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HISPANICS' UNDER-UTILIZATION OF HOSPICE CARE SERVICES

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HISPANICS’ UNDER-UTILIZATION OF HOSPICE CARE SERVICES

A Project
Presented to the
Faculty of
California State University,
San Bernardino

In Partial Fulfillment
of the Requirements for the Degree
Master of Social Work

by
Ian Manuel Montoya
June 2015
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Approved by:

Dr. Rosemary McCaslin, Faculty Supervisor, Social Work
Dr. Rosemary McCaslin, Faculty Supervisor, M.S.W. Research Coordinator
ABSTRACT

The purpose of this project was to learn about Hispanics’ utilization of hospice care and to increase knowledge about under-utilization of hospice services by the Hispanic community. Research in hospice services indicates that the Hispanic community underutilizes end-of-life resources when compared to their majority counterparts, European Americans. Research that has controlled for variables such as socio-demographic characteristics, medical history, prognosis, and access to health care demonstrate Hispanics significantly under-utilizing hospice services. This project was conducted within Southern California in the cities of Riverside and Anaheim which are predominantly Hispanic communities. A quantitative design was used to explore the perspectives of Hispanic individuals and their views on hospice care services. Data was collected through questionnaires. Results indicated correlations between language preferences and gender as possibly having an impact on knowledge and cultural acceptance of hospice care services.
ACKNOWLEDGMENTS

I would like to thank Dr. Rosemary McCaslin for her support, patience, guidance, availability and flexibility. Without her support and enthusiasm this project would not have been feasible.
DEDICATION

This project is dedicated to my Hispanic brothers and sisters who are vulnerable, oppressed, and poverty stricken. I hope that this project ignites a passion and spark for providing social services to an ever growing population who desperately need it. All people deserve the opportunity to succeed and thrive in life no matter the color of their skin or their socioeconomic background. Change begins with discussion and I hope that this project initiates such discussion, not only for Hispanics but for all people who encounter social injustices and inequities.

I would like to thank my friends and family members for supporting me in my time of need and vulnerability. I could have not gotten this far without your support and understanding. I would also like to thank my cohort class of 2015. We went on one heck of a roller coaster ride together for the past three years. Your passion, hard work ethic, and dedication to social issues has inspired me and are reason why I was able to complete my journey in the MSW program. Thank you.
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Chapter One explains the research focus and design. The chapter discusses the quantitative method used for this study. The literature review conducted will hopefully lead to and provide an understanding to which factors impact under-utilization of hospice care by Hispanics. This chapter reviews the social problem, the purpose of the study, and the significance this project has for the field of social work.

Problem Statement

Gaps currently exist in the knowledge base of hospice services among the Hispanic community. As a result, Hispanics often under-utilize hospice services. According to the U.S. Census Bureau, 50.5 million Hispanics currently reside in the United States (2010). Of those 50.5 million Hispanics, “only 4 percent of hospice patients nationwide are from Latino/Hispanic background” (as cited in Carrion, 2010, p. 197). This percentage reflects the under-utilization of hospice services among a burgeoning Hispanic population and is indicative of an overall lack of awareness of the availability of such services. A lack of awareness of the available end-of-life care services can prevent Hispanic caregivers from acquiring services that may be necessary
and beneficial once individuals and families experience caring for their terminally ill members.

The purpose of the social work profession, according to the National Association of Social Workers (NASW), is to improve the well being of vulnerable and oppressed individuals and communities (as cited in Hepworth, Rooney, Strom-Gottfried, & Larsen, 2013). In the realm of social work practice it is imperative to understand that the provision of opportunity in accessing hospice care among Hispanics is limited, making them a vulnerable population. Therefore it is the social worker’s responsibility to educate, assist, and provide the Hispanic population with an understanding of what hospice care is and what services are available to them so to improve their overall well being (Carrion, 2010, p. 209).

Previous literature suggests that there are many barriers as to why Hispanics are at greater risk in under-utilizing hospice services. Some of the underlying barriers are language and cultural barriers, lack of knowledge of the healthcare system, immigration status, and an overall lack of hospice competency and outreach.

Purpose of the Study

The purpose of this study was to increase knowledge about underutilization of hospice services by the Hispanic community. Research in hospice services indicates that the Hispanic community underutilizes end-of-
life resources when compared to their majority counterpart, European Americans. Research that has controlled for variables such as socio-demographic characteristics, medical history, prognosis, and access to health care among Hispanics demonstrate Hispanics significantly underutilizing hospice services and use those services at a lower rate than the majority population (Park, 2012, p. 149). A correlation between hospice use and ethnic background can therefore be implied as a reason why Hispanics underutilize such a crucial, beneficial service.

Hospice care provides essential supportive services for patients at their end of life stage. Despite provision of beneficial services Hispanics do not tap into the resources made available to them at end of life situations. The question then arises whether Hispanics’ cultural beliefs, beliefs about the medical health care system, socio-economic status, historical background, and unique language challenges impact utilization of hospice services.

This study served as an effort to discover what vertical stressors in particular contribute to Hispanics history of lower rates of hospice care services. This research has the potential to identify what unique challenges hinder Hispanics from utilizing end of life care services so to address the said hindrances with hopes to enhance the provision and access of hospice services among the Hispanic population. To discover the unique barriers the Hispanic population encounters, the research explored the Hispanic
populations’ perspectives on what hospice care is and what it can provide to enhance themselves and their family members.

This study collected quantitative data by use of a questionnaire instrument created specifically for Hispanic individuals. For purposes of this study Hispanics are any individuals that are from a Latin American country including Mexico, Central and South America, Cuba, Puerto Rico and the Caribbean. To control for the target population’s participation in this study, this researcher utilized a nonprobability sampling method.

Prior research indicates that Hispanics do underutilize hospice care services. This researcher contemplated surveying Hispanic’s at the end-of-life stage in hospice and within the medical setting, however believed the data captured would not realistically reflect Hispanics unfamiliarity with hospice care services. For this reason it was decided to reach out directly to Hispanic individuals residing in predominantly Hispanic communities to attain a more accurate gauge of how much is known about hospice care services. Snowball sampling was utilized to distribute the questionnaire surveys as this researcher believed the particular sampling method was most appropriate to disseminate the surveys, as reaching out to Hispanics directly could pose difficult due to distrust and lack of rapport.
Significance of the Project for Social Work

This study is significant for social work practice in that the data gathered from this study can provide potential solutions to alleviate the underutilization of hospice services. Hospice care is a great service that can be used in a nursing home, assisted living facility, hospital, or in the patient’s home environment. All people no matter their ethnic and socioeconomic background encounter the burdens and stressors of end of life whether be it for themselves or their family members. This study sought to discover why Hispanics in particular are not utilizing hospice care to its fullest potential. The Hispanic population continues to grow yet hospice is still underused. This underutilization then becomes a social problem as it prevents a certain population from having full access to a service that can assist with coping and access to healthcare when diagnosed with terminal illnesses.

Expectations from this study are to see what the leading contributions are to the low admissions to hospice care services by the Hispanic population. Social workers within the medical setting have the opportunity to assist the Hispanic community with making full use of hospice care services. In order to provide such opportunity and alleviate this social issue of underutilization, social workers must be aware of the unique needs that Hispanics may require. Hospice care is conterminously bounded with the social work mission in that both entities focus on improvement of quality of life for people. Social workers must therefore understand that immigration status,
lack of outreach, lack of understanding of the term hospice, and cultural perceptions are all factors that impede the Hispanic community from utilizing hospice.
CHAPTER TWO
LITERATURE REVIEW

Introduction

This chapter presents a brief review of the professional literature regarding the under-utilization of hospice care among the Hispanic community. The literature review covers three major factors that may hinder Hispanics utilization of hospice services. The first factor is culture and how cultural values impact perceptions of hospice services. The second factor is unfamiliarity of the healthcare system and misconceptions about hospice care. The last factor pertains to Hispanics’ philosophy on death and how it compares to Euro-American’s perceptions of death and dying.

Culture

Cultural barriers can prevent Hispanics from accessing end-of-life care. Both language and cultural differences between hospice care providers and the Hispanic community can contribute to the lower use of hospice care (Haas et al., 2007, p. 399). For many Hispanics, the ability to speak in their native language is crucial and comforting when experiencing care by hospitals, hospice, and nursing homes. The lack of Spanish material along with the availability of Spanish speaking staff is of concern to Hispanics. Research by Born et al., confirmed that Hispanics were likely to state that language barriers
prevented them from having the ability to communicate effectively with people in health care settings (2004, p. 252). People tend to gravitate toward services that elicit comfort, appropriate care, and support during difficult times. Hispanics with cultural and linguistic differences may find that hospice care services lack the tools necessary to provide appropriate end-of-life care, as they may not be culturally sensitive and culturally competent in servicing the Hispanic community.

Hispanic culture is less accepting of hospice care due to personal values and beliefs (Haas et al., 2007, p. 399). Hispanic cultures differ from Euro-American cultures in that they are more family oriented as opposed to being individualistically oriented (as cited in Valle, Yamada & Barrio, 2004, p. 536). The benefits of being family oriented are that there lies informal familial support when medical crises do occur. The downside to such benefits is that the Hispanic community may feel reluctant in seeking formal medical assistance elsewhere due to the perceived cultural resources available from within the family system. The reliance on familial networks due to culture can put stress onto the primary caregiver caring for the terminally ill. Hospice providers, as well as social workers, need to develop culturally sensitive services so that the Hispanic community can understand that outside assistance is available and reliance solely on familial systems is neither sufficient nor feasible at all times.
Hospice Care Misconceptions

Research demonstrated that Hispanic families are reluctant to receive hospice care services due to their misconstrued definitions of hospice. Many Hispanic family members associate Hospice care with death. These misconceptions impact the utilization of hospice care services among the Hispanic community.

To thoroughly grasp a holistic view as to what issues specifically affect Hispanics’ capacities in utilizing hospice, it is crucial to ensure that Hispanics have a clearly defined idea of what hospice is and what it can provide. According to the National Hospice and Palliative Organization (2013), hospice is defined as follows,

Considered to be the model for quality, compassionate care for people facing a life-limiting illness or injury, hospice care involves a team-oriented approach to expert medical care, pain management, and emotional and spiritual support expressly tailored to the patient’s needs and wishes. Support is provided to the patient’s loved ones as well. At the center of hospice and palliative care is the belief that each of us has the right to die pain-free and with dignity, and that our families will receive the necessary support to allow us to do so. (para. 2)

Furthermore, it is not enough to have an understanding of hospice care. Hispanics, because of culture, take great pride in caring for their loved ones. Simply defining what hospice is will not impact utilization of hospice services.
due to the fact that most Hispanics do not agree with putting their family members into nursing homes as it is not appropriate to allow strangers to take care of loved ones (Scharlack et al., 2006).

Death and Dying

Research indicates that Hispanics find issues of death and dying as taboo, which can limit the level of care provided at the end of life (Carrion & Nedjat-Haiem, 2012, p. 184). Within Hispanic families, the discussion of death is not preferred. Hispanics prefer to have conversations that revolve around hope rather than that of death and dying while encountering end-of-life circumstances (Gelfand et al., 2004). Hispanics’ views on death and dying and circumvention of the taboo topic are implications as to why hospice services aren’t utilized to the extent that they should be in relation to the population size.

Theories Guiding Conceptualization

General systems theory studies “reciprocal relationships among individuals, groups, organizations, and communities and mutually interinfluencing factors in the environment, in seeking to holistically change behavior by examining interacting components” (Turner, 2011, p. 242).

General systems theory was applied in this study to understand how Hispanic’s interactions within their familial subsystems influence their
interactions or lack thereof within larger systems such as hospice care service providers. Due to cultural-linguistic barriers, lack of hospice care knowledge, and reliance on familial relations to deal with death and dying circumstances, the homeostasis of the Hispanic family can be overwhelmed and thus thrown off equilibrium.

According to systems theory, all parts of any system are interrelated and interconnected and therefore have influence on various systems and subsystems which can directly affect a population of people (Turner, 2011). From a systems perspective, this study explored the transactions within the Hispanic population that are in place that impede utilization of hospice care services and thus interdependency with a crucial, beneficial service. Keeping systems theory in mind can be useful for social workers in having an understanding about the holistic nature of human functioning, and why the Hispanic population does not interact with the hospice care system to the extent that other populations do.

Summary

Chapter One explained the under-utilization of hospice services among Hispanics, the purpose behind the proposed study, and the significance and contribution this study will have for social work practice. This chapter presented a brief review of the professional literature that demonstrated the factors that contribute to the under-utilization of hospice care by Hispanics.
CHAPTER THREE

METHODS

Introduction

This chapter provides information pertaining to the methodology and procedures for this study. The study design and the nonprobability sampling strategy utilization are discussed in this chapter. Procedures for data collection and instrumentation will be explained. Protection of human subjects, data analysis and Institutional Review Board (IRB) application for this study are included.

Study Design

The purpose for this study was to increase knowledge about the underutilization of hospice services by the Hispanic Community so to increase utilization of hospice care among the population. The design utilized in this study was a quantitative research study design. This quantitative design used by the researcher consisted of a thirty-two question questionnaire aimed at discovering what factors and/or barriers prevent Hispanics from utilizing hospice care. All participants chose to participate in the study and were allowed by their own discretion to participate in answering the questionnaires. The researcher provided informed consent documentation to all participants.
who chose to answer the questionnaire and was provided a debriefing statement upon completion of the questionnaire.

Hispanics were the target population as this study focused solely on the perspectives of Hispanics and their views on hospice care services. The data collected by the questionnaire survey provided a glimpse into why Hispanics underutilize such a beneficial health care service and enabled the researcher to identify potential solutions. The use of a questionnaire was specifically selected as the researcher anticipated the Hispanic community may be reluctant to participate in a study consisting of face-to-face interviews. The questionnaire method provided a non-obtrusive method for participants to answer honestly without fear of being judged, enabling the researcher to obtain objective information that would otherwise be eschewed.

**Sampling**

Nonprobability sampling was used in this study as it is purposive in nature. Purposive sampling is useful for situations where one needs to reach out to a targeted sample quickly and where one is more likely to obtain the opinions of their target population. Hispanic participants for this study were obtained by utilizing the convenience of snowball sampling technique. Snowball sampling is useful for hard-to-reach interconnected populations (Grinnell & Unrau, 2011).
There is a large representation of Hispanics located in the Southern Californian region, however having them participate in this research study proved to be difficult due to distrust and a tendency to not reach out to outside systems in times of need, hence the researcher’s pursuit in understanding the underutilization of hospice care services among Hispanics. To increase the rate of participation snowball sampling was most appropriate for this questionnaire as the researcher was able to identify select individuals within local community entities who self-identified as being Hispanic and assisted with identifying other potential participants.

Two organizations populated predominantly by Hispanics were selected for this study. One organization was a school site located in Riverside, California. Riverside’s population is estimated at having 316,619 people, with 49 percent being identified as Hispanic or Latino (United States Census Bureau, 2010). The other organization selected was a Catholic church in Anaheim, California called St. Boniface. With a population of 345,012 people, 52.8 percent of the population is of Hispanic or Latino descent (United States Bureau, 2010).

Twenty-three questionnaires were completed for the study. For purposes of this study, a sample of twenty-three questionnaires appeared to be of appropriate size as it consisted of Hispanic participants, the targeted population. Though a greater sample size of more Hispanic participants would have been desired, the sample collected sufficed given the time restraints.
available to the researcher. The goal of utilizing this nonprobability sampling method was to provide clarification and some generalization of the underutilization of hospice care services among Hispanics in Southern California. Though generalization is limited due to the targeted, available population selected, the results nonetheless provided a sound glimpse as to why hospice care services are not used to the capacity that Hispanics should use them to and take advantage of.

Data Collection and Instruments

The research study utilized a self-designed 32 question questionnaire that was provided in both the English and Spanish language to accommodate the Hispanic target population’s language preference (see APPENDIX A). To test for reliability and cultural sensitivity of the self-designed instrument the researcher implemented the aid of family members and Hispanic friends and colleagues to overlook the content and adjusted the instrument appropriately based off constructive feedback.

Questions within the questionnaire were pertinent to the underutilization of hospice care services among Hispanics and gauged participants general knowledge about hospice care. The dependent variable in this study was the underutilization of hospice care services. The independent variables analyzed in this study were age, gender, ethnicity, educational status,
employment status, religion, citizenship status, language preference, and culture.

The questionnaire titled, “Hospice Survey Questionnaire”, consisted of two parts. Part one consisted of nine questions pertaining to demographics information. Part one enabled the researcher to distinguish between the following variables: age, gender, level of education, employment status, health insurance, religion/spirituality factors, citizenship status, and language preference. The level of measurement used in Part one was nominal as each variable was categorical in nature.

Part two contained twenty-three closed-ended questions that addressed culture, more specifically cultural knowledge and beliefs about hospice care services and the utilization of hospice care services. Part two of the questionnaire was based on a Likert Scale format ranging from 1 to 5, 1 representing a “strongly disagree” response and 5 representing a “strongly agree” response. The level of measurement used for Part two’s questions was scaled as the Likert Scale displayed a direction of order in level of agreement from “strongly disagree” to “strongly agree” responses. A Likert Scale was selected as the most appropriate method to capture participant’s beliefs, attitudes, values, ideas, and overall knowledge about hospice care.

The data collected from the questionnaires were analyzed and interpreted to seek to determine potential relationships between the dependent variable and the independent variables. The structure of the
questionnaire enabled for the questionnaire to be answered fairly quickly, and took between 15 to 30 minutes to complete. This structure allowed for sufficient and efficient participation and completion of the questionnaire.

Procedures

Knowledge and familiarity of the Southern California region enabled the researcher to identify two leading Hispanic individuals within the communities of Riverside and Anaheim. The identified participant in Riverside was employed as a middle school teacher who was able to identify and refer the questionnaire to Hispanic colleagues. Participants who agreed to voluntarily complete the questionnaires stayed after school to do so. The identified participant in Anaheim worked as a volunteer for the St. Boniface Catholic Church and informed the researcher of the weekly bible courses held every Wednesday in Spanish. The researcher attended one of the bible classes and was able to gather data from participant’s who wanted to participate in the study voluntarily before the start of the class.

The identified participants in each region ensured that participation of the questionnaires would be limited to Hispanics only as the purpose of the study was to determine what, if any, factors correlated to the underutilization of hospice care services among the Hispanic population. As stated earlier, due to distrust of outside systems, the researcher would have had difficulty otherwise in finding individuals to fill out the questionnaires without the aid of
identified participants and their social connections. Online surveys were contemplated, however, to capture a wider age range the method of snowball sampling was utilized as it was assumed that many Hispanic elders may have lacked internet access.

In total, twenty-three participants completed the questionnaire. Each participant had the option to complete the questionnaire in either English or Spanish. All participants were informed of the purpose of the study and those who voluntarily agreed to participate were provided an informed consent (see APPENDIX B) in their preferred language. The questionnaire consisted of thirty-two questions and took approximately 15 to 30 minutes to complete. A debriefing statement was provided upon completion for the participants (see APPENDIX C).

Protection of Human Subjects

The researcher provided each participant with informed consent forms either in English or Spanish dependent upon participant’s preferred language (see Appendix B). There were no known risks at the time for participation with the study. Participants were informed that participation in the questionnaire was voluntary and had the option to complete the questionnaire in its entirety or partially. Participants were made aware that withdrawing from the study would not result in any consequences or penalties.
Upon completion of the questionnaire, participants were provided with a debriefing statement and were informed that information collected from the study may benefit Hispanics in the future who may not be aware of what hospice is and who can potentially benefit from hospice care during end-of-life situations. Completed questionnaires were placed in a legal sized manila envelope by the participant. The data collected from the questionnaires remained locked in a filing cabinet in the researcher’s home office during the course of the study. Upon completion of the study the questionnaires were destroyed.

Data Analysis

It was important that the primary investigator be knowledgeable in analyzing data for a quantitative research study. According to Grinnell and Unrau, researchers utilizing a quantitative research design should be knowledgeable in levels of measurement, computer applications, descriptive statistics and inferential statistics (Grinnell & Unrau, 2011). The researcher/investigator adhered to these topics once the quantitative data was collected.

The quantitative data collected from the research study was coded and analyzed with the SPSS (Statistical Package for the Social Science) Data Analysis. The Spanish data collected was translated into English for purposes of coding and clarification. Frequency distributions were utilized to determine
the number of participatory responses and provide a summary for each categorized variable.

Summary

This Chapter outlined the design of the study, the sample, which instruments were utilized to collect data, the procedures utilized, analysis of the data, and the methods the researcher utilized to protect the subjects who participated in the study.
CHAPTER FOUR
RESULTS

Introduction
The purpose of this study is to determine what factors, if any, contribute to the underutilization of hospice care services among the Hispanic population. This chapter discusses the quantitative results obtained from the completed questionnaire. The demographics of the participants are discussed in this chapter. An analysis of independent samples t-tests between select group differences are also discussed in this chapter. Data analysis findings were generated from SPSS. The results were determined from evaluation of univariate and bivariate data analyses.

Presentation of the Findings
The sample was comprised of twenty-three participants (n = 23) who participated and completed the questionnaire. Of the twenty-three participants who participated, twenty-two (95.7%) identified as being Latino/Hispanic while one participant (4.3%) acknowledged being Native American rather than Hispanic. Participants’ ages ranged from 18 to 50 years and over. Ten men (43.5%) and thirteen women (56.5%) participated in this study.

Education levels varied among the twenty-three participants ranging from having a High School Diploma to having a Post-graduate degree. Seven
participants (30.4%) reported having a High School Diploma. Of the seven participants who attained their High School Diploma three (13%) were female and four (17.4%) were male. Five participants (21.7%) indicated they had “some college” experience. Of those who indicated some college experience three (13%) were female and two (8.7%) were male. Eight participants (34.8%) obtained a Bachelor’s Degree. Five females (21.7%) and three males (13.1%) had completed a Bachelor’s degree. A post-graduate degree was completed by three (13%) of participants, two females (8.7%) and one male (4.4%).

Employment status of each participant was identified in this study. Of the twenty-three participants nineteen (82.6%) were employed. Ten females (43.5%) and nine males (39.1%) indicated being employed. Three participants (13%) stated that they were self-employed. Of those participants who were self-employed two (8.7%) were female and one (4.3%) was male. One female participant (4.4%) reported being unemployed.

Health insurance was included in the demographic characteristics of the participants. Fourteen participants (60.9%), eight women (34.8%) and six men (26.1%), stated that they had private healthcare insurance. Five of the participants (21.7%), three women (13%) and two men (8.7%), reported having public healthcare coverage such as Medi-Cal and Medicare. The remaining four participants (17.4%), two women (8.7%) and two men (8.7%) indicated that they had no healthcare coverage.
Religion and spirituality data were captured and was included in the demographics portion of this study. Participants indicated that they were of the Christian faith and Catholic faith. A total of five participants reported being Christian (21.7%). Of the five Christians, two (8.7%) were women and three (13%) were men. Catholicism was the religion of the remaining eighteen participants (78.3%). Eleven women (47.8%) indicated that they were Catholic while seven men (30.5%) were Catholic.

Citizenship status and preferred language was also collected from the demographic portion of this study. A total of seventeen participants (73.9%) indicated that they were citizens of the United States. Of these seventeen participants eleven (47.8%) preferred English as their primary language while the other six participants (26.1%) preferred Spanish as their language preference. Six participants (26.1%) revealed that they were undocumented. All six undocumented participants (26.1%) indicated Spanish as being their preferred language. Table 1 (below) displays the demographic results of the sample attained by this researcher.
<table>
<thead>
<tr>
<th>Variable</th>
<th>Frequency</th>
<th>Percent</th>
</tr>
</thead>
<tbody>
<tr>
<td>(N = 23)</td>
<td>(n)</td>
<td>(%)</td>
</tr>
<tr>
<td><strong>Age</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>18-29</td>
<td>8</td>
<td>34.8</td>
</tr>
<tr>
<td>30-39</td>
<td>7</td>
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<tr>
<td>40-49</td>
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<tr>
<td>50 and over</td>
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<td>8.7</td>
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<tr>
<td><strong>Gender</strong></td>
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<td></td>
</tr>
<tr>
<td>Male</td>
<td>10</td>
<td>43.5</td>
</tr>
<tr>
<td>Female</td>
<td>13</td>
<td>56.5</td>
</tr>
<tr>
<td><strong>Race</strong></td>
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<tr>
<td>Latino/Hispanic</td>
<td>22</td>
<td>95.7</td>
</tr>
<tr>
<td>Native American</td>
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<td>4.3</td>
</tr>
<tr>
<td><strong>Education Level</strong></td>
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<td></td>
</tr>
<tr>
<td>High School Diploma</td>
<td>7</td>
<td>30.4</td>
</tr>
<tr>
<td>Some College</td>
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<td>21.7</td>
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<tr>
<td>Bachelor’s Degree</td>
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<td>34.8</td>
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<tr>
<td>Postgraduate Degree</td>
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<tr>
<td><strong>Employment Status</strong></td>
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</tr>
<tr>
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</tr>
<tr>
<td>Unemployed</td>
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<td>4.4</td>
</tr>
<tr>
<td>Self-Employed</td>
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<td>13.0</td>
</tr>
<tr>
<td><strong>Health Insurance</strong></td>
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<td></td>
</tr>
<tr>
<td>Private</td>
<td>14</td>
<td>60.9</td>
</tr>
<tr>
<td>Public</td>
<td>5</td>
<td>21.7</td>
</tr>
<tr>
<td>None</td>
<td>4</td>
<td>17.4</td>
</tr>
<tr>
<td><strong>Religion</strong></td>
<td></td>
<td></td>
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<tr>
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<td>5</td>
<td>21.7</td>
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<td>Catholic</td>
<td>18</td>
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<td><strong>Citizenship Status</strong></td>
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<td><strong>Language Preference</strong></td>
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<td>English</td>
<td>11</td>
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</tr>
<tr>
<td>Spanish</td>
<td>12</td>
<td>52.2</td>
</tr>
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</table>
To examine all possible associations among variables from the questionnaire, independent sample t-tests were utilized to determine reliability and significance. The subsequent comparisons among select variables were discovered to be significant. All p-values less than or equal to 0.05 were considered significant in this study as the alpha level of 0.05 was used for all statistical tests.

An independent samples t-test was conducted to compare the question, “You question a healthcare provider of another race that suggests hospice to you or a family member,” to the independent variable gender. Results showed that there was a significant difference in the scores for males (M=3.3, SD=0.95) and females (M=2.4, SD=0.87); t(21)=2.4), p=.025. These results indicate that the participant’s gender has an effect on the outcome of trusting a healthcare provider that suggests hospice is dependent based on that healthcare providers’ race.

A comparison of means in regards to language preferences was also conducted. Independent samples t-tests were run comparing the variable, language preferences, to the scaled responses from participants. The participant’s responses to the statement, “death is a transition”, varied depending on language preference of either English or Spanish. Results showed that there was a significant difference between English speakers (M=4.2, SD=0.75) and Spanish speakers (M=2.75, SD=1.29); t(21)=3.2, p-value=.004. Those who preferred English tended to agree more with the
statement that death was a transition as opposed to those who preferred Spanish.

Having a belief in a spiritual approach to dying was correlated with language preferences. There was a significant difference between those who preferred English and those who preferred Spanish. The results were English (M=3.8, SD=.75) and Spanish preference (M=4.8, SD=.39); t(14.7)= -4.017, p=.001. Those participants who preferred Spanish had a higher mean belief in a spiritual approach to dying.

Furthermore, it was discovered in the study that there was a correlation between regularly seeing a healthcare provider and language. Participants that indicated English as being their preferred language had a higher mean than the Spanish group of participants. Results demonstrated that there was a significant difference in the responses of Spanish preference (M=2.08, SD=1.4) and English preference (M=3.7, SD=.79); t(21)=3.5, p=.002, in regards to which participant's had regularly seen a healthcare provider. The results suggest that English preference results in a higher percentage of participants who see a healthcare provider on a regular basis.

The question about whether Hospice care is covered by insurance was compared with the participant's preferred language as well. English preference (M=3.2, SD=.6) and Spanish preference (M=2.3, SD=.97); t(21)=2.7, p=.012. The p-value suggests that there was a significant difference between the variable language and the knowledge of whether
Hospice care is covered by insurance since the p-value was less than 0.05. Interestingly enough, the Spanish condition of the variable language had an effect on the response to the question on the questionnaire, “Hospice is only available to those who can afford it.” Participant’s preferring Spanish as their primary language reported more often that Hospice was only available to those who could afford it (M=4.0, SD=1.0) compared to the reports of their English counterparts (M=3.2, SD=0.75); t(21)=-2.1, p=.044.

Participants believing that a healthcare provider of their own ethnicity will have their best interest in mind and who preferred Spanish had higher scores of agreement to the questionnaire statement (M=3.8, SD=0.9) than those who preferred English (M=2.2, SD=1.2); t(21)=-3.7, p=.001. English speakers did not care to the extent that Spanish speakers did about the ethnicity of their healthcare provider suggesting that any healthcare provider would have their best interest in mind regardless of ethnicity.

Independent samples t-test were used with the independent variable, religion and compared to all dependent variables from the questionnaire to see if there were any positive or negative correlations. It was assumed that a participant’s religion would affect the outcome of their responses to the questionnaire, however there were no significant differences detected in the data analysis among the t-test samples.
Summary

This chapter discussed the results of the study. Demographics of the participation were taken into consideration when analyzing the quantitative data. Descriptive and inferential statistical data along with correlations was described in this study. An independent samples t-test was used in this section to compare the means of a dependent variable for two independent variable groups. Independent variable groups in this study included Gender-male and females, language preferences-Spanish and English, and Religion.
CHAPTER FIVE

DISCUSSION

Introduction

This chapter provides a discussion on the findings and analysis of the study in regards to the underutilization of hospice care services among Hispanics. A section of the limitations to the study is included. Lastly, recommendations for future social work practice, policy and research will be discussed.

Discussion

The objective of this research study was to identify and address what variables effect Hispanics' underutilization of hospice care. This study has found that further studies are required to discover and compare the correlation of underutilization of hospice care services to the Hispanic population. The statistical data analyzed hinted at correlations between language preferences and gender among Hispanics as possibly having an impact on knowledge and cultural acceptance of hospice care services. Independent samples t-tests suggested that there were significant differences among selected independent variables. Hispanic identifiers such as language preference, English or Spanish, did display a significant difference between their understanding of what hospice care is and can provide. Participants who selected English as
their preferred language appeared to have more trust in the healthcare system and knowledge about hospice care coverage. While this does not confirm if Hispanics in general have a distrust in the healthcare system, as only Hispanics participated in the study, it does suggest that language may play a factor into the underutilization of hospice care services. Should hospice care resources and information be only available in English one can ascertain why Spanish speakers would potentially be hesitant or even not aware of such services.

A significant difference was discovered among gendered responses to questioning the suggestion of hospice care from a healthcare provider of another race. The results showed that males over females were more apt to question the healthcare provider who suggested hospice care depending on their race/ethnicity. Despite the t-test being run for gender in relation to each scaled variable this was the only instance of significant difference. All other descriptive statistics in comparison resulted in there being no significant differences.

T-tests were found to be most appropriate for this study as this researcher wanted to compare the differences between two groups. In this case the independent variables that included two categorical groups--gender (male/female), language preferences (English/Spanish), and religion (Christian/Catholic—were analyzed using the t-test and independent samples
t-test. There was no correlation between age, employment status, and educational status that could be identified by the t-test analysis.

Strengths of this research study were that the researcher was able to navigate in a community that is often hesitant to participate in such studies, and participants having the option to fill out surveys in either English or Spanish, as both were available. Utilizing snowball sampling as a technique to attain participants enabled the researcher to identify community leaders who in return identified potential participants. This researcher found that once rapport was established engagement of participants was feasible despite the misconception of the Hispanic community of being distrustful.

Limitations

There are several limitations to this research study. The first limitation is the sample size of this study. The sample size consisted of twenty-three participants, ten men and thirteen females. To gain an accurate, reliable understanding of what factors lead to an underutilization of hospice care services among Hispanics a larger sample size is necessary. Due to a small sample size the researcher was limited to what statistical analysis could be run. The few analysis conducted are negligible as they cannot be attributed to the Hispanic population majority.

A second limitation to this study is the sample population. The sample population consisted solely of Hispanic’s. Though the reason is clear as to
why Hispanic's were the target sample it may have proven beneficial to include their counterpart, European Americans; this way the reader can gauge for themselves how little or how much Hispanic's understanding of hospice care is when compared to European Americans. As mentioned, the target population for this study was Hispanics hence the utilization of snowball sampling. Though convenient and effective, the researcher had little control over which subjects participated. The subjects that partook in this study were limited to minor subgroup of an overall population that spans across the nation.

The last limitation noted was that of the research instrument questionnaire. The questionnaire utilized was self-designed. Reliability and validity of the questionnaire were limited to friends and colleagues input about the instrument. There was no re-testing accomplished to gauge the validity and reliability of the research tool. All questions were close ended questions. Utilization of open ended questions could have potentially revealed more perspective from the Hispanic participants.

Recommendations for Social Work Practice, Policy and Research

It is imperative that future studies are conducted regarding the Hispanic population’s underutilization of hospice care services. As the Hispanic population continues to grow hospice care services among the Hispanic
population remain stagnant. Impediments to a crucial healthcare service are a social injustice that needs to be remedied. It is the responsibility of social workers, specifically those in the medical field, to conduct research as to why hospice care still has yet fully assimilated and come up with ideas and goals on how to integrate hospice care for Hispanic's encountering end-of-life situations. Hispanics must be provided with the opportunity in knowing what hospice care services are and that they are available in a wide range of settings ranging from the hospital to a person’s own home environment.

This study is significant for social work practice and research in that the data collected can lead towards potential solutions to alleviate the injustice that is underutilization of hospice services among a select group of people. The underutilization of a beneficial service becomes a social problem. All people, regardless of ethnic and socioeconomic background will encounter end-of-life situations either personally or through a loved one. No one is immune to death and when a comfort measure such as hospice care is available it is the duty of social workers to educate and refer people and their loved ones to hospice care services.

Utilization of hospice care begins with awareness. Future studies with larger sample sizes and exploratory approaches in conjunction with explanatory approaches must be conducted to accomplish the goals of having the Hispanic population utilize hospice care to the same extent that their white counterparts do.
In order to provide such opportunity and alleviate this social issue of underutilization, social workers must be aware of the unique needs that Hispanics may require. Hospice care is conterminously bounded with the social work mission in that both entities focus on improvement of quality of life for people. Social workers must therefore understand that immigration status, lack of outreach, lack of understanding of the term hospice, and cultural perceptions are all factors that impede the Hispanic community from utilizing hospice. Studies have been conducted that suggest culture and language as being a factor that leads to underutilization. According to Haas et al. (2007), cultural barriers and language differences can prevent Hispanics from accessing end-of-life care due to the healthcare providers not being culturally competent when dealing with Hispanics. More studies that determine such correlations must be researched and followed through with in development of policies that respect and acknowledge cultural and linguistic differences.

Conclusions

The results of this study, though not conclusive, can be utilized to help initiate social change and provide the opportunity for Hispanics to not only become aware of what hospice is but to also become comfortable enough with the service with hopes of utilizing it and referring their friends and family members to do the same. As indicated in the literature review, there exists a gap in the service provided due to healthcare workers not having a thorough
understanding of the Hispanic population. Social work professionals must understand the ecological perspective of Hispanics and educate not only Hispanics but also health care workers so that the services are utilized.

By further analyzing which specific barriers are unique to Hispanics that lead to an obstruction of hospice care services, potential solutions can be created to address the underutilization gap.
APPENDIX A

QUESTIONNAIRE
Hospice Survey Questionnaire

Part I-Demographics

Please answer the following demographic questions to the best of your ability.

1. What is your age?
   [ ] 18-29 years
   [ ] 30-39 years
   [ ] 40-49 years
   [ ] 50 years and over

2. What is your gender?
   [ ] Male
   [ ] Female
   [ ] Other

3. Race/Ethnicity:
   [ ] African American/Black
   [ ] Asian
   [ ] Latino/Hispanic
   [ ] White
   [ ] Native American
   [ ] Other

4. What is your highest level of education completed?
   [ ] Less than High School
   [ ] High School Diploma
   [ ] Some College (2yr)
   [ ] Bachelor’s degree (4yr)
   [ ] Postgraduate degree

5. Employment Status:
   [ ] Employed
   [ ] Unemployed
   [ ] Self-Employed

6. Health Insurance
   [ ] Private
   [ ] Public (Medi-Cal, Medicare)
   [ ] None

7. Religion/Spirituality
[ ] Christian
[ ] Catholic
[ ] Muslim
[ ] Hindu
[ ] Jewish
[ ] Other

8. Citizenship Status
[ ] Citizen
[ ] Undocumented

9. Language Preference
[ ] English
[ ] Spanish
[ ] Other

Part II—Knowledge of Hospice care

For the following questions/statements, please select the response that best represents your level of understanding from 1 to 5 where 1 indicates you strongly disagree and 5 indicates you strongly agree.

10. You understand what is meant by hospice care.

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11. You believe hospice care is beneficial.

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12. If you were faced with a life limiting illness, would you consider hospice care?
13. Family members facing a life limiting illness would consider hospice care.

14. Death is a transition.

15. You believe in a spiritual approach to dying.

16. Your faith influences your decision about hospice care.

17. Culture and spirituality is important in your decision to use hospice.
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18. Hospice incorporates aspects of culture and spirituality.

19. You depend on others to make end of life decisions for you.

20. You regularly see a healthcare provider.

21. You have faith in the healthcare system.

22. Hospice care is covered by Insurance.
23. Hospice can be an in-home service.

24. Hospice care can include service in nursing home facilities.

25. Hospice care is expensive.

26. Hospice care means a person will die soon.

27. Hospice is only available to those that can afford it.
28. Healthcare providers incorporate culturally sensitive aspects into their healthcare practice such as spirituality and language.

29. You question a healthcare provider of another race that suggests hospice to you or a family member.

30. It is difficult to trust a healthcare provider of another race.

31. A healthcare provider of your ethnicity will have your best interest in mind.
32. There are healthcare agencies that represent the best interest of the Hispanic culture.

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Developed by Ian Manuel Montoya
Cuestionario de Hospicio (Spanish Questionnaire) 
Parte I-Demografía
Por favor conteste las preguntas al mayor de su capacidad.

1. Cuál es tu edad?
   [ ] 18-29 años
   [ ] 30-39 años
   [ ] 40-49 años
   [ ] 50 años y más

2. Cuál es su género?
   [ ] Hombre
   [ ] Mujer
   [ ] Otro

3. Raza/Etnia:
   [ ] Afroamericano
   [ ] Asiático
   [ ] Latino
   [ ] Caucásico
   [ ] Nativo Americano
   [ ] Otro

4. Cual es tu mayor nivel de educación?
   [ ] Menos de la Escuela Secundaria
   [ ] Escuela Secundaria
   [ ] Alguna Educación Superior (2 años)
   [ ] Licenciatura (4 años)
   [ ] Posgrado

5. Estado de Empleo:
   [ ] Empleado
   [ ] Desempleado
   [ ] Trabajar por cuenta propia

6. Seguro Medico
   [ ] Privado
   [ ] Público (Medi-Cal, Medicare)
   [ ] Ninguno

7. Religión
   [ ] Cristiano
8. Estado de Ciudadanía
   [ ] Ciudadano
   [ ] No ciudadano

9. Preferencias del Idioma
   [ ] Inglés
   [ ] Español
   [ ] Otro

**Parte II—El Conocimiento de Hospicio**

Para las siguientes preguntas / afirmaciones, por favor seleccione la respuesta que mejor representa su nivel de comprensión del 1 al 5, donde 1 indica que está muy en desacuerdo y 5 indica que usted está muy de acuerdo.

10. Usted entiende lo que significa el cuidado de hospicio

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11. Usted cree que el cuidado de hospicio es beneficioso.

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12. Si se le enfrenta con una enfermedad que limita la vida, ¿consideraría el cuidado de hospicio?

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13. Los familiares que enfrentan una enfermedad que limita la vida considerarían el cuidado de hospicio.

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14. La muerte es una transición.

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15. Usted cree en un enfoque espiritual para morir.

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16. Se le influye en su decisión sobre el cuidado de hospicio.
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17. Cultura y la espiritualidad es importante en su decisión de utilizar hospicio.

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18. Hospicio incorpora aspectos de la cultura y la espiritualidad.

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19. Usted depende de otros para hacer final de la vida para usted.

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20. Usted ve regularmente un profesional de la salud.

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21. Usted tiene la fe en el sistema de salud.

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22. El cuidado de hospicio está cubierto por el seguro.

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24. El cuidado de hospicio puede incluir el servicio en las instalaciones del hogar de ancianos.

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25. Cuidado de hospicio es caro.
26. Cuidados de Hospico significa una persona va a morir pronto.

27. Hospicio solo está disponible para aquellos que pueden permitírselo.

28. Los proveedores de salud incorporan aspectos culturalmente sensible en su práctica de la salud tales como la espiritualidad y el lenguaje.

29. Se pregunta un profesional de la salud de otra raza que sugiere hospicio para usted o un miembro de la familia.
30. Es difícil confiar en un profesional de la salud de otra raza.

31. Un proveedor de atención médica de su etnia tundra su major interés en mente.

32. Existen agencias de salud que representan los intereses de la cultura hispana.
INFORMED CONSENT

The study you are being asked to be in will explore why Hispanics under-utilize hospice care services. The purpose of the study is to gain an understanding about your own experience with hospice care. Your participation can assist future care for Hispanic families utilizing hospice. The study will be conducted by Ian Montoya, a Master of Social Work Student at California State University, San Bernardino, who will be under supervision of Dr. Rosemary McCaslin. The study has been approved by the School of Social Work Sub-Committee of the California State University, San Bernardino Institutional Review Board.

Taking part in this study is completely voluntary. You have the right to choose not to take part in this study. If you agree to take part in this research study you will be asked to complete a questionnaire and answer questions related to your experiences with hospice care. The questionnaire consists of 32 questions that should take between 15 to 30 minutes to complete.

As a participant in this research study there will be no direct benefit for you; however, information from this study may benefit Hispanics in the future who lack an understanding of hospice care. There are no known risks in the participation of this study. All information collected during the course of this study will be kept confidential to the extent permitted by law. Your identity will not be revealed at any time during and after this study.

If you have any questions or concerns about this study please contact Dr. Rosemary McCaslin at (909) 537-5507.

By placing a check mark and a date on this consent form, I acknowledge that I understand the nature and purpose of the study and consent to participate. I acknowledge that I am 18 years of age or older.

Place a check mark below:

☐ Date:__________________
CONSENTIMIENTO INFORMADO

El estudio que se le pide que sea en explorará por qué los hispanos menores de utilizar los servicios de cuidados paliativos. El propósito del estudio es obtener un entendimiento acerca de su propia experiencia con el cuidado de hospicio. Su participación puede ayudar cuidado futuro para las familias hispanas que utilizan hospicio. El estudio será realizado por Ian Montoya, un Maestro de Estudiantes de Trabajo Social en la Universidad Estatal de California en San Bernardino, que estará bajo la supervisión del Dr. Romero McCaslin. El estudio ha sido aprobado por la Escuela de Trabajo Social Subcomité de la Universidad Estatal de California en San Bernardino Junta de Revisión Institucional.

La participación en este estudio es completamente voluntaria. Usted tiene el derecho de optar por no participar en este estudio. Si acepta participar en este estudio de investigación, se le pedirá que complete un cuestionario y contestar preguntas relacionadas con sus experiencias con el cuidado de hospicio. El cuestionario consta de 32 preguntas que deben tener entre 15 a 30 minutos para completar.

Como participante en este estudio de investigación no habrá ningún beneficio directo para usted; Sin embargo, la información de este estudio puede beneficiar a los hispanos en el futuro que carecen de una comprensión de los cuidados paliativos. No hay riesgos conocidos para la participación de este estudio. Toda la información recopilada durante el curso de este estudio se mantendrá confidencial en la medida permitida por la ley. Su identidad no será revelada en cualquier momento durante y después de este estudio.

Si tiene alguna pregunta o inquietud sobre este estudio, por favor póngase en contacto con el Dr. Romero McCaslin al (909) 537-5507.

Al colocar una marca de verificación y una fecha en este formulario de consentimiento, reconozco que entiendo la naturaleza y el propósito del estudio y consentimiento para participar. Reconozco que tengo 18 años de edad o más.

Coloque una marca de verificación a continuación:  
Fecha:___________________
APPENDIX C

DEBRIEFING STATEMENT
Debriefing Statement

The questionnaire survey you have completed was developed to investigate Hispanic’s perceptions of hospice care services. This study was designed to examine what factors may be behind why Hispanics under-utilize hospice care services when compared to their European counterparts. The information gathered is anticipated to be useful for medical social work practice and hospice in general so to assess and provide quality, culturally sensitive care in the hospice care setting.

Thank you for your participation in this study. The data collected will be kept confidential and anonymous. The results of this study will be available at California State University, San Bernardino, John M. Pfau Library by September of 2015. If you have any questions regarding the study please contact Dr. Rosemary McCaslin at (909) 537-5507; email: rmccasli@csusb.edu.
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Declaración Informativa

La encuesta que haya completado fue desarrollado para investigar las percepciones de los servicios de cuidados paliativos de hispanos. Este estudio fue diseñado para examinar los factores que pueden estar detrás de por qué los hispanos menores de utilizar los servicios de cuidados paliativos en comparación con sus homólogos europeos. La información recopilada se prevé que sea útil para la práctica médico-social de trabajo y de hospicio en general, de manera de evaluar y proporcionar atención de calidad y culturalmente sensibles en el ámbito de la atención de hospicio.

Gracias por su participación en este estudio usted. Para proteger la validez del estudio por favor no discutir este estudio con otras personas que puedan planificar a participar y llenar la encuesta. Los datos recogidos serán confidenciales y anónimas. Los resultados de este estudio estarán disponibles en la Universidad Estatal de California en San Bernardino, John M. Pfau Biblioteca de septiembre de 2015. Si tiene alguna pregunta relacionada con el estudio, o si desea obtener una copia de los resultados, por favor póngase en contacto con el Dr. Romero McCaslin al (909) 537-5507; email: rmccasli@csusb.edu.
REFERENCES


