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The Impact of Latino Values and Cultural Beliefs on Brain Donation: Results of a Pilot Study to Develop Culturally Appropriate Materials and Methods to Increase Rates of Brain Donation in this Under-Studied Patient Group

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Abstract

Objectives—Increasing the number of Latino persons with dementia who consent to brain donation (BD) upon death is an important public health goal that has not yet been realized. This study identified the need for culturally-sensitive materials to answer questions and support the decision-making process for the family.

Methods—Information about existing rates of BD was obtained from the Alzheimer's Disease Centers. Several methods of data collection (query NACC database, contacting Centers, focus groups, online survey, assessing current protocol and materials) were used to give the needed background to create culturally appropriate BD materials.

Results—Decision was made that a brochure for undecided enrollees would be beneficial to discuss BD with family members. For those needing further details, a step-by-step handout would provide additional information.

Conclusions—Through team collaboration and engagement of others in the community who work with Latinos with dementia, we believe this process allowed us to successfully create culturally appropriate informational materials that address a sensitive topic for Hispanic/Latino families.

Clinical implications—Brain tissue is needed to further knowledge about underlying biological mechanism of neurodegenerative diseases, however it is a sensitive topic. Materials assist with family discussion and facilitate the family's follow-through with BD.

Keywords

Brain donation; Hispanic; Latino; outreach materials

Brain donation (BD) is critical for understanding pathological causes of neurodegenerative diseases. Having brain tissue from persons of diverse racial and ethnic backgrounds is important as well for research generalizability and may ultimately improve treatment and care of under-represented minorities. In a recent *Nature* article on the challenges of brain banking, Kretzschmar (2009) stated that autopsy rates, once the largest source for brain tissue, are declining worldwide. He noted need for greater understanding of attitudes toward post-mortem tissue donation. A study of attitudes must include understanding how culture influences decision-making. Culture is defined as shared knowledge, beliefs, values, attitudes and language which form worldviews shared by members of given subgroups – e.g. Hispanic/ Latino Americans (US Dept. Health & Human Services, 2000; Triandis, 1996). Although the label “Hispanic/Latino” is used in this paper we recognize that this term includes a heterogeneous mix of persons originally from diverse countries including Mexico, Cuba, South and Central America and Puerto Rico. As such, it is a non-specific though commonly used summary term for those who ethnically identify with the Spanish language and related cultures (Institute of Medicine, 2002). It is well documented that Hispanic/ Latino persons do not participate in either organ donation generally, or brain donation more specifically, to the same extent as non-Hispanic Whites (NHW) (Frates & Bohrer, 2002; George et al, 2014). Some barriers and facilitators have been identified, but to date there have been relatively few studies on factors influencing BD. Therefore, our knowledge base is limited at this time. Understanding culturally-determined values, attitudes and beliefs about BD among Hispanic/ Latino persons in the context of dementia should increase their willingness to participate in this essential component of dementia research.

Without BD, the neuropathologic studies that have served as the foundation of our understanding of degenerative neurologic diseases would not be possible. Brain donation allows the pathologist/scientist to observe the pathologic process and generate hypotheses about causes of the disease. Furthermore, brain donation provides critical research tissues to further probe the origins of disease. Finally, since there can be substantial overlap in the clinical presentation of neurodegenerative diseases, autopsy confirmation of the neuropathologic diagnosis is critical to understanding the individual patient as well as the neurodegenerative disease.

Although the BD process varies somewhat between institutions, it commonly includes three steps: consent, the donation plan and brain autopsy itself. Before this process can be initiated, discussions within the family take place while the potential donor is alive, so that family knows the person’s wishes. Often some form of consent is also included in the paperwork that is part of the enrollment process in the national network of Alzheimer’s Disease Research Centers established and funded by the National Institute on Aging. However, the brain donor’s consent while alive does not guarantee that the family will in fact follow through so actual consent to perform the brain autopsy is procured from the decedent’s next of kin upon their passing. Next of kin is the legally recognized person who will care for the decedent’s estate including their body. This may be a person identified in an advance directive, but typically it is a member of the decedent’s family prioritized in order of surviving spouse, then surviving children, surviving parents and surviving siblings. After BD consent is obtained, the team devises a BD plan to facilitate performance of the brain

autopsy in a rapid manner. Critical to this plan is the informed participation of both family, including the next of kin, as well as the professional medical staff that will be present at the bedside at the time of the brain donor's death, to inform the on-call BD team that the donor has died. They will then arrange mortuary transport of the brain donor's body to the hospital autopsy suite, where the brain autopsy is performed typically within 3–8 hours following death. The brain autopsy entails removal of the brain through an incision at the back of the head. This incision location allows the family's designated mortuary, who will pick up the brain donor's body following the autopsy, to subsequently conceal the incision and preserve the body for funeral viewing.

Following BD, the neuropathologist performs an examination of the decedent's brain that includes the preparation of slides from the brain for microscopic examination. The pathologies present in the decedent's brain that contributed to the clinical disease, including Alzheimer disease, Parkinson disease, large and small strokes (infarcts) and others, will be documented. Consensus diagnostic criteria are applied to the neuropathologic findings to arrive at a pathologic explanation of the decedent's clinical disease. The neuropathologist will discuss these findings with the decedent's neurologist and, in some cases, the clinical and pathology staff will convene at a Clinical-Pathologic Correlation (CPC) conference to discuss the case. The decedent's family can typically obtain a diagnostic report from the hospital's medical records department and/or discuss the neuropathologic findings with the decedent's neurologist.

A recent review of barriers to health research participation in general, not focused on organ donation, with African Americans, Hispanic/Latino Americans, Asian Americans and Pacific Islanders over a 10-year period revealed that of the 44 studies included, only three focused exclusively on Latinos (George et al 2014). This review noted a lack of distinct barriers which was attributed to the limited articles focused on Latinos. In a handful of studies on organ donation in general, not focused on brain donation, attitudes, values and beliefs of Hispanics/Latinos were compared to other minorities (McNamara et. al., 1999; Siegel, O'Brien, Alvaro, & Poulsen, 2014). In these studies, traditional barriers such as a lack of trust in medical providers to provide best care to delay death of the potential donor and concerns about disfigurement of the body after donation were noted across multiple race/ethnicities but in addition, unique barriers such as inability to miss work, disqualification due to being undocumented, and concerns that donating may interfere with the potential donor's ability to support their family if they donated were noted. A 1994 guest editorial by Rene and colleagues pointed out that Hispanic/Latino Americans are the second largest minority group in the US yet they participate in organ donation in a very limited way. This situation has not changed significantly in the 20+ years since, based on our review. The BD literature itself is similarly scant: few published studies were found on barriers to BD among African Americans (Bonner et al, 2000; Darnell et al, 2011) but only one on Hispanic/Latino Americans (Boise, Hinton, Rosen & Ruhl, 2016). Boise and colleagues found the four ethnic/racial groups they studied (Latinos, Asian Americans, African Americans, White Non-Hispanics) shared a lack of understanding about Alzheimer's research. For example, the participants largely believed that research would not require healthy control brains. They also expressed concerns about brain removal resulting in disfigurement, which would be problematic at open casket funerals. African Americans were

concerned with the history of racism in medical research and this was, to a smaller degree, shared by Latino and Chinese participants. Religious beliefs were strong barriers as well. Some participants were concerned with what would happen to their bodies following their death, and whether brain removal would interfere with the soul's journey in the afterlife (Boise et al., 2016). In sum, Hispanic/Latinos share barriers with other underserved races/ethnicities such as lack of trust in medical providers and the medical system, concerns over disfigurement, difficulty in discussing what will happen following end of life, and conflict with their spiritual/religious beliefs. However Hispanic/Latinos also had unique barriers concerning loss of work to and its effects on family income and effects on family due to members being undocumented impacting the family participation which is required in any BD Program.

The study of how cultural factors, ethnic/racial identity, and age-related factors interact to impact health and mental health access and outcomes is referred to as the study of "ethnogeriatrics." This term was coined by the Stanford Geriatric Education Center (SGEC) in 1987 and has come into widespread use in recent years. Factors such as level of acculturation, immigration status and history, family values, health beliefs, and level of health literacy all can impact how health related decisions are made (Hikoyeda, Miyawaki, & Yeo, 2015; Yeo, 2009) yet they are typically not included in research. The ethnogeriatric approach has been used to inform health care delivery for diseases such as diabetes (Fee et al., 2004), mental health conditions (Aggarwal, 2010) and to train health care providers to meet the complex needs of a more diverse older adult population (Talamantes & Sanchez-Reilly, 2010). While it has a long history, this conceptual framework has not yet been used to study facilitators and barriers to BD in Hispanic/Latino persons suffering from dementia.

The current research study, grounded in ethnogeriatric principles, was designed to explore two hypotheses: first, that the ratio of completed brain donations to number of patient enrolled will be significantly less in Hispanic/Latino patients compared to non-Hispanic White (NHW) patients at any given center, as well as across the 30+ Alzheimer's Disease Centers (ADC) nationally, consistent with national trends regarding post-mortem organ donation in general. The second hypotheses states that there are unique cultural factors that can be identified that impact the decision to donate a brain for medical research, some of which may be modifiable with education (e.g. body disfigurement precluding use of open casket for funeral) and others not (e.g. religious beliefs in resurrection of the body itself in afterlife).

Methods

To examine these hypotheses, this study gathered information about existing rates of BD in the 39 past and present Alzheimer's Disease Centers (ADCs) supported by NIA through their National Alzheimer's Coordination Center's (NACC) database during the time-period between June 2005 through May of 2016. The NACC database uses the Uniform Data Set (UDS) which was created in 2005 to collect standard clinical data on subjects at all the ADCs on an approximately annual basis and includes, for the subjects who participate in a brain donation program, neuropathology data if an autopsy was performed. A comprehensive description of the NACC database is provided in two previous reports

(Morris et. al., 2012; Beekly et. al., 2004). Rates of the top centers were compared to determine which were most successful in obtaining neuropathology data upon the death of those who had consented to BD.

To address the second hypothesis, and to give us needed background information to create culturally appropriate BD materials, we used several methods of data collection. First, the recruitment/ outreach leadership staff at the most successful ADCs, as identified in the first step, were contacted by email and/or telephone and asked to identify what, in their opinion, were key barriers to BD and key factors associated with success for their Hispanic/Latino families. Next, we conducted two local focus groups in Spanish with promotoras (indigenous persons who go into homes and provide health education and basic health screenings to Latino families) to ask about their attitudes and beliefs toward BD. We also asked them what kinds of materials might be useful to explain the BD process to Hispanic/Latino families. These groups were recorded, transcribed, and reviewed by two independent raters for common themes and illustrative quotes. Finally, we created a Qualtrics online survey (Qualtrics, Provo, UT) made available in both English and Spanish that was emailed to local Latino health providers and families, as well as other providers who worked with this community. An initial sorting question was used to identify whether they were a health provider or community member. Health providers were asked a total of 19 questions, which included queries about current topic knowledge, BD materials available, whether the topic was discussed with patients, comfort level surrounding topic, preferred method of obtaining topic information, thoughts on what Latinos may believe regarding brain donation and perceived barriers that may prevent donation. Health providers were also asked five demographic questions pertaining to type of provider, age, sex, race and ethnicity. Those who self-identified as Latino community members, were asked a total of 37 questions including current topic knowledge, preferred delivery of topic information, personal and familial beliefs surrounding disposition of body following death, and donation of the brain specifically. Personal and familial beliefs regarding medical research included perceived respect of decedent's body and trust of researchers were explored. Also included were questions design to understand the intersection of religion and faith in the decision process to donate and nine demographic questions of age, sex, origin country, time in US, language at home, language used to obtain medical information, education, ethnicity and race. This survey was intended to broaden the base of responses and expand our knowledge of the values, attitudes and beliefs associated with BD among Hispanic/Latino families. The information gathered during this phase of the pilot study was used to further the goal to create culturally appropriate materials to facilitate BD among Hispanic/Latino families enrolled in the national network of ADCs.

Results

Identifying the Top ADCs in Hispanic/Latino Brain Donations

We first examined the total available population of Hispanic/Latino persons enrolled in the ADCs (see Figure 1). For the time-period between June 2005 through May of 2016, of all participants enrolled (N=33,762), only 8% or 2,557 were Hispanic/Latino. Of all deceased participants (n=7,005), 4% or 311 were Hispanic/Latino and within this group,

neuropathology data (obtained when the brain autopsy is completed) were available on 4,159 of which 4% or 160 had self-identified as Hispanic/Latino. To identify the top nine Centers with the most successful BD programs, the ratio of deceased Hispanic/Latino American with neuropathology data (compared to those without) was computed. These top nine Centers accounted for 82% or 132 of the 160 deceased Hispanic/Latino persons. They were also the most successful at Hispanic/Latino enrollment with 85.5% or 2,187 of total 2,557 enrolled Latino participants for the time-period specified (see Figure 2).

Successful BD Programs were defined in two ways: first: the raw number of deceased Hispanic/Latino enrollees with neuropathology data available. This is used as the measure for successful donation of the deceased participant's brain. Figure 2 lists the top nine ADCs: four from California (University of Southern California, University of California San Diego, University of California Davis, & University of California San Francisco), three from New York (Columbia University, Mount Sinai School of Medicine, & New York University) and one each from Illinois (Rush University Medical Center) and Arizona (Banner Alzheimer Institute). The second measure of a successful BD program is the percentage of how many deceased Latinos successfully participated in the BD program (percentage located in the bottom row). Referring to Figure 2, the Arizona center while having only 15 Latino enrollees who died, had 80% of them proceed on to autopsy. The higher percentage represents Centers effective in getting families of participants who volunteer for BD to follow through at time of death.

Process of Material Creation: Identifying Culturally Relevant Information

The process of material creation consisted of four steps (see Figure 3). We began with a review of the literature, followed by reviewing BD information shared by the successful programs. Focus group results were then studied, and information summarized from the online surveys of health providers and Latino community members.

Data from centers with successful BD programs—Materials were requested from the top nine centers (as previously identified) but were sent by only five; the other four indicated they had no special BD materials. None of the materials received were in Spanish. The English versions were written at 10th grade or higher literacy level. Clearly new materials were needed to address a lower literacy population for whom Spanish was the preferred language.

Information Gathered from Focus Groups—Two separate focus groups were held with promotoras affiliated with our community based education partner in East Palo Alto: Nuestra Casa. Promotoras are persons from the community who are trained health educators that go into homes and provide education, support, and referrals to their clients. The Stanford Alzheimer's Disease Research Center (SADRC) bilingual, bi-cultural team has been working with Nuestra Casa on several projects to increase awareness of dementia in the Latino community – first, by training promotoras to recognize early warning signs, and second, by providing a series of “Charlas” (community conversations) directly to the East Palo Alto Latino community on topics related to dementia and healthy aging. Through this productive collaboration, 20 promotoras were trained in our “dementia awareness campaign”

program. As they expressed eagerness for more training when that was completed, we engaged them in the BD project by conducting focus groups with some of the same promotoras who were in the initial dementia awareness training (N=12) and an additional 11 who were new to us. Demographically, most were middle-aged women (18/23) with less than high school education. All were passionate about bringing a higher level of health care to their community. Each focus group meeting lasted 90 minutes and was conducted at Nuestra Casa from 6 –8 pm with refreshments provided. Each was co-facilitated by two bilingual/ bicultural staff affiliated with Nuestra Casa and/or SADRC who followed a script of questions to be asked (with suggested branching points) as well as allowing time for open-ended comments. Each session was tape recorded, and full transcriptions and translations done of the content. Although we did not use statistical methods to analyze themes, we had two raters listen to and/or read the content provided, and list the main themes. There was complete agreement that the two major themes were: lack of trust (in researchers in general and in Stanford in particular) and need for family engagement (not just focusing BD efforts on the person with dementia or the primary caregiver). Several representative direct quotes illustrate these themes.

Theme 1: Lack of Trust: “Stanford should create more awareness with people to create more trust and security to break the fear. A lot of that holds us back is the fear of being left to die. Something happens to me they are not going to care for me as good or in the best way. Since I agreed to donate my brain then they are going to let me die to obtain that donation. A lot of people believe this so you should work on creating more awareness in regards to the process to make our community feel more secure.”

Theme 2: Family Engagement: “This is only a suggestion but I believe that it is not only having someone choose and be sure about brain donation but providing some sort of formal orientation to the family and those that are responsible for when mother passes. This orientation can help the family be on the same page and know that I am sure and secure about my decision. The day I die my family will know what to do and why this is important. They all need to hear it.”

Information from Online Surveys—A total of 75 persons began the survey; 52 completed it. Of these, 42 identified as Latino community members and 10 as health professionals.

Health Professionals—Four were male, five were female and one declined to answer. 70% (7/10) reported they have never discussed BD with a patient, 20% (2/10) reported that if a patient brought up the subject they discussed it and 10% (1/10) reported that they discuss BD as part of organ donation. Most (60%) reported that they have no access to materials to support discussion on BD. Of the four who said they did have materials, only one said they were in Spanish. All ten respondents noted they feel comfortable discussing the importance of BD for AD research; however, the comfort level decreased when asked about such topics as: process of brain donation (4/10), removal of the brain (2/10), what is done with the brain once removed (4/10), what one needs to do ahead of time to make sure the brain is donated after a person dies (4/10), and how to talk to family members about wanting to donate your

brain (5/10). All respondents noted the need for more information to be available to support their discussions. None of the ten have ever attended a presentation on this topic. When asked if they believe that the Latino culture has beliefs or values about BD four said they were unsure; three said they believed that Latinos were opposed to donating their brain; three said that the Latino culture does not have specific beliefs or values about BD. Medical providers ranked the top barrier to brain donation as “no one asks Latinos” followed by “lack of trust in medical researchers” and “not understanding the importance of Latino participation.”

Latino Community Members—34 are female; 22 are between 40 and 60 years of age, and 20 are between 20 and 40. Fifteen were born outside the US; half the sample reported English as their primary language and the majority (38/42) prefer to receive medical information in English. They were highly educated with 38/42 having 16 years or more of education. A little over half (23/42) believe participation in BD would make a difference. When asked if Latinos had beliefs or values about brain donation, the report was mixed with 14/42 reporting being unsure, 12/42 reporting opposition to brain donation and 11/42 reporting no beliefs that would impact brain donation. A little over half of the respondents report that they personally do not believe the body needs to remain whole (24/42), 13/42 are unsure. However, this changes when asked if they thought their family members hold this belief as 24/42 report that their family do believe that the body should remain whole while 7/42 remain unsure. When asked if they believe medical researchers will be respectful of the decedent’s body only 10/42 reported not being at all concerned, with most reporting some level of concern (very 7/42, somewhat 15/42, little 10/42). Interestingly, 31/42 report generally trusting medical researchers, with only one respondent reporting they do not trust medical researchers at all. Most were Catholic (30/42), and unsure of the religious teachings regarding BD (25/42). The preferred delivery method of information was “watching a video,” followed by “written materials” and finally “attending a presentation.”

Process of Material Creation: Assess Current Procedure

The next step in this process (see Figure 3) was to assess current BD enrollment protocol and materials at the SADRC and decide what revisions and/or additional materials would be needed to inform and motivate Latino participation in our BD program. Currently the protocol was to obtain separate written informed consent for BD during the written informed consent process for enrollment in the Healthy Brain Aging study – the title for the longitudinal research program at the SADRC. The enrollee was told about the BD program during the consent process. If he/she agreed to BD a separate consent form was signed, and a written handout describing steps a family would take following death was given to the participant in English. It was noted that there were no materials available to assist individuals who wished to discuss the BD program with their family before making a decision, nor were there any materials in Spanish when this study began.

Process of Material Creation: Brochure

Based on information gathered from the top BD Programs, our local focus groups, and the online surveys, our multi-cultural, multi-lingual working group decided that a brochure to take home for undecided enrollees would be beneficial to discuss BD with family members.

This brochure needed to contain a description of the program, reasons why it is important, and a frequently-asked-questions area which addressed the common misconceptions and barriers. Information was required to be presented in an easy to read and understand format at an appropriate literacy level: we aimed for 8th grade or below. For those individuals who wanted more details about what would happen step by step, we decided that an additional handout would also be created that would provide that information in an easy to read and understand format. Additionally, all materials would need be created in both Spanish and English.

The third and fourth steps of this process consisted of developing these new materials and then eliciting feedback from local promotoras. Our team met frequently to create drafts of the materials which were reviewed for appropriate literacy comprehension. A near final version was then translated by bi-lingual staff. Next, feedback was requested from local promotoras for easy of conceptual understanding, review of graphics, and approachability of material. Final edits were made based on this feedback. Our final “products” include a colorful bilingual brochure on BD that is written at an appropriate literacy level, answers frequently asked questions, and provides encouragement to consider BD as a “precious gift” that will undoubtedly benefit future generations (Figure 4). Promotoras told us that the final brochure was engaging and welcoming, and should encourage discussion among relevant family members. We also have a more detailed step by step explanation of the BD process in both Spanish and English (Figure 5). We will gladly make these materials available to interested centers and individuals on request.

Due to funding limitations, we were not able to create a short video in Spanish that would feature a discussion about barriers & facilitators but we recommend that be created in the future, as Hispanic/ Latino families reported preferring to receive information concerning BD by video and could then use that information as a springboard for discussion – either with a professional facilitator or within their own families.

Discussion

Our first hypothesis, that the ratio of completed brain donations to number of patient enrolled will be significantly less in Hispanic/Latino patients compared to NHW, was supported by the NACC data: namely that from an initial sample of 4,159, only 160 were from individuals who identified as Hispanic/ Latino. This highlights the need for outreach and education into the Latino community. To address the second hypothesis – that there was a need for culturally appropriate educational materials about BD that we could begin to fulfill by creating new materials – we went through a series of steps to collect information about current materials, and then to obtain new information helpful to creating new materials. Throughout, we kept in mind that both outreach and education require commitment not only from content experts but also recognition of the need from the community itself. This was evident from the information that was shared from the focus groups. Change, in any form, first requires the foundational knowledge that informs the need for the change. For the content experts, the focus groups were time consuming and required the cultural sensitivity and humility that allowed individuals from the community to voice their world views first along with their recognition that change is needed in the number of

Latinos who participate in dementia research including BD. Collecting materials from other ADCs plus our on-line survey results were both somewhat disappointing. First, we found that no specific materials in Spanish existed on this topic and second, although we promoted the survey broadly with our community partners, we did not get the response we had hoped from, particularly from older Latinos and those who were themselves experiencing dementia in their families. Respondents tended to be younger and more highly educated than is typical of Latinos involved in dementia care.

Nevertheless, through team collaboration and engagement of others in the community who work with Latinos with dementia, we believe this process allowed us to successfully create culturally appropriate informational materials that address a sensitive topic for Hispanic/Latino families. Unfortunately, at this point in time we do not know the extent to which these materials will actually be adopted by the community of providers/ people who treat Hispanic/Latino persons with dementia and their family members. To increase knowledge of the existence of these materials, we plan a dissemination campaign that will include presentations directly to the Latino community regarding the need for brain donations, as well as demystifying the BD process. As well, at this point in time we do not know the extent to which these materials will be successful in actually increasing the rate of BD among Hispanic/ Latino families. That remains to be seen and is the subject of the next study that we are planning.

Neuropathology textbooks published over the past half century or so have consistently illustrated the important role studies of brain tissue have played in determining the causes and treatments of numerous neurological disorders. Even more often in recent times, access to neural tissue has been pivotal in furthering knowledge about underlying biological mechanisms of neurodegenerative diseases such as Alzheimer's disease (Gelpi, 2016). While progress has been made, definitive studies of causal mechanisms and treatment programs for AD are not yet available, and in the recent past post-mortem donation of brain tissue is known to be declining (Kretschmar, 2009). In particular, this is the case with racial/ethnic minorities, such as Hispanic/Latino Americans at a time when the prevalence of AD and related dementias in this group is increasing (2015 Alzheimer's Disease Facts & Figures; Haan et. al., 2003). Continued availability of donated brains from this group is essential for research on biological mechanisms underlying neurodegenerative disorders which may differ by race and/or ethnicity. At this point we do not know that for a fact and we will never know unless we increase the rate of successful BD among ethnic and racial minority groups. To do that, we need to educate the public, and relevant families, about the value of BD and what a truly "precious gift" they are giving to help future generations.

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Clinical Implications

- Brain tissue is needed to further knowledge about underlying biological mechanism of neurodegenerative diseases.
- Brain donation is a sensitive topic among Latinos for whom little relevant, culturally sensitive information has been available in the Spanish language.
- Discussions with relevant family members while the person with dementia is alive and can communicate, is likely to greatly facilitate the family's follow-through with brain donation upon the death of their loved one.
- We encourage practitioners who work with Latino families in the context of dementia to consider using our materials. They are available at no cost upon request.

Figure 1.
Percentage of Latino Participants in ADCs Nationally from June 2005 through May of 2016.

Figure 2.

Deceased Hispanic/ Latino Participants with and without Neuropathology Data from June 2005 through May 2016.

Note: Of the deceased Hispanic/Latino, the black section notes number of individuals with neuropathology data available.

Figure 3.
Process of Material Creation

Figure 4.

The Precious Gift brochure

Note: This brochure is available in electronic format in both English and Spanish. Please contact adrcstanford@stanford.edu.

Figure 5.

Brain Donation Step by Step

Note: This brochure is available in electronic format in both English and Spanish. Please contact adrcstanford@stanford.edu.