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HISPANICS' EXPERIENCE WITH HOSPICE CARE

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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  
Maria Rosario Diaz

June 2009

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San Bernardino


---

by


Maria Rosario Diaz


June 2009

Approved by:

  
Dr. Rosemary McCaslin, Faculty Supervisor  
Social Work

6/14/09  
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Lorraine Hedtke, L.C.S.W.  
VITAS Innovative Hospice Care®

  
Dr. Janet C. Chang,  
M.S.W. Research Coordinator

## ABSTRACT

The purpose of this project was to learn about Hispanics' experience with hospice care and to gain insight into their unique needs. The findings will offer Hospice programs with information on how to provide the most appropriate care to the Hispanic population. This project was conducted through VITAS Innovative Hospice Care®. Using the post-positivist paradigm, structured interviews were conducted with ten caregivers of deceased patients who received hospice care. The qualitative data were examined, themes were extracted and analyzed, their relationships were explored and a theory was developed.

This study found that the quality of patient care transcended cultural and spiritual boundaries. Hispanics valued the compassionate care provided to their loved ones more than they needed for staff to focus on their cultural and spiritual practices. Recommendations for further research include exploring Hispanics' needs and experiences in hospice during the different stages of care. To conclude, research on Hispanics and their experience with hospice care should continue and similar research should be expanded to other cultures.

## ACKNOWLEDGMENTS

This paper could not have been possible without the support and guidance of many. I would like to thank my field adviser Dr. Rosemary McCasslin. Her vast knowledge and expertise guided me through the success of this project. More importantly her supportive manner made this project less intimidating and achievable. I also want to express my gratitude to Lorraine Hedtke, L.C.S.W. She facilitated the agency to conduct the research. She made time to discuss my findings and gave me a direction in the analysis. She was an inspiration as a result of the passion she demonstrates for hospice care. I am grateful to my colleagues for their support. I am also thankful to all my professors for teaching me what I needed to know to complete this project. I want to thank my parents and siblings for their support during last three years of my education. I want to thank them for understanding my commitment to my education and for respecting the value I give to my profession. Their emotional support was a significant contributor to the success of this project and my education.

## DEDICATION

I want to dedicate this project to my parents. They have been an unconditional support from the start of my education, three years ago. They understood my absence from the family and my full dedication to school; to my mother, Rosario, for her prayers and encouragement before every test and every research paper; to my sister, Maria, for her understanding; to my brother for his support, to my nieces and nephew for their love; and to my colleges and professors for their camaraderie.

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## CHAPTER ONE

### ASSESSMENT

#### Introduction

Chapter One explains the research focus. It discusses and defines the post-positivism paradigm that was used for this study and explains the rationale for choosing this paradigm. Further, it provides a synthesis of the literature review conducted in an attempt to gain insight into the factors that have been found to impact the utilization of hospice care by Hispanic families. This chapter reviews the theoretical framework that was used to guide this study. Last, it explores the contributions that this study offered social work practice at the micro and macro level.

#### Research Focus

The focus of this study was to gain an understanding of the experiences of Hispanic caregivers of deceased patients who received hospice care. This study explored the phenomenological experiences of Hispanic caregivers. It examined Hispanic caregivers' views of hospice staff's cultural sensitivity. This study explored the caregivers' thoughts about what would make hospice services more

culturally sensitive and accessible. It explored what was helpful, did caregivers feel understood, was the material presented in a clear manner, were services and staff accessible, or did caregivers find services culturally insensitive, inaccessible, and inadequate.

This study also identified the cultural needs of the Hispanic population in hospice care. The study hoped to share the helpful information discovered to hospice agencies so that they can provide culturally sensitive care in a time of intense emotional stress during the journey of death.

#### Paradigm and Rationale for Chosen Paradigm

This project utilized the post-positivism paradigm. "Post-positivism is an inductive exploratory approach to understanding objective reality" (Morris, 2006, p. 71). This paradigm used qualitative data as its source of information (Morris, 2006). With this paradigm, the research study develops and evolves throughout the research process (Morris, 2006). Significant themes were identified and recorded and the interview was refined to accurately capture new emerging themes in order to develop a well-founded theory.

This paradigm was chosen because the means to gather the most accurate account of the phenomenological experiences of Hispanic caregivers is through objective exploratory interviews. The interviews included questions concerning the caregivers' perceptions of how culturally sensitive the care they received was, what they found helpful and explored caregivers ideas about providing more culturally sensitive care. The goal was to encourage an open discussion of their thoughts, feelings and experiences. These interviews produced the qualitative data needed for analysis using the post-positivism paradigm. Further, the interviews were conducted in the caregivers' home adhering to the post-positivist paradigm that considers that the most accurate research study is conducted in its natural environment (Morris, 2006).

The researcher took the position of an objective and unbiased listener, learner and facilitator while the participants were the teachers. Themes were identified from the qualitative data (interviews) for analysis and were used to guide the direction of the research study. The interviews were audio recorded with the permission of the participants, transcribed and analyzed; from there a theory was developed.

## Literature Review

This section presents a synthesis of the literature review that explored the findings of previous research studies on Hispanics and hospice care. The literature review was conducted to gain knowledge of the use of hospice care among Hispanics. The literature review served as a foundation for this study.

This section begins with an illustration of the growth rate of the Hispanic population in the United States and San Bernardino County. It discusses the underutilization of hospice programs and their services. This section also discusses the factors that have been suggested to impact the utilization of hospice care. Finally, it briefly explores caregiving, death, and dying, spirituality and culture.

### Statistics

According to the U.S. Census Bureau (2001), in 2000 Hispanics composed 35.3 million of the U. S. population. In 2004 this population increased to 40.4 million (U. S. Census Bureau, 2007). In 2000 there were 669,387 Hispanics in San Bernardino, California (U.S. Census Bureau, 2000). In contrast, in 2006 there were 918,706 Hispanics in San Bernardino (U.S. Census Bureau, 2006).



This demonstrates a significant increase in the Hispanic population that undoubtedly affects the rates of Hispanic mortality in the United States and San Bernardino County.

#### Underutilization of Hospice Programs

Gordon (1996) found that out of 832 hospices in the nation only two percent (2%) had serviced a Hispanic population of over 32%. Most of these hospices reported that they were disproportionately serving the Hispanic population. According to the Medicare Hospice Data (2007) there was an increase of 63% in the use of hospice services from 2000-2005. However, in 2006 the National Hospice and Palliative Care Organization (2008) reported that only 8.8% of hospice patients were multiracial (includes Hispanics among other ethnicities) while Caucasians composed 80.9% of the population served. These statistics demonstrate that although the rate of hospice use is increasing and the number of Hispanics in the U.S. is increasing, Hispanics are underutilizing hospice services in comparison to Caucasians.

Furthermore, once on hospice Hispanics used services provided by the hospice agency less frequently than other ethnicities. Colon and Lyke (2003) found that while on hospice, Latinos used services at lower rates than

African Americans and European Americans. Another study found that Hispanics received fewer social work visits and fewer spiritual visits than whites (Adams, Horn, & Bader, 2005). Furthermore, Hispanic females received fewer visits from nurse aids than white females (Adams et al., 2005).

#### Factors that Impact the Use of Hospice Care

Several studies identified factors that played a role in the underutilization of hospice services by Hispanics. Common themes identified were language barriers, lack of education, being unaware of the existence of hospice care, lack of knowledge and understanding about hospice services, low socioeconomic status, concerns about cost, discrimination, and differences in philosophy of death and dying (Born, Greiner, Arnp, Butler, & Ahluwalia, 2004; Gordon, 1996; Gelfand, Balcaza, Parzuchowski, & Lenox, 2004; Randall & Csikai, 2003).

Colon and Lyke (2006), and Adams et al. (2005) found that most Hispanics used Medi-Cal as their source of payment and suggested that the low-income status of Hispanics limited their resources. Scharlack, Kellam, Ong, Baskin, Goldstein, and Fox (2006) also suggested

that Hispanics may be somewhat aware of the resources but do not utilize them because they do not know where to find them or because of the complicated application process.

Another factor that Gelfand et al. (2004) found in their focus groups was that Mexicans feared being asked about their immigration status during the assessments and had concerns regarding discrimination. This may be related to negative past experiences with discrimination or fear of being reported if not legally in the country.

There were mixed findings regarding Hispanics' perspectives on the need of staff to be of their same culture. Gordon (1996) found a positive relationship between Hispanic intake staff, bilingual staff, and the availability of an interpreter with the number of Hispanic patients served. Randall and Csikai (2003) also found that Hispanics preferred to discuss their terminal illness with a Spanish-speaking doctor. In contrast, Gelfand et al. (2004) found that Mexicans believed it was important for practitioners to know Mexican culture, traditions, medical practices and even food but not necessarily to be of Hispanic descent. This implies that Hispanics may be receptive to hospice care if there is

Hispanic staff available as well as to non-Hispanic staff who understand their culture. This emphasizes the importance of being aware of cultural differences and the importance of staff's cultural sensitivity.

#### Caregiving Values of the Hispanic Family

Research demonstrated that Hispanic families have strong values regarding the provision of care for their loved ones. These values impact the utilization of formal services such as hospice care. Hispanics strongly value taking care of their loved ones (Scharlack et al., 2006; Adams et al., 2005). Most Hispanics do not agree with putting their loved ones in nursing homes and do not want strangers caring for them (Scharlack et al., 2006). Hispanics gain personal pride and satisfaction from caring for their loved ones even though they may have many unmet needs (Scharlack et al., 2006).

Family support appears to play a central role in caregiving in Hispanic families. Adams et al. (2005) found that 89% of the Hispanic caregivers in their study were family members and that more Hispanic families used extended family as caregivers compared to whites who utilized private paid caregivers. While on hospice care, more Hispanic patients lived in their own homes or with

relatives compared to whites who used more nursing homes or assisted living facilities (Adams et al., 2005).

Furthermore, one study found that familism was found to decrease the level of burden felt by Hispanic caregivers (Losada, Shurgot, Knight, Marquez, Montorio, Izal, & Ruiz, 2005). This illustrates the importance of family in the Hispanic culture. It seems that familism can mitigate the negative effects of caregiving but it can also become a barrier to accessing formal services such as hospice care.

#### Death and Dying and Spirituality

Research found that Hispanics preferred conversations of hope rather than talking about death and dying (Gelfand et al., 2004). Gelfand et al. (2004) found that Hispanics preferred not to discuss death and preferred "encouragement" (p. 11). Another study found that Mexicans chose life support interventions if they felt there was hope (Blackhall, Frank, Murphy, Michel, Palmer, & Azen, 1999). Mexicans felt that if the doctor advised for life support there was still hope (Blackhall et al., 1999). This implies that Hispanics' emphasis on hope can possibly become a barrier to hospice use if families do not understand the concept of hospice care.

There was limited research about spirituality and its affects on the use of hospice care among Hispanics. One study found that spirituality was an important component to help Hispanic families deal with death (Born et al., 2004; Scharlach et al., 2006). Gelfand et al. (2000) found that Hispanics have a "passive acceptance of death and complain less of pain" (p. 5). Gelfand et al. (2004) also suggested that this may be as a result of religious beliefs. Gelfand et al. (2004) also found hope to be an important value in Hispanic families. Adams et al. (2005) found in their sample of 294 Hispanics on hospice that 86% were Catholic. Learning how faith and beliefs about death and dying play a role in Hispanic families is an important component for effective hospice interventions.

### Culture

Scharlach et al. (2006) found that Hispanics reported the need for systems that are culturally sensitive and understanding of the familial and cultural traditions. A study on the affects of acculturation found a link between acculturation and an increased use of formal services with a decreased use of family (Scharlach et al., 2006). Older Hispanics had concerns regarding the

younger generation not continuing with the cultural values of caregiving (Scharlach et al., 2006). Radina and Barber (2004) suggested that Hispanic caregivers with higher acculturation used more formal services than those less acculturated. This is an important concept to notice when working with Hispanic families.

### Theoretical Orientation

#### Ecosystems Theory

Systems theory examines the "interactions between several systems such as individuals, families, groups, communities, and organizations" (Zastrow & Kirst-Ashman, 2007, p. 12). Specifically, ecosystem theory "describes and analyzes people and other living systems and their transactions" (Zastrow & Kirst-Ashman, 2007, p. 14).

Ecosystems theory was used in this study to understand Hispanic families' interactions within their familial subsystems and their interactions with the larger systems, such as hospice. With death and dying, the homeostasis of the Hispanic family has been threatened. The individual roles within the families' subsystems need shifting and roles change. For example, the daughter becomes the caregiver for the ill mother.

Further, the interactions between family members change as a result of the distress caused by the anticipation of the death and the death itself. According to ecosystems theory, there must be effective interactions among systems to survive and function properly (Zastrow & Kirst-Ashman, 2007). This study explored the transactions within the family, specifically caregiving norms. It also examined the transactions with the hospice program and staff, the larger system. This exploration generated important information that can be used by social workers in the hospice field to provide culturally sensitive care in order to make families' experience with death and hospice care a positive one.

#### Cultural Perspective

Culture's role in caregivers' hospice experiences was explored. From a cultural perspective, what is their view of death and dying? In the literature review familism was found to be an important value of the Hispanic culture. Familism is the belief that family comes first (Zastrow & Kirst-Ashman, 2007). Zastrow and Kirst-Ashman (2007) explain familism using Schafer's description that;



extended family provides greater emotional strength in times of crisis, gives importance to godparent/godchild relationships, has the benefits of financial dependency on kin, sees relatives as a source of advice and has high involvement of family with elderly. (p. 219)

Examples of family support are the nuclear family, extended family and religion. The low rates of Hispanics using formal services can be attributed to the strong sentiment of familism (Zastrow & Kirst-Ashman, 2007).

For this study, understanding the role that familism plays in Hispanic families can assist social workers to create interventions that support these values and facilitate the use of formal social resources. According to Zastrow and Kirst-Ashman (2007), to become a culturally competent practitioner a social worker needs to be self-aware of their own culture, aware that different cultures exist, learn about other cultures and modify their interventions to meet the needs of clients of different cultures.

## Potential Contribution of Study to Micro and Macro Social Work Practice

It is important that the field of hospice understands the unique circumstances of Hispanic families so that they can adequately address their needs.

Mortality is a reality for every human being. Death is an inevitable part of the human life cycle. Although people understand that physical death will eventually happen, when the reality of death faces families, regardless of age, it is a difficult time. Furthermore, people experience death in different ways. Culture, faith, family composition, beliefs and values are some of the factors that impact how people deal with death and dying. Hospice care is unique in that it provides quality of life by managing the physiological aspects of the disease essential for palliative care as well as the psychosocial and spiritual needs of the ill and their families.

Therefore, at the micro level understanding what has been effective, what can be improved and suggestions for improvement may help agencies develop culturally sensitive interventions for Hispanic families. Agencies can incorporate this information in cultural sensitivity trainings for their staff so that staff gains insight

into the unique dynamics and needs of Hispanic families. This information will make practitioners better equipped to assess, identify, and address the needs of Hispanic families. Patients and their families can then be cared for appropriately, adequately and in a sensitive manner.

At the macro level this study offers ideas to agencies and larger institutions on how to provide culturally sensitive care to Hispanic families. Furthermore, the findings provide information that hospice agencies can use to enhance their marketing strategies to include education and outreach activities where misconceptions of hospice care are clarified and Hispanic families understand the philosophy of hospice care.

#### Summary

Chapter One explained the research focus. It defined the post-positivism paradigm and explained the rationale for choosing this paradigm. This chapter presented a synthesis of the literature review that showed the underutilization of hospice care by Hispanics that provided a foundation for the development of the study. This chapter also reviewed the theoretical framework that

guided this study. Finally, the potential micro and macro contributions for social work practice were explored.

## CHAPTER TWO

### PLANNING

#### Introduction

Chapter Two discusses the planning process of this study. The plan for engagement, implementation, evaluation, termination and follow up is explained. This chapter explores how the study site and participants were engaged, the self-preparation conducted by the researcher and the ethical, diversity and political issues that were anticipated to be encountered. Data gathering using interviews, the phases of data collection, data recording methods and the selection of participants is explained. Data analysis using open coding is discussed. Finally, termination and follow up activities is explained.

#### Plan for Engagement

##### Research Site and Study Participants

The study site was VITAS Innovative Hospice Care® in San Bernardino, California. VITAS is a Latin word which means lives and this ties in with their mission "to provide the highest quality of life, products and case management to terminally ill and other appropriate patients and their families" (VITAS Innovative Hospice

Care®, 2008, Mission Statement, para. 1). VITAS Innovative Hospice Care® originated in 1976 with a group of volunteers who provided care to terminally ill patients and, in return, patients taught them what they needed. In 1978 their first hospice was created in Florida. In 1980, it was one of the first hospices to participate in the Medicare demonstration project. In 1982 it became the pioneer in the creation of the Medicare hospice benefit.

VITAS Innovative Hospice Care® is committed to providing the best palliative and comfort care that is free from pain and suffering. One of their values is that "patients come first" (VITAS Innovative Hospice Care®, 2008). Staff collaborates with patients to identify and address patient's needs and desires. To accomplish this, they have an interdisciplinary team that works together to ensure the provision of quality care for all their patients. The team is composed of a doctor and a nurse whom tends to the medical needs, a chaplain who tends to the spiritual needs, a social worker who tends to the psychosocial needs, and a home health aid who assists with activities of daily living and instrumental activities of daily living. Therefore, interventions and

support are at the medical, the spiritual and the psychosocial level for patients and their families. Furthermore, they are committed to assisting families after the death of their loved one with ongoing bereavement support.

Illness and death do not discriminate against age, gender, ethnicity, or socioeconomic status and it affects the patients and their families. Therefore, VITAS Innovative Hospice Care® provides care to individuals of all ages, ethnicities, genders, cultures, educational levels, and economic statuses.

The target population was Hispanics that received care from the hospice agency. For the purpose of this study, Hispanics included anyone from a Latin American country including Mexico, Central and South America, Cuba, Puerto Rico and the Caribbean. Participants were Spanish-speaking only or had limited English fluency as determined by self-report. The participants were the primary caregivers of deceased patients. The death of the patient occurred within the last year. Factors such as age, gender, educational status, marital status, relation to the patient, illness, family form, religion, or

socioeconomic status were not part of the selection criteria.

The study site was chosen for several reasons. San Bernardino's Hispanic population grew by 250,000 from 2000-2006. Therefore, one can safely assume that death rates are also increasing. VITAS Innovative Hospice Care® is located in San Bernardino, California in an area with a growing Hispanic population. They already provide care to Hispanics and can benefit from understanding Hispanics' experiences in order to provide more culturally sensitive care.

#### Engagement Strategies

Formal permission to enter the research site was obtained by contacting the authority gatekeeper, Steven P. Girod, general manager at VITAS Innovative Hospice Care® in San Bernardino, California. The study was conducted with the caregivers and not the patients (a vulnerable population) therefore, approval from the office manager was sufficient. The researcher was a MSW intern at VITAS Innovative Hospice Care® under the supervision of Mrs. Lorraine Hedteke MSW, ACSW, LCSW, bereavement service manager.



According to Morris (2006), it is crucial that the researcher be well prepared and knowledgeable when addressing the site. Being prepared means "discussing the focus, timelines, the possible impact on the site and how the research fits with the needs and priorities of the site" (Morris, 2006, p. 94). The research focus, the reason for choosing this site and how the research would offer beneficial information to the agency was discussed with Mrs. Hedtke. Mrs. Hedtke then communicated this information and how this study would benefit and support the agency's mission and goals to the general manager who provided verbal and written approval

The Social Work Sub-Committee of the Institution Review Board (IRB) approved the research. Following the IRB approval, the engagement of the participants proceeded. The name of approximately 40 Hispanic caregivers served by VITAS Innovative Hospice Care® within the last year was provided by Mrs. Hedtke. The goal was that out of 40, 10 to 15 would agree to participate in the study. First, a letter was mailed to the participants explaining the study (See Appendix A). The letter also stated that they would be eligible for a five dollar calling card if they choose to participate.

The letter provided a contact phone number to call for questions or to call if they decide to participate in the study. A follow up phone call was made to all participants to answer questions, confirm if they were interested in participating and to schedule a home visit.

After the participants gave a verbal agreement to participate, home visits were scheduled and conducted to obtain written consent (See Appendix B). The purpose of the study, the length of the interview, the data gathering process (recorded interviews) and how their participation would benefit the social work field was explained in greater detail at this time. Questions from the participants were also addressed.

As described by Morris (2006), the nature of the post-positivism paradigm involves direct interactions between the researcher and the participants. Therefore, building and maintaining positive rapport was imperative for the success of this study. Micro skills such as active listening and proper interviewing were practiced throughout the research study with both the gatekeepers of the study site and the participants.

### Self Preparation

To prepare for the research study a review of the existing literature in the area of Hispanics and hospice care was conducted. In the literature review several themes were identified: the underutilization of hospice programs by Hispanics, culture and caregiving norms, view of death and dying and spirituality. Themes from the literature review provided a starting point for the study. The preliminary research provided a basic understanding of what others have found to be possible factors that influenced the underutilization of hospice services by Hispanics. This information guided the qualitative questions used for the interviews.

The social work code of ethics was at the forefront of this study. The post-positivist paradigm requires that the researcher be objective and aware of personal biases (Morris, 2006). The researcher is of Hispanic culture and therefore conducted a self examination of personal values and possible biases regarding caregiving and hospice care in order to reduce the risk of jeopardizing objectivity by imposing or making generalizing statements using personal cultural values. The researcher's Hispanic culture however, was also used to assist in building

rapport and creating a comfortable environment for the participants. Being an intern at the hospice agency helped the researcher to build knowledge, understanding and sensitivity of the caregiver's experiences with death and facilitated the connection with the participants.

Social work micro skills such as starting where the client is, were useful techniques that helped participants feel comfortable regardless of their educational and socioeconomic status. Professional discourse was avoided which decreased confusion and avoided exerting power differentials. The use of active listening by using minimal prompts, clarifying, paraphrasing, and summarizing ensured that the participants felt heard and that the data recorded adequately represented what the participants expressed. Participants were encouraged to ask clarification questions which also created a comfortable environment.

#### Diversity Issues

In planning for the study, diversity issues such as age, gender, perceptions of power, culture, and religion were anticipated and plans for addressing them were explored. One issue that might arise was the caregiver's perceptions that the researcher may not have the

expertise, sufficient knowledge or life experiences to understand their situation due to the researcher's age. Therefore, to deal with this issue the participants were informed of the extensive literature review and the work as an intern at the hospice agency by the researcher so that they would feel understood. Similarly, gender might pose a barrier. A male caregiver might not be used to discussing emotional thoughts and feelings with others, especially women. Further, their culture might dictate that they be emotionally strong and that displaying emotions is equal to weakness. To handle this issue, male participants were reassured of the confidentiality of their disclosures and that their participation would be an important contribution for hospice care in order to improve the care for Hispanic families. The latter might provide them with a sense of purpose.

Barriers might rise as a result of power differentials perceived by participants related to the researcher's level of education and perceived socioeconomic status. Therefore, the interviewer dressed in informal attire. The interview questions were in a language free from professional jargon and in the participants preferred language (Spanish). To further

reduce the power differential the participants were advised that they were the teachers/experts of their experience and that the researcher was the learner. Further, the interviews were conducted in their homes so that they felt comfortable and safe in their environment and to reduce the barriers that the lack of transportation may impose. In using these techniques the goal was to minimize the power differential and to allow for a safe and genuine interaction.

The researcher recognized that not all Hispanics share the same cultural values, beliefs and practices. Self-examination was conducted by the researcher. Further, in order to understand the caregivers' experiences the researcher asked the participants what their cultural beliefs were with regards to death and dying.

### Ethical Issues

Prior to beginning the research study ethical issues were considered. The first step was to acquire the approval to conduct the research from the Social Work Sub-Committee Institution Review Board (IRB) which ensures that the participants are not harmed. To do so an informed consent that includes the introduction of the

researcher, an explanation of the research focus, the research procedures, the length of the interviews, confidentiality, contact information and debriefing strategies was developed. The Post-positivism paradigm involves intense engagement with the participants; therefore confidentiality of conversations and identifiable information was protected.

Since this research involved intense engagement with the participants the moral value guiding this study was to do the right thing to protect the participants. To achieve this the researcher ensured that the participants understood the research focus, that their right to confidentiality was protected, that their cultural and spiritual values and beliefs were respected and provided an accepting and non-judgmental environment. The researcher practiced objectivity by being aware of and minimizing the influence of personal values on the interviews. The value of competency was displayed by conducting an extensive literature review, by learning at VITAS Innovative Hospice Care® as an intern and by developing study methods with the guidance of a research adviser that ensured the safety of the participants.

Terminal values such as social values were practiced by utilizing the findings of the study to provide feedback to the agency on their strengths and on how they can enhance their cultural interventions. A significant guiding force for this study was the personal value of wanting to add knowledge to social work practice and to the hospice field in order to improve the care available for Hispanics.

#### Political Issues

Political issues related to power may rise as a result of the worldview of post-positivism. The researcher "consults with participants but keeps the power to decide which data shall be collected and how it will be used. Study participants are a source of data" (Morris, 2006, p. 258). To ameliorate the impact of power issues, the purpose and methods of the study were thoroughly explained. The participants' role was of teachers/experts and the researcher's role was of a learner. The participants were informed that only what was relevant to the study would be used for analysis and that the findings would be reported to them, to the study site, and to the university. Therefore, the participants had the power of knowing what the research was about, the



power to decide to participate and the expert power of their experiences by informing the researcher. However, the power to analyze and to choose what to analyze was held by the researcher and was made known to the participants.

Power issues associated with the research site consisted of the agency's policies on conducting research. The site held the power of what data were available to use for the research. Therefore, all phases of the research process was reviewed and approved by agency's gatekeeper.

#### Plan for Implementation

##### Data Gathering

The post-positivism paradigm approach to data gathering involves identifying themes/concepts from narratives or observations (Morris, 2006). The data gathering method that was used for this research study were interviews. The researcher prepared the questions prior to the start of the interviews. The questions were translated into Spanish using back translation. The initial questions were created from some of the themes found in the literature review. Participants were contact

by mail and phone and a home visit was scheduled. The interviews were conducted in the caregivers' home and privacy during the interviews was ensured.

### Selection of Participants

The post-positivism paradigm uses a sampling technique called purposive sampling (Morris, 2006). Purposive sampling involves choosing participants that will be best equipped to provide the most specific data related to the research topic (Morris, 2006). For this study, caregivers of deceased patients who received hospice care were the best sample choice because they provided first hand insight of their experiences. Purposive sampling was essential for this study because the goal was to acquire objective data from the participant's phenomenological perspectives and only those close to the topic, those who experienced hospice services were able to provide the richest information.

This study used a homogeneous sample. Homogeneous samples "identify subgroups for in-depth study" (Morris, 2006, p. 6). The subgroup for this study was Hispanics. The sample was Hispanic caregivers of patients who received hospice care when their loved ones died. The focus of the study was to conduct an in-depth examination

of the experiences of these caregivers and therefore this type of sampling was the most appropriate for this study.

Mrs. Hedtke, bereavement manager at the study site provided names of 40 Hispanic caregivers of deceased patients. The participants were of Hispanic descent and had experienced the death of a loved one while receiving hospice care within the last year. Their participation was voluntary. They were Spanish speaking only or had limited English fluency that was determined by self-report.

#### Phases of Data Collection

Adhering to the post-positivist paradigm, the qualitative data gathered were through the medium of interviews. The interviews were guided by the four phases of data collection described by Morris (2006). The phases are "engagement, the development of focus, maintaining focus and termination" (Morris, 2006, p. 98). In the engagement phase of the research study, the research methods, the length of the interview, informed consent and right to confidentiality were reviewed with the participants. Questions from the participants were addressed. Throw away questions were used to build

rapport, to create a comfortable environment and to begin to engage them in the interview.

In the second and third phase, developing and maintaining the focus, the researcher used three types of questions. The questions were throw away, essential and probing questions. Throwaway questions are non-threatening general questions that request demographic information which help to develop rapport with the participants (Morris, 2006), for instance, "what country in Latin America do you identify with?" Essential questions are exclusively related to the research topic and probing questions are used to further explore the research topic (Morris, 2006). For example, (essential question) "did you feel the information presented to you was clear?" If so, what made it clear, if not, why not (probing question)?" Throw away questions were used at the beginning to engage the participants in the interview. Essential and probing questions were used in the middle of the interview to develop and maintain focus on the study topic (See Appendix C).

At the end of the interview, the termination phase, the participants were debriefed and a verbal summary of the interview was provided. Participants were thanked and

questions from the participants were addressed. The participants received a five-dollar calling card. They were also provided with a list of bereavement and counseling resources and the phone number to VITAS Innovative Hospice Care® in case the participants needed further bereavement support (See Appendix E).

Descriptive, structured and contrast questions were the type of questions used to gather information during the interviews. Descriptive questions are broad open-ended questions that cover a wide area of the research topic (Morris, 2006), for instance, "What does your culture tell you about death?" Structured questions enhanced the comprehension of the research topic (Morris, 2006), for instance, "How was your culture respected?" Contrast questions developed the criteria for inclusion and exclusion and helped with sorting questions into topics that were then labeled as concepts and helped begin the coding process (Morris, 2006, p. 96), for instance, "how did the staff demonstrate an understanding of your cultural beliefs?"

#### Data Recording

The mode of recording was through audio tape recording and transcribing. The transcriptions were saved

in a computer memory stick that was stored in a locked cabinet. The researcher obtained the permission of the participants to record their interviews. The researcher obtained names, addresses and phone numbers of the participants to contact them and to conduct the interviews. Therefore, in adherence to HIPPA law to secure protected health information (PHI) was maintained confidentially, kept in a locked cabinet and shredded at the end of the study.

The researcher kept two journals. One journal contained the transcribed interviews. The second journal was the reflection journal. In the second journal the interviewer documented reflections on the interview. These included ideas on how to improve the interview process, the rationale for the need to modify the interview, themes identified, as well as positive and successful experiences. Areas of countertransference were also noted and processed in the second journal.

## Plan for Evaluation

### Data Analysis

This study required qualitative data analysis. Qualitative analysis is the analysis of language (Morris,

2006). This study used the bottom-up approach. "The bottom up approach is a narrative text transformed from a series of words to a theoretical statement" (Morris, 2006, p. 112). This study recorded and transcribed the interviews of caregivers. Using an open coding process themes were extrapolated from the narratives, they were placed under categories and given a dimension. Then, using axial coding, the categories were linked and an explanation of their relationship was explained. In selective coding, core categories were thoroughly examined in order to develop a theory. Macro and micro implications were also explored.

Using open coding the caregivers' narratives were micro analyzed. The narratives were dissected in order to identify themes. Some of the anticipated themes were identified as staff was prompt and caring, staff attempted to provided culturally sensitive care, information was not presented in a clear manner, patient/family did not understand what was happening, Spanish material was not provided, and Spanish speaking staff was unavailable. The category would be culturally sensitive experiences. The dimension would be positive and negative experiences.

In the axial coding the relationship between the categories was explored. The category of culturally sensitive experiences would be linked with another category identified such as understanding of hospice care. In selective coding these relationships were further explored to develop a theory. Finally, the conditional matrix is where the "developed theory fits into the social macro and micro context" (Morris, 2006 p. 119). At the micro level the goal was that through the stories of Hispanics' experiences of hospice care, agencies gain insight into the unique needs of the Hispanic community, therefore, giving the agencies tools to share with their social workers in order to implement culturally sensitive interventions. At the macro level the hope was that creating critical consciousness of the experiences of the Hispanic community motivated agencies to increase their bilingual staff, to conduct cultural trainings and to develop outreach activities that target the underserved Hispanic community. Also, the study hoped to motivate agencies to develop materials in Spanish so that the patients and their families understand hospice care.



## Plan for Termination

### Communicating Findings to Study Site and Study Participants

The study's findings were communicated to the research site, the study participants and to California State University San Bernardino's MSW program. The findings were presented to VITAS Innovative Hospice Care® in a social work staff meeting. The presentation discussed the research study, the interview questions and the findings. The participants were mailed a letter with the results of the findings. The study findings were also displayed at California State University, San Bernardino on Poster Day. A formal written document of the study is available at California State University San Bernardino John M. Pfau Library. A copy of the written document was provided to the gatekeeper of the study site.

### Termination of Study

Due to the nature of the study that involved personal interactions between the participants and the researcher it was important to terminate the relationship in a formal process. A letter of the findings was mailed to the participants in Spanish. The researcher once again thanked them for their participation and acknowledged

their contributions to the social work field. The hope was that the caregivers were left with a feeling that their experience with death was not in vain and can help in the care of other families.

Termination with the study site occurred during the formal presentation at the staff meeting where snacks and drinks were provided. A thank you note was given to the authority gatekeeper, Steven P. Girod, general manager and to Lorraine Hedtke, bereavement service manager, who facilitated the study. During the presentation, a copy of the formal document was gifted to VITAS Innovative Hospice Care®.

#### Plan for Follow Up

##### Ongoing Relationship with Study Participants

An ongoing relationship with the study participants was not be maintained. The mailing of the findings to the participants represented the formal termination of the relationship. The researcher will maintain an ongoing relationship with the agency as a resource/referral for families who need bereavement support or hospice care. Although an ongoing relationship was not continued with the participants and the researcher would not be a MSW

intern at the study site, the contribution to the researcher's knowledge was of great significance. This study has helped the researcher gain insight into the experiences and needs of Hispanics. The researcher will use this knowledge in other areas of social work practice.

### Summary

This chapter discussed the engagement of the study site and the participants, the self-preparation conducted by the researcher and the ethical, diversity and political issues related to the study. The plan for implementation, how the participants were selected, the data gathering process, the phases of data collection and the process of data recording was discussed. Further, the evaluation plan consisting of data analysis using open coding was described. Last, the activities and plan for termination and follow up were presented.

## CHAPTER THREE

### IMPLEMENTATION

#### Introduction

This chapter discusses the selection of the study site and the study participants. Purposive sampling was used in the selection process. Data gathering using qualitative interviews is explained and the phases of the interviews are discussed. Last, the method of data recording using audio recording and written documentation is explained.

#### Research Site and Study Participants

The purpose of this study was to understand the experiences of Hispanics with hospice care and possibly to identify the unique needs that can be addressed in hospice care in the future. Therefore, the researcher conducted qualitative interviews with Hispanic family members that had a loved one who received hospice care within the last year at Vitas Innovative Hospice Care®. The hospice agency was selected because the researcher was an intern for one year and was familiar with the staff and the agency. The researcher met with the bereavement manager, Loraine Hedkte, who facilitated the

approval. Mrs. Hedkte met with the authority gatekeeper, Steven P. Girod, general manager, explained the study and acquired the permission for the study to be completed.

### Selection of Participants

The method of sampling was purposive sampling. According to Morris (2006) this type of sampling involves choosing participants that will be best equipped to provide the most specific data related to the research topic. The researcher believed that this type of sampling would be most appropriate because it would provide the most precise data. The reason is that this study aims at acquiring individuals' phenomenological experiences and to achieve this understanding only those who lived through hospice and death can describe their experience authentically and accurately.

Mrs. Hedtke provided the researcher with a list of 40 family members who experienced the death of a loved one during August of 2007 through August of 2008 while receiving hospice services. Contrary to the original plan, participants were contacted twice by mail and up to three times by phone. The first letter was mailed early July of 2008 and was followed by a phone call or a phone

message. After two weeks with no response a second letter was mailed followed by another phone call or a phone message. A third and last phone attempt was made and if no response was received the name was removed from the list. Most of the family members did not respond to the calls or mailings, others declined to participate and others had moved away. Out of the 40 family members, 10 agreed to participate in the study. The interviews were conducted in Spanish and in the participants' homes. By early September the researcher had completed all ten of the interviews. It took approximately two months for the data gathering process to be completed.

Although this was a qualitative study the first part of the interview consisted of demographic information. All of the participants were female and only one male participated with his wife in the interview. Their marital statuses included being married, widowed, single and divorced. Although the researcher had hoped for a diverse Hispanic population, the participants' country of origin consisted primarily of Mexico and one was from Central America Their level of education ranged from the majority having no school to having a college degree. Their religious affiliations consisted of Catholicism,

Christianity and Seventh Day Adventist. Their years in the United States ranged from eight months to 44 years. Their relationship to the deceased varied from being parents, siblings, spouses and children of the deceased. This data is presented in more detail in table 1.

#### Data Gathering

Since this study was conducted using the post-positivism paradigm, qualitative data was gathered. A structured questionnaire was created and translated into Spanish (see Appendix C). Once contact was made with family members and questions were clarified, ten agreed to participate in the study. Interview dates were scheduled at the convenience of the participants in their homes. Interviews were conducted in the evenings and on weekends.

Table 1. Demographics

Variables N = 10	Frequency (n)
<b>Gender</b>	
Females	10
Males	1
<b>Marital Status</b>	
Married	2
Single	2
Widowed	5
Divorced	1
<b>Country of Origin</b>	
Mexico	9
Guatemala	1
<b>Level of Education</b>	
No schooling	2
Elementary- but did not finish	2
High School- but did not finish	3
High School Graduate	2
College/Academy Degree	1
<b>Religious Affiliation</b>	
Catholic	5
Christian	4
Seventh Day Adventist	1
<b>Years in the United States</b>	
8 months	1
1 -10 years	3
10-20 years	2
20-30 years	2
30-40 years	2
<b>Relation to the deceased</b>	
Parent	3
Sibling	1
Child	4
Wife	2



## Phases of Data Collection

The four phases of data collection, engagement, developing and maintaining the focus and termination guided the interview.

1. Engagement phase. The interview was conducted in the participants' home. There, the informed consent was read by the participant and in some instances the researcher read it to the participant. The participants' acknowledged their agreement to participate and to be recorded by checking the box on the consent form. Questions from the participants were addressed at that time. Most of the participants' questions asked for clarification on the purpose of the interview. Demographic questions and general questions such as how they were doing were utilized at this time to build rapport and to get to know the participant.
2. Development of the focus and maintaining focus occurred simultaneously. Participants were asked questions using the structured questionnaire. The questions began with asking

about their spiritual and cultural meanings of death and were followed by questions regarding their experience in hospice care. Questions such as did staff ask them about their spiritual beliefs and how it was or was not helpful were asked. The researcher was asked to clarify some of the questions. For instance, the question that asked what their culture taught them about death was often not understood.

3. Termination phase. In this stage the debriefing statement was read to the participants and questions from the participants were addressed. Referrals to community support groups and the Vitas Memory Bear program were offered. Finally, the participants were verbally thanked and given a five dollar international calling card.

#### Data Recording

The interviews were recorded using a digital voice recorder. The day after the interview the researcher transcribed the data using a laptop computer. The

transcripts were saved in CDs that were stored in a locked cabinet. The researcher transcribed and translated the data simultaneously into the English language to facilitate data analysis because the interviews were in Spanish

The researcher took a copy of the questionnaire to the interview to help guide the interview and took hand written notes. After each interview the researcher documented reflections about the interview in a journal. The researcher also documented any similarities found among the interviews. Modifications made in the questions were also documented in the journal.

#### Summary

This chapter discussed the selection of the site and study participants, the data gathering and the data recoding methods used in this study. It clarified why and how the research site was selected. It also explained the selection of the participants, the sampling process and described the demographics of the participants. It explored the data gathering process using qualitative interviews and the different phases of the interviews.

Last, it explained the data recording methods using audio recording and written documentation.

## CHAPTER FOUR

### EVALUATION

#### Introduction

In post-positivism the process of data analysis and interpretation involves open coding, axial coding and selective coding. According to Morris (2006), open coding is the process where themes are extracted from the narratives then placed in categories and given a dimension. Axial coding is further analysis of the data by linking the categories with its dimensions and selective coding is developing a theory based on the relationship of categories and dimensions (Morris, 2006). This chapter discusses how the data, narratives provided in the interviews, were analyzed using open coding, axial coding and selective coding to develop a theory. Further, the theory is explained in terms of its implications for the micro and macro practice of social work. Last, it explores limitation of the study.

#### Data Analysis

Using open coding several themes were identified and placed into categories. The following paragraphs explore the categories developed and explain in detail the themes

selected. It provides supporting data from the narratives to illustrate the reason the themes were selected. Each paragraph is headed by the category that the themes were grouped into and then explores the themes selected.

#### Beliefs about Death and Caring for Loved Ones

To help social workers understand Hispanics' experiences with hospice and how to help Hispanics using hospice services the study examined cultural beliefs. Participants' cultural beliefs on death and dying and caring for their loved ones were explored. In the narratives the following four themes were identified: peace and resting time, a destiny, a part of life, a cultural and religious interconnectedness and the belief that family should take care of their loved ones.

The following figure illustrates the open coding for the four themes identified. The themes were grouped in a category of beliefs about death and caring for loved ones. The dimensions range between culture and religion and were created because participants' explanations of death had spiritual and cultural interconnectedness.

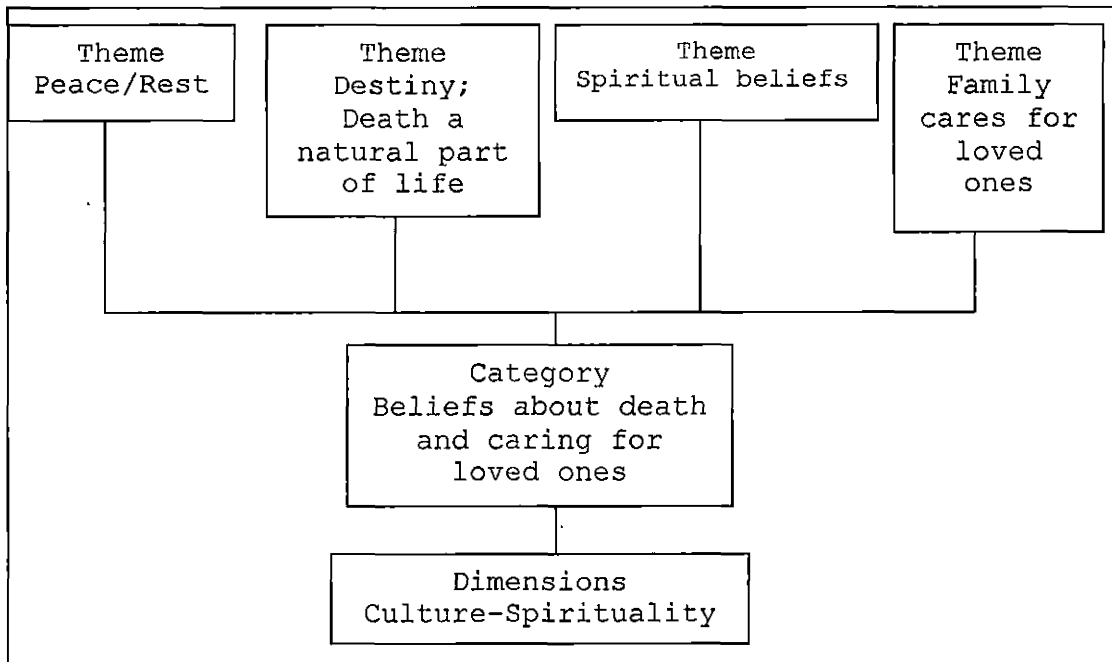


Figure 1. Beliefs about Death and Caring

Six participants described death as peace and a resting place. For instance, one participant stated that death was peace because their loved one had suffered so much. Another participant said that the patient felt at peace because of the patients own spiritual beliefs. Other participants explained death as a step towards heaven to rest or that their loved one was resting in peace.

Six participants also explained death as a destiny, a natural part of life. For instance, one said "we are not eternal, one is born and one has to die some day". Another said "it is a step that everyone has to take" and

another said "we are here until GOD wants and it is something natural".

In relation to spiritual definitions all of the participants associated culture with spirituality in their cultural explanations of death. One participant stated that "if we are with Jesus in life He would have a spiritual place for us". Similarly, another stated that "Jesus would come for His church, meaning His followers". Two participants talked about resurrection mentioning that death does not exist that we will resurrect when Jesus returns for us. Three stated that there is another life after death, that there exists an eternal life. One stated she believed her mom was with GOD and two participants stated that death meant going to heaven and that their loved one was in heaven. However, only one participant believed that there was nothing after death, it was simply eternal rest.

When asked about what their culture taught them of who should care for their loved ones, all participants mentioned that family should have a role in the caregiving. However, three participants mentioned that some circumstances require the help of professionals, such as nurses or nursing home care.



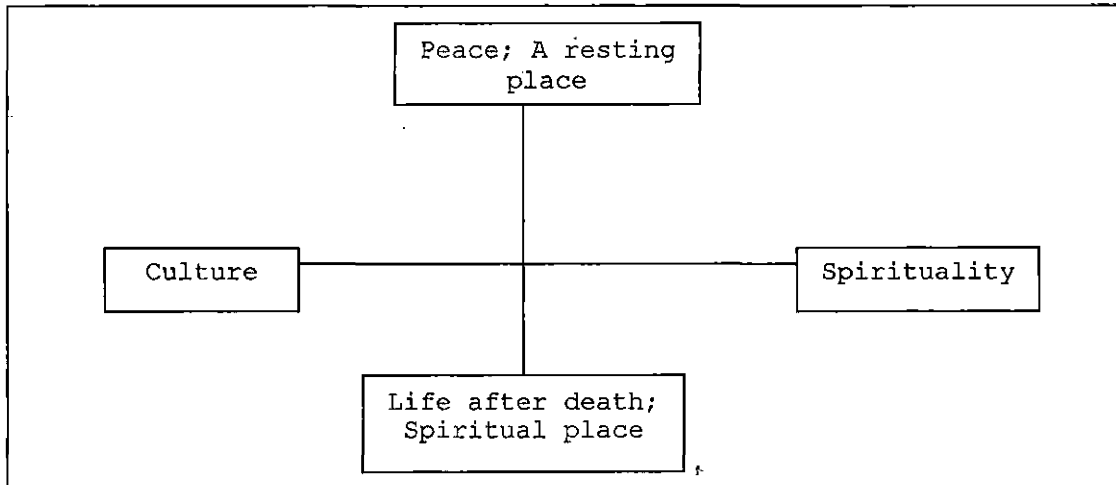


Figure 2. Quadrants- Beliefs of Death/Culture and Spirituality

Next, the researcher examined the relationship between the category, beliefs about death and their connections with the dimensions of culture and spirituality in the axial coding process. The answers the participants gave on what their culture taught them about death was interconnected with spirituality.

Participants' explanation of death fell into all four quadrants. Their cultural explanation of death was that of a time of peace and a resting place after suffering from an illness. They also explained death as a part of life that everyone must endure. More often the participants provided spiritual explanations when asked about their cultural view of death. They stated that they

believed in a life after death, a step towards heaven, if you believe in GOD and behave well you go to GOD, that we are here until GOD wants and GOD has us here for a certain time. Therefore, their view of death falls within all four quadrants since it appeared that their cultural and spiritual explanations of death overlapped.

#### Respect of Hispanics' Culture

It was important to explore the participants' experience about if and how their culture was respected and if there was anything more that could have been done to respect their culture. Participants were asked if staff inquired about their cultural beliefs and seven participants answered no, two did not remember and only one said yes. When asked if their culture was respected nine acknowledge that their culture was respected and one felt the contrary.

Although, most participants were not asked about their cultural beliefs or practices, they felt their culture was respected and explained how respect was demonstrated. The following themes were identified in their responses: good care was provided for their loved ones, Spanish speaking staff was provided and one

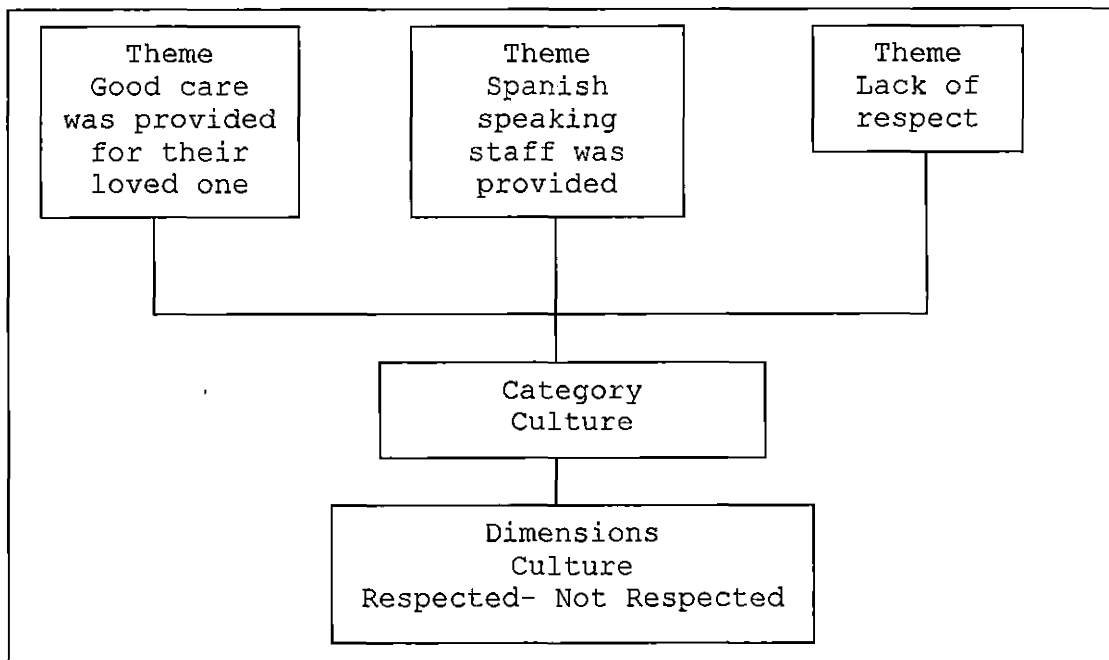


Figure 3. Respect of Culture

participant explained how respect for their culture was not demonstrated (See figure 3).

Seven participants stated that although no one asked about their culture they felt "good" about the care provided by the staff. One participant stated she was happy with the care provided by staff because her daughter was happy during the last days of her life, her daughter had chosen the program because she wanted to be at home. Two participants stated that staff treated their father and brother well and when they called hospice they received help. One stated "they treated my father as a human being without the need to be identified as a

Mexican". Similarly, another participant stated that although unhappy with the lack of Spanish speaking staff, the staff did their job and treated her mother like a person. Another participant stated that cultural respect was shown by helping her take her son home and helping with his care. Three participants stated that respect was shown by providing Spanish speaking staff. One participant described how staff and the participant traded recipes, joked and listened to her husband's requests and that demonstrated respect for her culture.

During the interviews six of the ten participants reported having at least one hospice staff member that spoke Spanish at one point in the care. Two of the four participants who did not have a Spanish speaking staff stated that they would have preferred it, however they were satisfied with the care provided to the patient. Both of these participants had someone in the home to translate. The remaining two participants without Spanish speaking staff were unsatisfied with hospice care. One stated that she did not feel her culture was respected. This participant stated that staff did their job however she was not able to understand what was happening at the initial sign up or during the care and felt that staff

did not make any attempts to help the participant understand. The other participant without Spanish speaking staff hesitated and stated she felt that staff did their job, treated the patient as a person however felt that the lack of Spanish speaking staff was a negative experience. These two participants did not have someone in the home to translate.

Next, the relationship between cultural respect and the staff and care provided is examined using the axial coding (See figure 4).

Participants fall into the four quadrants displayed in Figure 4. Based on the narratives, respect was shown through the provision of good care for their loved one's regardless of not being asked what their cultural beliefs or practices were and some did not have Spanish speaking staff. There were also participants that through the provision of Spanish speaking staff felt that their culture was respected. Contrarily, two participants had a negative response regarding respect for their culture even though they reported their loved one had proper care. They stated the reason was due to having difficulty communicating and understanding staff.

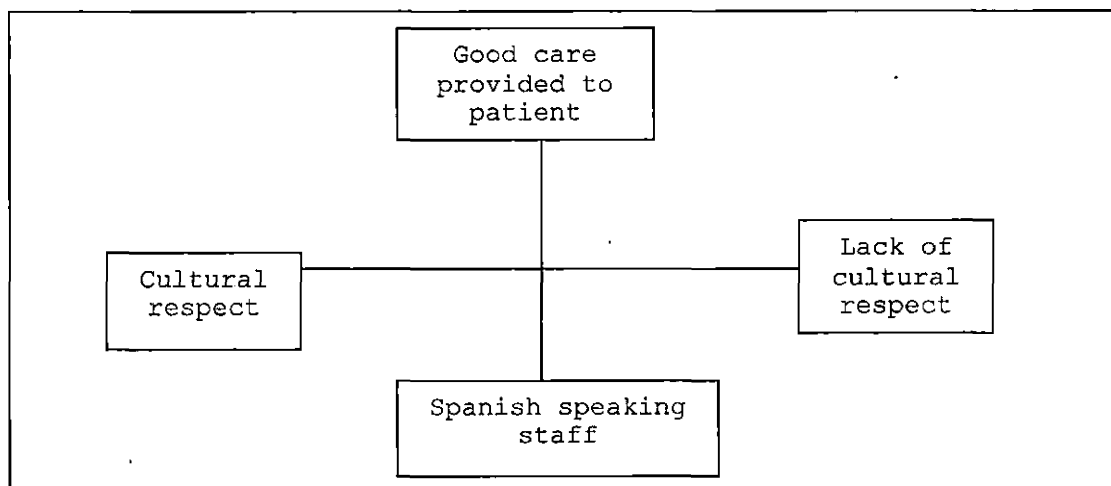


Figure 4. Quadrants - Respect of Culture with Care and Language

Experience with Respect towards Spirituality

When participants were asked about culture and death the majority of their answers had a spiritual undertone. Therefore, it was important to explore and understand the participants' experience and the role that spirituality plays with Hispanics during death and dying. All ten participants mentioned spirituality as an important part of their experience. Three themes were identified in these narratives. Participants either had spiritual support from hospice, or from their religious organization. Others were not offered support but were satisfied with the overall care provided. Others were not offered spiritual support but would have preferred if

spiritual support were provided by hospice (See Figure 5.)

The majority of participants stated that staff did respect their religious or spiritual beliefs either through offering spiritual support or respecting their religious practices. Yet others without hospice's spiritual support highlighted the care provided to the patient as equally valuable. One participant described the support provided by the Spanish speaking chaplain as "she understood the hope I had." Another participant stated how the patient appeared to calm down after the prayer lead by a priest sent by hospice. Another participant stated that a female chaplain from hospice went to the home however, due to the religious beliefs of the patient, the chaplain was turned away but appreciated hospice's respect for the patients request and beliefs.

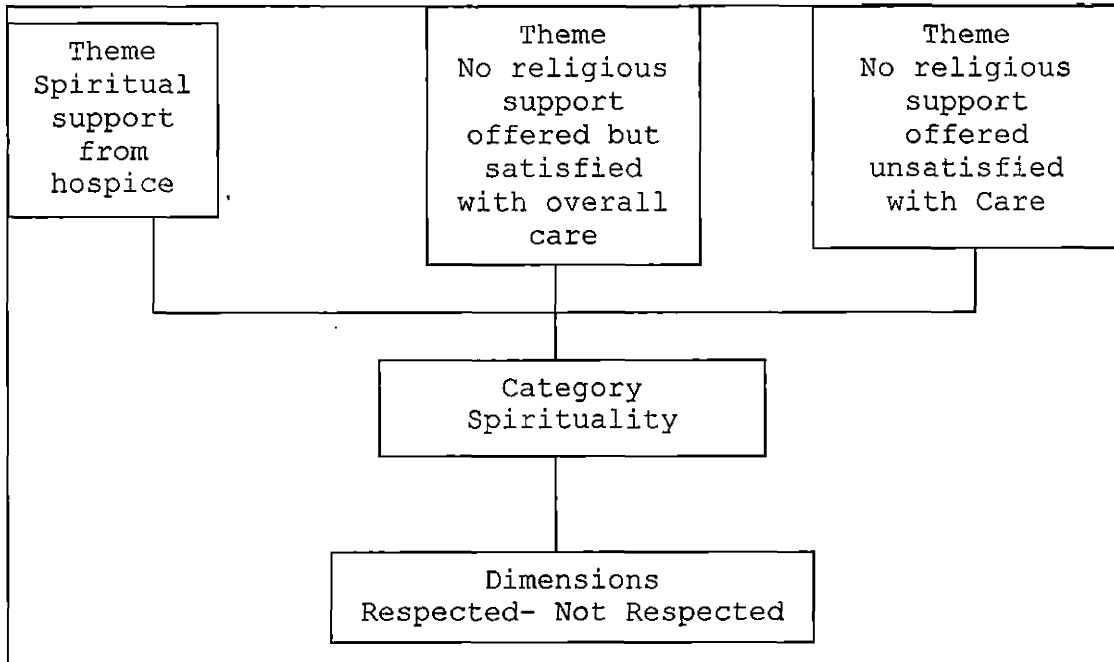


Figure 5. Respect for Spirituality

One participant stated that although hospice did not provide a chaplain or spiritual support they received a lot of support from their religious affiliation. This same participant stated that the care provided to their daughter was good and that was what the family valued most, that "it was wonderful that resources like these are available to those who lack resources." Similarly, a participant stated that they called their own pastor for prayer, but she was very satisfied with the care provide by hospice because she did not feel alone. Another participant stated that no spiritual support was offered however, they had neighbors and a priest or pastors of



diverse religions pray for the patient and that the staff present was respectful. This same participant also stated that she was satisfied with hospice care regardless of the spiritual support because she had others provide it.

However, four participants stated that hospice did not offer spiritual support. One participant stated that spiritual support was not offered or provided and would have preferred it. However, she was appreciative that counseling was offered. Another participant stated that she did not like that a chaplain or prayer was not provided. Two participants stated that nobody offered spiritual support and they would have liked to receive that service. One of them stated that her religious beliefs were not respected as she had no spiritual support, no Spanish speaking staff and was not satisfied. This participant's loved one was on hospice for only a few hours. However, she was appreciative of the referral to the funeral home. The other participant stated that pastoral help was offered but never provided and would have liked them to provide prayer. However, they had a priest from a local church visit.

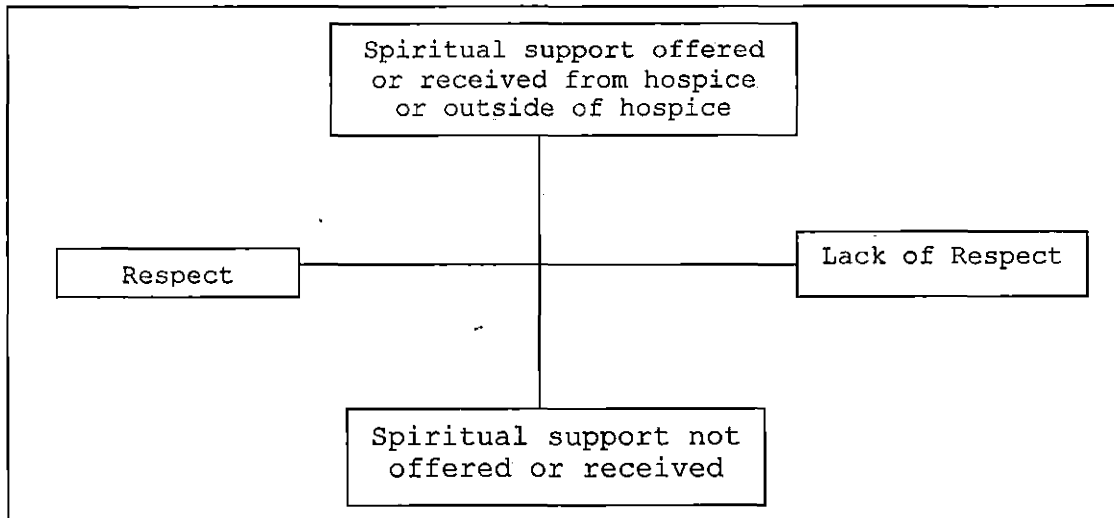


Figure 6. Quadrants - Respect with Spiritual Support

Next, the relationship between receiving spiritual support from hospice and perceptions of respect are examined (See Figure 6). Participants' responses fall into one of these four quadrants.

It appears that those who received spiritual support from the hospice agency felt their spirituality respected and welcomed the support. Similarly, those who accessed spiritual support from their religious ties either by preference or because hospice did not offer it, also felt respected in that their loved ones were taken care of in other ways by the rest of the staff. However, two participants who did not receive spiritual support from hospice were not satisfied with the overall care due to lack of Spanish speaking staff. It appears that the

combination of not having the Spanish speaking staff and lack of offering spiritual support contributed to their reports of experiencing a lack of spiritual respect.

#### Experiences with Communication

To understand the experiences of the Hispanic population with hospice care an analysis of communication is essential. This information will help in understanding what kind of communication was helpful as well as what can help improve the communication to make the hospice experience a positive one. When examining the narratives the following themes were identified as staff respecting the patients' wishes and that they felt comfortable with calling and asking staff for help. However, there were also some experiences of poor communication. The following figure illustrates these three themes categorized as experience with communication with dimensions ranging from positive to negative.

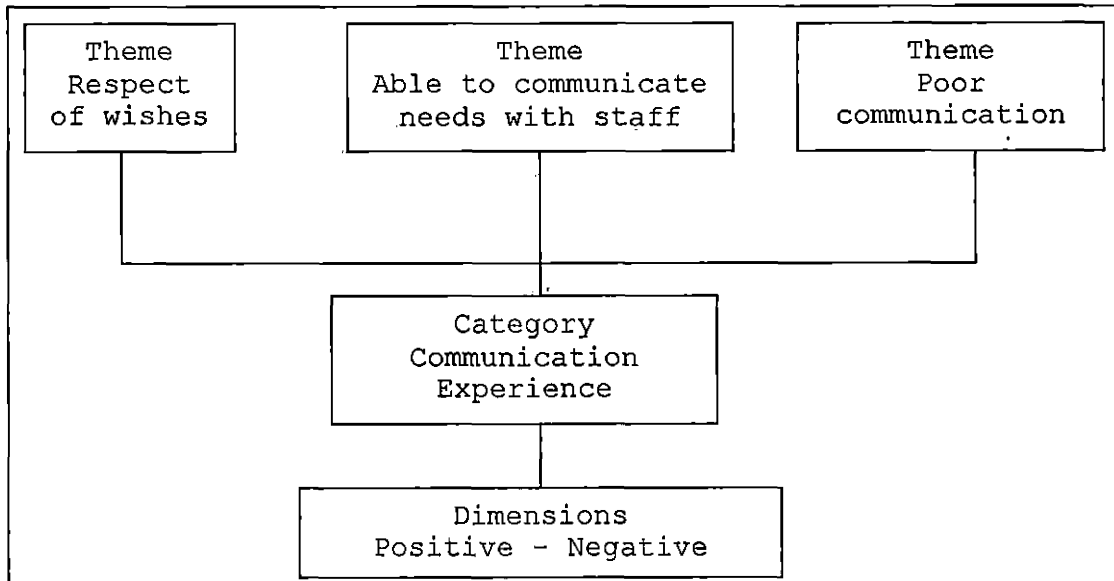


Figure 7. Communication Experience

Respect of patients' wishes was identified as a theme because several participants mentioned how staff listened to the patient and respected their desires. For instance, one participant stated that the patient was a nurse's aid and spoke English and never complained. This patient was comfortable with her pain under control and that was what the patient wanted. Similarly, another participant stated that the wishes of the patient were respected in that the patient was well taken care of and the pain under control. One participant noted that although the patient was too ill to notice, the family noticed that the patient was comfortable and calm once the patient was under hospice care. Further, two

participants mentioned that the staff listened to the patients' wishes when they did not want to take a shower or take the pain medications. Two other participants stated that the fact of being able to bring the patient home was a demonstration of respect to the terminally ill patient.

The ability to communicate needs to staff was selected as a theme because the majority of participants concurred in that they were able to communicate with staff. Two participants mentioned that they felt "comfortable" asking for help because when they needed something they could call and get the help. Two participants' acknowledged how having Spanish speaking staff made communicating their needs possible. One participant stated "I was enchanted because I could communicate with them." Yet another mentioned how the patient looked forward to the aid's visits because they were friendly, caring and talkative. Four participants had the benefit of having a person in the home that spoke Spanish and facilitated the communication when needed. However, two of them would have preferred a Spanish speaking staff so they would have understood and communicated more easily with staff. Further, eight of

the participants expressed that staff was able to explain what was happening so that they were able to understand the care being provided to their loved one. They described the program as a program that provided "comfort" and "pain relief."

Last, the theme of poor communication was chosen because three participants described their frustrations with not being able to communicate with staff and the researcher found their experience valid and worth noting. One participant stated that none of the staff spoke Spanish. This participant described her experience as "these are difficult moments and I did not like it because a lot of things I did not understand and I made a decision I did not understand ... they injected my mom and I did not know what it was... I did not know they were going to stop her regular medication." Similarly, another participant mentioned that although the nurses and aids were good, at the initial sign on for hospice she understood that the program was going to provide comfort and pain relief but did not understand the extent of hospice services and would have preferred a Spanish speaking person to explaining the program. Another participant described that only the bathing aid spoke

Spanish, the nurses did not and that it was difficult for them to communicate with each other. This participant stated that it was difficult to communicate the dosages of morphine. This participant's mother lived a block away and her sisters were constantly calling her to try to translate and she was not always available. Similarly, these two participants did not believe they understood the care being provided to their loved one by hospice staff.

Upon further exploring the participants experience with communication whether positive or negative, it was found that the majority of the participants fell in the positive quadrant. Figure 8 illustrates the four quadrants.

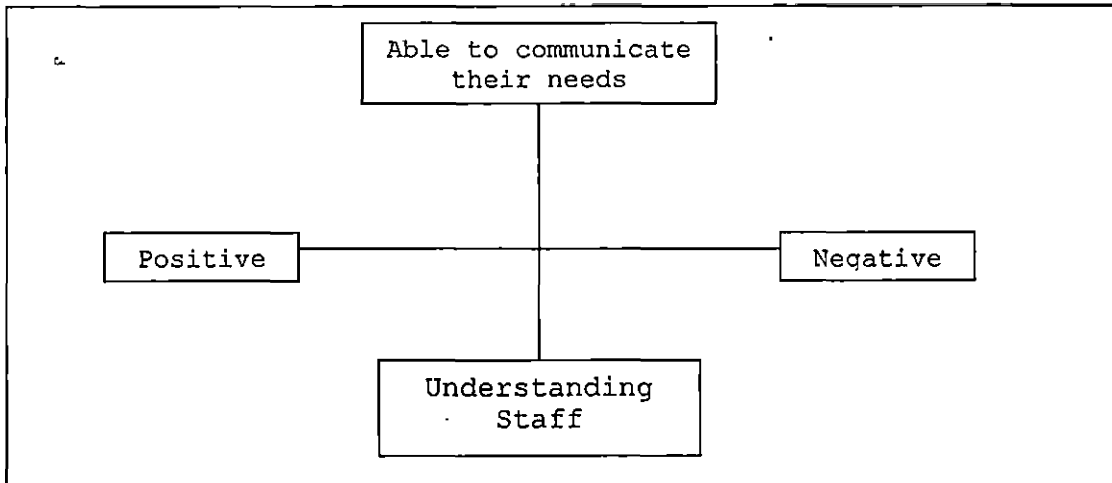


Figure 8. Quadrants of the Communication Experience

The majority of the participants were able to communicate their needs to the staff and understand staff either through Spanish speaking staff or the availability of family translators. Those who fell in the negative quadrants were not able to understand staff and were not able to communicate comfortably their concerns. These participants stated that they did not have Spanish speaking staff available, hospice did not provide translators and the family did not have family members readily available to assist with translation.

#### Participants' Perception of Hospice Care

In an attempt to explore participants' overall experience of the program the research inquired about the participants' prior knowledge of hospice programs, their



initial understanding of the program and if it was a program they would recommend. The common themes identified were: that for all of the participants this was their first experience with hospice care, overall they described their experience as good, they preferred loved ones to be at home and they would recommend it to others. (See Figure 9.)

Prior knowledge of hospice was identified as a theme for two reasons. One reason was that all ten participants stated that this was their first experience with hospice. The second reason was because prior knowledge of hospice care would have had an impact on the participants' preconceptions of hospice and their experiences. However, in this study all participants had never experienced hospice care and therefore they had a clean slate from which to evaluate the program.

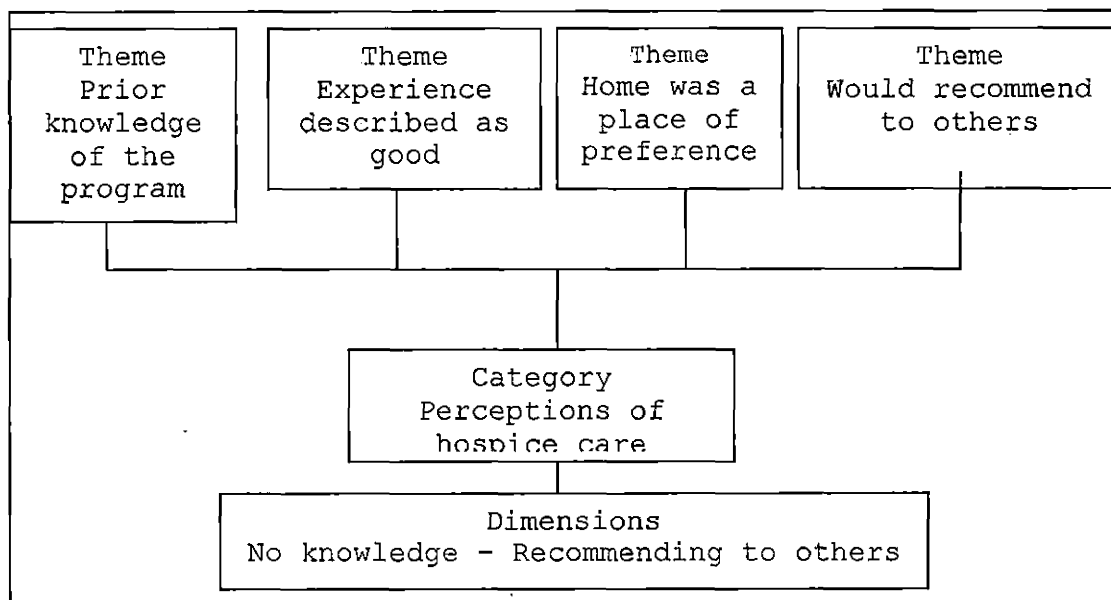


Figure 9. Perceptions of Hospice Care

The theme of hospice care described as good was selected because eight of the participants described their experience as a positive experience. One participant stated "we are so grateful for the program ... the organization helps death to be without pain ... grandiose help, without the morphine my daughter would have died of the pain alone." Another participant stated that her son was well taken care off and his pain controlled and she did not think she would get this help because they did not have money. Similarly, other participants stated that their loved ones were at peace. Another participant stated that although at first she did

not understand that concept, she felt the program was good because it offered her mom relief from pain. Other participants stated that staff such as nurses, did their job and it was a good job. Two participants mentioned that being able to take their loved one home was a benefit and one of them stated that not being alone with the patient's care was a "big help,"

However, the two participants who had poor communication experience with hospice staff did not have a positive overall experience of hospice care. One of them stated "there was no attention ... they did their work, paid no attention to us, I did not speak English and they had no patience." The other participant, although unsatisfied, mentioned that the concept of taking her mother home made her mother happy and that was important.

Recommending hospice to others was selected as a theme was because the majority, nine of the ten participants stated that they would recommend it. Two of them had already recommended it. One stated "I have told others how it helped me." Another said they would recommend it "because I was not alone." Although one participant did not clearly state she would recommend

hospice she stated "thank GOD for this program being available for people during their last days." One of the participants who rated her experience as poor stated that she would recommended it because of the hospice concept however emphasized that communication was a big problem in her experience. The other participant that also had a poor experience did not state whether or not she would recommend it, however she suggested that more Spanish speaking staff should be made available.

Being able to take their loved one home was identified as a theme because most participants, eight of the ten, mentioned that the preference of their loved one was to be at home and not living out their last days in a hospital. One participant stated she was happy with hospice because her daughter wanted to be home with family. Two participants stated that their loved ones wanted to be home. Another participant stated that her cultural preference dictated for loved ones to be at home. Yet another stated that her son was "happy at home." One participant stated that although they hesitated bringing her father home because of concerns of not being able to care for him the family and the patient preferred him to be home. Another participant felt

satisfied that her husband spent his last holidays at home with family instead of in a hospital. Of the remaining two participants, one had their loved one on hospice for a few hours at home and was more focused on the issue of poor communication due to language barriers and the other participant was in nursing home because family was not available to care for their loved one during the day.

Next, the relationship between participants' overall experience of hospice care and having no knowledge and recommending it is explored. Figure 10 illustrates the four quadrants regarding knowledge, hospice experience and recommending hospice.

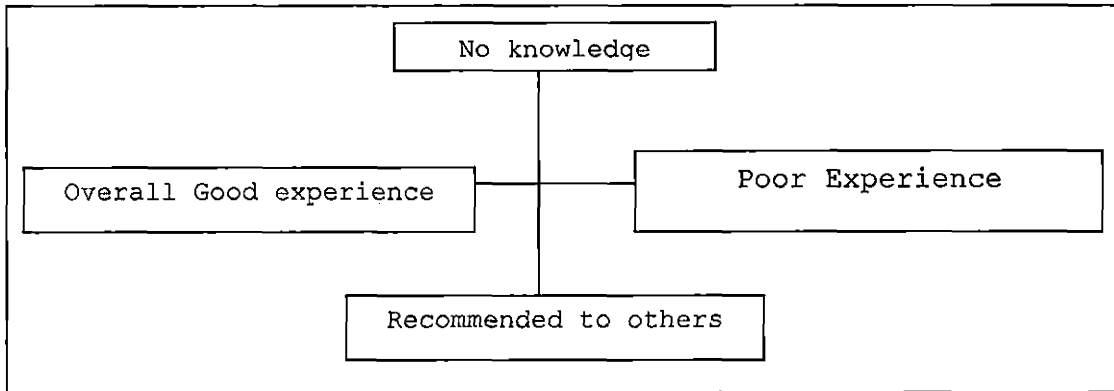


Figure 10. Perceptions of Hospice Care

All participants stated that this was their first experience with hospice care services. Those with no knowledge who had overall a good experience with staff would recommend it to others. Similarly, one participant who had no prior experience with hospice and described their communication as poor stated would still recommend hospice care because of the concept of caring for the terminally ill at home. The other participant who had a poor communication experience would not say if she would recommend it. However, she mentioned that Spanish speaking staff should be available and also noted that her mother was on hospice for a 10 hours and that probably did not help with her experience with hospice care.

## Data Interpretation

According to Morris (2006) selective coding is the “process of integrating and refining the categories and their dimensions to develop a theory” (p. 116). The next paragraphs will explore the analysis of the narratives that guided the development of the theory. The following is an analysis of the stories extrapolated from the narratives within each category and their support from the previous literature review. Further, the connection among these stories was identified and a theory was developed. To help explain the findings, the following figure illustrates the connections between the categories and dimensions and how these were found to have a connection with the category of perceptions and its dimensions of prior knowledge and recommending hospice care.

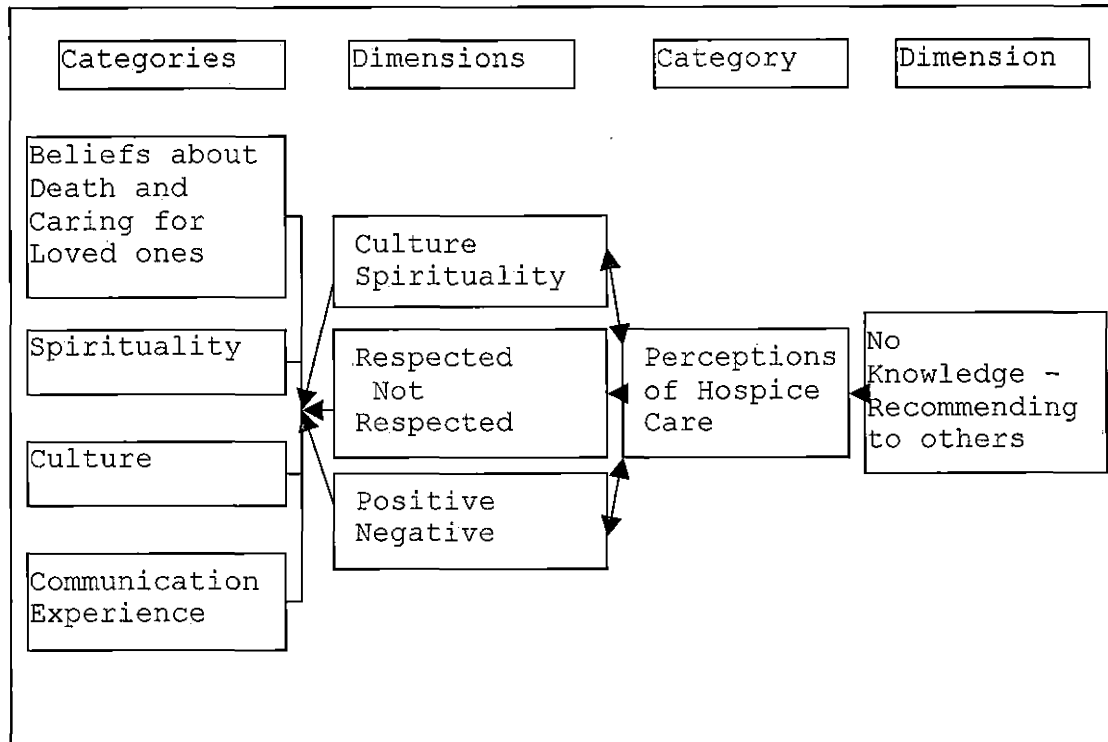


Figure 11. Themes, Categories and Dimensions their Connections

Beliefs about Death and Caring for Loved Ones

From the narratives it appears that for Hispanics culture and spirituality are interconnected. When the participants spoke about their cultural beliefs regarding death the majority answered in reference to their spiritual beliefs. This statement is supported by the words used by participants to explain their cultural understanding of death: heaven, place where GOD is, resurrection, Jesus will come for us, a spiritual place and eternal life. One participant described death as a



destiny, a part of life; it is up to GOD to determine when we come and when we go.

Although the literature review in this study found little research on spirituality and hospice care, Adams et al. (2005) found in their study of 294 Hispanic families that 86% were Catholic. Further, Born et al. (2004) found that spirituality was important in helping Hispanic families handle death. This is supported in this study in that all participants had a religious affiliation, eight of them were Catholic, one was a Christian, another was a Seventh Day Adventist and they all described cultural aspects of death in terms of spirituality.

In the literature review, Scharlach et al. (2006) found that Hispanics put a significant value on caring for their loved ones, they are not in favor of nursing home placement and they get personal pride from caring for their loved ones. Similarly, in this study all participants' stated that family should take care of their loved one. However, one variation of this was that professionals should care for their loved ones if their health requires the care of medical professionals in a nursing home or a hospital.

## Respect of Hispanics' Culture

What was the participants' perception of the respect demonstrated towards their Hispanic culture? The stories found within the narratives were that respect was demonstrated with more than just having a Spanish speaking staff. This study found that culture was respected not only through acknowledging nationality or respecting their spiritual beliefs but by the care provided to the patient. Seven participants stated that respect was demonstrated through the good care given to the patient. The words found in the narratives were my daughter was happy, everything was good, they listened, they helped, they treated the patient like a human and they did their job. One previous study alluded to this finding. Gelfand et al. (2004) found that it was important for Mexicans for staff to know the culture but not necessarily to be of Hispanic decent.

However, Spanish speaking staff were provided to six of the ten participants and two participants stated that the provision of Spanish staff was a show of respect to their culture. All participants agreed that having Spanish speaking staff was helpful. Two participants who reported having a few interactions with Spanish speaking

staff reported they had translators and reported good care was provided for their loved one. However, two participants reported their culture was not respected because of the lack of availability of Spanish speaking staff. One of these participants did not like the care that the staff provided to the patient either and the other participant had the patient on hospice for only a few hours.

#### Experience with Respect towards Spirituality

What were the participants' stories regarding hospice's respect towards their spirituality? Previously the research explored the emphasis on spirituality that Hispanic participants placed in their experiences with death. In terms of the respect shown by hospice the findings were mixed, the majority felt respected and a few did not. However, the common thread identified was that the care for the patient was what was valued the most. Eight of the participants answered yes to the question, about their spiritual values being respected. Although only three participants reported being offered chaplain support, most participants used their own pastors or priests for prayer and felt staff respected that.

Of the three participants who received spiritual support through a chaplain, two were very grateful and the other appreciated that Hospice respected the patient's preferences when the chaplain was turned away because she was a female. One participant described how the patient became calm and at peace after the prayer provided by a priest sent by hospice. Three of the participants were not offered spiritual support. However, they were satisfied with the overall care provided to the patient. One stated that their family and friends prayed and stated how staff was respectful during prayer. Another stated that they had their own spiritual support but were happy because their daughter was happy with the care provided by staff. The other participant was simply happy with staff being available to care for their loved one. The remaining four participants who did not receive spiritual support stated would have liked the spiritual support. However, one stated the overall services were good and the other stated even though she was not offered a chaplain she was offered counseling.

In this study participants demonstrated placing a significant value on spirituality. This study found that participants prefer having spiritual support during these

times. Those who had spiritual support appreciated and benefited from it and those who did not would have liked it.

### Experiences with Communication

The participants' stories regarding their experiences with communication ranged from positive to poor communication. In this study good communication was found to encompass respecting patient's wishes and having Spanish speaking staff available. Poor communication was explained as not having Spanish speaking staff or translators available.

The ability for the patient to have their wishes respected was also important to the participants. The words used to explain respecting wishes were being able to be at home, comfort and pain control provided by staff and staff listened to the patient if they did not want a shower or to take a certain dosage of medication. Communication was valued in terms of providing the care the patient needed or wanted to maintain the patient comfortable and respect their wishes. The patient still had some control over what was happening.

Another positive experience with communication was being able to communicate their needs to staff. As

previously mentioned seven participants had at least one hospice team member that spoke Spanish and those participants reported being able to communicate comfortably. However, not all of the hospice team spoke Spanish and most participants had a Spanish speaking person available to translate their needs or questions. Overall eight participants felt that they were able to communicate their needs.

Poor communication experience was described by two participants. These two participants were not provided Spanish speaking staff and did not have translators from their family nor were translators provided by hospice. They reported having a difficult time understanding what was happening with the patient's care and had difficulty with communicating their concerns to staff.

#### Participants' Perception of Hospice Care

In examining the stories of Hispanics experience with hospice care four ideas were extrapolated: prior knowledge of hospice, overall how they described their experience, their choice of placement and would they recommend hospice. The participant's narratives demonstrated that all ten participants did not have prior knowledge of the existence of a hospice program nor did

some understand it fully once utilizing hospice services. This supports the previous literature review that found language barriers, lack of education, being unaware of the existence of hospice care, lack of knowledge and understanding about hospice services, low socioeconomic status, concerns about cost, discrimination, and differences in philosophy of death and dying to be factors in the underutilization of hospice services (Born, Greiner, Arnp, Butler, & Ahluwalia, 2004; Gordon, 1996; Gelfand, Balcaza, Parzuchowski, & Lenox, 2004; Randall & Csikai, 2003).

Overall the participants explained care as good and stated that they would recommend the program. When the participants assessed hospice they talked about comfort care, pain relief and being able to care for the patient at home. These terms defined both their understanding of the program and what they valued about the program. Some participants stated that they valued being able to take the patient home because that was what the patient wanted or would have wanted. Most participants noted how they valued having professional help for the medical needs of the patient. Eight participants described their hospice

experience as good. Eight would recommend it to others and two would recommend a better communication processes.

### Theory

The theory found was that the experience of hospice care is evaluated primarily by the quality care provided to the patient rather than the focus on culture and spirituality. Although, spirituality was found to be an important component in the culture of the Hispanic population in dealing with issues of death, this study found that patient care transcended religion and culture. Quality care for the patient was found to be the underlying theme among all the categories explored. How was culture respected? Most participants agreed that respect for culture was displayed through the good care provided to the patient and that was what they valued. How was spirituality respected? Participants stated that respect was provided through meeting the patient's needs and wishes. How was their communication experience? Participants responded positively when their loved one's needs were heard and met. The common denominator here is the value placed on the care and attention paid to the needs of the patient.



Let us further examine Figure 11. This figure illustrates how beliefs about death and caring for loved ones, spirituality, culture and communication are connected with culture and spirituality and their evaluations of their negative/positive experiences of respect. Further, all of the above influenced their perceptions of their hospice experience. Participants' perceptions of hospice care was found to revolve around the quality of care provided to the patient. Upon further dissecting patient care, attached to expectations of quality care are values and values come from beliefs that come from culture or spirituality. Therefore, if hospice staff provided quality patient care then hospice staff indirectly met the cultural and spiritual components of and individual. Further, this study found that without having prior knowledge of the existence of hospice programs, participants were willing to recommend the program on the basis of their evaluation that was primary based on the quality of patient care. However, it would be irresponsible not to mention that having the availability and accessibility of Spanish speaking staff was identified as a helpful component in addition to the provision of quality care.

## Implications of Findings for Micro and Macro Practice

From the micro perspective this study contributed to social work knowledge in that it provided insight into the factors that are involved in Hispanics' definition of a good experience with hospice care. This information is useful because it provides social workers with the knowledge they need to provide more sensitive care to Hispanics and their families on hospice.

At the micro level, for these participants the most important component described was the provision of good care for the patient. Therefore, it was the caring staff that took good care of patients, that listened and addressed their needs for comfort and pain relief that was important. These findings are a testament for the hospice team, composed of doctors, nurses, social workers, bath aids and chaplains to understand the value placed on patient care.

An important idea to take from this study is that in the death and dying experience for these Hispanics, care, comfort and communication was what mattered most not the attention paid to their culture. Therefore, rather than placing a cultural label or having a predisposed idea of

a patient based on their culture, hospice professionals should focus on the quality of care and on ensuring good communication.

Some professionals know little about certain cultures or may make inaccurate generalizations about Hispanic cultures regardless of the country of origin or level of acculturation. According to Monk, Winslade and Sinclair (2008), culture is a social construction rather than a truth. They state that culture is made up social discourse not solely on ethnicity, age, gender, religion or environment. Culture is not an "objective truth" based on what country they are from (Monk, Winslade & Sinclair, 2008, p. 33). Therefore, hospice staff should focus more on patient care and treating the patient with dignity and respect rather than trying to place a cultural label on them. Care and compassion transcended language and culture. Care and compassion seem to be universal concepts in hospice care. This is an area that merits further research.

Further, culture may sometimes become a barrier to quality care in that professionals may choose to maintain distance between them and their patients due to feeling inadequate from their lack of knowledge and understanding

of the culture and fear of disrespecting them. However, in this study lack of cultural knowledge did not hinder or help the experiences as it was the good care provided to the patient and the ability to communicate needs and concerns that mattered.

Participants also concurred that the accessibility of communicating with staff in their language or through a translator was important. Good communication leads to feeling heard, respected, understood and valued. Participants explained good communication as having Spanish speaking staff, as being able to get help when needed, as understanding what was happening and as respecting the wishes of the patient. This is important for social workers to be aware of. Providing Spanish speaking staff as well as staff that listen and respond to their needs and concerns is important. Not necessarily does all staff have to speak Spanish. The accessibility of having at least one Spanish speaking staff available was valued.

Further, in regards to spiritually, professionals should be aware that the Hispanic population is highly spiritual. They value and are highly receptive to spiritual support. Therefore, hospice professionals

should be sensitive to the spiritual needs of the families and provide them with needed spiritual resources since spiritual support is part of the hospice concept. This study found that participants explained death using spiritual terminology. Therefore, finding out early on in their hospice experience their spiritual needs, whether they have spiritual leaders or would like spiritual support is an important component for hospice care workers when working with Hispanics.

At the macro level the implications of this study affects professionals at the management level who train the staff. Multicultural trainings in organizations frequently follow rigid descriptions of the rules, values, norms and practices that are attributed to a specific culture. However, the Hispanic population encompasses a large community from Latin American countries with different, values, beliefs and practices. Therefore, attributing one characteristic to all would be inappropriate and disrespectful. The macro use of this study is to create critical consciousness and create change from the traditional teachings of Hispanic culture. It is to avoid making generalizations and to treat patients not as Hispanic, Mexican, Puerto Rican, or

Cuban, but to treat them as human beings that are dealing with death, to listen to their needs, to provide quality care regardless of nationality because this study found that quality patient care and compassion transcended the barriers of language and culture.

Another implication at the macro level is hiring more Spanish speaking staff. Although for the majority, this did not influence their overall evaluation and experience of hospice care, all participants responded positively when they expressed their experience with having a Spanish speaking representative. Those who did not have Spanish speaking staff wished they would could have had that.

#### Limitations of the Study

Several limitations were encountered during this study and are important to make note of for future research. The sample size was small. It was composed of ten participants made up of ten females and one male who participated with his spouse. For future studies a larger sample size with mixed genders may help in gaining a broader understanding of hospice care and to understand both female and male perspectives. During this study it was difficult to convince participants to agree to

participate. For future studies, it may be worth exploring having the staff who had contact with the patient or family to conduct the interviews.

Another limitation encountered was language. The questions were translated into Spanish using back translation and were reviewed by another Spanish speaking colleague for accuracy. However, participants needed clarification of the questions that asked what culture and religion taught them. When the researcher further clarified and explained the question, the risk of leading the participant to an answer was taken. For future research it would be beneficial to implement the questionnaire to a few individuals who meet the sample criteria but who will not participate in the study. This would help clarify and modify confusing questions or terms.

Another limitation of this study was the time the participants' utilized hospice services. The time ranged from a few hours to a few months. This affected the research in that some participants had time to develop rapport with staff and experience the full range of services, while those who had hospice care for a few hours or one or two weeks did not have the benefit of

that connection. Future research may explore the experiences of short-term versus long-term hospice care.

#### Summary

This chapter explored data analysis and data interpretation using the post-positivism paradigm. It discussed how the data, narratives provided in the interviews, were analyzed using open coding, axial coding and selective coding to develop a theory. The theory was stated and explained. Further, the theory was explained in terms of its implications for micro and macro practice of social work. Last, it explored the limitations of the study and areas of future study.



## CHAPTER FIVE

### TERMINATION AND FOLLOW UP

#### Introduction

Chapter Five discusses the termination process that was implemented by the researcher. This chapter describes how the findings were communicated to the study site and to the participants. Then the researcher discusses how termination was accomplished with the study site and the participants. The nature of the ongoing relationship with the study site is explained and the reason an ongoing relationship with the participants was not maintained is discussed.

#### Communicating Findings to Study Site and Study Participants

After completing the data analysis and after the approval by the field advisor, the researcher went to VITAS Innovative Hospice Care™ and presented the results of the study. The presentation was completed during a monthly staff meeting. Present during the meeting was Lorraine Hedtke, L.C.S.W., bereavement service manager, the chaplains, the social workers, the doctors and the social work student interns. The researcher presented how

the research study was conducted, reviewed some of the interview questions, shared quotes from the participants and discussed the results from the analysis. The researcher answered questions from the agency's staff. The staff was thankful and appreciative of the information and the insight provided with regards to Hispanic's experience with hospice care.

The findings were communicated to the participants at the end of the study. A letter written in Spanish was mailed to the participants informing them of the study's findings. The letter also explained that the study findings are available at the California State University, San Bernardino Library.

#### Termination of Study

Termination with the study site was conducted during the presentation of the findings at the staff meeting. The researcher thanked Lorraine Hedtke, L.C.S.W. for facilitating the research site and for her guidance. A thank you note was given to the authority gatekeeper, Steven P. Girod, general manager and to Lorraine Hedtke, L.C.S.W., bereavement service manager.

Termination with the participants was completed via a letter mailed to them explaining the findings of the study. The letter once again thanked the participants for their participation and acknowledged their contributions to the social work field.

#### Ongoing Relationship with Study Participants

Due to the nature of the agency an ongoing relationship with the study participants was not maintained. The participants no longer receive services from hospice and the researcher is not an employee or intern of the agency. However, the researcher believes that the study contributed to the researcher's knowledge through the insight gained into the experiences and needs of Hispanics with death and dying. The researcher will use this knowledge in other areas of social work practice. Further, the researcher will maintain an ongoing relationship with the agency as a referral source for families who need bereavement support or hospice care.

#### Summary

Chapter Five discussed how the termination with the study site and the participants was conducted. This

chapter described how the researcher communicated the study findings to the study site and to the participants. The researcher discussed how termination with the study site and the participants was conducted. Further, it discussed the reason an ongoing relationship was not maintained with the participants and explained the nature of the ongoing relationship with the study site.

APPENDIX A  
LETTER TO PARTICIPANTS

Maria Diaz  
Graduate Student  
California State University, San Bernardino

Hello,

My name is Maria Diaz and I am a student currently working on my social work Master's degree at California State University, San Bernardino. For one of my requirements, I am interested in studying Hispanics' experience with hospice care. My intent is to gain an understanding of Hispanics' experience with hospice care and to provide the hospice field with useful information so that they can provide culturally sensitive care to Hispanic families.

I am hoping to meet with individuals interested in discussing their experiences with hospice care services. I have asked VITAS Innovative Hospice Care® to help identify Hispanic families that have received hospice care. The study will consist of interviews. The interviews will be confidential and will last approximately one hour. Your decision to participate will not affect the services you receive with VITAS Innovative Hospice Care®.

I welcome an opportunity to talk with you about participating in my research project. I will be calling you in a few days to discuss any questions or concerns and to confirm if you are interested in participating. If you choose to participate you will be eligible for a five dollar calling card.

If you have any questions or decide to participate you can contact me at 562-412-1597.

Thank you,

Maria Diaz  
MSW Student  
California State University, San Bernardino

Maria Diaz  
Estudiante en la Universidad de California de San Bernardino

Hola,

Mi nombre es Maria Diaz y soy una estudiante en la Universidad de California de San Bernardino. Actualmente estoy trabajando para adquirir mi Maestría en Trabajo Social. Para cumplir con uno de mis requisitos estoy estudiando la experiencia de hispanos que recibieron cuidados de un programa de hospicio. Mi propósito es comprender las experiencias de las familias Hispánicas recibiendo cuidados de hospicio y proporcionar esta información a programas de hospicio para que puedan ofrecer cuidados sensibles a la cultura de la comunidad Hispánica.

Deseo conversar con personas interesadas en compartir sus experiencias del programa de hospicio. E recurrido a VITAS Innovative Hospice Care® para que me ayude a identificar personas que hayan recibido cuidados de hospicio. El estudio consiste de una entrevista. La entrevista será estrictamente confidencial y durara aproximadamente una hora. Su decisión de participar no afectará los servicios que este recibiendo en VITAS Innovative Hospice Care®.

Agradezco la oportunidad que me de para hablar con usted sobre participar en este estudio. Le hablaré en unos días para discutir preguntas o inquietudes suyas y para confirmar si esta interesado(a) en participar. Si decide participar se le obsequiara una tarjeta de llamadas prepagada de cinco dólares.

Si tiene alguna pregunta o desea participar puede hablarme al 562-412-1597.

Gracias,

Maria Diaz  
Estudiante en la Universidad de California de San Bernardino

APPENDIX B  
INFORMED CONSENT



## INFORMED CONSENT

The study in which you are being invited to participate will explore your experiences with receiving hospice care for your love one. The purpose of the study is to gain an understanding of your experience and your needs with hospice care and this may help facilitate care for other Hispanic families on hospice. The study will be conducted by Maria Diaz, a student at California State University, San Bernardino who will be under the supervision of Professor Rosemary McCaslin Ph.D., A.C.S.W. The study has been approved by the Department of Social Work Sub-Committee of the California State University, San Bernardino Institutional Review Board.

In this study you will be asked to participate in an interview. With your permission the interview will be audio recorded. The audio recordings will be destroyed at the end of the study. The interview will take about one hour. Your responses will be maintained in strict confidentiality. Your name will not be identified in the final document. Your name will not be documented with your responses. Your responses will not be shared with other participants. VITAS Innovative Hospice Care® will not know if you participated or your responses to the interview. The interview will be conducted in your home to ensure privacy. There are no foreseeable risks associated with this study.

Your participation in the study is completely voluntary. You are free to refrain from answering any questions and to withdraw from the study at any time and your relationship with VITAS Innovative Hospice Care® will not be affected. When you have completed the interview you will receive a statement that will describe the study and a five dollar calling card. We ask that you do not discuss this study with others in order to protect its validity.

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, I acknowledge that I understand the nature and purpose of the study and I freely consent to participate. I acknowledge that I am 18 years of age or older.

Place a mark here                           Today's date \_\_\_\_\_  
I consent to be recorded                      Yes                      No

## INFORMED CONSENT TRANSLATION IN SPANISH

### Consentimiento Informado

El estudio en el cual usted esta siendo solicitado es para investigar su experiencia del programa de VITAS Innovative Hospice Care®. El propósito de esta investigación es para comprender su experiencia y sus necesidades. Esta información podría facilitar el cuidado hacia otras familias en el futuro. Este estudio esta siendo conducido por Maria Diaz, estudiante de la Universidad Estatal de California de San Bernardino bajo la supervisión de la Dra. Rosemary McCaslin, Profesora del Departamento de Trabajo Social. Este estudio ha sido aprobado por el Subcomité del Departamento de Trabajo Social del Consejo Institucional de Revisión de la Universidad del Estado de California, San Bernardino.

En este estudio se le pedirá que participe en una entrevista en la cual se le hará una serie de preguntas. Con su permiso la entrevista será audio grabada. Al terminar el estudio las grabaciones serán destruidas. La entrevista tomara aproximadamente una hora. Todas sus respuestas se mantendrán en estricta confidencia. Su nombre no será identificado en el documento final. Su nombre no será anotado con sus respuestas. Sus respuestas no serán compartidas con otros participantes. VITAS Innovative Hospice Care® no será informado sobre su participación en el estudio ni se le proveerán sus respuestas. La entrevista se conducirá en su hogar para proporcionarle privacidad. Nosotros no prevemos ningún riesgo para usted en este estudio.

Su participación en este estudio es completamente voluntaria. Usted es libre de no contestar las preguntas y de retirarse del estudio en cualquier momento y su relación con VITAS Innovative Hospice Care® no será afectada. Cuando usted haya completado la entrevista usted va a recibir una explicación sobre el estudio y recibirá una tarjeta prepagada de cinco dólares para hacer llamadas. Nosotros le pedimos que no hable de este estudio con otros participantes a fin de asegurar la validez del estudio.

Si usted tiene algunas preguntas o inquietudes acerca del estudio por favor siéntase libre de contactar a la Dra. Rosemary McCaslin al teléfono 909-537-5507.

Al poner una marca en el cuadro de abajo yo reconozco que he sido informado y entiendo la naturaleza y el propósito del estudio y doy libremente el consentimiento de participar. También reconozco que tengo 18 años de edad o más.

Ponga una marca aquí  Fecha de hoy \_\_\_\_\_

Doy mi consentimiento de ser grabado(a)                      Si                      No

APPENDIX C  
QUESTIONNAIRE

Structured Interview

Demographic Information

Date \_\_\_\_\_

Interview number	Assigned number	
Gender	Male	
	Female	
Marital Status	Single	
	Married	
	Widowed	
	Divorced	
	Other	
Level of Education	No school	
	Primary School	
	Secondary school	
	College	
	University	
	Other	
Spirituality/Religion	Name of religion	
Country of origin	Name of Country	
Primary Language Spoken	Name of language	
Number of Years in the USA	Number of years	
Relation to the deceased	Name of relationship	

What does your culture teach you about death? *¿Que le enseña su cultura sobre la muerte?*

What do your spiritual beliefs tell you about death? *¿Que le enseña su religión sobre la muerte?*

---

Did staff ask you about your cultural beliefs or practices? *¿Le pregunto el personal sobre sus creencias o practicas culturales?*

If yes, how did that make a difference in the patient's care? Si- *¿Como hizo la diferencia en el cuidado del paciente?*

If not, how would that have made a difference? No- *¿Como hubiera hecho la diferencia?*

---

Were there times your cultural preferences were not respected? Please explain. *¿Hubo momentos cuando sus preferencias culturales no fueron respetadas? Por favor explique.*

---

Do you believe hospice staff respected your cultural beliefs? *¿Usted cree que el personal respeto sus creencias culturales?*

If yes, how was that demonstrated? Si- *¿Como se lo demostraron?*

If not, how could they have respected your culture? No- *¿Como pudieran haber respetado su cultura?*

---

Do you believe staff respected your spiritual/religious beliefs? *¿Usted cree que el personal respeto sus creencias espirituales/religiosas?*

If yes, how was that demonstrated? Si- *¿Como se lo demostraron?*

If not, how could your spiritual/religious beliefs been respected? No- *¿Como pudieran haber sido respetuosos hacia su religión/creencias espirituales?*

---

Do you believe staff respected you or your loved one's end of life wishes? *¿Usted cree que el personal respeto los últimos deseos de usted o su familiar?*

If yes, how was that accomplished? Si- *¿Como fueron sus deseos respetados?*

If not, how could staff have better addressed end of life wishes? No- *¿Que pudiera haber hecho el personal para respetar sus deseos?*

---

Do you believe you understood what hospice care was at the time you or your loved one signed on? *¿Usted cree que entendió el programa de hospicio cuando se inscribió su familiar o inscribió a su familiar?*

If yes, how was it explained to you? Si- *¿Cómo le explicaron el programa?*

If not, how could it have been better explained? No- *¿Como le pudieran haber explicado mejor?*

---

Were you provided with material in Spanish? *¿Le previeron material en español?*

If yes, how did that make a difference in the care received? Si- *¿Cómo hizo la diferencia en el cuidado que recibieron?*

If not, how could it have helped? *No- ¿Como le hubiera ayudado el material en español?*

---

Were you provided with a staff member that spoke Spanish or a translator? *¿Le previeron una persona que habla español o un traductor(a)?*

If yes, how was that helpful in the care of your loved one? *Si- ¿Como le ayudo ese servicio para el cuidado de su familiar?*

If not, how would it have made a difference in your loved ones care? *No- ¿Que diferencia hubiera hecho en el cuidado de su familiar?*

---

Were you able to communicate you or your loved one's needs/concerns to the staff? *¿Usted pudo comunicar las necesidades o inquietudes al personal?*

If yes, what was that like? *Si- ¿Como fue esa experiencia para usted?*

If not, how could the personnel have facilitated the communication? *No- ¿Como pudiera el personal haber facilitado la comunicación?*

---

Was the care of the patient conducted in a way that you understood what was happening? *¿Usted cree que el cuidado del paciente fue manejado de una manera en la cual usted entendía lo que estaba sucediendo?*

If yes, what do you think facilitated this? *Si- ¿Que cree usted que ayudo a que usted entendiera?*

If not, what could have been done to facilitate your understanding of what was happening? *No- ¿Que cree usted que hubiera ayudado a que usted entendiera lo que estaba sucediendo?*

---

Did you feel you were understood by staff? *¿Usted sintió que el personal le entendió sus necesidades?*

If yes, how was that facilitated? *Si- ¿Qué ayudo a que el personal entendiera sus necesidades?*

If not, how could that have been provided? *No- ¿Como cree usted que el personal pudiera haber entendido sus necesidades?*

What does your culture say about using social or community services to care for your loved ones? *¿Qué dice su cultura sobre el uso de servicios sociales de la comunidad para el cuidado de su familiar?*

---

What does your culture say about who should care for your loved one? *¿Qué dice su cultura sobre quien tiene el deber de cuidar a su familiar?*

APPENDIX D  
DEBRIEFING STATEMENT

## DEBRIEFING

### Hispanics' Experience with Hospice Services

The interview you have completed was developed to investigate Hispanic's experiences with hospice services. This study was designed to examine how your cultural and spiritual values were respected, how you felt your needs were met and how staff could improved their cultural sensitivity. The information gathered will be used for social work practice in order to continue providing culturally sensitive care in hospice settings.

Thank you for your participation in this study. To protect the validity of the study please do not discuss this study with others who may plan to participate. If you have any questions about the study please feel free to contact Dr. Rosemary McCaslin at 909-537-5507. The study results will be available at California State University, San Bernardino, John M. Pfau Library after September 2009. A copy will also be available at VITAS Innovative Hospice Care® in San Bernardino, California. You will be mailed a highlight of the findings in Spanish upon the completion of the project.



## DEBRIEFING STATEMENT TRANSLATION INTO SPANISH

### La Experiencia de Hispanos Recibiendo Servicios de Hospicio

La entrevista que usted acaba de completar fue desarrollada para investigar las experiencias de hispanos recibiendo cuidados de hospicio. Este estudio fue diseñado para examinar si sus valores culturales y espirituales fueron respetados, si sus necesidades sobre el cuidado de su familiar fueron complacidas, y como podríamos mejorar nuestra sensibilidad a la cultura Hispana. La información adquirida será utilizada para uso de trabajo social para continuar proveyendo cuidado sensible a la cultura Hispana en programas de hospicio.

Gracias por su participación en este estudio. Para proteger la validez del estudio por favor no comparta este estudio con otros participantes. Si usted tiene preguntas sobre este estudio por favor siéntase libre de contactar a la Dra. Rosemary McCaslin al numero 909-537-5507. Los resultados de este estudio serán disponibles en la biblioteca John M. Pfau. de la Universidad Estatal de California, San Bernardino. Otra copia estará disponible en VITAS Innovative Hospice Care®. A usted se le mandara una carta al final del estudio explicándole los puntos importantes sobre los resultados del estudio.

APPENDIX E  
RESOURCES

**Bereavement Resources** (Recursos para Conserjería)

VITAS Innovative Hospice Care®  
San Bernardino  
909-386-9115

Riverside Hospice  
Nancy Foster 909-424-3233

Inland Valley Hospice  
Riverside  
951-360-5848

West Coast Hospice  
Rancho Cucamonga  
909-581-7575

**General Counseling Services** (Servicios de conserjería general)

Behavioral Health Services  
San Bernardino  
909-387-7000

Family Service Agency of San Bernardino  
909-886-6737

Family Service Agency of Fontana  
909-822-3533

Family Service Association of Riverside  
909-686-3706

Loma Linda Marriage and Family Therapy Clinic  
909-558-4934

Caritas Counseling  
Find a group in your area (preguntar por un grupo en su área)  
909-370-1293

## REFERENCES

- Adams, C., Horn, K., & Bader, J. (2005). A comparison of utilization of hospice services between Hispanics and Whites. *Journal of Hospice & Palliative Nursing*, 7(6), 328-336.
- Blackhall, L. J., Frank, G., Murphy, S. T., Michel, V., Palmer, J. M., & Azen, S. P. (1999). Ethnicity and attitudes towards life sustaining technology. *Social Science and Medicine*, 48(12), 1779-1789.
- Born, W., Greiner, K., Sylvia, E., Butler, J., & Ahluwalia, J. (2004). Knowledge, attitudes, and beliefs about end-of-life care among inner-City African Americans and Latinos. *Journal of Palliative Medicine*, 7(2), 247-256.
- Colon, M., & Lyke, J. (2003). Comparison of hospice use and demographics among European Americans, Africans, and Latinos. *American Journal of Hospice and Palliative Care*, 20(3), 182-190.
- Gelfand, D. E., Balcazar, H., Parzuchowski, J., & Lenox, S. (2004). Issues in hospice utilization by Mexicans. *The Journal of Applied Gerontology*, 23(1), 3-19.
- Gordon, A. K. (1996). Hospice and minorities: A national study of organizational access and practice. *The Hospice Journal*, 11(1), 49-70.
- Losada, A., Shurgot, G., Knight, B., Márquez, M., Montorio, I., Izal, M., et al. (2006). Cross-cultural study comparing the association of familism with burden and depressive symptoms in two samples of Hispanic dementia caregivers. *Aging & Mental Health*, 10(1), 69-76.
- Medicare Hospice Data. (2008). Medicare Hospice Data 1998-2005. Retrieved on January 14, 2008 from <http://www.cms.hhs.gov/ProspMedicareFeeSvcPmtGen/downloads/HospiceData1998-2005.pdf>

Monk, G., Winslade, J., & Sinclair, S. (2008). *New horizons in multicultural counseling*. Thousand Oaks, Ca: Sage Publications Inc.

Morris, T. (2006). *Social research methods; Four alternative paradigms*. Thousand Oaks, CA: Sage.

National Hospice and Palliative Care Organization. (2008). *NHPCO's facts and figures on hospice*. Retrieved January 14, 2008, from [http://www.nhpco.org/files/public/Statistics\\_Research/NHPCO\\_facts-and-figures\\_Nov2007.pdf](http://www.nhpco.org/files/public/Statistics_Research/NHPCO_facts-and-figures_Nov2007.pdf)

Radina, M. E., & Barber, C. E. (2004). Utilization of formal support services among Hispanic Americans caring for aging parents. *Journal of Gerontological Social Work*, 43(2-3), 5-23.

Randall, H., & Csikai, E. (2003). Issues affecting utilization of hospice services by rural Hispanics. *Journal of Ethnic & Cultural Diversity in Social Work*, 12(2), 79-94.

Scharlach, A. E., Kellam, R., Ong, N., Baskin, A., Goldstein, C., & Fox, P. J. (2006). Cultural attitudes and caregiver service use: lessons from focus groups with racially and ethnically diverse family caregivers. *Journal of Gerontological Social Work*, 47(1-2), 133-156.

U.S. Census Bureau. (2000). *Fact sheet*. Retrieved on January 14, 2008, from [http://factfinder.census.gov/servlet/SAFFacts?\\_event=&geo\\_id=05000US06071&geoContext=01000US%7C04000US06%7C05000US06071&street=&county=san+bernardino&cityTown=san+bernardino&state=04000US06&zip=&lang=en&sse=on&ActiveGeoDiv=&useEV=&pctxt=fph&pgsl=050&submenuId=factsheet\\_1&ds\\_name=ACS\\_2006\\_SAFF&ci\\_nbr=null&qtr\\_name=DE](http://factfinder.census.gov/servlet/SAFFacts?_event=&geo_id=05000US06071&geoContext=01000US%7C04000US06%7C05000US06071&street=&county=san+bernardino&cityTown=san+bernardino&state=04000US06&zip=&lang=en&sse=on&ActiveGeoDiv=&useEV=&pctxt=fph&pgsl=050&submenuId=factsheet_1&ds_name=ACS_2006_SAFF&ci_nbr=null&qtr_name=DE)

U.S. Census Bureau. (2001). *Overview of race and Hispanic origin*. Retrieved on January 14, 2008, from <http://www.census.gov/prod/2001pubs/c2kbr01-1.pdf>

U.S. Census Bureau. (2006). *Quick tables*. Retrieved on January 14, 2008, from [http://factfinder.census.gov/servlet/QTTable?-ds\\_name=PEP\\_2006\\_EST&-qr\\_name=PEP\\_2006\\_EST\\_DP1&-geo\\_id=05000US06071](http://factfinder.census.gov/servlet/QTTable?-ds_name=PEP_2006_EST&-qr_name=PEP_2006_EST_DP1&-geo_id=05000US06071)

U.S. Census Bureau. (2007). *Residence population by sex, race, and Hispanic origin status 2000-2005*. Retrieved on January 14, 2008, from <http://www.census.gov/prod/2006pubs/07statab/pop.pdf>

VITAS Innovative Hospice Care®. (2008). Retrieved on February 24, 2008, from <http://www.vitas.com>

Zastrow, C., & Kirst-Ashman, K. K. (2007). *Understanding human behavior and the social environment* (6<sup>th</sup> ed.) Belmont, California: Thomson Brooks/Cole.