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## Attitudes, Beliefs and Behaviors Surrounding Organ Donation among Hispanic Women

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### Abstract

**Purpose of review**—Hispanic individuals are disproportionately in need of donor organs and are less likely to consent to donation than their non-Hispanic counterparts. This review addresses psychological constructs including attitudes and beliefs surrounding organ donation within Hispanic communities and highlights the importance of women in the domain of organ donation.

**Recent findings**—Attitudes toward living and posthumous donation are favorable. Mistrust of the medical profession, concerns about religious acceptance of donation, perceptions of inequity in the distribution of donated organs, and the context in which donation requests typically are made serve as barriers to consent. Women are more likely to consent to donation than men.

**Summary**—Hispanic American groups are heterogeneous. Culturally-sensitive approaches to communicating a donation request must consider ethnic origin and language preference. Family discussion of donation should be encouraged by the medical community as part of health care decision making (independent of death or crisis); women may serve as an excellent bridge between healthcare providers and families in this regard.

### Keywords

Hispanic populations; organ donation; attitudes

### Introduction

The waiting list for donor organs recently surpassed 100,000 individuals (Organ Procurement and Transplantation Network [OPTN], Organ by Ethnicity, [www.optn.org/latestData/rptData.asp](http://www.optn.org/latestData/rptData.asp). accessed 28 October 2008). This figure includes a disproportionate number of candidates of Hispanic origin. Specifically, individuals who are Hispanic or Latino comprise 12.5% of the U.S. population[1] yet they comprise 16.9% of the candidates on the U.S. waiting list (OPTN data as of October 24, 2008). Projections suggest that the Hispanic-origin population will be the largest growing group in the U.S., contributing 39% of the Nation's population growth between 2000 and 2010, and comprising 22.5% of the U.S. population by the year 2050 (U.S. Census Bureau, Population Profile of the United States, [www.census.gov/population](http://www.census.gov/population). accessed 28 October 2008). In conjunction with this growth, increasing demand for donor organs among Hispanics is imminent, as certain diseases and conditions that can lead to a greater need for transplantation are more prevalent among Hispanics. For instance, Hispanics have the highest estimated lifetime risk for diabetes mellitus

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[2] and a greater incidence of end stage renal disease (ESRD) relative to non-Hispanic individuals.[3]

Hispanic Americans are less likely to donate their organs; across a 20-year span, only 10.6% of deceased donors recovered were Hispanic, relative to 73.9% white and 12.4% black (OPTN, January 1, 1988–July 31, 2008). Ultimately, Hispanic individuals are less likely than whites to be placed on the waiting list or receive a transplant,[4] wait longer on the list for donor organs and, relative to whites, exhibit a lower percentage transplanted 1 year post-listing for a single organ with the exception of the heart (OPTN, 2003–2004 data). Data from a retrospective cohort study of deceased donor recipients (1996–2002) show that prior to the expanded donor criteria policy, Hispanics had 19% greater odds (relative to non-Hispanic whites) of receiving a lower-grade kidney, however when using the expanded donor criteria designation, Hispanics and whites did not differ[4]. Given access to renal transplantation, outcomes such as graft failure do not differ between Hispanics and whites.[5] The goal of this paper is to review what is known about attitudes, beliefs, and behaviors surrounding organ donation among Hispanic individuals, and examine the potentially important role of women in organ donation decision making.

## Attitudes

The importance of understanding attitudes derives from a rich body of empirical, theory-based literature which substantiates a positive relationship between attitude toward a voluntary behavior and behavioral performance. Unlike other voluntary health behaviors, translating favorable attitudes toward organ donation directly into acts of donation is not acutely possible in cases other than living donation. Thus, approaches to influence a favorable attitude toward donation have measured key intermediate behaviors such as family discussion about organ donation and donor registration.

The most recent nationally-representative household survey addressing the American public's attitudes toward organ donation and transplantation was conducted over one decade ago.[6] Data from this survey administration revealed general favorability toward organ donation; Hispanic respondents were more likely than white or black respondents to believe that economic status does not interfere with a person's chances of getting an organ transplant.[6] Hispanic and black individuals expressed greater concern over body disfigurement and greater doubt that doctors do all they can to preserve life before pursuing organ donation than did whites.[7] Other studies at this time depicted less favorable attitudes among Hispanic groups, implicating language barriers, myth and superstition.[8]

More recent accounts indicate that efforts to increase positive attitudes toward living and posthumous organ donation have been successful among Hispanic individuals. For instance, a Spanish-language mass media (television and radio) campaign targeting organ donation in two Arizona counties resulted in increasing pro-donation attitudes and family discussion one month post-exposure to the campaign. The theme for the television advertisements was the effort to save the life of potential donors while demonstrating the gift of life that organ donation can bring. The radio advertisements primarily addressed the position of the Catholic Church on organ donation.[9] This campaign can be compared to the results of a 4-year campaign by the Ad Council/Coalition Campaign with the theme "Organ and Tissue Donation: Share your life. Share your decision." This campaign, which did not specifically target a particular ethnic group, resulted in a higher proportion of individuals reporting that they had signed an organ donor card, yet no measurable change in overall attitude toward donation was found.[10]

A paid media advertising campaign targeting Spanish language dominant Hispanic adults residing in southern California resulted in more favorable attitudes toward organ donation during the first two years following the campaign; moreover, the Hispanic consent rate for

organ donation exceeded the project goals.[11] The theory-based, culturally-sensitive campaign presented three scenarios that highlighted children or young adults, in recognition of the importance of family to most Hispanic groups. The campaign did reveal continued distrust of the medical system however this finding was contemporaneous with media accounts of the death of heart transplant patient Jessica Santillan due to medical errors. Thus, attitudes are influenced by both positive and negative media accounts, particularly among Hispanic populations whom market researchers indicate may watch more television than the general U.S. population.

Interviews with Spanish-speaking people in Chicago, Houston, Los Angeles, Miami and New York City revealed that Hispanics who intended to be organ donors were *uninformed* about organ donation while those who were against or undecided about organ donation were *misinformed*. [12] Thus, in a targeted effort to reach the Hispanic American community, the Coalition on Donation launched a campaign which focused not on increasing the number of donors, but on disseminating correct information about organ donation.[12]

The changing U.S. demographics, the growing overall need for donor organs and among Hispanic individuals in particular, suggest that a national survey focusing on Hispanic American populations may be timely and critical. Survey development should recognize that Hispanic Americans are a heterogeneous group, and differences in attitudes and beliefs about donation may vary greatly depending on one's national background.[9] Furthermore, language preference (Spanish vs. English) may contribute to diversity among Hispanic populations, as recognized by Siegal et al. [13] National campaigns that reach multiple Hispanic American groups are necessary to ultimately increase expressed commitment to organ donation and instill trust in the medical establishment. Additionally, approaches to increase attitudes toward organ donation among Hispanics may vary depending upon whether living or posthumous donation is considered. Specifically, a number of barriers to posthumous donation within many Hispanic groups would be overcome by living donation, such as limited time for decision making, involvement of all family members, concerns about surveillance or not making every effort to save the life of the donor, and equity in organ distribution.[14] Finally, promoting favorable attitudes toward organ donation among Hispanic American families facing donation decisions necessitate culturally-sensitive approaches by health care providers.[11]

## Beliefs

Beliefs surrounding organ donation among Spanish-language-dominant Hispanics were examined in a qualitative interview study conducted in Southern California among 5 families (all of Mexican origin) who consented to the donation of a loved one's organs in the past year and 7 families (5 from Mexico, 1 from El Salvador, 1 from Guatemala) identified from the community who were ambivalent or opposed to organ donation.[15] The interviews revealed that many did not realize that donation takes place after death and that brain death is death. Opposing families expressed the belief that known organ donors may be under surveillance or pursued by organ retrieval organizations and doubted that organ donation is handled honestly and not for profit. Both opposing and consenting families expressed suspicion that there is a black market for organ sales, particularly in Mexico, and an overall reluctance to "plan for death." Consenting families were motivated to donate by the beliefs that their loved one would go on living and that by agreeing to donate their loved one's organs, someone else would be able to live.[15]

Hispanic families are often not sure that their group is getting equal treatment and that organs are distributed equitably across ethnic groups.[7,16] In fact, the Hispanic media campaign that was successful in increasing favorable attitudes toward donation and family discussion was

not effective in changing perceptions of discrimination regarding the distribution of donated organs between Hispanic vs. Anglo Americans.[9]

Strong beliefs related to the Catholic faith are found among many Hispanic populations, including the belief in a miracle that delays death. Until a final declaration of death is made, Hispanic families may not be receptive to a discussion about organ donation. [16] In fact, many Hispanics do not like to talk about death and hold an aversion to planning for events surrounding death; some believe by talking about death one may cause it to occur.[12] Statements arising from the Vatican indicate that transplants are morally and ethically acceptable and organ donation is encouraged as a genuine act of love and charity. Many Hispanics, however, do not realize that the Catholic Church supports organ donation.[12] For Hispanics who are not Catholic, position statements from a majority of religions indicate support for organ donation and transplantation.[17] How individuals conceptualize death and integrate the concepts of death, donation, and religious beliefs may, however, be newly complicated. A recent article appearing in the *New England Journal* [18] refers to “flawed definitions of death” and argues that informed consent from patients or surrogates should be the ethically relevant precondition for donation, and not the dead donor rule. Following publication of this article, a Vatican Conference was held on organ donation during which the Pope cautioned that in the question of determination of death, “there must not be the slightest suspicion of arbitrariness. Where certainty cannot be achieved, the principle of precaution must prevail.”[19] Future directives from the Vatican will be necessary to guide Catholics in their decision making and to discern whether singularly-occurring, life-saving organs can continue to be removed for transplantation under conditions of informed consent and declaration of brain death in Catholic hospitals.

## Behaviors

Hispanic individuals are less likely than non-Hispanic whites to agree to donate the organs of a deceased family member,[15,20] including pediatric organ donation.[21] Very often, failure to allow donation reflects doubt regarding the wishes or intentions of the decedent. Thus, expressing one’s wishes to be an organ donor, particularly to one’s family, remains a critical step in increasing the availability of donor organs. In one study, more than half of Hispanics surveyed did not know how to sign up to be an organ donor in the event of death, while between 36% and 41% of individuals in this same study indicated they would sign up if asked.[13] Signing up at the doctor’s office, by way of the driver’s license, or at one’s place of worship/church were the preferred methods of registration.[13] These methods may facilitate discussion about the topic, which is an important part of decision making among many Hispanic families. Discussions often include extended family,[22] with Hispanics of Native American descent including the matriarch, while in families where Spanish culture is strong, the patriarch will be an important participant.[16] Data collected among 1,200 Hispanic Americans in Pima and Maricopa counties in Arizona using computer-assisted telephone interviewing revealed that knowing a potential organ donor and disagreeing that carrying a donor card results in inadequate medical care were two key factors associated with family discussion about organ donation.[23]

Effective communication within families regarding donation intentions and between medical staff and potential donor families is of critical importance. Latin Americans favor high-context communication, i.e., communication that is rich in detail where both physical and personal factors are brought into the context of the topic under consideration. Factors such as social status, relationship, history, setting, voice, gesture and posture all are important in the overall interpretation of the situation.[24] North Americans and men in general, favor low-context communication, which focuses on the primary issue and gets straight to the point. The critical care context in which a donation request takes place may pose a crucial mismatch between the

practical setting in which donation is discussed and the preferred context of communication for Hispanic families.

Examination of family refusal for organ donation in Puerto Rico revealed several mitigating factors including: fear of mutilation and suffering (often accompanied by an inability to accept the argument that the dead relative was not suffering because s/he was dead), denial of death (particularly for relatives on mechanical ventilation), and family dynamics and communication regarding decision making and death. With regard to family dynamics and communication, “the extended family” became a critical factor in the refusal to agree to donation. Specifically, although the opportunity to donate may be presented by medical staff to the next-of-kin, these individuals often preferred to wait for other senior or more prominent relatives to arrive to make the decision. As a consequence, critical time passes and different perspectives must be incorporated into decision making; greater time pressure and family dissent often leads to the next-of-kin deciding against donation. With regard to family dynamics surrounding death in this culture, Fernández et al.[22] describe “collective hysteria” in which the grieving process can be characterized by a contagious form of hysteria in which arriving family members shout, scream, cry uncontrollably and sometimes succumb to fainting spells and convulsions. Collective hysteria can result in a trance-like state, or the injury of key family members – two outcomes that render communication impossible. [22] To address these factors effectively, Fernández et al. suggest that staff share in the grief process of the family. Becoming more involved in the process and knowing who is in the room, their relation to the deceased, and who the family intends to involve in the decision making regarding organ donation renders it less likely that medical staff will interrupt or intrude upon the grief process, thereby shutting down communication.

In Puerto Rico, a “culture of donation” was achieved by first decoupling the organ procurement efforts from the transplant program and implementing an aggressive administrative and educational plan to identify problems in the steps leading to donation and transplantation in hospitals. Subsequent to these efforts, public education campaigns and training for hospital administration and staff were carried out. The recognition that all Hispanics are not the same led to an appreciation of the importance of cultural sensitivity among coordinators, including language, accent, and cultural background. Together, these efforts resulted in a 16-fold increase in organ donation from 1984–1995 to 2001–2006 among Hispanics living in Puerto Rico. [25]

## Importance of Women

Gender is related to organ donation and transplantation in important ways. For instance, between the years 1988 and 2008, only 39% of the transplants performed were on females. Furthermore, females with ESRD have reduced access to the transplant waiting list relative to males and are less likely than men to receive a transplant, even after accounting for co-morbid medical conditions, social class and health status.[26–28] Importantly, women are often the decision makers of the family when it comes to health-related issues, and on average, women live longer than their spouses. Women also tend to have more contact with the medical community than do men, be it for their own health and well-being, or that of their children. For these reasons and others, women of Hispanic and non-Hispanic ethnicity represent an important group to target in efforts to increase organ donations.

The survey of Hispanic Americans in Arizona revealed that women were more likely than men to have told someone of their desire to be an organ donor and to have discussed organ donation with their family,[23] which is consistent with earlier data showing that women who were likely to donate their own organs were significantly more likely than men to have shared this wish with their family.[6]

Between June 2006 and November 2007 organ donation beliefs and intentions were surveyed among 2,583 women (74% Hispanic) attending a women's health clinic in southeast Texas. Sixty-eight percent of the Hispanic women surveyed were immigrants, of these the majority (86%) were born in Mexico and 34% moved to the U.S. at 19 years of age or older. Our data revealed that 16% of Hispanic women were unaware that individuals could be organ donors when they die relative to 4% of whites and 8% of blacks ( $P<.0001$ ). With regard to key intermediate behaviors, 33% of women reported talking about organ donation with a family member, however minority women were less likely to have done so (31% of Hispanics, 26% of blacks, 46% of whites,  $P<.0001$ ). Similarly, fewer Hispanic and black women reported having signed a donor card or driver's license relative to white women (11% of Hispanics, 12% of blacks, 26% of whites,  $P<.0001$ ). Over half (51%) of the women surveyed indicated they would like to become an organ donor however fewer (42%) Hispanics indicated this relative to blacks (64%) and whites (79%),  $P<.0001$ .

Considering only the Hispanic sub-sample ( $n= 1,898$ ), relative to U.S.-born Hispanics, immigrant Hispanics were less likely to be aware of organ donation, discuss donation with their family, intend to be a donor, or sign a donor card/driver's license (all  $P<.05$ ). Immigrant (vs. U.S.-born) Hispanics indicated greater agreement that a poor person has as good a chance as a rich person of getting an organ ( $P<.0001$ ) and that racial discrimination prevents minorities from receiving organ transplants ( $P<.05$ ).

## Conclusion

Hispanic Americans and women represent two segments of the U.S. population that hold great importance with regard to the future availability of donor organs. Recognizing the diversity within the Hispanic culture and the important role of women in taking care of the health of the family are likely to be instrumental in increasing family discussion and commitment regarding organ donation. Addressing living donation and posthumous donation separately within the Hispanic community is justified by existing data and may result in increased donations. Creating a "culture of donation" among Hispanic Americans (as was accomplished in Puerto Rico) represents a tremendous challenge with potentially rich rewards for families of donors and recipients.

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