

UNDERSTANDING BARRIERS TO WHOLE-BODY DONATION TO FORENSIC  
ANTHROPOLOGY FACILITIES: IMPLICATIONS FOR CRIMINAL  
INVESTIGATIONS

by

Katlyn Casagrande, B.S.

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Committee Members:

Lucia Summers, Chair

Scott Bowman

Kate Spradley

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## **ABSTRACT**

Criminal investigations of recovered human remains often must start with identification. If the remains are skeletonized, this is much more difficult, and forensic anthropologists must be called in. Forensic anthropologists rely on donated cadavers to conduct research that will enable better identification of human skeletal remains for law enforcement. Facilities like the Forensic Anthropology Center at Texas State (FACTS) have a disparity of the number of Hispanic remains in their collection, despite a large Hispanic population in Central Texas. Hispanics are murdered at a similar, sometimes higher, rate as whites in the United States, and thus it is important that we can properly identify those remains. Identification is also important for the border patrol in their examination of remains along the U.S.-Mexico border. To understand the underrepresentation at FACTS and other facilities, ten interviews were conducted with Hispanics in Central Texas to understand their knowledge of and willingness to donate to forensic anthropology facilities. The most common barrier that emerged from these interviews was a lack of knowledge about the facilities. Generational differences, cultural beliefs, and religious practices served as barriers as well. With the information gathered here, efforts can be made to increase donations and better serve law enforcement in identification of Hispanic remains.

## I. INTRODUCTION

Criminal investigations of recovered human remains often must start with identification. If the remains are skeletonized, this is much more difficult, and forensic anthropologists must be called in. Forensic anthropologists rely on donated remains, but they have a lack of donations from the Hispanic population. It is important that Hispanics be represented in these donated collections and other forensic research, as they make up roughly eighteen percent of the population and fifteen percent of homicides in the United States (Federal Bureau of Investigation, 2018; U.S. Census, 2018). Despite the large percentage of homicides against Hispanics in the U.S., only about four percent of current collections are Hispanic individuals (Shirley et al., 2011). Local police and larger agencies, such as the Border Patrol, are often tasked with identification of Hispanic remains, and without good scientific research about how to identify those remains, it is much more difficult for them to close those cases and return the remains to loved ones.

To improve methods of identification, investigators, medical schools and forensic researchers rely on individuals and family members of deceased individuals' bequeathing their remains to the scientific community. This is a process known as 'whole-body donation,' in which an individual donates his or her cadaver for scientific use (Larner et al., 2015). Currently, members of our society have many options for disposal and disposition of their remains after death. Whole-body donations are used to improve autopsy procedures, forensic tests, and identification methods for criminal investigations. Donated bodies are also used to train doctors, nurses, and surgeons, as well as to advance scientific research and anatomical knowledge for the betterment of society. While whole-body donation continues to grow in popularity, it remains relatively unknown as an



option (Bolt et al., 2010). Additionally, those who know of its existence may not be fully educated on the process to donate, further limiting the number of people who participate. Despite its lack of recognition, whole-body donation is an essential part of medical, scientific, forensic, and criminal investigation processes in the United States and abroad (Bolt et al., 2011). The inherent importance of donations notwithstanding, there remains a relative shortage of donated cadavers for scientific purposes (Larner et al., 2015).

Often less well known than traditional donations to medical schools, forensic anthropology research facilities conduct research on all aspects of postmortem investigations for forensic purposes (Christensen, 2006; Martinez, 2013). Colloquially known as ‘body farms,’ these facilities enable research on time-since-death estimation parameters, body recovery practices, technology, human variation, biochemical knowledge relating to death, and more, which all help to improve forensic methods for homicide investigations (Christensen, 2006). Some of the facilities are also used to train FBI and law enforcement investigators, as well as cadaver dogs (Bass and Jefferson, 2003). Investigators have been increasing the use of forensic anthropologists for body recovery, crime scene information, and estimating time since death (Wescott, 2018). Law enforcement has recognized a need for forensic anthropology research and has increased usage of these individuals and their knowledge, which increases the need for donated remains to forensic facilities.

The first forensic anthropology research facility (ARF) was opened by Dr. William M. Bass at the University of Tennessee, Knoxville (UTK), in 1987 (Bass and Jefferson, 2003). The idea was in response to a case in which remains were dated incorrectly due to the lack of information and research regarding time-since-death

intervals (Bass and Jefferson, 2003). The case involved remains of a Confederate soldier being discovered and thought to be a recent forensic case. Dr. Bass estimated the remains to be approximately one year old, but it was later discovered they dated to the early 1860s. This 113-year error sparked a scientific quest to fill this gap in forensic knowledge (Bass and Jefferson, 2003). Today, there are seven facilities in the United States, and two outside of the United States (Wescott, 2018). The research conducted at these facilities has helped to ensure better estimation of time-since-death for more accurate forensic investigations (Shirley et al., 2011). Time-since-death is one of the first questions that must be answered in a criminal death investigation, so these facilities are invaluable to the police and forensic science in general. A second important area of research is identification. The ARF and its sister facilities conduct osteological studies on the skeletonized remains resulting from decomposition studies, to further understand human variation and improve medicolegal identification (Christensen, 2006; Martinez, 2013).

Essential to this important and influential research is the continuous supply of donated cadavers (Shirley et al., 2011), and of further importance is an increased diversity among donated remains. Skeletons vary based on biological sex, ancestry, environment, and lived experiences (Christensen et al., 2013). To fully understand these differences and use them to better identify remains for law enforcement, forensic anthropologists need access to skeletal remains from varied backgrounds.

When identifying a set of skeletal remains, forensic anthropologists often start with sex, age, height, and ancestry (Burrows et al., 2003; Flasetti, 1995; McFadden and Bracht, 2009). The reason ancestry is one of the first characteristics identified is not just because it can narrow down a pool of potential missing people, but because it can help

with methods of identifying age and sex. Differences in skeletal size, shape, and sexual dimorphism vary by human groups, i.e. racial or ancestral groups (Falsetti, 1995). Sexual dimorphism refers to differences in size and/or appearance between the sexes. Sexual dimorphism allows forensic anthropologists to distinguish between male and female skeletons, but this is easier if ancestry is known (Falsetti, 1995). For example, human hand bones can be used to determine the sex of a human skeleton but research has found that ancestry must first be known about the skeleton in order to use the hand to estimate sex (McFadden and Bracht, 2009). Male metacarpals tend to be larger than female metacarpals, but a white woman's metacarpal may be similar in size to a Hispanic or Asian man's metacarpal, and thus if ancestry is not known, a metacarpal could be misidentified (Falsetti, 1995; McFadden and Bracht, 2009). Therefore, it is important to have a comparative collection of skeletal remains. If we can improve methods of ancestry estimation, by looking at skeletons of different ancestries, we can better use existing methods of sex estimation.

Current osteological collections housed at forensic anthropology research facilities are made up of mostly old white men. As of 2011, the University of Tennessee's donated collection was made up of only seven percent Blacks and four percent Hispanics, from an American population (Shirley et al., 2011). Research has shown that the average whole-body donor is an educated, married, white male over the age of sixty-five (Anteby et al., 2012). Hispanics living in the United States have been found to be sixty percent less likely to donate organs compared to non-Hispanic Americans, despite the growing need for organ and whole-body donations among this group (Rios et al., 2015). The literature shows that first- and second-generation migrants do not receive the same level

of health care as native-born individuals, and this is likely to affect their decisions to donate organs or cadavers of themselves or loved ones (Anteby et al., 2012). Still, little research has been conducted to address this disparity. If it was understood what is affecting underrepresented groups in whole-body donation, we could better address their concerns and work to increase donations among these groups.

Hispanics are one of the most underrepresented groups in anthropological skeletal collections but are becoming increasingly important for forensic identification and criminal investigation purposes. Texas and Arizona have experienced a striking increase in migrants crossing the border from Mexico, resulting in medical examiners and law enforcement agencies becoming overwhelmed with migrant remains (Giordano and Spradley, 2017). Many of these remains are still unidentified, and better methods are needed to identify more individuals and return them to their families (Weisensee and Spradley, 2018).

Criminal investigations also rely on identification procedures developed by forensic anthropologists. As the population of Hispanics in the United States increases, so does the need for identification methods for this population (Weisensee and Spradley, 2018). Without a comprehensive comparative collection, it is impossible to improve methods for identification of Hispanic individuals. To address this issue, the current research aims to understand the disparity in donation rates by exploring Hispanic individuals' views about whole-body donation. Additionally, the Catholic religion is common among Hispanics and has very specific teachings regarding body disposal (Catholic Church, 1994), including encouraging cremation and return of donated remains to the family. Therefore, Hispanic individuals identifying as Catholic will be included in

this research and are likely to make up a sizeable proportion of the sample. Once more is understood about why this group is not donating, better campaigns, educational programs, and/or practices can be implemented to increase donations.

The goal of this research is to explore what factors impact a Hispanic individual's decision to donate or not donate their body to a forensic anthropology research facility.

To achieve this goal, the research will attempt to answer the following questions:

- 1) What do participants know about whole-body donation and, if relevant, the Catholic Church's teaching on it?
- 2) Have participants considered whole-body donation to forensic anthropology research facilities, and are they willing or unwilling to donate?
- 3) Why are participants willing or unwilling to donate?
- 4) Have participants discussed whole-body donation with family members?

## II. BACKGROUND

According to the Uniform Crime Report (UCR), in 2018, fifteen percent of the homicides reported to the FBI were against Hispanic individuals (Federal Bureau of Investigation, 2018), and Hispanics were estimated to amount to eighteen percent of the population was Hispanic (U.S. Census, 2018). In comparison, the percentage of Hispanics among donated collections is below ten percent (e.g., Shirley et al., 2011), making this subpopulation underrepresented in forensic research. There is a need to increase donations to forensic anthropological facilities from Hispanics to improve criminal investigation for Hispanic victims of homicide. Additionally, Boarder Patrol investigators need improved forensic methods for Hispanic remains, as they oversee identification of remains along the Mexico-U.S. Border. As the population of Hispanics continues to rise in U.S., and especially in Texas, there will be a similar increase in homicides against Hispanics and investigations of Hispanics remains. Without a similar increase in donations and forensic research relating to Hispanic remains, investigators and forensic scientists will not be able to keep up. It is thus important to research the barriers that Hispanics face to donating their remains, in order to better serve this community, and increase donations from this population.

It is important to understand what motivates potential whole-body donors to improve recruitment, because campaigns are far more effective if they understand the target group (Bolt et al., 2011). Research has shown there are numerous elements that influence the decision to donate, including personal, psychological, educational, economic, and cultural factors (Alexander et al., 2013). One study found three major themes emerging from open-ended questions relating to the decision to participate in

whole-body donation, namely a desire to be useful postmortem, unfavorable attitudes surrounding funerals, and a belief that their donation was an expression of gratitude (Bolt et al., 2010). Funeral costs have risen to almost ten thousand dollars in the last twenty years, and consequently many families experience difficulties paying for burials. Whole-body donation thus provides a cost-effective alternative (Slocum, 2016).

A study of registered donors for the Forensic Anthropology Research Facility at Texas State (FACTS) found they were generally motivated by a desire for their remains to be useful and the belief that funerals were too costly, making donation a better financial option for themselves and their families (Martinez, 2013). Additionally, registered donors of FACTS reported a general interest in forensics or science, often resulting from careers in law enforcement or other related fields (Martinez, 2013). This pattern can also be found among medical school donors; often people who have been directly affected by medical innovations are more likely to want to contribute to the continuation of these efforts by donating their remains (Alexander et al., 2013; Bolt et al., 2010).

Conversely, there are many cultural and social reasons that prevent people from donating to medical schools and forensic programs. There is a consensus among researchers that ethnicity, education level, and religious affiliation have strong impacts on one's decision to donate (Alexander, 2013; Bolt et al., 2010; Boulware et al., 2004; Cornwall et al., 2012). Perceived religious constraints, cultural myths and traditions, fear of being disfigured after death, a distrust in the healthcare system, and family members' disapproval have all been shown to affect one's decision to donate (Wong, 2010).

Religion is an important factor in decision making for many individuals in our society, so it is important to understand how it affects whole-body donations.

Some researchers have suggested that it is not religious beliefs that cause concern regarding donation, but rather cultural myths or superstitions passed down from generation to generation (Wong, 2010). Other researchers disagree. Results of regression analyses showed that respondents belonging to an organized religion were less likely to donate their bodies than those who classified themselves as atheist or agnostic (Alexander et al., 2013). In a study of the demographics of donated cadavers, it was discovered that donors were twenty-one percent less likely to be church-oriented than the general population (Bolt et al., 2010). A survey conducted in 2004 found that participants who reported religious affiliation, or that religion/spirituality played an important role in their lives, were sixty to seventy percent less likely to show a willingness to donate than the rest of the sample (Boulware et al., 2004).

People also report a fear of ‘experimentation’ as a barrier to donation, as well as a desire to be buried whole (Christensen, 2006), which is often related to religious beliefs. Furthermore, Cornwall et al. (2012) found a general lack of religious affiliation among donor cohorts included in their study, further suggesting that religious groups may perceive body donation as conflicting with their beliefs. This conclusion is not surprising given that religion often dictates attitudes toward death and dying for many people (Alexander et al., 2013). However, it has also been found that the effect of religion on body donation could potentially be mitigated with better public education and a greater understanding of the true conditions and practices of body donation programs (Cornwall et al., 2012).



The Catholic Church specifically teaches that remains must be buried postmortem in faith and hope of the Resurrection (Catholic Church, 1990). They allow donation to medical schools and research, so long as the research being conducted is not in conflict with the teachings of the Church, and that the remains are buried after the research is concluded. Roman Catholics are taught to treat the body with respect through life and in death, with the belief that all will be resurrected in the future (Slocum, 2016). This is a potential problem for donation to forensic research facilities and programs, as remains are generally not returned to the families for burial after research has been completed. However, families are welcome to visit the skeletonized remains, which may help mitigate this problem.

The Catholic Church is strongly in favor of organ donation and has publicly supported it as an act of Christian love (Messina, 2015). Donation of one's body or organs and tissue have been endorsed as morally acceptable by the Catholic Church, as long as there is informed consent and it does not deprive the donor of life (Messina, 2015). However, many people refer to the position of their religion as the reason for deciding not to donate their organs or bodies (Randhawa and Neuberger, 2016). One study found that despite no major religions ban donations, one quarter of their respondents stated their aversion to donation was religious in nature (Kobus et al., 2016). Recent research looking into how religious factors affect donation attitudes found that, while ninety-three percent of their respondents identified themselves as religious, sixty-seven percent of them did not know the stance of their religion, and four percent believed their religion was against donation (Rios et al., 2015). While top leaders of these religions have come out in favor of organ donation, these findings suggest that more conversations

about the Church's teachings on topics such as these should be addressed in weekly services occasionally. If followers do not know their Churches' stance, it can significantly impact their decision to donate. Overall, both religious and cultural issues can influence potential donors, though the role each issue plays may differ by individual.

While religion plays a considerable role in one's decision to donate, it is also important to note that simply lacking information can be a significant barrier to donation. In a survey conducted by Larner et al. (2015), fifty-eight percent of participants responded that they did not have ample information to enable them to make an informed decision to become a whole-body donor, and seventy-seven percent of participants responded that they did not know how to register/donate. Respondents in prior studies have stated they were interested in donation but lacked the necessary information to do so (Wong, 2010). This research suggests that an increase in the dissemination of information would have resounding effects on the number of registered donors.

In addition to knowing that the option exists and how to go about donating, there is also the issue of misunderstandings regarding what happens when an individual donates their remains, especially at facilities like ARF and FACTS. This is seen even more amongst marginalized groups, as they often fear they will not be treated as aggressively for serious illness if it is known they are a potential donor (Christensen, 2006). Study participants have previously reported concerns about disrespectful behavior in relation to their remains (Alexander et al., 2013), indicating that misconceptions about what happens to donated cadavers discourages people from donating.

It was recently reported that education, annual income, and ethnicity are all associated with donation rates (Boulware et al., 2014). Historically, cadavers for

dissection were procured through grave robbing (Alexander et al., 2013; Slocum, 2016). Most often, it was the graves of African Americans that were looted for remains. Since the legalization of whole-body donation in 1930, it has been mainly wealthy Caucasians who donate their remains to science, with African Americans and Hispanics being underrepresented in donation programs. Historical mistreatment and cultural values may be preventing these ethnic groups from agreeing to the donation of their own and their family's remains to medical schools and other scientific research.

Minority groups often suffer from issues of identity and belonging, stemming from experiences that make them feel like outsiders (Morgan et al., 2008). These experiences can increase worries about the donation process and may explain the relatively low rate of donations among minority groups. Members of these groups often report support of donation as a 'gift of life,' however, find it difficult to reconcile this ideal with the trust and sacrifice required for donation (Morgan et al., 2008). Many of the concerns expressed by minority groups have been shown to be false, however the misconceptions persist. As Dr. Bass, the founder of ARF, has said, increasing public awareness would potentially increase understanding and put to rest the notion that body donation and decomposition research is repulsive and macabre (Christensen, 2006). Better education on all aspects of human body donation is likely to increase donations and improve perceptions of the public.

Postmortem arrangements are ultimately made by family members; however, research has failed to explore the impact of the family members' decision regarding donation of a loved one's remains (Guadagnoli et al., 1999). Relatives of deceased donors continue to be a critical link in maintaining donation rates (Sque et al., 2006), so it is

important to include the family in education materials and campaigns. Registering to donate one's body or organs does not guarantee that the family will be aware of or honor one's wishes (Guadagnoli et al., 1999). It is thus important to understand the factors associated with willingness to discuss postmortem wishes with their family. In a recent study, respondents reported not being willing to donate their body if their family was against it. Another respondent had registered to donate despite knowing that their parents would not support the decision, and as such they were hesitant to share their decision (Wong, 2010).

Sex and ethnicity have both been shown to be related to willingness to discuss one's wishes with family. Males, whites, and Hispanics were all found to be more likely to be willing to talk to their family about the decision to donate (Guadagnoli et al., 1999). Age and religion have also been shown to impact readiness to speak with relatives about donation. One study found that the younger the respondent, the more likely they were to have spoken to their families about their desire to donate organs (Kobus et al., 2016). It was also found that a higher percentage of Baptists had talked to their family compared to other religions, with Catholics being the least likely to have discussed donation with relatives (Kobus et al., 2016). Exploring the reasons for this disparity could further any attempts to increase donations, by encouraging open discussions with families and friends.

### III. THEORETICAL FRAMEWORK

When talking about what motivates someone to donate their body, it is important to consider psychological theories surrounding motivation. A debate has long existed as to whether humans are egoistic or altruistic in nature. Altruism is defined as the state in which the overall goal of any action is to increase or improve another person's welfare; in contrast, egoism is the state in which the overall goal is to increase one's own welfare (Batson and Shaw, 1991). The distinction between these two motives is a qualitative one, which is why any study of motivation, such as the one described here, would benefit from a qualitative approach. Egoistic motives for whole-body donation can be seen in responses relating to a negative attitude towards the funeral industry, while altruistic motives can be seen in responses about usefulness and gratitude (Bolt et al., 2010). According to Batson and Shaw (1991), people can be both altruistically and egoistically motivated for the same action, but the motives themselves are separate. This is important because subjects of previous research have noted multiple reasons for donating, stemming from both altruism and egoism.

According to the empathy-altruism hypothesis, strong attachments to a source of need increase empathy, thus increasing motivation to reduce need (Batson and Shaw, 1991). As seen in Martinez's (2013) research, individuals who worked in law enforcement or other fields related to forensics and science were motivated to donate because of their interest in furthering the field. Alexander et al. (2013) reported that people who had taken anatomy courses or had seen a loved one be cared for by a medical professional were more likely to consider whole-body donation important and to want to participate. These are all altruistic responses. Donors who are exposed to the need

through work or family are more likely to feel an attachment to that need, and thus want to reduce or fulfill the need, not for themselves, but for everyone who could potentially benefit. Donor motivation can often be seen as stemming from both personal reward and a desire to help (Bolt et al., 2011); the better we understand these motives and how individuals arrive at those motives, the better we can address the lack of donations and increase motivation to donate.

Another theory that may apply to the discussion of whole-body donation is gift exchange theory. According to Sque et al. (2006), gift exchange theory is rooted in ideas of ritual and obligation and may offer some insights into the reciprocity and kinship found to be important in donation. The theory argues that gifts are never free, and as such any giving can be predicted. Giving is thus seen as a contract with three major concepts: the obligation to give, the obligation to receive, and the obligation to repay (Sque et al., 2006). According to gift exchange theory, the act of giving has within it an expectation for reciprocity. Through giving, individuals share a part of themselves. Looking at organ and whole-body donation through the lens of gift exchange theory, there is a potential for psychological effects on living organ donors, or families of donors, due to the inability to repay the gift (Sque et al., 2006). This theory may explain why many families refuse donation, as they cannot see the immediate effect of their gift, and they are unable to receive anything in return, while those who have previously benefited from medical research may see the act as returning a favor.

#### **IV. THE PRESENT RESEARCH**

Most research about whole-body donation has focused on factors that make people more likely to donate, interviewing and surveying those who have agreed to donate (Bolt et al., 2011; Martinez, 2013; Lerner et al., 2015) or looking at demographics of donated cadavers (Boulware et al., 2004; Cornwall et al., 2012; Shirley et al., 2011). These studies provide important insights into motivation but fail to address barriers to donation. Further, very little research has focused on the ever-growing Hispanic population in the United States (Salim et al., 2013). The present research serves to fill this gap by attempting to understand the concerns of the Hispanic community in Central Texas regarding whole-body donation. Hispanics remain underrepresented in donated collections, which limits research into developing better methods of identification to aid in such matters as criminal investigations. Cultural beliefs and practices, religious views, and education are all expected to have an impact on this decision (Alexander, 2013; Bolt et al., 2010; Boulware et al., 2004; Cornwall et al., 2012), but through semi-structured interviews with Hispanic community members, we can attempt to understand how and why these factors play such a significant role.

The U.S. Census defines Hispanic as “a person of Cuban, Mexican, Puerto Rican, South or Central American, or other Spanish culture or origin regardless of race” (U.S. Census, 2011). The Office of Management and Budget (OMB) report for the U.S. Census further clarifies that “Hispanic origin can be viewed as the heritage, nationality group, lineage, or country of birth of the person or the person’s parents or ancestors before their arrival in the United States” (U.S. Census, 2011). That definition will be used for the research presented here.

## **V. METHODS**

The research presented here is a qualitative study of the barriers to whole body donation among members of the Hispanic population in Central Texas. This study was completed through semi-structured interviews as this provided the best method of gathering the information needed while generating rapport to illicit more truthful and complete answers. Since very little research has been done on motivations for donating to forensic anthropology facilities, and no research has been done on what is preventing more Hispanics and/or Catholics from donating, a qualitative approach is best to answer this question, as it is a very exploratory question. Close-ended surveys would not be applicable because comprehensive answer choices cannot be developed from the current knowledge. Focus groups were not used for the current research, as many people consider death and end-of-life decisions to be sensitive and may not wish to discuss them in a group setting. Instead, one-on-one interviews were conducted to make the participants more comfortable with discussing death.

### **Sample and Recruitment**

For the research presented here, ten interviews were conducted lasting an average of thirty minutes with members of the Hispanic community in Central Texas. Interviews lasted a minimum of twenty minutes and a maximum of forty-five minutes. Interviews took place in local coffee shops in San Marcos and New Braunfels, a public park in Seguin, and on Texas State University's campus, as well as in one individual's home in New Braunfels. All locations were chosen based on where both the interviewee and interviewer felt most comfortable. Seven of the participants were female and three were male, ranging in age from eighteen to sixty-four (see Table I). All participants had at least some college credit, with most having a bachelor's or master's degree. All participants



were employed for wages, four participants were students, one was retired, and two were self-employed. All participants identified themselves as either ‘single, never married,’ or ‘married or domestic partnership.’ The majority of the sample, seven individuals, did not have any children; those that did have children had between two and three children. Seven of the respondents were raised Catholic, and three of those were still actively participating in the church.

**Table I.** Sample characteristics.

		N
Age	18-24	2
	25-34	5
	35-44	2
	45-54	0
	55-64	1
Education	Some college	3
	Bachelor’s	4
	Master’s	3
Marital status	Single, never married	5
	Married / in partnership	5
Employment	Employed	10
	Self-employed	2
	Student	4
	Retired	1
Children	No children	7
	1 child	0
	2 children	1
	3 children	2
Religion	Catholic	7
	Other	3

Passive recruitment through flyers (see Appendix A and Appendix B) and snowball sampling were used to recruit participants. In order to use passive recruitment, community centers, churches, and public buildings had to agree to display the flyer. The researcher went to the San Marcos public library and the Price Center in person to get permission to hang flyers. For the rest, the researcher reached out to several organizations, only some of which responded. The researcher emailed several churches the following email:

My name is Katlyn Casagrande and I am a graduate student at Texas State University.

As part of my master's thesis, I am conducting research on whole-body donation to forensic research facilities. I am specifically looking to understand why Hispanics donate at a considerably lower rate than all other ancestral groups. The study will involve interviewing local Hispanic individuals and asking them about their views on this topic. I have copied in Dr. Lucia Summers, who is the professor supervising the research.

To identify potential study participants, I am reaching out to community centers and Catholic churches in and around San Marcos, hence my email to you.

If you are willing, I would like to post flyers or post an announcement in your bulletin asking for participants for one-hour interviews with myself to discuss their views on donation. I am also interested in interviewing a small number of religious leaders about their own views and the church's teachings on the issue. The interviews would take place in local libraries or coffee shops.

Please let me know if you are able to assist and if you have any questions.

Attached is the flyer I would post/distribute and my IRB approval. I can be reached at this email or by calling 512-348-7355. I am also willing to sit down with you in person to answer any questions you have. Thank you so much!

These emails were sent to the following San Antonio Catholic Churches: Our Lady of Guadalupe, Our Lady of Perpetual Help, St. Timothy, and Our Lady of the Angels. The email was also sent to St. John's Catholic Church in San Marcos, The Price Center in San Marcos, the Teatro de Artes De Juan Community Center in Seguin, and the Centro Esperanza in San Marcos. The only places to respond were St. John's, the Teatro de Artes, and the Centro Esperanza, however St. John's did not agree to post flyers.

The centers and churches were chosen because they were majority Hispanic-serving, or a central location for all community members in the local area. Churches were determined to be Hispanic-serving based on number of Spanish masses offered, including in comparison to how many English masses were offered. For example, if only one Spanish mass was offered a week, with four or five English masses a week, this was determined to not be a Hispanic-serving church. If a church had an equal number of Spanish masses, or a majority Spanish masses, then this was determined to be Hispanic-serving in nature. Those churches were then contacted regarding posting of the recruitment flyer. Community centers and churches seemed most responsive to showing up in person, rather than through email, although that strategy only worked for a handful of locations.

In the end, flyers were posted at the San Marcos public library, the Price Center in San Marcos, and the Teatro De Artes De Juan Community Center in Seguin. Flyers were also handed out by the researcher at a community event at the Centro de Esperanza in San Marcos. The event was called Senior Commodity Box day, in which elder members of the community came to get boxes of donated food provided by the San Antonio food bank. The researcher approached everyone that came to get a box, introduced herself, and provided them with a flyer. The flyer included an email and phone number to contact the researcher (see Appendix B). Despite a few positive interactions and some interest having been shown, no contact was ever received as a result of this drive.

The researcher also asked participants and other community members known to her to suggest participants and spread information about the study others in the community. Seven of the participants were the result of this snowball sampling. Several of the participants suggested others to be interviewed, but only three of these individuals ended up agreeing.

Despite extensive recruiting, many people were not willing to participate. It is possible that the flyers (Appendix B) were not clear enough about the goal of the research, or that community members were not willing to participate because there was no compensation, because they felt they did not have enough information about donation to discuss it, or because they were not willing to donate nor discuss the issue. It may also have been beneficial to have the posters in English and Spanish for those individuals who spoke English but were not able to read it well. Despite the difficulty finding participants, the ten interviews conducted reached saturation, and thus were considered satisfactory for this project.

## Procedure

Interviewees who were responding to flyers or had been provided contact information by other participants reached out to the researcher either by email or text advising they were interested in being interviewed. The researcher then responded with any requested information and asked when and where they would like to meet, offering days and times that might work, and possible meeting locations. For example, one participant chose to meet on campus between classes, another chose to meet at a local park during their child's cheerleading practice, and another agreed to a local coffee shop that was convenient for them.

For some participants, the researcher obtained their contact information from other participants and the researcher texted them first, explaining who she was and what she was doing. Those that responded back were prompted to pick a time and place to meet. This was most often at a local coffee shop. Coffee shops were chosen despite the noise because there are many of them, so it was easy to find one close by to a participant. In addition, coffee shops are public locations, which provided a safe atmosphere for both participant and researcher. When meeting in a public place, the researcher tried to find the most private areas to ensure the participant's privacy.

Once the chosen time came around, interviews began by the researcher introducing herself further and explaining the purpose of the research. The researcher also reiterated that participation was voluntary, that all questions were optional, and that the participants could refuse any questions and end the interview at any time. The consent packet was shared at that time (see Appendix D), with participants signing consent form after having read it carefully. The consent form was collected by the researcher but the

participant received a copy of the form they had any questions after the interview. Due to printing issues, some consent forms had a question about audio recording, and some did not, so all participants were asked on the recorder if they consented to recording. None of the participants objected to audio recording. Once consent to participate and to have the interview recorded was obtained, the interviewer began asking questions using the protocol found in Appendix C as a guide.

Interviews were audio recorded with a portable recorder that was password protected. The researcher's phone was not used for recording to ensure security. The researcher refrained from using any names while being recorded. The researcher then transcribed all the interviews by hand in Microsoft Word and saved the audio files on a secure drive that was erased when all recordings were transcribed fully. Once all the interviews were transcribed, the interviews were uploaded into NVivo, and the word files stored on a password encrypted drive. Since no identifying information is included in the transcriptions, the files can be saved until results are disseminated. Signed consent forms are stored in a separate, locked file cabinet, in a locked office on Texas State University's campus. No digital files contain real names, only pseudonyms.

### **Interview Protocol**

Interviews began with an introductory script, and then went into a section of questions about general knowledge of whole-body donation and forensic anthropology facilities (see Appendix C). Some information about the facilities was shared with participants and more questions were asked about what the goal of the facilities were and how the donation process worked. The next section of questions related to whether the participant had ever considered donation, and whether they would consider it based on

the information the researcher provided. Next came questions related to family, and whether the participant had ever discussed theirs or their family members' end-of-life wishes, including, but not limited to, whole-body donation. The final section asked about religion. Any participant who was raised in, practicing, or familiar with the Catholic Church was asked what they knew about the church's teachings, and whether this played any role in their end-of-life wishes.

Since these were semi-structured interviews, questions were not always asked in order, and sometimes other, related questions were asked. Interviews were participant-led. If a participant started talking about family in the beginning of the interview, then that section was prioritized, and the rest of the questions were returned to later. If the participant wanted to talk about how to give more information to the community, follow-up questions were asked about that.

### **Analytical Strategy**

Interviews were transcribed and coded in NVivo based on emergent and existing themes. Existing themes from the research questions were used, and any new information that came up was included in a new, emergent theme. The codes were then analyzed for how often something was discussed and how what was said informed the research questions. Eight codes were developed, with several sub-codes. Codes for existing themes included 'Education,' 'Culture,' 'Familiarity with Donation,' 'Religion,' and 'Willingness to Donate.' 'Familiarity' was broken down into 'Organ Donation,' 'Whole-Body/Medical School Donation,' and 'Forensic Facilities,' which was further broken down into 'Texas State Facility' and 'No Specific Facility Known.' 'Religion' was broken down into 'Catholicism' and 'Other Religions.' Finally, 'Willingness to Donate'

was broken down into 'Prior to Interview' and 'After Interview.' Codes that were based on emergent themes included 'Generational Differences' and 'Negative Media Portrayal.'

### **Quality Issues**

The researcher's epistemological position is one grounded in interpretivism, which is the view that the researcher and the environment are related and will impact each other and the results of the study. Since, from an interpretivist perspective, it is impossible to keep bias out of research, the researcher used reflexivity to ensure any subjectivity was made explicit. Reflexivity is the process by which the researcher acknowledges any presumptions and preconceptions, as well as any personal history that may bias their perceptions, and the theories related to the research interest (Malterud, 2001). Rather than assuming the research can be conducted completely objectively, the researcher tried to be completely transparent about any potential bias, thus accounting for the effects of the researcher on the research.

The researcher entered the project with certain biases. Having done extensive research, the researcher expected to find certain things. The researcher also had a bias of being in support of donation to forensic research facilities and having extensive knowledge on the importance and inner workings of these facilities. Finally, the researcher had biases based on being raised Catholic and having since left the church. Since religion, and specifically the Catholic Church, was discussed in this research, there was the potential for this bias to affect how participants felt discussing religion with the researcher. To avoid this, the researcher did not share her religious background with the participants and tried to keep any personal commentary out of the discussions and questions. The researcher is also planning to donate her remains, and this support could



provide further bias in participants willingness to donate, however this support was not made known to the participants to try to avoid this bias influencing their answers.

Many participants viewed the researcher as an expert on forensic research facilities and a potential expert on the church, given her background research. Participants often asked the researcher questions about these topics during the interview. The researcher did her best to answer the questions without any opinions, just providing facts, however it is possible that her bias still entered the equation. It is impossible for the researcher to have completely kept her bias out of the research, so it is important that they are listed here so that their potential effects on the results can be evaluated by the reader.

### **Ethical Issues**

To maintain confidentiality, all identifying information was kept out of recordings and transcriptions, and all consent forms were kept separate from the data. This was accomplished by avoiding names and identifying information while the audio recorder was on, using pseudonyms, and removing any identifying information from transcriptions. All possible effort was made to ensure that participants could not be identified by responses included in the presentations of the findings. To prevent any harm and maintain confidentiality, the researcher was sensitive about who, where, and when interviews were conducted.

Death can be a sensitive topic, so it was anticipated participants may feel uncomfortable answering questions about their end-of-life decisions and beliefs. To prevent any harm to participants, the topic was made clear from the outset, and participants were reassured that they were free to refuse any questions or end the interview at any time. Participants were advised that should the need arise, information

about where to receive counseling would be provided upon request. Approval was obtained from the Institutional Review Board at Texas State University before any interviews took place, and subjects were provided with resources to ask questions about the research and their rights as a participant. Finally, participants were made fully aware of their role and the goal of the research and asked to sign an informed consent form before interviews begin (see Appendix D).

Permission for this research was provided by the Texas State University Institutional Review Board (Application #6648). The research was classified as exempt under review category level two: surveys, interviews, or public observation. IRB approval was received on April 8<sup>th</sup>, 2019. Interviews began in September 2019 and were completed in February 2020.

## VI. RESULTS

Participants in this research overall were uninformed on the process and idea of whole-body donation and thus were not able to consider it as an option for their remains after death. Participants also expressed certain cultural and religious beliefs and practices that affected their decision to donate. A possible generational difference also emerged from the data as a potential reason for the lack of donations. Younger, more educated participants were more likely to be willing to donate their remains than older generations of their family or older participants in the research. All these barriers are important and are discussed in detail below. All names used in the results are pseudonyms, and quotations are presented as stated in the interviews.

### **Familiarity and Willingness to Donate**

The most common theme that emerged during interviews was ‘Familiarity.’ One of the biggest factors affecting the participants’ decision to donate their remains was whether they had heard of body donation, and how much information they had on it. There are several different forms of body donation, several of which were brought up by participants, so the familiarity code was further broken down into ‘Forensic Facilities,’ and specifically ‘Texas State,’ as well as ‘Medical Schools,’ and ‘Organ Donation.’ All participants in this study were familiar with organ donation, and several were registered donors.

The most common reason that participants gave for not considering whole-body donation was not being familiar with it. Gabriel stated that he was not against donation; he attributed not having considered donation more to a lack of information, as well as not having considered his own death. This was another common reason for not considering

donating: simply not having thought about what they wanted with their remains. Catalina also expressed this idea that she had simply “not given it much thought.” The final reason participants gave for not considering whole-body donation was not being interested. This was expressed by two of the participants.

Several donors were only familiar with organ donation and, when asked about whole-body donation, they responded in relation to organ donation instead. For example, Liliana, when asked what she knows about whole-body donation, said,

um, though Gray’s Anatomy actually, I learned a lot, because there was this one episode where an individual was brain dead, but he had all, like, functioning parts of his body, so they were asking the families, like do you want to donate his skin, eyes, his fingers, or like whatever and that’s how I kind of like, punched through to become an organ donor myself, because I was like, there are families who may benefit from my body, what do I get with my body, like decomposing in the ground, when someone could get a beautiful life because of my eyeballs.

This quote illustrates how participants tended to think of organ donation and whole-body donation as the same thing but were more positive and familiar with organ donation specifically.

Another participant, Diego, responded to the same question regarding what they know about whole-body donation with, “I don’t, other than for my driver’s license they asked if I wanted to be a donor but I don’t think that’s quite the same thing.” In this interview as well, the respondent was only familiar with organ donation, and not educated on whole-body donation.

Interestingly, some participants had heard of donation to forensic research facilities, and specifically the one at Texas State University, but had not heard of donating to medical schools and other forms of body donation to science. However, participants who were familiar with medical school and science donations generally had not heard of forensic facilities. One respondent stated that, prior to the interview, when

thinking about whole-body donation, she would always just think of medical schools, rather than forensic facilities, because she was just not familiar with those facilities.

Isabella, a Ph.D. student at Texas State, stated “the only thing I know about whole-body donation is that we have such a thing here at Texas State. Other than that . . . I don’t know what they do.” She was only familiar with the forensic facility, with little to no familiarity with medical school and other scientific donations.

Many respondents who were familiar with forensic anthropology research facilities were specifically familiar with the facility at Texas State University, like the participant mentioned above. This is likely due to their proximity to the facility. It is very possible that, had this same project been done in an area that does not have a facility close by, the researcher would have seen less familiarity with forensic facilities. Gabriel specifically stated that,

probably one of the first things I ever heard about was, actually, ’cause I’m from so close to here that I heard about Texas State’s archaeology department and how they like, Texas State, don’t they have a body farm or something like that?

Participants that were familiar with the facility had not heard about it through any official sources, but rather had heard about the facility from friends, co-workers, informal conversations with teachers, or classmates; however, having attended college emerged as a possible factor for having heard of the facility.

Many of the individuals who stated they were familiar with the facilities stated they had learned about them while obtaining a college education. Ana had the following to say,

there’s not a lot of education around it. Like, I know about it because of school, and my mom, she has a GED and she never went to college and so she came from like living in a very low-income lifestyle and I did too, so I grew up in a place that was predominantly Hispanics and black people and none of us knew about [donating].

Savannah heard about donating due to a cadaver lab during their undergraduate degree. “I know once I heard about having a cadaver class I was like, ‘what? People do that?’ and that’s whenever I started talking about it with my best friend.” These two participants, like many others, were only familiar with the concept, not because they went to college, but because the classes they took were related and discussed donation.

Many participants stated they were familiar with forensic research facilities, but when asked about what the facilities did, they were often unable to explain. One such respondent, Liliana, stated she had heard of ‘body farms’ but when asked what the facilities do with the remains, her response was simply, “not much, I just kinda heard it in, like, ’cause I became obsessed with like medical stuff, so I would just hear about like body farms, but I never really knew about the whole thing they do.”

Some respondents seemed to be taking the word forensics and using that to guess what the facilities do. Elena, when asked if she had heard about forensic anthropology facilities before the interview, responded,

about forensics, yes, but I didn’t, I mean, I know they study, how, you know, the bodies decompose and all that, but I always just, really, kind of related to like crime, not just where ok, now let’s see how this one goes. I didn’t see it like that, I would always just have that relation between a crime and then forensics.

Elena was expressing that she was familiar with the concept of forensics, but not forensic facilities relating to whole-body donation. She explained that she had not thought about how these facilities work, but based on the use of the word forensics, she could come to some kind of conclusion about what they did. This was a common theme among participants in the study.

Almost all participants, whether familiar with the facilities or not, were unaware of how to go about donating their bodies, to science, medical schools, or forensic

facilities. When asked how they thought one could donate, most respondents guessed they could let the facility know about it ahead of time, put it in their will, or leave it to a power of attorney. Whether the person was willing to donate or not, they tended to be unaware of how to actually donate. This is another area in which more education would be useful.

Whether or not the individual has heard about donating is important, but so was where they got the information from. Many of the participants heard about donating through television shows and news articles. The potential problem with these sources is that television shows may not always be accurate about the process, or clear enough about how important donation is, and how few people donate. Diego even stated several times that he had heard about the facilities through “CSI-type shows” but he was not willing to donate unless it was “for something other than solving crimes.” Despite many attempts from the researcher to expand on this idea, the participant did not explain further.

A few participants also mentioned learning about donation through news articles on the topic. The problem with this was that these articles tended to be negative. The articles focused on illegal operations or less ethical practices. The articles focused on the rare, but problematic, instances of unethical uses of donated remains. Elena stated she was only familiar with body donation through an article she saw on Facebook a year or two ago. The article was negative in nature, talking about an instance of donated remains being used for explosive testing, without the donor’s prior knowledge. “Yeah, basically it was just saying, it was like, um, shaming the, I guess the science, like body testing and all that. That’s all it was. Before that, I had never heard about it. Never.”

Another respondent, Maya, expressed concern over some facilities not treating the bodies with respect, and that she would need to carefully choose a place to donate, otherwise she would not be willing to donate.

I don't like a lot of the stuff that I've been reading lately about a lot of the facilities that have issues, like specific people black-marketing organs and using the bodies in weird like cult things, was it Nevada or California that had that issue recently, defacing bodies instead of using them for their intended purposes, kind of makes me angry and makes me hesitant to donate to any facility, 'cause they're not also like well-regulated for the most part, so it would be cool if something like that could change, I still want my body to be used, but I don't want it to be like given away for use and then abused, basically. So, I guess that's a reservation that I would have about something like that. And then the, what happens with the remains after they've been used kind of thing. I don't think it's a reservation, but it's more of like a curiosity so I could plan for that sort of thing.

Based on these responses, it can be hypothesized that improving the image and amount of information going out about forensic anthropology research facilities is extremely important for increasing donations, however future research would be needed to confirm this. Results of this research also suggests that information needs to be given to younger groups, and those that are not receiving a college education, whether just having graduate high school, or being well into their careers, otherwise large portions of the population will be missed.

When asked about willingness to donate before participating in the study, eight of the participants had considered or were open to organ donation, and five were open or willing to donate their whole-body, while the other five had not considered it. The respondents that were interested in donation or had previously considered it offered very similar answers as to why they wanted to donate. The most common reason given was the desire to advance science. Eight of the participants who had considered donation



expressed this reason for donating. Another reason offered was that they had no other use for the remains and that cemeteries “are a waste of space.”

Participants were offered some information on donations during the interview and then asked how this discussion changed their willingness to donate. This was then coded as ‘willingness to donate now.’ The majority of participants that were not previously willing to donate said after learning more about it would be open to donating to forensic facilities, or other forms of organ donation. Only one participant, Diego, was still opposed to the idea, saying he simply was not interested. A few reasons that participants gave for being willing to donate was that it was beneficial, they felt it was “just a body”, and that they were encouraged by learning that they can still donate after being autopsied, donating organs, and/or having a funeral. This is important to know as it can inform future educational campaigns with what to focus on and include to encourage more donations.

### **Culture**

In addition to familiarity, a common theme that emerged from the interviews was cultural beliefs and how they affect one’s decision to donate their remains. Different cultural beliefs emerged as potential barriers that all merit discussion. These major themes were a need to be buried, the body as sacred, superstitions, and Día de Los Muertos (Day of the Dead).

The most common of these themes was a need to be buried, especially as it relates heavily to the view that the body is sacred, and it must be treated with respect. For many participants who had experienced deaths in the family or had discussed end-of-life wishes with their family, their family members often expressed an interest in being buried whole,

rather than cremated. A few participants even mentioned family plots and wanting the family to be buried together. For Gabriel, whose father had recently passed, he explained he had considered several different options, including organ donation, and in the end, Gabriel and his family decided to honor their father's biggest wish; to be buried on the family's privately owned land. Gabriel and his family went through the process to set up a family plot on the family's land, and that is where his father now rests. His father had always expressed a desire to be returned to the land and, despite having considered organ donation himself, had always felt strongly about being buried whole, and being buried in the family land.

Other respondents stated members of their family were also concerned with being buried whole and together as a family. Liliana explained,

My grandma, she says she wants to be buried in a casket and everything, alongside with her husband. She wants everyone to get, like, a burial spot next to her, so that's kind of a thing right now, my mom has told her, like, no we're not doing that, I want to be cremated, mom, but in El Salvador, my grandparents, they have the, their families right next to their home, they have their family plot right there.

These stories convey a strong cultural belief in not only being buried whole but in being buried together.

“Hispanics are just very traditional about the way that they, like, go about the burial process, I guess. It's kind of like, you wouldn't want, I don't know, it's like the sense that a person can't rest properly without being buried,” said Ana. Those participants who expressed familial reservation to cremation or donation referred to concept of rest only coming for those who are buried. This is further exemplified in another quote from Ana: “That's why even like, as a kid, I was like ‘I don't know if I

could donate my organs', 'cause you do have to be like, complete as a person to like rest essentially.”

Ana expressed that she has since decided to become an organ donor, and has strongly considered whole-body donation, but she had to contend with familial beliefs that were against these actions she valued as important. She mentioned she is still struggling with whole-body donation and has not told her family, because she knows her familial beliefs are strongly against any kind of disruption of a person's ability to rest for eternity. As she says, “you have to go out the way you came in.”

Isabella also discussed the concepts of needing to be buried whole, and how it affected her grandfather's decisions during life.

I think in our culture they say, you die whole, I mean, my grandfather was 84 when he died and they wanted to cut his toe off because he had gangrene from diabetes, and he would not let them because he needed to die a whole man, not part of a man.

Isabella stated the belief was more cultural than religious, and that this would affect his burial decisions as well.

Related to this idea of being buried whole is the view of the body as a sacred vessel that must be treated with respect. This is another traditional belief that appears to hold many individuals back from considering donation. Maya advised,

Mexican culture has a lot of reverence for deceased ancestors and stuff, there's a lot of South American cultures that will actually remove the bodies from the ground after a certain amount of time, and clean them and redress them, and I think that might have, depending on whatever... have an impact on if they want something done with their bodies because their bodies are considered like, sacred, like they're still alive like they're still using that post-death.

This example exemplifies the reverence that many Hispanic cultures have for their deceased and their remains, which affects their decision to donate the remains to science.

Ana also mentioned Hispanic superstitions that affect what is done with remains after a person dies. The belief discussed was that, if a person is cremated, they cannot rest in the afterlife, and they will haunt the house that their cremains are retained in.

So I guess the best way to put it, we had a, we cremated our dog, and like my little sister was convinced something was scratching her at night, and my mom was like it's because the dog's cremains are in the house, and so we had to get rid of them, and we had to bury them outside in order for like, that to stop happening. And so, if you, it's essentially like trapping someone and they can't like, find peace, and they basically just haunt your home, and it's not good to keep them here, in that sense. And so, even like, with our dog, we had to bury the remains because we had cremated her, and we couldn't keep her in the house.

This belief, according to the participant, relates back to a person not being able to be put to rest if they have not been buried properly. This has the potential to affect donation to a facility like FACTS, where a person's remains are not buried, they are left to the elements, and then the skeleton is stored for research and education. In a traditional household, such as the one above, the family may view this as disrespectful and believe that the person is not able to properly rest.

The final cultural theme that emerged was Día de Muertos, also known in American culture as Day of the Dead. Not all of the respondents celebrated Día de Muertos with their families, but a few did mention it, and Ana was able to serve as a key informant and explain some of the details of how the celebration works. Her words really exemplify how this practice affects whole-body, and organ, donation.

So once a year you get to bring this person back and you get to remember them so it's very important to like, have somewhere to go to celebrate that . . . you would celebrate it at the cemetery but you would also have like a shrine sort of set up at your house and so the idea is that, you have the shrine set up at your house and you take things that this person liked in life and you, and like I said, the like villages in Mexico are a lot smaller so you would have marigold flowers and that's kind of what that's representative of, kind of like lighting the way for you to get back to your home, so that's how they like, find you. So you would like trail these flowers from the cemetery to your house and that's where all this person's favorite things would be set up and that's kind of how you keep them alive for

that day. . . you know you celebrate in the cemetery but then you like make your home open to your family members, and I guess that's why you want to go out like you want to be buried the way you were born 'cause you're coming back to see your family in that way, so you don't want to come back as something, like as an incomplete person.

The researcher followed this up with a question about how having the skeletal remains in a box in a forensic lab at a research facility would affect Day of the Dead. Ana responded that it would affect the individual's ability to come back for Día de Muertos,

and I can't really explain why, 'cause it's the same thing like, as you would be in the cemetery but I guess it's just like because your family doesn't have any way to like connect with you anymore. And I guess that would be the biggest thing holding you back from doing it.

Ana's insight suggests that those who practice Día de Muertos are unlikely to donate their remains. However, this is only a cultural practice, religious beliefs and practices are also important to consider.

### **Religion**

Nine out of ten of the participants in this study had a significant mention of religion and how it affected their own or their family's decisions about how to treat their remains. Only three of the participants were current, practicing Catholics, but seven of them had been raised in or around the Catholic church. Very few of the participants claimed to know anything about what the church teaches about whole-body donation and/or organ donation, and those who felt they did know were not up to date with current teachings, using the Catechism as a basis for current teachings. Many participants referenced the pre-Vatican II teaching that cremation and organ donation was wrong. Only a few of the respondents knew that the church changed its stance in 1965 to allow cremation, organ donation, and body donation, albeit within the confines of church-approved research and with the body being returned to the family at the end of the

research. It was expected at the beginning of this research that this policy would affect the decision to donate to a facility where the remains are not returned, but none of the participants were familiar with this teaching. Rather, the teaching against cremation was more likely to affect the decision to donate, because if they were unwilling to be cremated, they were unwilling to be donated.

Many participants stated they believed the church was against cremation and donation, but that they were raised to believe, or personally believed, that this was a less important teaching to follow. Consequently, they felt this church teaching would not affect their decision. The participants that stated the church teaching would not affect their decision, often also believed that there were few others who felt this way and other Hispanics would need to follow all church teachings. However, most of the participants reported they did not let the church affect their end-of-life decisions, so the prevalence of it is higher than the participants believed it was.

For example, Isabella had this to say stated that the Catholic church teaches against several things, but that “our mom was very opinionated and said that no one tells us what to do with our own bodies” and that, in this sense, she came from a different background. Liliana felt a similar way, stating that her parents always taught her to praise God and pray, but keep a balance and do not hurt people, and that way you will be ok. She said that by keeping these boundaries, she’s been able to “keep my Catholic faith, but also keep my individualism and not just depend on my life decisions on what the church says.” Elena also agreed that while she believed in the church, her religion would not affect her decision to donate. Overall, religion was clearly important in how donation was viewed, yet it was not considered overall to be a huge barrier to actually donating.

## Family

All ten participants had significant portions of their interview coded under ‘Family,’ because all of the participants were asked about how their family affected their views on donation and their decision to donate or not. They were also asked about their family’s view on donation, and if any family members had shown interest in donation. Respondents were asked about this because an individual’s family plays a major role in their development and decisions.

One of the major themes that were discussed in this research was whether or not participants had talked about end-of-life wishes with their families, as this affects how the family changes or does not change those wishes. Six of the participants had discussed end-of-life wishes with their family in some form, though two of those had only discussed their parents’ wishes and not their own. Four participants had not discussed any kind of end-of-life wishes with any of their family members, and were often unsure how the family would react to some of their wishes, but imagined the response would not be positive.

In some cases, the discussion that did take place was not positive either. Liliana mentioned that when she told her mother she was an organ donor, her mother was very upset and unsupportive.

I had told my mom that I was an organ donor, and she was like, ‘you need to take that off right now, like I don’t know why you have that, your body is your body, you need to take care of it’.

Liliana went on to say that she has continued this discussion with her mother and as she has gotten older, her opinion and wishes have been accepted more by her mom and she has been able to educate her mother on the importance of donation.

Two of the participants mentioned that they have discussed their mother's end-of-life wishes with her, but their fathers were not open to the discussion. Additionally, two of the male participants, Diego and Javier, who had children and would be close in age to the fathers of the other two participants, were very unresponsive and not open to discussion of end-of-life wishes. This was an interesting theme that emerged, that had not shown up in the previous literature. There appears to be a trend among fifty to sixty-year-old, Hispanic males/fathers and their willingness to confront or discuss their own mortality. It is unclear without further studies if this is common amongst all fifty to sixty-year-old males, or just those who have children.

Another theme that emerged was individuals being against cremation and having a strong desire for a funeral, which affects how individuals make decisions regarding their loved ones. A great example of this comes from a story that Isabella shared. A member of Isabella's community passed away and she had the opportunity to speak with the individual's mother about what would be done with the remains. This is what Isabella had to say about the experience:

I'll give you an example, so we had someone die recently, and she's very young, in my opinion, she's fifty-six years old, and she told her mom, it was very interesting after I had met you, but like a day later she dies, tells her mother who is in her seventies that she wanted to be donated over here [FACTS], but the mother couldn't do it. She had only verbalized it to her mother, that that's what she wanted, and the mother, her mother, who buried her, couldn't do it. And I sat there, and I didn't ask why, but she said, she has to go to church, she has to be buried, and that's why I'm not doing it. Even though she said, that's what she wanted, she goes, I don't understand what that's about. And they called it the body farm, so that could have been a reason, that they, I mean if you say body farm, I mean, I think that's, you know, not a good connotation to what your research is, so I think that making sure you get out the right words. But like I said, she's fifty-seven years old and wanted to be donated over here and was not due to the mother.



This is an interesting example of how the older generations' thoughts about cremation, donation, and funerals led to a mother not following her daughter's wishes because it was against what she believed.

The participants in this research were asked how their family's feelings on donation affected their decisions on what to ultimately do with their remains. While many participants said that their family's opinions would not affect their decisions, or that their family was pretty much in agreement, two participants did indicate that it depended on which family member was expressing the opinions. For Elena, her mother would not change her mind about donating, but her husband would, and in fact, had. Elena stated that she had registered as an organ donor on her driver's license, but then her husband expressed displeasure with that, and as a result, she took it off but told him that he was allowed to give the doctors permission to donate her organs if he felt that nothing else could be done to save her. She insinuated this would be the same for whole-body donation; if her husband was against it, she would not do it. Ana advised that her parents would not change her mind about donating, but her grandmother would. Ana said, "I'm very independent but I'm still very, even though I'm twenty-five, I'm still very like swayed by her opinion on a lot of things." It was interesting that, for both participants, their parents' opinion on their end-of-life decision did not carry much weight, but there was another person in their family who did have the power to change their wishes, or at least their actions.

### **Generational Differences**

Within the families, a generational difference emerged. The older participants in the sample were less likely to be willing to donate or discuss donation, while younger

respondents were very open to donation. Participants even noted a generational shift that has occurred in the last several years, where younger generations are more open to donation and cremation, as well as other body modifications such as tattoos and piercings. For example, Ana said that,

I think it's just going to be the way that like other opinions about things are changing, like body alterations, like tattoos, something as simple as that because like, my grandparents are, they think I'm like disrespecting myself, and I guess in a sense, that's what they believe about like donating your organs too, so like you don't want to do that because you can't rest after you're dead.

It is possible that this generational shift is due to the move into the United States, as families try to assimilate, and become ruled by different laws regarding the handling of dead bodies. Future research should ask participants about whether they are first, second, or third, etc. generation Americans, and consider how this effects respondents' responses. As Maya mentioned, some cultures believe in removing bodies from the ground and redressing them. This would not be legal in the United States. As the family stops practicing certain traditions like this, and the younger kids are more exposed to the cultural beliefs of the United States, they may become more open to whole-body donation, such as many of the participants in this study appeared to have done.

When asked about the change in traditional beliefs and the generation shift, Liliana stated that she felt the assimilation of her family to American culture affected how they viewed donation. Isabella advised that it would be easier to convince younger generations to accept whole-body donation because "older communities are set in their ways; kids are still malleable, and they listen." Ana agreed that there was likely a generational shift, stating,

I think there's a lot of shift that's happening right now, culturally, obviously with the change in generations, so like my grandparents, I don't think they would

consider it at all, even if they had more education about it, because they're like, they're much older and it's a lot harder to break like traditional beliefs about things, and so even with, like, any type of research or knowledge about it, I don't think they would do it.

This generational shift is very interesting and should be explored further in future research, as it could advise future methods of educating people about donation and explain changes in the acceptance of donation in general.

## VII. DISCUSSION AND CONCLUSION

Many of the themes seen in the background research emerged in the research presented here as well. Participants reported a desire to be useful postmortem and an interest in forensics. However, in the background research, the interest in forensics stemmed from careers in law enforcement and science, however the interest of the participants here stemmed from television shows like CSI and Grey's Anatomy. Cultural myths and traditions, a distrust in healthcare systems, and desire to be buried whole was also expressed by both current participants and those of previous research. There was also an emphasis placed on the approval of family members. Finally, the background research discussed perceived religious constraints, and the participants being unaware of their church's stance on donation. This theme emerged in interviews conducted here as well. Most participants were not familiar with the Catholic Church's teaching on donation, but believed the church was against it, and some used that as a reason for not wanting to donate. The only themes that did not re-emerge in this research was the unfavorable attitudes towards funerals and the idea of donation as an expression of gratitude.

The themes that emerged in the present research suggest that greater education for Hispanic communities would increase donations among younger generations in the United States. Educational campaigns that are based on the results of interviews with members of the community could increase favorable opinions of donation and increase knowledge about donation amongst the community. Cultural and religious beliefs may not be able to be averted, but those who do not donate solely because of a lack of information can be mitigated by increasing the educational materials available to this community and population of potential donors.

The research presented here set out to answer four research questions. The first question related to what participants know about whole-body donation, and, if relevant, the Catholic Church's teaching on it. Participants were, overall, very unfamiliar with donation. All of the participants were aware of organ donation, but very few had prior knowledge of forensic anthropology research facilities. Even when participants had heard of the facility, they were unlikely to know much about the facility, or how to donate to it. Despite the fact that eight of the participants were raised Catholic, and three of those considered themselves active Catholics, none of the participants were overly familiar with the church's teaching on organ and whole-body donation, or the current teachings on cremation versus burial, which can affect an individual's decision to donate.

The second research question asked whether participants had considered whole-body donation to forensic anthropology facilities, and whether they were willing to donate. Overall, very few participants had considered donating to a forensic facility prior to the interview. Only two of the participants had ever seriously considered it, and few more indicated it had crossed their mind, but they had not given it a great deal of thought. Once they had given it more thought, about eight of the participants were willing to donate, with more information. Participants expressed a generally positive response to the idea of donating, but still required more information before they could make a decision.

The third research question was why participants were willing or unwilling to donate. This turned out to relate back to the first question, that participants really did not have enough information to make this decision. Further, there were some cultural and religious factors that affected respondents and their family's decisions to donate, such as

a belief in being buried whole, teachings against cremation, and celebrations such as funerals and Día de Muertos.

The fourth and final research question was whether participants had discussed whole-body donation with family members. The answer was yes for some and no for others. Six of the participants had discussed their own or their family's end-of-life wishes, including whether to donate their remains. Those who had discussed it with their family were generally those who were interested in, or willing, to donate.

Overall, the results of this study suggest that the main barrier to whole-body donation to forensic anthropology facilities among Hispanic individuals was a lack of familiarity. It can then be hypothesized that if more information were to go out to this community, of all ages and educational backgrounds, there would be an increase in donations. Whether they are interested or not, most respondents showed an interest in learning more, to at least have the information available, so they could make an informed choice. It is thus likely to be important that people from all walks of life can get the information about donation needed to choose what is best for themselves and their family.

### **Limitations**

A limitation of the current research is that all interviews were conducted in English, despite sampling from a heavily Spanish-speaking community. This is a potential issue for transferability as the opinions of the whole Hispanic Catholic community are not being sampled, rather a subset of English-speaking Hispanic Catholics. The researcher does not speak Spanish, limiting interviews to English. Conducting the interviews with a translator was not deemed suitable due to potential risks

for translation issues, and an impact on confidentiality and rapport building. While it is unknown exactly how a non-English speaking sample might differ from an English-speaking sample, the differences are expected to be minor. Having said that, English-speaking participants might be more integrated into American culture and society and thus be more open to donating for research or have more prior knowledge of the process. Another limitation is the area the participants were sampled from. San Marcos and the surrounding cities are a relatively small region in Texas. There may have been beliefs that are specific to those living in Central Texas, or Texas itself. Potential sample differences could be further addressed in future research when more resources and researchers are available.

Despite these limitations, the current research contributed to addressing a knowledge gap in the literature. The hypotheses developed through this qualitative, inductive study may be then subjected to deductive testing to determine whether the patterns identified are transferable to a wider population. At that point, it is hoped the newly acquired knowledge can be used to develop strategies for increasing whole-body donation rates among Hispanics, so that this subpopulation can be better served when it comes to criminal investigations.

**APPENDIX SECTION**

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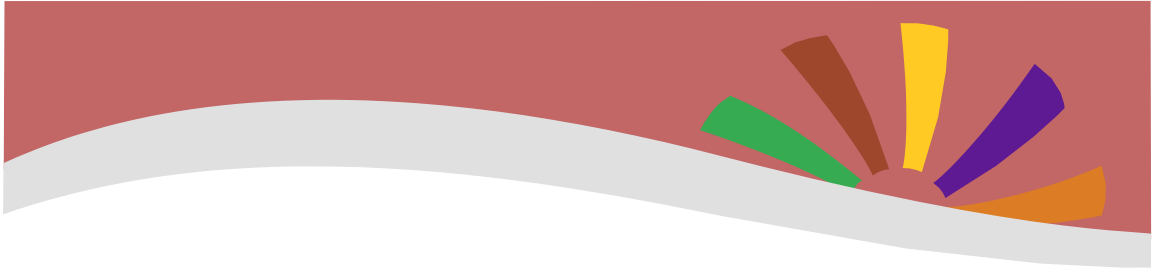
## **Appendix A: Community Centers Used for Recruitment**

The community centers used for passive recruitment in the present study were:

- Centro Esperanza Community Center (San Marcos, TX)
- Price Center (San Marcos, TX)
- Teatro De Artes De Juan Community Center (Sequin, TX)
- San Marcos Public Library (San Marcos, TX)

## **Appendix B: Participant Recruitment Flyer**

The flyer used to recruit participants for this study is shown in the next page.



# Research Participants Needed

Research is being conducted on the reasons for donating or not donating one's body to forensic research facilities.

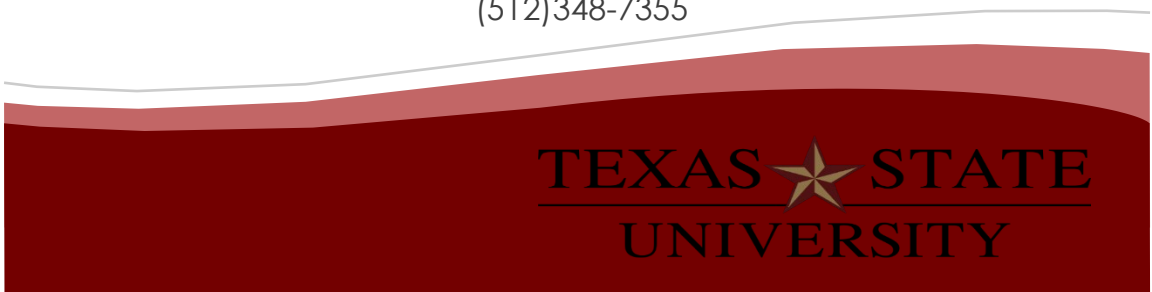
We are looking for Hispanic individuals who can participate in an hour-long interview where they will discuss their thoughts and feelings about body donation.

You will not be paid to take part, but your participation could assist scientists increase donations and, in turn, their ability to identify the remains of deceased individuals.

If you are interested in participating, please contact:

Katlyn Casagrande  
School of Criminal Justice  
kmc243@txstate.edu

(512)348-7355



## **Appendix C: Interview Protocol**

### **Understanding Barriers to Whole-Body Donation among Hispanic (and Catholic) Communities**

#### **INTERVIEW SCRIPT**

Hello, thank you so much for agreeing to see me today.

My name is Katlyn Casagrande and I am a researcher from Texas State University. I am here today to talk to you about your feelings and opinions about whole-body donation to forensic research facilities.

As it says in the consent form, you don't have to take part and you can skip any questions that make you uncomfortable; you can also end the interview at any time, without having to give a reason for that. Everything you say will be used just for research purposes and we will keep your responses and your participation confidential. This means no one will know the things you tell me actually came from you.

We think the interview will last for about an hour, and I will simply be asking about your familiarity with and your thoughts about whole-body donation. I want to make it clear that I am not here to ask or encourage you to donate your body. I am only interested in what affects people's decisions to donate or not to donate. If you're interested, at the end of the study, we could send you a summary of the results.

So, if you're ready, we'll start with the questions. So that I don't have to make lots of notes during our conversation, I'm audio-recording the interviews. Is this okay with you?

#### **QUESTIONS**

Have you heard about whole-body donation?

- a. What do you know about it?
- b. How/when did you learn about it?

Have you ever heard about forensic [Anthropology] research facilities? \*

(\* ) If they have never heard about the facilities, establish what information they do have and then cover the basics with them, so they have the information needed to answer some of the remaining questions.

- a. Are you familiar with the work that they do?
  - i. What do you know about it?
- b. What do you think is the goal of these facilities?
- c. What do you know about the process of donating your body to these facilities?
- d. What do you think they do with donated remains?

Before today or hearing about this study, had you ever considered donating your body to science [in any form]?

- a. Why/Why not?
- b. What type of donation had you considered/would you consider?

Before today or hearing about this study, had you ever considered donating to a forensic research facility?

- a. Why/Why not?

Now that you have some information about these facilities, what is your reaction to the idea of donating?

- a. Would you be willing to donate?
- b. Why/Why not?

Have you ever discussed your end-of-life wishes with your family?

- a. Why/Why not?
- b. If yes, what family members did you discuss it with?

- c. If yes, what did you talk about?
- d. If yes, what was their reaction?
- e. If yes, did the conversation change any of your wishes?
- f. If no, how do you think your family would react if you chose to donate your body? Would this affect your decision?

How would you feel if a family member wanted to donate?

- a. Why would you feel/react this way?

When making end-of-life decisions, what kind of things do you consider?

- a. Can you tell me more about that?

Are there any aspects of donating that particularly interest you?

Are there any aspects of donating that make you not want to donate?

(If Catholic) What does the Catholic Church teach about whole-body donation?

- a. Do you agree with that?
- b. Do you consider the Church's teachings when deciding what to do with your body after death?

Demographic Survey: All answers are confidential, your name will not be associated with them, and they will be used for research purposes only. You are not required to answer any of the questions to continue with the interview.

What is your age?

- 18-24 years old
- 25-34 years old
- 35-44 years old
- 45-54 years old
- 55-64 years old
- 65-74 years old
- 75 years and older

What is the highest degree or level of school you have completed? *If currently enrolled, highest degree received.*

- No schooling completed
- No higher than 8<sup>th</sup> grade
- Some high school, no diploma
- High school graduate, diploma or the equivalent (for example: GED)
- Some college credit, no degree
- Trade/technical/vocational training
- Associate degree
- Bachelor's degree
- Master's degree
- Professional degree
- Doctorate degree

What is your marital status?

- Single, never married
- Married or domestic partnership
- Widowed
- Divorced
- Separated

How many children do you have?

- No children
- 1 child
- 2 children
- 3 children
- 4 children
- 5 children
- 6 or more children

Employment status: Are you currently....

- Employed for wages
- Self-employed
- Out of work and looking for work
- Out of work but not currently looking for work
- A homemaker
- A student
- Military
- Retired
- Unable to work
- Other: \_\_\_\_\_



## Appendix D: Informed Consent



### INFORMED CONSENT

#### **Study Title**

Understanding Barriers to Whole-Body Donation among Hispanic (and Catholic) Communities

#### **Principal Investigator**

Katlyn Casagrande

#### **Co-Investigator/Faculty Advisor**

Dr. Lucia Summers

Email: [kmc243@txstate.edu](mailto:kmc243@txstate.edu)

Email: [lsummers@txstate.edu](mailto:lsummers@txstate.edu)

This consent form will give you the information you will need to understand why this research study is being done and why you are being invited to participate. It will also describe what you will need to do to participate as well as any known risks, inconveniences or discomforts that you may have while participating. We encourage you to ask questions at any time. If you decide to participate, you will be asked to sign this form and it will be a record of your agreement to participate. You will be given a copy of this form to keep.

#### **PURPOSE AND BACKGROUND**

You are invited to participate in a research study to learn more about the reasons why Hispanic individuals may choose to donate or not to donate their bodies to forensic anthropology research facilities. The information gathered will be used to help increase donations. You are being asked to participate because you are of Hispanic ancestry/ethnicity and perhaps also a member of the Catholic faith. To better serve the Hispanic community in forensic identification (e.g., when trying to identify remains found near the U.S.-Mexico border, and hopefully return these to the deceased person's family), more donors of that ethnicity are needed. However, this researcher is not here to ask you to become a donor; instead, the goal is simply to better understand the barriers facing the community when it comes to whole-body donation.

#### **PROCEDURES**

If you agree to participate in this study, you will be asked to participate in one face-to-face interview. This interview will last for approximately one hour. During the interview, you will be asked about your understanding of and opinions about whole-body donation. The interview will be audio-recorded, and the researcher may take notes as well.

## **RISKS/DISCOMFORTS**

Your information and participation will be kept confidential at all times. Consent forms will be kept in a locked file cabinet, and any computer files will be password-protected. Only the two researchers above and the Texas State University Office of Research Compliance (ORC) may access the data (the ORC monitors research studies to protect the rights and welfare of research participants). Your name and any identifying information will be kept out of audio-recordings and interview transcripts, as well as from any written reports or publications that result from this research. Data will be kept for three years (per federal regulations) after the study is completed and then destroyed.

If there are questions in the interview you don't want to answer, it is of course okay not to do so. You can also stop the interview at any time, without having to give a reason.

## **PARTICIPATION IS VOLUNTARY**

You do not have to take part in this study if you do not want to. You may also refuse to answer any questions you do not want to answer. If you volunteer to be in this study, you may drop out at any time without consequences of any kind.

## **BENEFITS/ALTERNATIVES**

There will be no direct benefit to you from participating in this study. However, the information that you provide will help us to understand the motivations and barriers to whole-body donation from Hispanic individuals. This knowledge will be used to improve the information used when trying to find donors. To be able to identify skeletal remains, we need to scientifically study bodies of different ethnicities. Increasing whole-body donations from Hispanic individuals helps us with projects such as OpID, which aims to identify the remains of those who die while crossing the U.S.-Mexico border, so that they can be returned to their families.

## **PAYMENT/COMPENSATION**

You will not be paid for your participation in this study.

## **QUESTIONS**

If you have any questions or concerns about your participation in this study, you may contact the Principal Investigator, Katlyn Casagrande, by email ([kmc243@txstate.edu](mailto:kmc243@txstate.edu)) or phone (512-348- 7355).

This project was approved by the Texas State Institutional Review Board (IRB) on April 8, 2019. Questions or concerns about the research, research participants' rights, and/or research- related injuries to participants should be directed to the IRB Chair, Dr. Denise Gobert (512-716-2652, [dgobert@txstate.edu](mailto:dgobert@txstate.edu)) or to Monica Gonzales, IRB Regulatory Manager (512-245-2334, [meg201@txstate.edu](mailto:meg201@txstate.edu)).

**DOCUMENTATION OF CONSENT**

I have read this form and decided that I will participate in the research project described above. The goals of the research, what I will have to do as a participant, and the possible risks have been explained to my satisfaction. I understand I can drop out at any time.

Your participation in this research project may be recorded using audio recording devices. Recordings will assist with accurately documenting your responses. You have the right to refuse the audio recording. Please select one of the following options:

I consent to audio recording:

Yes \_\_\_\_\_ No \_\_\_\_\_

\_\_\_\_\_ **Printed Name** of Study Participant    **Signature** of Study Participant    \_\_\_\_\_ **Date**

\_\_\_\_\_ **Signature of Person Obtaining Consent**

\_\_\_\_\_ **Date**

**Keep the consent for your records**  
**Return only this last page to the researcher if you would like to participate**



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