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# Hispanic perceptions of organ donation

The low rate of organ donation among Hispanics is of increasing concern to the transplant community at a time when the Hispanic population is growing rapidly, especially in Southern California. OneLegacy, the nation's largest organ procurement organization, commissioned a series of in-depth individual interviews with Spanish-language-dominant Hispanics to identify barriers and motivators to organ and tissue donation. Participants included 5 families who had consented to the donation of a loved one's organs within the past year and 7 families from the general Hispanic public who were either opposed to or ambivalent about organ donation. Individuals from both groups indicated a common reticence to speak of or make plans for either their own or a family member's death and lacked knowledge of procedures surrounding donation (whether consenting or being a donor themselves). Some respondents from the opposing group did not understand that organ donation takes place after death, expressing fears that declaring themselves donors would put them at risk of being allowed to die so that their organs could be recovered. Other attitudinal barriers included the wish to die with all body parts intact and reluctance to have another person's organ in their bodies. Consenting respondents found comfort in having helped another person to live. They wished for a personal expression of thanks from the recipients and an opportunity to learn more about and meet them. Interview findings suggest a great need to further educate the Hispanic community about organ donation, especially concerning brain death, the process for organ donation, and the protections afforded to donors and their families in the United States. Overcoming the taboos surrounding discussion of death and planning for death is an essential first step. (*Progress in Transplantation*. 2002;12:169-175)

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**I**n Southern California, the growing disparity between the number of patients waiting for an organ transplant and the number of organ donors is exacerbated by profound demographic shifts. Recent census data indicate that the Hispanic population increased 58% from 1990 to 2000 in the nation, 4 times faster than the rate for the total US population.<sup>1</sup> In California, Hispanics are projected to become the state's largest single ethnic group by 2025 and to account for between 41% and 47% of the population.<sup>2</sup>

OneLegacy is the nation's largest organ procurement organization. It serves 7 Southern California counties (Los Angeles, Orange, San Bernardino, Riverside, Santa Barbara, Kern, and Ventura) that comprise the largest Hispanic market in the United States. Latest data available for the service area show that the consent rate for organ donation among Hispanics, although it is improving, is still far below that of non-Hispanic whites. In 1999, the consent rate for organ donation among Hispanics was 38% as opposed to a

rate of 61% among non-Hispanic whites; in 2000, the Hispanic rate increased to 44% and the non-Hispanic white rate increased to 67%.<sup>3</sup>

Recognizing that the growth of the Hispanic population in the service area and the low consent rate for the Spanish-language-dominant subgroup pose new challenges for the organization, OneLegacy developed a multifaceted campaign to increase rates of organ and tissue donation in the Hispanic community of Southern California. In late 1999, the agency produced a television spot that could be aired as either a public service announcement or commercial. In preparation for the media launch, OneLegacy conducted a qualitative research project with 2 objectives: The first objective was to pretest the advertising message with members of the intended target audience, a time-honored principle of effective marketing.<sup>4(318)</sup> Because of the sensitivity and complexity of the topic, OneLegacy thought that it was important to elicit in-depth information from Spanish-language-dominant Hispanics, to effectively

gauge their understanding of the message of the television spot and their emotional responses to it. This feedback would be used to refine the message before the spot aired. The second objective was to better understand the various factors that influence Spanish-language-dominant Hispanics to support or oppose organ donation and to learn more about how Hispanic families make decisions about organ donation.

The results from OneLegacy's research support the results of studies conducted in the past quarter century with the general population in the United States and Sweden. Verble and Worth<sup>5</sup> recently reviewed several of these studies. These researchers found that the major reasons for not donating were remarkably consistent: concern for the condition of the body after death, fear of organs being removed before the donor is really dead or doctors taking action to hasten a patient's death, and suspicion about the fairness of the organ distribution system. However, OneLegacy's interviews with Spanish-language-dominant Hispanics revealed a much more fundamental misunderstanding of the relationship between death and organ donation, and the findings suggest that efforts to recruit Hispanic organ donors may need to encompass a broader educational program than most organ procurement agencies currently use with this population.

These findings refuted an assumption that Spanish-language-dominant Hispanic people understood the concept of brain death, as distinct from cardiac death, and that organ donation occurs after death. OneLegacy used this information to reformulate a key aspect of its advertising message to explicitly include the information that a person must have not only died but died a specific type of death, brain death, before he or she can become an organ donor. This new insight became an essential element in OneLegacy's educational and promotional campaign for the Hispanic community.

After producing the video spot in 1999, OneLegacy obtained a grant in the fall of 2000 from the federal Health Resources and Services Administration to conduct an outreach and advertising campaign targeted to Hispanics in the greater Southern California region. This grant enabled OneLegacy to conduct a paid advertising campaign instead of airing the video spot as a public service announcement. It also provided funding for quantitative research, a telephone survey employing a pre-post design, to evaluate the impact of purchased advertising in the Hispanic community on organ and tissue donation. Preliminary results of the first 2 telephone surveys indicate a slightly positive trend; the full results of the survey research project will be available in the summer or fall of 2002.

## Methods

This qualitative research project consisted of 12 in-depth interviews conducted during October 2000

with Spanish-language-dominant Hispanics. Five participants (all originally from Mexico) had consented to organ donations within the past year ("consenting families"). Seven others (5 from Mexico, 1 from El Salvador, and 1 from Guatemala) were either opposed to or ambivalent about organ donation ("opposing families"). With the exception of 2 consenting families, all participants were accompanied by a friend or close relative (spouse, child, or mother-in-law). Respondents were encouraged to attend the interview with a friend or relative for 2 reasons: to increase their comfort levels and to help OneLegacy learn how the participants shared information in dealing with a sensitive topic and in making a difficult decision.

OneLegacy retained a commercial market research firm with bilingual/bicultural telephone interviewers to locate and recruit Spanish-language-dominant Hispanics in the Los Angeles area where demographic data indicated large numbers of Hispanics reside, specifying a limit of 2 participants from any single zip code. Recruiters used a screening script to recruit participants from both Mexico and Central America who spoke either only Spanish or Spanish more than English at home and watched at least 10 hours of Spanish-language television a week. The script also included a general question about the respondent's knowledge of organ donation and a brief explanation: "Organ donation is making the decision that at the moment of death, you choose to donate any organ of your body like your heart, kidney, liver, even skin tissue, to someone who is very ill and whose life would be saved by receiving a transplant of that organ." Then the recruiter asked about the respondent's attitude toward organ donation. Respondents who declared themselves strongly in favor of organ donation were excluded. Those who said they were somewhat in favor, unsure, or opposed to organ donation were asked to comment on what they believed were the most important health issues facing Latinos today. Those who were unable to express themselves clearly and easily were excluded from the survey; those who expressed themselves well were invited to participate, with 1 other family member, in a 1-hour session to further discuss their opinions and hear their thoughts about some information on the topic of organ donation. Respondents and their partners were offered payment for participation of \$50 and \$40, respectively. The telephone script contained an explicit assurance of confidentiality: "All of your and your partner's opinions will be held highly confidential, there will be no follow-up calls or solicitations, and no one will attempt to sell you anything." A copy of the screening tool is provided (see Table).

OneLegacy staff recruited consenting family participants from among the Spanish-language-dominant Hispanic families who had consented to organ donation

Non-consents screener: OneLegacy project approved 9/28/00

Good morning/afternoon. I'm (name) from Meczka Marketing Research. We are talking to people to find out their opinions about an important topic. May I speak with the male or female head of your household?

Male \_\_\_\_\_ Female \_\_\_\_\_

1. Which of the following best describes your ethnic background? (READ LIST)

- European American  TERMINATE
- African American  TERMINATE
- Hispanic/Latino  CONTINUE
- Native American  TERMINATE
- Asian  TERMINATE
- Other  TERMINATE

2. Where were you born? (DO NOT READ LIST.)

- Mexico  CONTINUE
  - Any Central American country  CONTINUE
  - Any other  TERMINATE
- (RECRUIT no less than 9 Mexicans, and no more than 4 Central Americans.)

3. In your home, would you say you personally speak...? (READ COMPLETE LIST BEFORE ACCEPTING A RESPONSE.)

- Only Spanish  CONTINUE
- Spanish more than English  CONTINUE
- Both languages equally  TERMINATE
- English more than Spanish  TERMINATE
- Only English  TERMINATE
- Refused (DO NOT READ)  TERMINATE

4. On average, how many hours per week do you usually watch TV? Of those, how many hours are of Spanish TV?

RECORD # OF HOURS: \_\_\_\_\_ PER WEEK AND

# OF HOURS OF SPANISH TV: \_\_\_\_\_

TERMINATE IF RESPONDENT DOES NOT WATCH 10 OR MORE HOURS OF SPANISH TV PER WEEK.

5. The topic we are discussing is organ donation, and we realize some people may be uncomfortable with this topic. We would like to ask you a few questions about your own thoughts and experience regarding organ donation. Do you know what organ donation is?

- Yes  SKIP EXPLANATION Q.6.; GO TO Q.7
- No  READ EXPLANATION Q.6.

6. Organ donation is making the decision that at the moment of death, you choose to donate any organ of your body like your heart, kidney, liver, even skin tissue, to someone who is very ill and whose life would be saved by receiving a transplant of that organ. Do you understand this? (ELABORATE IF NEEDED, UNTIL YOU ARE SURE THEY ARE CLEAR ON THE CONCEPT.)

7. Now, knowing what organ donation is, would you say that, for yourself, you are:

- a. Strongly in favor of organ donation  TERMINATE
  - b. Somewhat in favor of organ donation  CONTINUE
  - c. Not sure if you're in favor or not of organ donation  CONTINUE
  - d. Somewhat against the idea of organ donation  CONTINUE
  - e. Completely against the idea of organ donation  CONTINUE
- (RECRUIT NO MORE THAN 3 CANDIDATES OF ANY ONE TYPE.)

8. And what do you believe are the most important health issues facing Latinos today? (THIS IS TO CHECK ON HOW LITERATE THEY ARE. IF THEY CANNOT EXPRESS THEMSELVES CLEARLY AND WITH EASE, TERMINATE.)

9. In what zip code do you live? \_\_\_\_\_  
(RECRUIT NO MORE THAN 2 PERSONS PER ZIP CODE.)

We would like to invite you and the one member of your family with whom you would be most likely to discuss the topic of organ donation to participate in a 1-hour discussion group to further discuss your opinions and get your thoughts on some literature addressing the topic of organ donation. You will be paid \$50 for your time, and your partner will be paid \$40. All of your and your partner's opinions will be held highly confidential, there will be no follow-up calls or solicitations, and no one will attempt to sell you anything.

Would you be willing to attend? \_\_\_ Yes \_\_\_\_\_ No

(Details on date, pick-up time, etc... tell them that the "partner family member" needs to either live in the same general neighborhood as they do (within 3 miles), or the partner will need to be at the respondent's home for the two to be picked up together.

for a loved one within the previous year. With only a few exceptions, the organ requesters who had worked with the families during the donation process recommended potential participants and contacted them. The requesters explained that the purpose of the study was to gather information from families like theirs who had made the difficult decision to donate a loved one's organs in order to better educate the Hispanic community. Some participants had also served as spokespersons for OneLegacy by discussing their experiences in the community. Most of those contacted readily agreed to participate. Several volunteered that they felt it was important for people in the Hispanic community to hear from people who had been through the experience and learn the truth about organ donation.

Consenting family participants and their partners were offered the same payment for their time as the other respondents. Because OneLegacy privately commissioned and funded these interviews as a social marketing research project in support of the agency's public outreach and educational program, the interview tool was not submitted to an institutional review board. All consenting families had previously signed consent forms with OneLegacy for organ donation that contained a promise of confidentiality. Both the organ requester who first contacted the families by phone and the interviewer at the focus group facility explained that the interviews would be taped and their comments would be summarized in a written report, but that no identifying information about individual participants would be released.

The interviewer was a bilingual/bicultural Hispanic psychologist, an independent qualitative market research consultant not employed by OneLegacy, and the setting was a focus group facility in Los Angeles, Calif. The interviews, lasting approximately 45 minutes, consisted of open-ended questions designed to elicit participants' views on organ donation, either by themselves or by a loved one, and on organ transplantation generally. The participants also viewed 2 television commercials, the first produced by a Hispanic advertising agency in Southern California and another produced by the Mexican Ministry of Health, and were asked to comment on the message, meaning, and motivational influence of each spot.

Consenting participants discussed their recent experiences donating the organs of a loved one and the reasons they made the decision; then they viewed the commercials. After acknowledging the sensitivity of the topic and expressing appreciation for their willingness to participate, the interviewer explained that the purpose of the interviews was to design effective communication messages to help people understand organ donation and to encourage decisions to donate. The discussion guide included the following questions:

- What, if any, discussions took place with the loved one about organ donation before the moment of

decision? When?

- If there was no prior discussion, what factors influenced your decision?
- Did both of you participate in the decision? What other family members or other persons participated?
- What was the hardest part of making the decision? What part, if any, was most gratifying?
- How do you feel today about the decision you made back then?
- Would you be willing to accept an organ for transplantation if you needed one?

After viewing the videos, consenting family participants were asked to discuss the message, target, relevance, and the feelings evoked, with the following questions used as a guide:

- What feelings and emotions did you experience watching this video?
- What do you think is the most important message in this video for people who have not ever had to make a decision about organ donation?
- Having been through the difficult decision of organ donation, what was the video's most important point for you personally?
- What, if anything, was missing or did not feel right for you in this video?

The interviewer began her discussions with opposing participants by explaining that the objective of the interviews was to understand the various factors that make people consent or not consent to allowing the donation of a loved one's organ or tissue. After the second interview, opposing participants viewed the commercials first, then engaged in a discussion about organ transplantation and the commercials. The first portion of the discussion explored their feelings about helping someone in need. Sample questions from the discussion guide included the following:

- Can you describe any situations where you helped someone in real need?
- If the health or life of (a) someone you didn't know or (b) a family member was in danger, how willing would you be to help? To what extent?
- Have you ever donated blood? (If yes, why? If no, why not?) If a family member or loved one needed a blood transfusion, would you donate for them?

The next portion of the interviews with opposing participants covered planning for their own or a loved one's death. Questions in this segment focused on whether the respondents had ever talked about death to another person, with gentle probes for any consideration of organ donation. Examples of questions include the following:

- Have you ever talked about the preparations and plans for a loved one's or family member's death?
- Have you ever talked about the preparations and plans for your own death?
- Do you have a will? Or specific desires regarding

your care in case of severe health circumstances or death? (Probe for living will/advance directives; life support/do-not-resuscitate vs resuscitation; custody of children.)

- Have you ever stated these wishes to anyone? (If yes, to whom? If not, why not?)
- Have any loved ones discussed with you their specific wishes regarding their severe illness or death?

The discussion with opposing participants also elicited their thoughts about organ donation, including whether they had ever thought about it or had been asked to be an organ donor. Those who expressed unwillingness to donate were asked what circumstances might prompt them to change their minds. They were also asked under a variety of circumstances, "If a loved one or family member were dying, would you consent to their organs being donated to a person whose life could be saved by receiving that organ?"

Opposing participants were asked the following questions about the TV spot:

- What action is suggested by the spot?
- What if any action would you take based on this spot?
- Would you be willing to accept an organ for transplantation if you needed one?

All recruitment contacts and interviews were conducted in Spanish. Interviews were videotaped and audiotaped with key quotes transcribed and content analyzed. The interviewer made notes immediately after conducting the interviews and subsequently listened to the tapes. She then prepared a detailed report that included basic demographic characteristics of each respondent and his or her partner and the key findings from the interviews, which included many verbatim quotes. The analysis of the tapes focused on identifying key themes, revealing underlying fears, and clarifying concerns.

## Profiles of Participants

### Consenting Families

The 5 consenting family participants, all from Mexico, had agreed to donate organs from children, siblings, and spouses. A brief description of each follows:

1. Married couple, both more than 60 years old; several children. Donor: son, age 26, declared brain dead following an automobile accident.
2. Single mother and daughter, 40 and 16 years old, respectively; 3 younger siblings. Donor: son, age 19, pronounced brain dead after being shot in the head.
3. Married woman, early 40s; several young children. Donor: sister, age 36, died of a brain hemorrhage.
4. Widow, 35 years old; 2 young children. Donor: husband, age 35, died of a brain hemorrhage.
5. Widow, mid-30s, Jehovah's Witness; 2 young children. Donor: husband, age 35, died of a brain hemorrhage.

### Opposing Families

Opposing participants also were mostly from Mexico. Similar to those who consented, all were parents.

1. Mexican couple, 30s or 40s, each with 2 grown children. Great fear of speaking about death; distrust organ donation because of myths, taboos, ignorance, and religious prejudices.

2. Mexican couple, 2 young children. Husband's aunt died of cancer. She needed a bone marrow donation, but her sister (husband's mother) was the only suitable donor and she was denied access to the United States to donate. Husband felt that speaking about death will cause bad luck; wants family to make decision. Both expressed suspicion that organ donation may lead to people being murdered in order to obtain their organs.

3. Mexican couple, 2 young children. Both expressed willingness to accept a donated organ to save their children's lives, but not for themselves.

4. Guatemalan couple, 5 children from previous relationships. Neither understood brain death, and thought organ donation was a decision made when a person knows he or she is going to die. Both expressed suspicion that organ donors may be under surveillance so that their organs may be retrieved in case of an accident.

5. El Salvadoran couple, 2 children. Husband understood that organ donation takes place after death; wife did not. They feared that by becoming organ donors they would be pursued by a donor retrieval organization.

6. Mexican couple, both 44 years, 4 children. Husband expressed fear that if he were to become a declared organ donor and have a serious illness requiring hospitalization, he would be allowed to die so that his organs could be obtained. After viewing the commercials, both expressed support for organ donation, especially for children; however, they still had doubts and wanted organ donation handled honestly and not for profit.

7. Mexican man, 52, and mother-in-law, 64; respondent has 2 children 27 and 25 years old. Neither understood the messages in the commercials, preferring to think of living donation. Mother-in-law considered the topic so distasteful that she crossed herself as moderator left the room. She would not want to accept an organ transplant because she would not know how the donor took care of his or her body. Both expressed a wish to be buried whole. Their opposition created mental blocks that allowed them to misinterpret the messages of the video spots.

### Key Findings

The most surprising finding from these interviews was that *several of the participants did not realize that organ donation takes place after death*. Consenting family participants recalled having heard of organ donation in news stories or from some other source

that they did not pay much attention to, thinking it would never apply to them. None had ever considered becoming an organ donor, even when they renewed their driver's licenses or when they were asked about it in some other context. And it was not until they were faced with the death of their loved one that they learned that the organ donor needs to die for someone else to receive the donated organ.

One of the commercials that participants pre-viewed featured a little girl, with a voice-over narrator saying, "If your daughter needed a heart to live, and you could give her yours when you no longer needed it, would you?...And if it were your niece...or the daughter of a friend...or this child?" Three of the opposing participants misinterpreted this commercial as if it were asking the viewers to agree to die to donate their hearts to save the child. It was at this point that the researchers realized that these participants did not understand that a person must die to donate his or her organs.

Consenting family participants discussed their initial shock when approached at the time of their loved one's death with the request for organ donation, and the difficulty they had accepting the idea of brain death and the reality that their loved one would not come back to life. It was at this point that they realized that even though the ventilator was still connected, the loved one was no longer really alive; however, his or her organs could be transplanted into another person's body—someone who was very sick and could not live much longer without a new organ. Still, some participants acknowledged lingering doubts about whether the loved one was really dead, and having wondered if the loved one's organs might be sold on the black market.

The primary motivating factor for consenting family participants to agree to donate their loved one's organs was the hope that in some way their loved one would go on living and that their organs would allow someone else to live. They attached particular meaning to having the loved one's heart continue to beat in someone else's body. They wished for a personal expression of thanks from the recipients and an opportunity to learn more about and, in some cases, meet the recipients. The hardest part of the decision to consent was not knowing the loved one's wishes. All consulted with relatives before making the decision; all expressed confidence in the wisdom of their decision to donate; and all subsequently decided to become organ donors themselves. One young widow, the only consenting family participant to discuss her religious affiliation, made the decision to donate her husband's organs in spite of the presumed opposition from both her church (Jehovah's Witnesses) and her in-laws, with the concurrence of her oldest child. She agreed, however, not to discuss her action with friends or family in Mexico to protect her in-laws from the criticism they feared.

Opposing participants were opposed to organ donation for a variety of reasons that reflected fear, ignorance, misperceptions, and religious prejudices. Some were worried that if they became organ donors they would be at risk of being allowed to die so that their organs could be recovered. Other attitudinal barriers among opposing participants included the wish to die with all body parts intact; discomfort with the idea of having another person's organs in their bodies; and the misperception that the Roman Catholic Church opposes organ donation and transplantation (even though the Pope had recently issued another strong statement of support for organ donation at the time these interviews were held).

Some opposing participants indicated somewhat more favorable attitudes toward organ donation after viewing the commercials and discussing the concept of brain death and the process of donor and family consent with the researcher and learning of the Pope's statement of support for organ donation. However, for some the fear factor was extreme. They expressed the belief that if they called the toll-free number mentioned in the commercial, they would be forced to sign papers to become organ donors, or that the organ donation organization would keep track of them, waiting for them to die in order to retrieve their organs. Individuals from both groups expressed suspicion that, especially in Mexico, there is a black market in organ sales.

Individuals from both participant groups expressed a common reticence to speak of or make plans for either their own or a family member's death, such as making a will. Opposing participants lacked knowledge of how organ donation takes place and the procedures for individuals and families to consent to donation, whereas consenting family participants indicated that they learned about and came to understand these issues only through their donation experience. Participants from both groups expressed support for more education about organ donation and promoting it through such methods as the commercials they pre-viewed. They also suggested more in-depth discussion of the topic on popular television talk shows and *telenovelas* (soap operas) to encourage people both to learn more about organ donation and to become more comfortable talking about it.

## Discussion

The results of this project underscore the importance of conducting in-depth, qualitative, and culturally sensitive research to pretest an advertising message carefully with members of the target audience. Findings from these interviews helped OneLegacy revise and refine its Hispanic advertising campaign message in 2 important ways. The first change was to ask viewers to consider donating their hearts "when you die"

instead of using the softer, but more likely to be misunderstood phrase, "when you no longer need it." The second modification was to formulate an explicit call to action, asking viewers to call the toll-free number for more information about organ donation, instead of simply flashing the 800 number on the screen.

The research provided important new insights for the implementation of a major public educational and promotional campaign to increase organ and tissue donation in the Hispanic community of Southern California. OneLegacy also hopes to use these findings, and the results from its quantitative research project, to encourage the Southern California Spanish-language television stations to devote more time in the future to public education on organ donation and transplantation.

### Conclusions

The results of this research indicate a great and ongoing need to further educate the Hispanic community about organ donation, especially concerning brain death, the process for organ donation, and the protections afforded both to donors and their families in the United States. Opposition to organ donation and transplantation reflects deep-seated suspicions about the influence of socioeconomic status on the organ pro-

cedure process, as well as misperceptions about the position of the Roman Catholic Church. Overcoming the taboos surrounding discussion of death and planning for death is an essential first step. The challenge will be to tell the story of organ donation in a way that both teaches and reaches the Hispanic community effectively.

### Acknowledgments

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