159)

Step	Factor Entered	Class	Adjusted Odds Ratio	95%CI	Max-scale R-square	Cumulative R-square	p-value
1	Family Support	Belief vs. not belief	4.53	(1.67, 12.33)	9.68%	9.68%	0.003
2	Wealthy people more likely receive a transplant	Not belief vs. belief	5.39	(2.02, 14.37)	5.55%	15.23%	0.0008
3	Hispanic more likely need organ transplants	Belief vs. Not belief	0.30	(0.14, 0.65)	4.80%	20.03%	0.002
4	National matching program	Belief vs Not belief	3.36	(1.43, 7.88)	3.92%	23.95%	0.005
5	Most religions prohibit organ donation	Not belief vs belief	0.28	(0.1, 0.76)	4.69%	28.64%	0.013

Factors included in the model ($p < 0.20$): wave, family support, and 16 questions (4 in knowledge, 9 in perception, and 3 in belief). Total number of cases used in the model is 159; 87 intent-to-donate, 72 no intent-to-donate