Using Data to Plan Multicultural Strategies

To Reduce Racial and Ethnic Disparities in Organ, Eye and Tissue Donation

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Center for Transplant System Excellence (UNOS)

Association for Multicultural Affairs in Transplantation
20th Annual Meeting
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The Center’s Mission

The Center for Transplant System Excellence (CTSE) strives to improve transplantation through integrated system approaches that provide evidence-based solutions to complex problems intersecting transplantation.
Long, Healthy, and Productive Lives for Persons with Chronic Conditions to End-Stage Organ Failure

Equitable Organ Allocation and Access

Efficient Transplant Care

System and Workforce Standards, Innovation and Improvements

Increase Organ Supply

Effective, High Quality and Safe Care

Preventive Care Initiatives that Reduce or Curb Demand for Organs

Our Vision: A Systems View

AMAT envisions a nation where transplant organizations apply a multicultural perspective to their relationships with donor families, transplant patients, healthcare professionals and the general public, and people of all cultures embrace organ, eye and tissue donation as a social responsibility.
Data and the Multicultural Perspective

- Data
- Information
- Actionable interventions
- Wouldn’t a roadmap to overcome racial and ethnic barriers help reduce disparities?
- Quantitative AND qualitative approaches NOT “either or”
- Rich narratives are embedded in microcultures
  - Informative AND limiting
- How can we coordinate these points into a strategy?
A quick review of recent research into multicultural aspects of community members and their views on donation
Study Design
The following data from the Southern California regional organ procurement organization were reviewed between 2004 and 2008: age, race (Caucasian, African-American, Asian, Hispanic, and other), the numbers of eligible referrals for organ donation and actual donors, types of donors, consent rates, conversion rates, organs procured per donor (OPPD), and organs transplanted per donor (OTPD). Logistic regression was used to determine independent predictors of ≥4 OTPD.

Results
There were 1,776 actual donors out of 2,760 eligible deaths (conversion rate 64%). Hispanics demonstrated a significantly lower conversion rate than Caucasians (64% vs 77%, p < 0.001), but a considerably higher rate than African Americans (50%) and Asians (51%, p < 0.05 for both). There were no significant changes in conversion rates over time in any race. Age was a negative predictor (odds ratio [OR] 0.95), and trauma mechanism (OR 2.1) and standard criteria donor status (OR 2.5) were positive independent predictors of ≥4 OTPD. Race did not affect OTPD (all groups, p > 0.05).
Abstract: Objective: As the shortage of suitable organs for transplantation is especially pronounced among Hispanic Americans (HA), our objective was to determine whether a focused media campaign including culturally sensitive educational material on organ donation would positively influence organ donation awareness, perceptions, and beliefs, and increase the likelihood of organ donation in the HA community.

Methods: Cross-sectional telephone surveys were conducted before and after a media campaign in four Southern California neighborhoods with a high percentage of HA. Respondents, age ≥18 yr, were drawn randomly from lists of Hispanic surnames. Awareness, perception, and belief regarding organ donation and intent-to-donate were measured. The differences between the Pre- and Post-media surveys were analyzed.

Results: A total of 524 Pre-media and 528 Post-media subjects were evaluated. The Post-media surveys demonstrated improvements in: organ donation awareness (43% vs. 31%, p < 0.0001), the belief that donation is a social responsibility (54% vs. 45%, p = 0.008), and the belief that donation helps people (91% vs. 87%, p = 0.09).

Conclusions: A media campaign emphasizing culturally sensitive educational material can significantly influence organ donation awareness and beliefs in HA.
Organ Donation and Hispanic American High School Students: Attitudes, Beliefs, Perceptions, and Intent to Donate

Authors: Berry, Cherisse; Salim, Ali; Ley, Eric J.; Schulman, Danielle; Anderson, Jacqui; Navarro, Sonia; Zheng, Ling; Chan, Linda S.

Source: The American Surgeon, Volume 78, Number 2, February 2012 , pp. 161-165(5)

Abstract:
The growing need for transplantable organs continues to outpace supply. This discrepancy is most pronounced in minority populations. Hispanic Americans, however, are significantly less likely to donate their organs for reasons that remain poorly understood. We sought to identify factors that influence Hispanic American high school students' intent to donate organs. A prospective observational study was conducted in five Los Angeles high schools within four separate zip codes known for a high percentage of Hispanic Americans. High school students, ages 15 to 20 years, were surveyed to assess demographic factors, cultural factors, awareness and knowledge, perception, and belief regarding organ donation and the intent to donate. A total of 5444 surveys were collected over a 4-month period. After logistic regression analysis, independent risk factors for predicting the intent to donate were: family support, 11th and 12th grade high school students, being female, religion, and the belief that Hispanics are more likely to need an organ transplant. This study represents the largest study to date examining factors associated with the intent to donate in Hispanic American high school students. To address the organ shortage crisis in Hispanic Americans, these risk factors should be considered using specific, effective educational programs.
Summary
Little is known about racial/ethnic differences in preferred methods of disclosing deceased organ donation intentions among persons not previously designating their organ donation preferences publicly or the association of medical mistrust with preferences. We surveyed 307 United States (US) adults who had not yet designated their donation intentions via drivers’ licenses or organ donor cards (nondesignators) to identify their preferred disclosure methods (personal discussions with family, physicians, or religious representatives or public registration via mail/telephone/computer, workplace, place of religious worship, or grocery store/bank/post office) and to assess the association of mistrust with preferences. In multivariable models, we assessed racial/ethnic differences in preferences and the influence of medical mistrust on preferences. Nondesignators most preferred discussions with physicians (65%) or family members (63%). After adjustment, African Americans (AAs) were more likely than Whites to prefer discussion with religious representatives. In contrast, AAs and Hispanics were less likely than Whites to prefer registration at a workplace or through mail/telephone/computer. Medical mistrust was common and associated with less willingness to disclose via several methods. Encouraging donation intention disclosure via discussions with physicians, family, and religious representatives and addressing medical mistrust could enhance strategies to improve nondesignators’ donation rates.
The Immortal Life of Henrietta Lacks

The Immortal Life of Henrietta Lacks is a non-fiction book by American author Rebecca Skloot. It is about Henrietta Lacks and the immortal cell line, known as HeLa, that came from her cervical cancer cells in 1951.

Published: February 2, 2010
How do you prototype and design an organizational approach, interventions and evaluation?

Use data, information and narratives to understand your service area, your community and the people living in various states of health (and dying) there.

In about one-tenth of all counties, the minority population composed 50 percent or more of the total population.

The Asian population grew faster than any other major race group between 2000 and 2010.

More than half of the growth in the total population of the United States between 2000 and 2010 was due to the increase in the Hispanic population.
A Roadmap and Best Practices for Organizations to Reduce Racial and Ethnic Disparities in Health Care*

- Past 7 years, RWJF funded 33 research projects, 12 systematic literature reviews, synthesizing into a Roadmap

- 6 overarching steps:
  1. Recognize disparities and commit to reducing them
  2. Implement a basic quality improvement structure and process
  3. Make equity an integral component of quality improvement efforts
  4. Design the intervention(s)
  5. Implement, evaluate and adjust the intervention(s)
  6. Sustain the intervention(s)

- Across disciplines (across asthma, HIV, colorectal cancer, etc.)

# Levels of Influence of an Intervention (Alignment)

<table>
<thead>
<tr>
<th>Intervention Level</th>
<th>Definition</th>
<th>Examples</th>
</tr>
</thead>
<tbody>
<tr>
<td>Patient</td>
<td>Change the knowledge and/or behaviors of patients (individuals) to improve outcomes</td>
<td>Culturally targeted outreach, patient narratives</td>
</tr>
<tr>
<td>Provider</td>
<td>Change the knowledge and/or behavior of providers to improve outcomes</td>
<td>Cultural competency training, disparity report cards</td>
</tr>
<tr>
<td>Microsystem</td>
<td>Add new members to team with special training AND responsibility for multicultural interventions</td>
<td>Community health workers integrated into team</td>
</tr>
<tr>
<td>Organization</td>
<td>Change organizational operations; Redesign service model to reflect multicultural goals</td>
<td>Improve the clinical encounter, improve systematic literacy</td>
</tr>
<tr>
<td>Community</td>
<td>Continue outreach AND increase recruitment of commitment into multicultural community organizations</td>
<td>Engagement with integrity for perpetual partnering</td>
</tr>
<tr>
<td>Policy</td>
<td>Influence policy, resource allocation, regulation</td>
<td>Accreditation, Memberships, Reimbursement, Federal Law*</td>
</tr>
</tbody>
</table>

The one message for all
DOES NOT WORK
at the community level

To segment, to specify, to impact the community for positive change, you must understand the community in its many and changing characteristics (age, race, ethnicity, location, mobility, health, morbidity and mortality).
One thing to remember is to talk to the animals. If you do, they will talk back to you. But if you don't talk to the animals, they won't talk back to you, then you won't understand, and when you don't understand you will fear and when you fear you will destroy the animals, and if you destroy the animals, you will destroy yourself.

Chief Dan George
Native Canadian Indian
Mortality: Different Conclusions by Averaging?

<table>
<thead>
<tr>
<th>Rank</th>
<th>&lt;1</th>
<th>1-4</th>
<th>5-9</th>
<th>10-14</th>
<th>15-24</th>
<th>25-34</th>
<th>35-44</th>
<th>45-54</th>
<th>55-64</th>
<th>65+</th>
<th>Total</th>
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<tbody>
<tr>
<td>1</td>
<td>5,785 Congenital Anomalies</td>
<td>1,588 Unintentional Injury</td>
<td>965 Unintentional Injury</td>
<td>1,229 Unintentional Injury</td>
<td>15,897 Unintentional Injury</td>
<td>16,931 Unintentional Injury</td>
<td>50,167 Malignant Neoplasms</td>
<td>103,171 Malignant Neoplasms</td>
<td>496,095 Heart Disease</td>
<td>616,067 Heart Disease</td>
<td></td>
</tr>
<tr>
<td>2</td>
<td>4,857 Short Gestation</td>
<td>546 Congenital Anomalies</td>
<td>480 Malignant Neoplasms</td>
<td>479 Malignant Neoplasms</td>
<td>5,851 Homicide</td>
<td>5,278 Suicide</td>
<td>13,288 Malignant Neoplasms</td>
<td>37,434 Heart Disease</td>
<td>65,527 Heart Disease</td>
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<tr>
<td>3</td>
<td>2,453 SIDS</td>
<td>398 Homicide</td>
<td>196 Congenital Anomalies</td>
<td>213 Homicide</td>
<td>4,140 Suicide</td>
<td>4,758 Homicide</td>
<td>11,839 Heart Disease</td>
<td>12,777 Chronic Low. Respiratory Disease</td>
<td>115,961 Chronic Low. Respiratory Disease</td>
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<tr>
<td>4</td>
<td>1,769 Maternal Pregnancy Comp.</td>
<td>133 Homicide</td>
<td>180 Suicide</td>
<td>131 Chronic Low. Respiratory Disease</td>
<td>173 Heart Disease</td>
<td>110 Heart Disease</td>
<td>1,084 Congenital Anomalies</td>
<td>3,223 Heart Disease</td>
<td>3,572 Suicide</td>
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<td>5</td>
<td>1,285 Unintentional Injury</td>
<td>173 Heart Disease</td>
<td>110 Heart Disease</td>
<td>178 Congenital Anomalies</td>
<td>1,084 Heart Disease</td>
<td>1,084 Heart Disease</td>
<td>1,084 Heart Disease</td>
<td>1,084 Heart Disease</td>
<td>1,084 Heart Disease</td>
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<td></td>
</tr>
<tr>
<td>6</td>
<td>1,135 Placenta Cord Memb.</td>
<td>109 Influenza &amp; Pneumonia</td>
<td>54 Chronic Low. Respiratory Disease</td>
<td>131 Heart Disease</td>
<td>402 Congenital Anomalies</td>
<td>1,091 HIV</td>
<td>3,052 Homicide</td>
<td>6,385 Cerebro-vascular</td>
<td>5,150 Diabetes Mellitus</td>
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<td></td>
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<tr>
<td>7</td>
<td>820 Septicemia</td>
<td>78 Influenza &amp; Pneumonia</td>
<td>48 Chronic Low. Respiratory Disease</td>
<td>195 Heart Disease</td>
<td>415 Chronic Low. Respiratory Disease</td>
<td>505 Cerebro-vascular</td>
<td>1,153 HIV</td>
<td>4,153 Unintentional Injury</td>
<td>3,052 Homicide</td>
<td></td>
<td></td>
</tr>
<tr>
<td>8</td>
<td>789 Respiratory Distress</td>
<td>70 Perinatal Period</td>
<td>41 Benign Neoplasms</td>
<td>55 Influenza &amp; Pneumonia</td>
<td>55 Chronic Low. Respiratory Disease</td>
<td>555 Cerebro-vascular</td>
<td>1,153 HIV</td>
<td>4,153 Unintentional Injury</td>
<td>3,052 Homicide</td>
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<td></td>
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<tr>
<td>9</td>
<td>624 Circulatory System Disease</td>
<td>38 Benign Neoplasms</td>
<td>45 Cerebro-vascular</td>
<td>45 Influenza &amp; Pneumonia</td>
<td>163 Congenital Anomalies</td>
<td>417 Diabetes Mellitus</td>
<td>1,984 Chronic Low. Respiratory Disease</td>
<td>4,153 Nephritis</td>
<td>4,440 Unintentional Injury</td>
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<tr>
<td>10</td>
<td>597 Neonatal Hemorrhage</td>
<td>36 Chronic Low. Respiratory Disease</td>
<td>36 Septicemia</td>
<td>43 Benign Neoplasms</td>
<td>160 Three Tied</td>
<td>384 Liver Disease</td>
<td>910 Septicemia</td>
<td>2,815 Viral Hepatitis</td>
<td>4,231 Septicemia</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

*The three causes are: Complicated Pregnancy, HIV, Septicemia
Source: National Vital Statistics System, National Center for Health Statistics, CDC.
Produced by: Office of Statistics and Programming, National Center for Injury Prevention and Control, CDC.
Do we know our community and its multicultural “signature”? 

*US Census 2010 Results*
## Table 1. Population by Hispanic or Latino Origin and by Race for the United States: 2000 and 2010
(For information on confidentiality protection, nonsampling error, and definitions, see [www.census.gov/prod/cen2010/doc/pl94-171.pdf](http://www.census.gov/prod/cen2010/doc/pl94-171.pdf))

<table>
<thead>
<tr>
<th>Hispanic or Latino origin and race</th>
<th>2000</th>
<th>2010</th>
<th>Change, 2000 to 2010</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Number</td>
<td>Percentage of total population</td>
<td>Number</td>
</tr>
<tr>
<td><strong>HISPANIC OR LATINO ORIGIN AND RACE</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Total population</td>
<td>281,421,906</td>
<td>100.0</td>
<td>308,745,538</td>
</tr>
<tr>
<td>Hispanic or Latino</td>
<td>35,305,818</td>
<td>12.5</td>
<td>50,477,594</td>
</tr>
<tr>
<td>Not Hispanic or Latino</td>
<td>246,116,088</td>
<td>87.5</td>
<td>258,267,944</td>
</tr>
<tr>
<td>White alone</td>
<td>194,552,774</td>
<td>69.1</td>
<td>196,817,552</td>
</tr>
<tr>
<td><strong>RACE</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Total population</td>
<td>281,421,906</td>
<td>100.0</td>
<td>308,745,538</td>
</tr>
<tr>
<td>One Race</td>
<td>274,595,678</td>
<td>97.6</td>
<td>299,736,465</td>
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<tr>
<td>White</td>
<td>211,460,626</td>
<td>75.1</td>
<td>223,553,265</td>
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<tr>
<td>Black or African American</td>
<td>34,658,190</td>
<td>12.3</td>
<td>38,929,319</td>
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<tr>
<td>American Indian and Alaska Native</td>
<td>2,475,956</td>
<td>0.9</td>
<td>2,932,248</td>
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<tr>
<td>Asian</td>
<td>10,242,998</td>
<td>3.6</td>
<td>14,674,252</td>
</tr>
<tr>
<td>Native Hawaiian and Other Pacific Islander</td>
<td>398,835</td>
<td>0.1</td>
<td>540,013</td>
</tr>
<tr>
<td>Some Other Race</td>
<td>15,359,073</td>
<td>5.5</td>
<td>19,107,368</td>
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<tr>
<td>Two or More Races</td>
<td>6,826,228</td>
<td>2.4</td>
<td>9,009,073</td>
</tr>
</tbody>
</table>

Sources: U.S. Census Bureau, Census 2000 Redistricting Data (Public Law 94-171) Summary File, Tables PL1 and PL2; and 2010 Census Redistricting Data (Public Law 94-171) Summary File, Tables P1 and P2.
Table 2.  
**Population by Hispanic or Latino Origin and Race for the United States: 2010**  
(For information on confidentiality protection, nonsampling error, and definitions, see www.census.gov/prod/cen2010/doc/pl94-171.pdf)

<table>
<thead>
<tr>
<th>Hispanic or Latino origin and race</th>
<th>Number</th>
<th>Percent</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>HISPANIC OR LATINO</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Total</td>
<td>50,477,594</td>
<td>100.0</td>
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<tr>
<td><strong>Race</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>One Race</td>
<td>47,435,002</td>
<td>94.0</td>
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<tr>
<td>White</td>
<td>26,735,713</td>
<td>53.0</td>
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<tr>
<td>Black or African American</td>
<td>1,243,471</td>
<td>2.5</td>
</tr>
<tr>
<td>American Indian and Alaska Native</td>
<td>685,150</td>
<td>1.4</td>
</tr>
<tr>
<td>Asian</td>
<td>209,128</td>
<td>0.4</td>
</tr>
<tr>
<td>Native Hawaiian and Other Pacific Islander</td>
<td>58,437</td>
<td>0.1</td>
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<td>Some Other Race</td>
<td>18,503,103</td>
<td>36.7</td>
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<tr>
<td>Two or More Races</td>
<td>3,042,592</td>
<td>6.0</td>
</tr>
<tr>
<td><strong>NOT HISPANIC OR LATINO</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Total</td>
<td>258,267,944</td>
<td>100.0</td>
</tr>
<tr>
<td><strong>Race</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>One Race</td>
<td>252,301,463</td>
<td>97.7</td>
</tr>
<tr>
<td>White</td>
<td>196,817,552</td>
<td>76.2</td>
</tr>
<tr>
<td>Black or African American</td>
<td>37,685,848</td>
<td>14.6</td>
</tr>
<tr>
<td>American Indian and Alaska Native</td>
<td>2,247,098</td>
<td>0.9</td>
</tr>
<tr>
<td>Asian</td>
<td>14,465,124</td>
<td>5.6</td>
</tr>
<tr>
<td>Native Hawaiian and Other Pacific Islander</td>
<td>481,576</td>
<td>0.2</td>
</tr>
<tr>
<td>Some Other Race</td>
<td>604,265</td>
<td>0.2</td>
</tr>
<tr>
<td>Two or More Races</td>
<td>5,966,481</td>
<td>2.3</td>
</tr>
</tbody>
</table>

Source: U.S. Census Bureau, 2010 Census Redistricting Data (Public Law 94-171) Summary File, Tables P1 and P2.
Figure 4.

Minority Population as a Percentage of County Population: 2010

(Minority refers to people who reported their ethnicity and race as something other than non-Hispanic White alone in the 2010 Census. For information on confidentiality protection, nonsampling error, and definitions, see www.census.gov/prod/cen2010/doc/pl94-171.pdf)

Source: U.S. Census Bureau, 2010 Census Redistricting Data (Public Law 94-171) Summary File, Tables P1 and P2.
Figure 5.

**Percentage Change in Minority Population by County: 2000 to 2010**

(Counties with a minority population of at least 1,000 are included in the map. Minority refers to people who reported their ethnicity and race as something other than non-Hispanic White alone in the decennial census. For information on confidentiality protection, nonsampling error, and definitions, see www.census.gov/prod/cen2010/doc/pl94-171.pdf)
Number of People, 2000

One Race: Asian

Number of people indicating exactly one race, Asian, by state:
- 1,000,000 to 3,698,000
- 100,000 to 999,999
- 10,000 to 99,999
- 2,771 to 9,999

Number of people indicating exactly one race, Asian, by county:
- 50,000 to 1,138,000
- 10,000 to 49,999
- 5,000 to 9,999
- 1,000 to 4,999
- 100 to 999
- 0 to 99


(For information on confidentiality protection, nonsampling error, and definitions, see www.census.gov/prod/cen2010/doc/p24-171.pdf)

<table>
<thead>
<tr>
<th>Area</th>
<th>2000</th>
<th>2010</th>
<th>Percentage change, 2000 to 2010</th>
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<tbody>
<tr>
<td></td>
<td>Total</td>
<td>Non-Hispanic White alone</td>
<td>Minority</td>
</tr>
<tr>
<td>United States</td>
<td>281,421,906</td>
<td>194,552,774</td>
<td>86,869,132</td>
</tr>
<tr>
<td>REGION</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Midwest</td>
<td>64,392,776</td>
<td>52,386,131</td>
<td>12,006,645</td>
</tr>
<tr>
<td>South</td>
<td>100,236,820</td>
<td>65,927,794</td>
<td>34,309,026</td>
</tr>
<tr>
<td>West</td>
<td>63,197,982</td>
<td>36,911,587</td>
<td>26,286,345</td>
</tr>
</tbody>
</table>
Figure 4.

**Number in Poverty and Poverty Rate: 1959 to 2010**

Numbers in millions, rates in percent

Note: The data points are placed at the midpoints of the respective years. For information on recessions, see Appendix A. Source: U.S. Census Bureau, Current Population Survey, 1960 to 2011 Annual Social and Economic Supplements.
Perceptions About Organ Donation Among African American, Hispanic, and White High School Students
Brian L. Quick, Nicole R. LaVoie, Allison M. Scott, Dave Bosch and Susan E. Morgan
*Qual Health Res* 2012 22: 921 originally published online 6 March 2012
DOI: 10.1177/1049732312439631

The online version of this article can be found at:
http://qhr.sagepub.com/content/22/7/921

**Abstract**

We applied the Health Belief Model (HBM) to better understand perceptions of organ donation among African American, Hispanic, and White high school students. We conducted 14 focus groups with 18-year-old students to identify strategies to reach this audience when promoting the First-Person Consent Registry (FPCR) for organ donation. We found that African American, Hispanic, and White high school students are largely unaware of the need for organ donors, and are unfamiliar with how to join the FPCR. Participants identified more barriers to joining the FPCR than benefits. Two aspects of self-efficacy emerged related to joining the FPCR: decisional and task efficacy. Overall, few differences were found with respect to organ donation myths across the three ethnic groups. The results are discussed, with an emphasis on how the findings compare and contrast with previous organ donation research. We focus on message design and dissemination strategies for practitioners targeting 18-year-old high school students with organ donation promotional materials.
High School students & donor registry enrollment in Illinois

- Focus groups to understand behaviors influencing decision-making rejoining the Registry

Health Belief Model (Glanz & Bishop, 2010)

- 6 constructs:
  1. Severity (perceived need for organ donors)
  2. Susceptibility (probability of needing a transplant in future)
  3. Benefits (desire to save lives or benefit others)
  4. Barriers (mistrust, “ick” factor, culture)
  5. Self-efficacy (confidence to perform a behavior)
  6. Cues to action (messages to join registry)
General Findings

- 98 students (N = 39 AA; 27 H; 32 W)
- Severity: Few knew about need for organ donors
- Susceptibility: Most thought someone might need a transplant in their family
- Benefits: Altruism, Heroism, Public recognition
- Barriers: (Many more barriers than benefits) common organ donation myths, fears, pre-existing belief systems, family disapproval, distrust, premature death declaration, issue “not on radar” of HS students...across all groups
- Self-efficacy: high task efficacy (easy to do), low decisional efficacy (decision harder to make than realized)
- Cues to action: conversations with others, visual-audio (Facebook?)
  - ++ W
  - --- AA & H (“we don’t talk about it”)
  - Specific to each groups and variable
- Key finding: Barriers 3x benefits across all groups
  - Medical mistrust, bodily integrity, perceptions from negative media stories (TV)
Some conclusions

- Multicultural issues are variable across racial and ethnic groups AND
- Variable across age groupings
  - 18 yo high schoolers
  - 50+ adults (HRSA initiative)
  - Narratives of adults still passed to next generation within cultural groups
  - Peer effects influence decision-making
- But, in this study, ALL groups were ill-informed, with few perceptual differences among the students
- Segmented, specific messages need to be crafted based on evidence, and deployed based on a carefully designed organizational and community-based strategy
- This is serious stuff
- Shotgun approach is not effective
An idea

- Call center data on all deaths with location (zip code) available
  - By age, cause of death, hospital
  - Organ, tissue, eye, excluded / deferred
  - By many geographic units...fips, county, HRR, HSA, etc.
  - Where is REL data gathered (race, ethnicity, language)?

- Donor Registry enrollment data
  - Geographic unit
  - Age
  - Both dead (realized potential & outcomes...donor or non-donor, organs transplanted or not) & alive (enrollment rates) drive efforts to enroll (age, ethnicity, SES, reflective of changing population)

- Actual / Potential by ________?

- Registered donors/donors

- Registered donors/population dying and/or population living
  - segments
  - location
How can we make this practical in our work?
Get the **zip code** on ALL referrals regardless of screening decision by call center

*Place of residence*

*AND*

*Place of death*
Living Population by County and/or Zip Code
Census.gov
Location of residence, demographics
[age, sex, race, ethnicity, language (REL), other]

Reported Deaths via Referral Center
(age, sex, REL, cause of death) & potential or not by type (eye, tissue, organ) & zip code location

Donor Registry Details extracted

Designated Deaths / Reported Deaths By Geographic Unit & Demographic Cuts

Undesignated Deaths / Reported Deaths By Geographic Unit & Demographic Cuts

Repeat Metrics for Potential as described to the left and actual
(Donor Registry Impact on patients transplanted vs traditional consent & track trends within targeted geographic units)
Create a roadmap for your organizations to reduce racial and ethnic disparities in transplantation

- 6 overarching steps:
  1. Recognize disparities and commit to reducing them
  2. Implement a basic quality improvement structure and process
  3. Make equity an integral component of quality improvement efforts
  4. Design the intervention(s)
  5. Implement, evaluate and adjust the intervention(s)
  6. Sustain the intervention(s)

- Abundant data sources (quantitative and qualitative) can guide your planning, implementation and evaluation!
“Knowing is not enough; we must apply. Willing is not enough; we must do.”

-Goethe

Thank you!

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