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INCREASING INTENT TO DONATE IN HISPANIC AMERICAN HIGH SCHOOL STUDENTS: RESULTS OF A PROSPECTIVE OBSERVATIONAL STUDY

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Abstract

Background—High school students are an important target audience for organ donation education. A novel educational intervention focused on Hispanic American (HA) high school students might improve organ donation rates.

Methods—A prospective observational study was conducted in five Los Angeles High Schools with a high percentage of HA students. A 'culturally sensitive' educational program was administered to students in the 9th to 12th grades. Pre-intervention surveys that assessed awareness, knowledge, perception and beliefs regarding donation as well as the intent to become an organ donor were compared to post-intervention surveys.

Results—A total of 10,146 high school students participated in the study. After exclusions, 4876 pre-intervention and 3182 post-intervention surveys were analyzed. A significant increase in the overall knowledge, awareness, and beliefs regarding donation was observed after the intervention, as evidenced by a significant increase in the percentage of correct answers on the survey (41% pre- v. 44% post-, p<0.0001). When specifically examining HA students, there was a significant increase in the intent to donate organs (AOR 1.21, 95% CI: 1.09, 1.34, p=0.0003).

Conclusion—This is the first study to demonstrate a significant increase in the intent to donate among HA high school students following an educational intervention.

Keywords

High school; Organ Donation; Education; and Hispanic Americans

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INTRODUCTION

Due to a number of medical advances, transplantation is a preferred treatment for end stage solid organ failure. The growing demand for organs continues to outpace supply, such that the critical organ shortage remains a public health crisis. In 2010, 26,218 transplants were performed from 13,000 donors (1). Unfortunately, with over 110,000 people awaiting organs, more than 7000 patients die every year before receiving their organs (1). Currently, over 40% of the national waiting list comprises minority populations (1). One of the most represented minorities on the list is Hispanic Americans, comprising nearly one-fifth of the total patients on the national organ transplant waiting list (2). Additionally, it is anticipated that Hispanic Americans will become California's largest single ethnic group by 2025(3). Despite the population's need, Hispanic Americans remain 60% less likely to donate when compared to non-Hispanic Americans (4).

Teenagers are an important target audience for organ donation education as the decision to register as an organ donor is often first introduced while acquiring a driver's license or permit at the Department of Motor Vehicles (DMV). We previously established that family support, 11th and 12th grade high school students, female gender, religion, and the belief that Hispanics are more likely to require an organ transplant were the strongest predictors for the intent-to-donate among over 5000 surveyed high school students (5). The purpose of the current study was to investigate the effect of an educational program targeting Hispanic Americans high school students on organ donation outcomes. Our hypothesis was that a culturally sensitive educational intervention that targets Hispanic American high school students to donate organs.

METHODS

This research is part of an ongoing project sponsored by the National Institute of Diabetes and Digestive and Kidney Diseases (Grant number 5RO1DK079667) to help increase organ donation rates in Hispanic American communities in Los Angeles County. This study was approved by the Institutional Review Board of the Cedars-Sinai Medical Center.

The Target Neighborhoods

As described previously (6,7) 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. Three of the neighborhoods were study communities where interventions, including the one described below, were implemented, and one neighborhood served as the control community. From these neighborhoods, five high schools were chosen for the current research.

Intervention

The high school intervention targeted students, grades 9 through 12, from each of the five high schools and were surveyed to assess various factors regarding organ donation. Before arriving at each high school, consents were distributed two weeks prior to the initial survey. The consent was designed as an opt-out and those that did not wish to participate were taken to a supervised environment.

The actual intervention (termed Bridging Lives) was a 45 minute 'culturally sensitive' educational program created specifically for high school students. The presentation delivered factual information about the need for organ and tissue transplantation, as well as how the organ donation and allocation process serves this critical social need. Each presentation was supervised by a dedicated youth education coordinator. The presentation

was given in assemblies throughout the week to all of the students in the schools used for the study. Four of the high schools received the educational program while one of the schools served as a control and did not.

The Survey and Survey Instrument

A cross section survey was administered to participants to assess demographics and baseline awareness, knowledge, perception and beliefs regarding organ donation, as well as the intent to become an organ donor. The surveys were administered during a special assembly at each school. The pre-intervention surveys were distributed two weeks prior to the educational intervention. Immediately following the education program, the survey was re-administered to participants to assess the effect of the educational program. This survey was identified as the post-intervention survey. The survey includes one general question on awareness and 18 other questions measuring different aspects for awareness/knowledge (four questions), perception (ten questions) and beliefs (four questions). The responses were based on a 7 point Likert scale with 1 as strongly disagree and 7 as strongly agree. The main outcome measure was the "intent-to-donate".

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 demonstrated in Table 1.

To measure awareness, knowledge, perception and beliefs, there is one general question on awareness and 18 questions measuring different aspects for awareness/knowledge (4 questions), perception (10 questions) and beliefs (4 questions). For these 18 questions, due to the mix of true and false statements in the questions, we translated them into "correct" and "incorrect" responses based on the educational materials put forth. For false statements, correct responses included answers 1–3 and incorrect responses included answers 4–7, where 1 indicated strongly disagree and 7 indicated strongly agree. For true statements, correct responses included 5–7 and incorrect responses included 1–4.

For assessing the likelihood of donation, we used the combined responses to two questions, one to measure intent-to-donate and the other to measure actual donation. A positive answer to "Have you ever discussed any issues regarding organ donation with family members?" and/or a positive answer to "Are you a registered donor?" was considered as a measure of intent-to-donate.

To assess the effect of the educational intervention, we compared the changes in the outcome measures between the pre-intervention and the post-intervention surveys in several steps. First we performed a univariate analysis to identify the demographic and cultural factors that were significantly different between the two surveys. Significance of categorical variables was assessed by the Chi-Square test or 2-sided Fisher's Exact test and significance for continuous variables was assessed by the two-sample Student t test or the Mann-Whitney Rank-Sum test. Differences were considered significant if the p-value was <0.05. Independent demographic and cultural factors with p<0.05 from the univariate analysis were identified from the stepwise logistic regression. The significant independent risk factors were entered into the multivariable logistic regression analysis to derive the adjusted odds ratio and its 95% confidence interval (CI) for intent-to-donate between the pre- and post-intervention surveys. If there was a discrepancy between the crude and adjusted odds ratios, a stratified analysis was conducted to identify the subgroups of subjects that had significant changes in terms of 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 6,093 high school students were surveyed from the 5 high schools in the two weeks before the intervention and 4,053 were surveyed from 4 high schools immediately after the intervention. One high school did not participate in the post intervention survey (control) and thus was excluded in this analysis. Unknown gender, unknown grade, or unknown designated high school cases were excluded from the analysis. Furthermore, we restricted our analysis to only 15–20 year-olds in order to exclude outliers. After exclusions, we had 4,876 surveys from the pre-intervention time period and 3,182 surveys from the post-intervention period.

Demographic and Cultural Factors (Table 2)

Compared to the pre-intervention period, the post-intervention period: had a significantly higher percentage of upper grade levels, were less likely to be born in the US, were more likely to be Hispanic, were less likely to speak English at home, were less likely to be religious (and less likely to be Catholic), but were more likely to be influenced by religion (stated that religion had an influence), and were more likely to seek family support in organ donation decisions. The stepwise logistic regression identified grade, Hispanics, African Americans, being religious, and "would seek family support" as independent predictors that differed between the two surveys. These predictors were then used to adjust the intent-to-donate outcome between the two surveys.

Awareness, Knowledge, Perception, and Belief (Table 3)

Compared to the pre-intervention period, the post-intervention period had a significantly higher percentage of correct responses to the 18 questions on awareness, knowledge, perception and belief, (41% for pre- vs. 44% for post-, p<0.0001).

Intent-to-donate

We examined the intent-to-donate (Table 4) based on the two measures previously mentioned: having discussed any issues regarding organ donation with family members and being a registered organ donor already. The crude odds ratio and 95% confidence interval (CI) for intent-to-donate at post-intervention was significant at 1.19 (95% CI: 1.08, 1.31; p=0.0005). However, when we adjusted for the factors that were identified as independent predictors between the surveys (grade, Hispanic, African American, religious influence, and family support), there was no longer a significant difference for the post-intervention intent to donate (AOR: 1.08 (95% CI: 0.98, 1.20; p=0.13).

When we examined the pre- and post-intervention odds ratio for intent-to-donate stratified by subgroups defined by the independent risk factors, we identified significant changes among the 9th graders (AOR 1.39, 95% CI: 1.16, 1.66, p=0.0003), Hispanics (AOR 1.21, 95% CI: 1.09, 1.34, p=0.0003), and subgroups related to religion (Table 5). Further analysis revealed that 9th graders who were Hispanic and had family support, regardless of religion had the highest increase in the intent-to-donate from pre to post intervention (AOR 2.05, 95% CI: 1.30, 3.22, p=0.002).

DISCUSSION

The purpose of the study was to examine Hispanic American high school students' attitudes and knowledge regarding organ donation and subsequently compare their intent-to-donate before and after a culturally sensitive educational program. Our findings support the capability of a tailored educational intervention to increase the intent- to-donate within HA high school students. In addition to HA students (OR 1.21, p=0.0003), the program was

particularly effective in younger, 9th grade students (OR 1.39, p=0.0003), suggesting that these students are receptive to the educational program. In fact, the program appears to have had the greatest impact among 9th grade HA students who had family support (OR 2.05, p=0.002).

Hispanic American teenagers are important targets for organ donation interventions. In California, it is anticipated that Hispanic Americans will account for 41% - 47% of the state's population by 2025(3). Additionally, the minority comprises 18% of the total patients on the national organ transplant waiting list (1). Teenagers comprise almost one-fifth of all organ donors (8) and are often confronted with the decision to donate when applying for a driver's license. In our study, 10,146 surveys were administered and over half of the students were freshmen and sophomores. Our study is the largest to date on Hispanic American students to improve organ donation rates.

The results of the post-intervention student surveys demonstrated a significant increase in the students' overall knowledge, awareness, and beliefs regarding organ donation following the intervention, as evidenced by a 3% increase in the percentage of correct answers on the survey (44% vs. 41%, p<0.0001). Specifically, the correct answers to four of the survey questions increased significantly. Those questions focused on the success of organ transplantation, costs associated with registering to donate, and myths surrounding the transplant process (e.g. doctors being less likely to save an organ donor's life or priority for organs given to wealthy individuals). All of these issues were addressed in the educational program presented to the students, which reinforces the impact that the intervention had on the group.

It is not surprising that the overall knowledge was increased due to an educational program aimed at increasing the knowledge and understanding of transplantation and donation. A number of similar programs have targeted high school students. Weaver and colleagues (9) provided an educational program to high school students in Seattle. This program resulted in increased knowledge about the donation process and more favorable attitudes toward organ donation. Reubsaet and colleagues (10) implemented a program that resulted in increased registration intent, greater willingness to be an organ donor, greater knowledge, more positive social outcome expectations, and increased self-efficacy. Smits et al. (11) put forth a program that resulted in increased intentions among participants to register as organ donors. Similar favorable results were reported elsewhere (12, 13). While these interventions were conducted in high schools across the country, there is a dearth of programs focusing specifically on Hispanics. Cardenas and colleagues (13) recently wrote about the lack of programs focused on ethnically diverse high school students. They sought to change this by intervening with ethnically diverse students, but their sample only consisted of African- and Asian- Americans.

Our intervention altered the intent-to-donate in Hispanic American High School student. We note a 20% increase in the intent-to-donate after the educational intervention in HA students. In addition, ninth graders demonstrated the only change among all grades, with an increase in the intent-to-donate by almost 40% after the intervention. Despite our previous findings that religion was an independent risk factor for the intent-to-donate (5) the current study demonstrated that religion did not appear to make a difference with respect to the educational intervention. Finally, with respect to the role of family support, there was a trend towards a positive effect from the intervention. In our previous baseline study, one of the strongest predictors for the intent-to-donate was family support (5). In fact, our current study dealt with the implementation of a tailored intervention that would encourage family discussions and support. In sum, the educational intervention appears to be most effective in younger HA students with family support.

This study has a number of limitations that require discussion. The study is limited by the nature of the data, which was derived from cross-sectional surveys, as well as the target population, which included only lower income and lower education neighborhoods. The post intervention surveys were taken immediately after the educational program. Therefore, we are unable to determine whether the positive gains noted in the current study were sustained for a long period of time. We intend to implement a delayed survey to determine if the positive results are maintained longitudinally. An additional limitation includes the large group setting of the presentation. An auditorium model may decrease student attention. Despite these limitations, this study provides important insight into the role of a targeted educational program in Hispanic American high school students.

In conclusion our study represents the largest study to date that examines the effect of a culturally sensitive educational program on the intent-to-donate organs in HA high school students. The increase in HA students expressing intent-to-donate suggests that a well-designed educational program is effective at increasing overall organ donation among teenage HA students. To address the issue of limited knowledge about organ donation among HA high school students and subsequently improve organ donation rates among this population, we recommend further implementing customized educational programs in low income, minority neighborhoods.

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TABLE 1

List of factors within each domain and outcomes of the survey

(A) Independent Factor	S
Demographic	 Age Gender Ethnicity Born in US Language used at home
Cultural	 Being religious Religion Religion influence Family support
(B) Outcome Measures	
Awareness/knowledge	 General awareness Aware of driver's license sign-up Everyone who dies can be an organ donor There is a national system that matches donated orgenas to the most needy That there is a waiting list and not enough organs available
Perception	 Organ transplants are rarely successful Doctor may not save an organ donor's life Increase hospital cost Wealthy people likely to receive organ transplant Brain dead has a chance to survive Individuals can choose which organ(s) to donate US is the only country in which organ transplants are performed If I register as an organ donor I will be put on other government list Registering to become a living donor is the same as registering to become a donor after I die Compared to others, Hispanics are more likely to need organ transplants
Belief	 Organ donation helps people Organ donor can have an open casket at funeral Most religions prohibit organ donation Social responsibility
Likelihood to donate	 Intent to donate (composite of the following 2 questions) Registered as an organ donor Discussed organ donation with family

Comparison of Demographic and Socioeconomic Characteristics Before and After the Educational Intervention Among 15–20 year-olds.

Demographic Characteristic	Categories	Pre-intervention (N=4876)	Post-intervention (N=3182)	p-value
Age (years)		17.26 (1.16)	17.32 (1.17)	0.01
Gender	Male	47.3%(2307)	47% (1495)	0.77
	Female	52.7%(2569)	53% (1687)	
Grade	9	35.6%(1734)	32.7% (1041)	0.03
	10	30.1%(1467)	30.2% (960)	
	11	18.8%(918)	20.7% (660)	
	12	15.5%(757)	16.4% (521)	
US Born	Yes	85.3%(4157)	80.4% (2558)	< 0.0001
	No	13.8%(672)	18.1% (577)	
	Unknown	1%(47)	1.5% (47)	
Hispanic or Latino	Yes	88.1%(4296)	90% (2865)	0.012
	No	10.5%(511)	8.5% (270)	
	Unknown	1.4%(69)	1.5% (47)	
Caucasian/White	Yes	1.6%(79)	1.3% (42)	0.54
	No	97%(4728)	97.2% (3093)	
	Unknown	1.4%(69)	1.5% (47)	
Asian/Pacific Islander	Yes	9%(437)	6.9% (221)	0.005
	No	89.6%(4370)	91.6% (2914)	
	Unknown	1.4%(69)	1.5% (47)	
Black or African	Yes	5.2%(253)	7% (224)	0.003
	No	93.4%(4554)	91.5% (2911)	
	Unknown	1.4%(69)	1.5% (47)	
Native American	Yes	0.1%(6)	0% (0)	0.14
	No	98.5%(4801)	98.5% (3135)	
	Unknown	1.4%(69)	1.5% (47)	
Language at home	Only or Mostly English	31.3%(1528)	24.6% (784)	< 0.0001
	English and Other equally	33%(1609)	35.4% (1126)	
	Only or Mostly Other	31.2%(1520)	35% (1113)	
	Unknown	4.5%(219)	5% (159)	
Cultural Influence				
Religious	Yes	68.8%(3355)	65.2% (2074)	0.0007
Religion Influence	Yes	5.7%(279)	7.2% (230)	0.007
Family Support	Yes	52.2%(2543)	58.5% (1860)	< 0.0001

Comparison of Knowledge/Awareness, Perception, Belief and Intent-to-donate Before and After the Educational Intervention Among 15–20 year-olds

	Categories*	Pre-intervention (N=4876)	Post-intervention (N=3182)	p-value
Awareness/Knowledge				•
General Awareness	% (n) Yes	98.2%(4787)	97% (3087)	0.0007
Aware of driver's license sign-up	% (n) Correct	47.8%(2333)	43.1% (1370)	< 0.0001
Everyone who dies can be an organ donor	% (n) Correct	34.4%(1677)	36% (1146)	0.14
There is a national system matches donated organs to the most needy	% (n) Correct	43.5%(2119)	45.5% (1449)	0.07
There is a waiting list and not enough organs available	% (n) Correct	54.1%(2637)	53% (1686)	0.33
Perception				
Organ transplants are rarely successful	% (n) Correct	32.5%(1583)	42.9% (1364)	< 0.0001
Doctor may not save an organ donor's life	% (n) Correct	43.6%(2125)	55.2% (1757)	< 0.0001
Organ donation increases hospital cost	% (n) Correct	50%(2436)	63.8% (2029)	< 0.0001
Wealthy people likely to receive organ transplant	% (n) Correct	30.8%(1503)	51% (1623)	< 0.0001
Brain dead has a chance to survive	% (n) Correct	43%(2095)	40.6% (1293)	0.038
Individuals can choose which organ(s) to donate	% (n) Correct	55.6%(2711)	47% (1495)	< 0.0001
U.S. is the only country in which organ transplants are performed	% (n) Correct	50.5%(2462)	46.7% (1486)	0.0009
If I register as an organ donor I will be put on other government list	% (n) Correct	30.6%(1493)	33.6% (1068)	0.006
Registering to become a living donor is the same as registering to become a donor after I die	% (n) Correct	29.1%(1421)	27.5% (874)	0.1
Compared to others, Hispanics are more likely to need organ transplants	% (n) Correct	15.8%(768)	22.4% (712)	< 0.0001
Belief				
Organ donation helps people	% (n) Correct	65.6%(3198)	64.3% (2045)	0.22
Organ donor can have an open casket at funeral	% (n) Correct	52.2%(2545)	54.4% (1730)	0.06
Most religions prohibit organ donation	% (n) Correct	32.3%(1573)	44.5% (1415)	< 0.0001
Organ donation is a social responsibility	% (n) Correct	20.5%(999)	25.1% (800)	< 0.0001
% Correct response **	% (n) Correct	40.65 (17.74)	44.24 (21.29)	< 0.0001

* For false statements, correct response=1, 2, 3; incorrect response=4,5,6,7, and missing; For true statements, correct response=5,6,7; incorrect response=1,2,3,4, and missing

** calculated using total no. of correct responses divided by 18 and then times 100

Comparison of Intent-to-Donate Before and After the Educational Intervention Among 15-20 year-olds. (N = 8058)

	Intent to Donate, No./Total No. (%)	OR (95% CI)	P value
Univariate Model (Unadjusted)			
Wave			
POST	972/3182 (30.6)	1.19 (1.08, 1.31)	0.0005
PRE	1315/4876 (27.0)	1 (Reference)	
Multivariate Model (Adjusted) *			
Wave			
POST	972/3182 (30.6)	1.08 (0.98, 1.20)	0.13
PRE	1315/4876 (27.0)	1 (Reference)	

* adjusted for grade, Hispanic, African American, religious influence, religion effect, and family support.

Comparison of Intent-to-Donate Before and After the Educational Intervention Among 15–20 year-olds for Subgroups Defined by Independent Risk Factors Differentiating the two surveys

	Intent to Donate, No./Total No. (%)	OR (95% CI)	P value
GRADE=9			
Wave			
POST	289/1041 (27.8)	1.39 (1.16, 1.66)	0.0003
PRE	376/1734 (21.7)	1 (Reference)	
GRADE=10			
Wave			
POST	266/960 (27.7)	1.08 (0.9, 1.3)	0.38
PRE	383/1467 (26.1)	1 (Reference)	
GRADE=11			
Wave			
POST	225/660 (34.1)	1.15 (0.93, 1.42)	0.2
PRE	285/918 (31.0)	1 (Reference)	
GRADE=12			
Wave			
POST	192/521 (36.9)	1.05 (0.83, 1.32)	0.7
PRE	271/757 (35.8)	1 (Reference)	
HISPANIC=1			
Wave			
POST	897/2865 (31.3)	1.21 (1.09, 1.34)	0.0003
PRE	1176/4296 (27.4)	1 (Reference)	
HISPANIC=0			
Wave			
POST	75/317 (23.7)	0.98 (0.71, 1.36)	0.92
PRE	139/1580 (24.0)	1 (Reference)	
AA=1			
Wave			
POST	81/224 (36.2)	1.32 (0.9, 1.93)	0.16
PRE	76/253 (30.0)	1 (Reference)	
AA=0			
Wave			
POST	891/2958 (30.1)	1.18 (1.06, 1.3)	0.002
PRE	1239/4623 (26.8)	1 (Reference)	
RELIGIOUS=1			
Wave			
POST	659/2074 (31.8)	1.13 (1.01, 1.28)	0.038
PRE	977/3355 (29.1)	1 (Reference)	

	Intent to Donate, No./Total No. (%)	OR (95% CI)	P value
RELIGIOUS=0			
Wave			
POST	313/1108 (28.3)	1.38 (1.15, 1.65)	0.0004
PRE	338/1521 (22.2)	1 (Reference)	
RELIGIONEFFECT=1			
Wave			
POST	100/230 (43.5)	1.49 (1.04, 2.13)	0.03
PRE	95/279 (34.1)	1 (Reference)	
RELIGIONEFFECT=0			
Wave			
POST	872/2952 (29.5)	1.16 (1.05, 1.29)	0.004
PRE	1220/4597 (26.5)	1 (Reference)	
FAMILY SUPPORT=1			
Wave			
POST	756/1860 (40.7)	1.12 (0.99, 1.26)	0.07
PRE	966/2543 (38.0)	1 (Reference)	
FAMILY SUPPORT=0			
Wave			
POST	216/1322 (16.3)	1.11 (0.92, 1.34)	0.27
PRE	349/2333 (15.0)	1 (Reference)	