

BEREAVEMENT SERVICES FOR HISPANICS:  
AN EXPLORATORY STUDY OF  
FLORIDA HOSPICES

by

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A DISSERTATION

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## ABSTRACT

Hispanics are the fastest growing minority group in the United States, numbering over 42 million and making up 15% of the total population. Hispanics are a diverse, intricate, and heterogeneous group that experiences various disparities in health care, including care at the end of life. One specific area, bereavement care, has received minimal attention in the literature, and previous national bereavement studies have not discussed ethnic variations related to the provision of bereavement services.

This exploratory study, conducted in Florida, was undertaken to address existing policy, research, and practice gaps regarding bereavement services available to Hispanics. An on-line survey was developed to explore five research questions that centered on bereavement services offered by hospice agencies, bereavement coordinators' perceptions about the needs of Hispanics, and the strengths and challenges of hospice agencies when offering bereavement services to Hispanics. The sample consisted of all hospice bereavement coordinators in Florida. Initial contact was made by telephone to solicit participation and confirm contact information. An electronic survey was responded to by 73% ( $n = 30$ ) of the total state sample.

Results of this study reveal language and cultural barriers as major challenges in communicating with Hispanics and in offering and delivering bereavement services. Embedded within these challenges were reports by bereavement coordinators of the lack of Spanish-speaking personnel available to provide bereavement services. Additionally, results disclose that the number of Hispanics participating in bereavement services was much lower than the estimated number of potential Hispanic families and individuals eligible to participate in these

services. Referrals to religious and spiritual support systems were considered an important referral source for Hispanics in bereavement agencies.

Implications for social workers include the need to increase access to and the effectiveness of bereavement services for Hispanics through efforts in research, policy, and practice. Social work practitioners and researchers need to focus on the creation of instruments and processes for tracking bereavement services, and establishing practice standards for bereavement services. Needed policy efforts include advocating for more attention to the bereavement needs of Hispanics in state and national venues in addition to securing funds for creating grass-roots interventions.

## DEDICATION

This dissertation is dedicated to you, David B. Simpson, my life partner, spouse, and best friend. Thank you for your love, encouragement, support, patience, and acceptance. You, along with Murphy and Emily, have taught me to laugh and enjoy life to the fullest.

I would like to also dedicate this dissertation to my family and friends. Gracias “Mami” por todo lo que has echo por mi y mis hermanos en asegurar que tuvieramos una vida llena de cosas buenas y un futuro mejor. Tú eres mi mejor profesora.

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## CHAPTER 1

### INTRODUCTION

In the United States, end-of-life (EOL) care has evolved from a general concept to a specialized discipline monitored and controlled by various groups including academic, professional, public and private organizations, as well as governmental agencies and consumer groups. Each of these groups has contributed to the advancement of the field in various areas including research, policy, and practice, and in domains such as bereavement and psychosocial care. However, as expected in any new area of inquiry, various gaps currently exist in the general knowledge base of specific EOL domains. For instance, a review of the EOL literature provides evidence that gaps exist in the area of bereavement care and research pertaining to minority populations and specifically with respect to Hispanics.

There has been increased interest by social scientists to understand the general health care needs of Hispanics in the United States. Randall and Csikai (2003), for example, stated that, “Hispanics are at greater risk of not receiving adequate health care, such as hospice, as a result of language and cultural barriers” (p. 80). Shifting U.S. demographics have identified Hispanics as the number one minority group in the United States, which provides a basis for an increased need to understand this population.

Although some research has sought to understand general access to bereavement services and to establish standards of practice, a recent review of the literature yielded no research focusing on bereavement services with Hispanics. A need exists to increase the general understanding of bereavement care and services offered to this population for several reasons.

First, there is evidence that bereavement care can have a positive impact on the mental and physical health of bereaved individuals (Allumbaugh & Hoyt, 1999; Forte, Hill, Pazder, & Feudtner, 2004). Second, the population of Hispanics, as predicted by the U.S. Census Bureau (2008), will reach 103 million by the year 2055, thus making Hispanics the number one minority population in the United States. There is also a need to reduce disparities in the area of access to bereavement care services, in addition to understanding the role that culture and ethnicity play within such services. Relating to EOL, there is evidence that Hispanics will use EOL services, such as hospice, when the gap between culture and practice is bridged (Robert Wood Johnson Foundation, 2008). However, to date, this has not been explored with bereavement services. In fact, the only two national bereavement studies that have been done in the United States failed to discuss Hispanic access to bereavement services.

Collectively, these reasons serve as anchors for this study's efforts to document hospice bereavement service delivery to Hispanics. Given the need for an exploratory study, the state of Florida, with 3.6 million Hispanics who comprise 14.8% of the total U.S. Hispanic population (U. S. Census, 2001), was selected as the site for the study for several reasons: (1) Florida is one of the primary gateways to and from Latin America; (2) Its population includes people from every Latin American country; (3) The diversity and heterogeneity of Florida's Hispanic population reflects the general diversity and heterogeneity of the Hispanic population in the United States; and (4) Florida ranks third highest in the United States for hospice care use.

A survey was created from a comprehensive review of the EOL and bereavement care literature. Two general domains were identified, and specific questions were written to support and operationalize each content area. The first domain gathered factual information about general characteristics and specific services offered by Florida hospices, including bereavement

services offered to Hispanics. The second domain explored perceptions of bereavement coordinators in three different areas: bereavement needs of Hispanics, challenges faced in provision of bereavement services to Hispanics, and identification of hospice programs' virtues (strengths) in the provision of bereavement services to Hispanics. A small section at the end of the survey requested demographic information from the respondents.

Responses were solicited by E-mailing a survey to all bereavement coordinators working at Florida hospices who are members of the Florida Hospice and Palliative Care Organization (FHPC) as well as listed on Florida's Agency for Health Care Administration (FAHCA). Findings have the potential to enhance bereavement service provision to Hispanics and contribute to the general awareness of current bereavement practices with Hispanics in Florida. In addition, findings may identify best practices for bereavement programs, as well as identify areas of improvement relating to bereavement service provision to Hispanics.

#### *Purpose of the Study*

The purpose of this study was to increase knowledge of the current state of bereavement services offered to Hispanics in Florida. Research in the area of bereavement service provision to Hispanics is scant. Previous researchers who have studied bereavement services in the United States have not considered ethnic variations in the population. To date, the current state of bereavement services available, offered, and provided to Hispanics in the United States is generally unknown and undocumented in the literature.

This study serves as an exploratory effort to document bereavement services offered to Hispanics in Florida, and stimulate similar research efforts throughout the United States. Such research has the potential to enhance the quality and quantity of bereavement services offered to this population. The paucity of documented research and knowledge in this area precludes the

development of policies and services offered to Hispanics. Exploring bereavement services offered to Hispanics is a process that brings together research with practice and policy.

## CHAPTER 2

### RELEVANT LITERATURE REVIEW

#### *End-of-Life Care in the United States*

##### *Historical Events*

In the United States, EOL care has been influenced by different considerations, including the promulgation of the hospice philosophy beginning in the 1960s and policy developments, both at the federal and state levels in the 1980s. An increase in EOL research, practice, and policy has occurred in the past 30 years. Academicians, researchers, practitioners, and policy-makers alike have contributed to the advancement of EOL. For example, policies have been developed to focus on patients and their families when facing a terminal illness, such as passage of the Patient Self Determination Act (PSDA) of 1990, which gave a federal mandate to organizations receiving Medicare and Medicaid funding to provide adult patients with specific information about what advance directives are and their right to formulate such a document (Werth & Blevins, 2002). The Medicare Hospice Benefit Act (MHBA), under the Tax Equity and Fiscal Responsibility Act (TEFRA) of 1982, provided funding for terminally ill people to receive hospice services (Bulkin & Lukashok, 1988). Also, the Balanced Budget Act (BBA) of 1997 modified hospice standards to include different benefit periods (Werth & Blevins, 2002). These federally mandated services empowered healthcare personnel to provide attention to healing beyond the narrow focus of medicine and helped to emphasize the role that families have at the end of life.

The period between 1965 and 1975 was marked by groundbreaking efforts to advance EOL in the United States. These efforts were initiated and chronicled by several researchers, practitioners, and policy makers. During this time, two key individuals helped pave the road to shaping and molding EOL in the United States. Schonwetter (2006) discussed the role of Dame Cicely Saunders, who founded St. Christopher's Hospice in London, England in 1967 and brought the hospice concept to the United States. As a result, the first hospice in the United States opened in Connecticut in 1974. In 1969, Dr. Elizabeth Kubler-Ross wrote the book *On Death and Dying*, which reinforced the need to understand people who are dying and the families who are caring for them. She discussed the Stages of Grief Theory, which she believed people and families experienced throughout a terminal illness. These stages are denial, anger, depression, bargaining, and acceptance.

The work that Saunders and Kubler-Ross initiated was perhaps influenced by the seminal work of Zelda Foster in 1965. An influential person in the field at the time and a Veterans Administration (VA) Social Worker, Foster focused her work on social work roles/interventions and the impact they have on micro and macro systems of practice. Foster's work was an initial attempt to highlight the need for professionals to discuss dying and EOL with patients and families. The importance of communication, specifically listening to patients facing a terminal illness, was at the core of her work. Today, communication continues to be a significant variable discussed and explored by various EOL researchers (Baker, Hayes, & Fortier, 1998; Berzoff & Silverman, 2004; Csikai, 2006; Shrank, Kutner, Richardson, Mularski, Fischer, & Kagawa-Singer, 2005; Wilson, Chen, Grumbach, Wang, & Fernandez, 2005). Collectively, the work of Saunders, Kubler-Ross, and Foster, as well as professionals and researchers who have followed

in their footsteps throughout the past three decades, have helped to shape society's EOL awareness and understanding.

### *Growth of Hospice Services in the United States*

The United States has witnessed a tremendous growth in the development of the hospice movement and promulgation of hospice services since the 1970s. These services are delivered in individual's private homes, nursing homes, assisted-living facilities, and in-patient facilities (any place the individual calls "home"). Since the enactment of the Hospice Medicare Benefit in 1982, the number of U.S. hospices has increased dramatically. According to the National Hospice and Palliative Care Organization (NHPCO, 2008), the number of U.S. hospices increased from 2,900 in 1996 to over 4,000 in 2007.

The observed increase in number of hospice agencies throughout the United States has led to competition among hospice agencies to maintain and often increase the agencies' census. Hospice agencies have not, generally, used bereavement services as a marketing tool to distinguish themselves from other hospice agencies. Bereavement services have often been considered an ad hoc service within hospices, and the concept of hospice has not been well operationalized. Furthermore, bereavement services have not, historically, been the primary focus with hospice agencies (Demmer, 2003; Lattanzi-Licht, 1989). Challenges related to the provision of bereavement services have included limited staff and funding (Demmer, 2003).

An increase has also been observed in the number of patients serviced by hospices in the United States. Data from the NHPCO reveals that in 1985 the number of patients served by hospice was 158,000, and in 2007 this number increased to 1,400,000 (NHPCO, 2008). This amounts to approximately one in three older Americans using hospice services. The observed and documented increase in both the number of hospice agencies and in the population served

has, in part, enhanced society's awareness and education of alternate care and healthcare options at the end of life.

### *Hospice Interdisciplinary Teams*

The need to provide bereavement services to individuals and families has come to the attention of specific professionals such as social workers, nurses, and psychologists. Such response has, in part, been driven by Medicare guidelines mandating that hospices provide bereavement services to bereaved families. In hospice, these professionals are members of interdisciplinary teams delivering EOL care to dying patients and their families. This is unique in that various professional disciplines join efforts to provide holistic, patient and family-centered care at the end of life. The members of these interdisciplinary teams include, at a minimum, a physician, nurse, and social worker. Other team members may include nurses' aids, spiritual counselors, psychologists, home health aides, bereavement counselors, as well as volunteers. In a collaborative manner, all team members contribute their own expertise to the holistic treatment of the individual and family. It is important to mention, however, that overlapping roles may exist, as it is the case with nurses who may provide counseling during a home visit.

These professionals' contributions are rooted in recent end-of-life policies and standards enacted by various professional organizations. For instance, the National Association of Social Workers (NASW) the American Psychological Association (APA) the American Medical Association (AMA), and the American Nursing Association (ANA) all have specific EOL practice guidelines that serve to guide the delivery of services to individuals and families facing a terminal illness.

### *Minorities and End-Of-Life Care*

Significant disparities can be found within the EOL field with respect to minority populations and people of color that require attention. General EOL disparities experienced by minorities, and discussed by researchers, include inadequate pain control, leaving patients to experience more pain at the end of life (Crawley, Marshall, Lo, & Koenig, 2002; Vallerand, 2003; Weissman, Gordon, & Bidar-Sielaff, 2004), and limited or nonexistent language-concordant services. Minorities continue to lack equal representation in EOL research studies. For example, a recent study by Connor, Elwert, Spence, and Christakis (2007) used data from the Centers for Disease Control's (CDC) death certificate records, along with the Centers for Medicare and Medicaid, to identify demographics of hospice users and nonusers. The reported data is fairly comprehensive and inclusive of gender and geographic areas; yet there is no mention of hospice use or nonuse by ethnic variation. With the Hispanic population increasing, it would seem crucial to know hospice use and nonuse by specific ethnic populations in order to best service this group.

To date, there is no clear evidence on hospice utilization by minorities. For example, there is limited psychosocial research that has been conducted with Hispanics in the area of EOL care. Researchers have documented the limited interest in research to focus on the mental health needs, for example, of Hispanics. Castro and Ramirez (1997), quoted by Zecracki and Stancin (2007), indicated that "less than 1% of manuscripts published during the past 25 years in six leading psychology journals were about Latinos" (p. 4). These limitations serve as a reminder that a greater emphasis needs to be placed on research on Hispanics.

### *Hispanic's Use of Hospice Services*

The phenomenon of the low use of hospice services by Hispanics in the United States has not been well understood. For example, Randall and Csikai (2003) reported in their study of utilization of hospice services by rural Hispanics that in 1998 the NHPCO revealed that, “only 3% of those receiving hospice services in the U.S. were Hispanics” (p. 80). The most recent statistics from the NHPCO show that 5.1% of the estimated 1.4 million hospice patients served in 2007 were Hispanic. The NHPCO uses the U.S. Census guidelines to classify hospice patients (race and ethnicity are treated as two separate concepts) and only collects provider-level data not patient-level data. This limits data analyses, as cross tabulation, for example, of ethnicity and race cannot be done.

Although authors such as Colón (2005), Gordon (1996), O’Mara and Arenella (2001), and Pawling-Kaplan and O’Connor (1989) have contributed causal explanations (i.e., language barriers, socioeconomic disparities, cultural variations, provider-patient barriers) for the low percentage of hospice use by Hispanics, their studies have not been able to specifically determine the rationale for such low access and use of hospice services. Colón and Lyke (2003) found in their retrospective study that Hispanics underutilize hospice services when compared to the general population. On the other hand, authors such as Adams, Horn, and Bader (2006) compared Hispanic and White hospice decedents in hospice use, and yet findings from their study failed to validate the hypothesis that Hispanics are indeed underrepresented in hospice.

Lackan et al. (2004) provided a fairly comprehensive literature review of the increased interest that exists among researchers about hospice use by patient ethnicity. Several of the research studies cited by Lackan et al. (2004) address the disparity of hospice utilization among minorities (especially Hispanics). Congruent with Adams et al.’s (2006) findings, Lackan et al.’s

(2004) study revealed “similar rates of hospice use for Hispanics and non-Hispanic whites” (p. 969).

Therefore, there are unclear explanations about rate of hospice use among Hispanics, which reveals a need for additional studies to determine hospice use by this population in the United States. In summary, accurate reporting and census tracking mechanisms are needed to decipher and understand, more accurately, the current state of hospice use and nonuse by Hispanics.

#### *Demographic Characteristics of Hispanics in the United States*

The Administration on Aging (AOA, 2008) reported that in 2006 the number of Americans over the age of 65 was 37.3 million, representing 12.4% of the U.S. population. By 2030, the AOA predicts that this number will increase to 71.5 million. The AOA also predicts that the number of people over the age of 85 will triple by 2030. Specific demographic changes are also evident in minority populations. For example, the total number of older Hispanics was 2.4 million in 2006 and it is expected to rise to 15 million by 2050 (AOA), classifying Hispanics as the largest ethnic minority among people age 65 and older. Congruently, in 2001 the Census Bureau predicted that the number of Hispanics will triple in the next 30 years, thereby representing approximately 20% of the U.S. population by the year 2035. In 2008, the U.S. Census Bureau reported that Hispanics represented 15.1% of the total U.S. population, with over 45.5 million total Hispanics.

The diversity and heterogeneity of the U.S. Hispanic population is depicted in the 2000 Census, which measured a total of 35.2 million Hispanics, accounting for 12.5% of the total population at the time. When these numbers are compared to the 1990 Census Report, it is clear that the number of Hispanics has dramatically increased from the 21.9 million reported in 1990

(Ramirez, 2004). The number one country of origin of Hispanics within those identified is Mexico (20,900,102), followed by Puerto Rico (3,403,510), Central America (1,811,676), South America (1,419,979), Dominican Republic (799,768), and Spain (112,999). It is important to mention that a number of Hispanics have been categorized under the “Other Hispanic” category. Ramirez reported that in the 2000 Census Report, 5,540,627 people were included under the “Other Hispanic” category, which “included all other general Hispanic-origin responses such as *Hispanic, Spanish, and Latino* (p.1).

The label *Hispanics*, created by the Office of Management and Budget (OMB) in 1978, classified the new growing population of Spanish-speaking people immigrating to the United States. *Directive No. 15: Race and Ethnic Standards for Federal Statistics and Administrative Reporting* defined *Hispanics* as “A person of Mexican, Puerto Rican, Cuban, Central or South American or other Spanish culture or origin, regardless of race” (OMB, 1978). In research, different labels are found to classify Hispanics. Words such as *Latinos, Spanish-speaking*, and using the birth-country of the person predominate the literature. To avoid confusion of terms, the word *Hispanic* will be used in this document as defined by the OMB and frequently used by social scientists in research and policy.

#### *United States’ Mortality Rates*

Data from the U.S. 2003 Census Report indicate that close to 75% of all U.S. deaths involved those over the age of 65, and the majority of these deaths were from natural (expected) causes. Specifically relating to Hispanics, general death rates have been challenging to understand for two main reasons: under-reporting of Hispanic origin on death certificates, and race and Hispanic-origin classification (CDC, 2005). Despite the Office of Management and Budget’s clarification in 1978 that ethnicity and race are two separate concepts, confusion

continues to exist when classifying Hispanics. This is further complicated by Hispanics' own dilemma when reporting their classification. Some Hispanics will classify themselves according to their race (i.e., White) and others according to their ethnicity (i.e., Hispanic), whereas others will classify themselves according to their birth-country (e.g., Argentina) (U.S. Census, 2001).

In 2007, Minino, Heron, Murphy, and Kochanek reported general age-adjusted death rates for Hispanics for the year 2004 by using information from National Vital Statistics Reports. They reported that the Hispanic death rate of 586.7 per 100,000 U.S. population, decreased by 5.6% from the rate of 621.2 in 2003. Minino et al. (2007) also reported that the total number of deaths by Hispanic origin was 122,416 in 2004. Of this number, 67,236 deaths occurred with Hispanics over the age of 65.

### *Bereavement Care in the United States*

#### *Definition of Bereavement*

Various definitions of bereavement are found in the literature. For example, the NASW defined *bereavement* as “the objective situation of a person who has experienced the loss of a significant person or other attachment figure” (NASW, 2006, p. 12). Researchers have used terms such as *grief*, *distress*, and *mourning* interchangeably when defining bereavement (Waldrop, 2007). However, these terms are mutually exclusive and operationally different. For the purpose of this study, however, Baohui, El-Jawahri, and Prigerson's (2006) definition of bereavement will be used. They defined bereavement as “the experience of losing to death a person to whom one is attached” (p. 1188). This succinct yet conceptual definition of bereavement underscores the “experience” of an individual. This definition allows the framing and understanding of the process of bereavement within different cultural contexts. Furthermore, it allows for the inclusion of people who may have had an attachment to the deceased person but

are not related through families of origin or by marriage. These family members may include in-laws, neighbors, *Comadres* (close female friend and/or the godmother of one of the deceased patient's children) and *Compadres* (same definition as *Comadres* but for a male person).

### *Theoretical Concepts Related to Bereavement*

The process of bereavement by family members has experienced much interest from researchers. This interest dates back to 1917 when Freud discussed the term *grief work* and introduced a stage structure model of bereavement (the process of hypercathecting and then decathecting mental images of a deceased person), for which the ultimate goal was emotional detachment from a loved one (Rothaupt & Becker, 2007). Kubler-Ross (1969) and Bowlby and Parks (1970) expanded Freud's work and presented other stages and models of bereavement. Kubler-Ross introduced the five stages of grief (denial, anger, depression, bargaining, and acceptance). The goal of Kubler-Ross's stages is to accept that the person has died.

Kubler-Ross's stages of grief along with the work of Bowlby and Parkes (1970), who also introduced different stages (numbness, searching and yearning for bereaved, depression, and reorganization), continued in a linear manner oftentimes unquestioned or unchallenged until the 1980s when researchers questioned major grief-related theories that had little or no empirical evidence (Bonanno & Kaltman, 1999). One of these challenged theories was the Stage Theory of Grief presented by Kubler-Ross (1969). Beem, Eurelings-Bontekow, Cleiren, and Garsen (1998) discussed the questions surrounding the perception of mourning in specific stages that was challenged in the literature and how there were "serious doubts about the validity of such theoretical stage models" (p. 54).

Worden (1982) introduced a new structure model for bereavement focusing on tasks rather than stages. Worden provided a new viewpoint thereby challenging psychoanalytic

perspectives. Worden stated that bereavement is an experience composed of four different aspects (accept the reality of the loss, experience the pain of the grief, adjust to the loss, and emotionally relocate the deceased person). These four aspects are not linear and are quite fluid in that they can be experienced in any order and at any given time.

Marrone (1999) introduced a phase structure mode of bereavement that identified four phases (cognitive restructuring, emotional expression, psychological reintegration, and psychospiritual transformation). The ultimate goal of these phases is to grow and transform oneself in spiritual and existential ways. These changes lead to changes in assumptions about the world. Marrone's work is based in postmodernism and nonpositivism bereavement perspectives.

Walsh and McGoldrick (2004) returned the focus to a task structure model of bereavement. They presented four adaptational tasks: shared acknowledgment of the reality of death, shared experience of the loss, reorganization of the family system, and reinvestment in other relationships and life pursuits. The ultimate goals are to adapt to the loss, allow for unique experiences of grief, and strengthen family as functional units.

Other researchers such as Rando (1985) have focused on discussing the relationship or bond that remains after the death of a loved one. The continued bonds perspective has been discussed extensively in the literature. The main idea of this perspective is that the bereaved person continues to have a relationship with the deceased person. This relationship evolves from a physical relationship into higher levels that may involve a spiritual and emotional connection. The continued bonds perspective is an important concept because it gives permission to the bereaved individual to continue with the relationship instead of terminating the relationship and disconnecting from the memory of the deceased person as previously considered and believed.

The actions taken by these researchers have led to a proliferation of research articles and commentaries that address bereavement and responses to grief. For example, the initial work by Stroebe and Stroebe (1987), and later work by Wortman and Silver (1989), paved the way for understanding bereavement within different theoretical perspectives and focused on empirical evidence. Normative ways of coping with the death of a significant other were challenged, as well as assumptions about grief responses. The general bereavement knowledge base will continue to evolve as a result of the acknowledgment that death is an event shared by all living beings and that grief is a result of experiencing the death of a significant other.

Recently, researchers have dichotomized the response to bereavement into two different perspectives: the *relief* response and the *complicated* response. Some caregivers may experience relief upon the death of the ill person and they may resume previous roles and proceed with their own lives and responsibilities fairly easily. On the other hand, some caregivers may experience a complicated response to the death of the care recipient. This may be a direct result of missed opportunities, feelings of guilt over the relief response, and/or the inability to put closure to the relationship. A complicated response may also be a result of the caregiver's perception that caregiving is difficult (Bass & Bowman, 1990; Schulz & Beach, 1999; Waldrop, 2007). In these instances, individuals may have difficulty resuming previous roles and responsibilities.

### *Bereavement Services*

In the United States much of bereavement services have traditionally been housed within hospice organizations. The provision of bereavement services by hospices is usually dependent on financial support and staff with specialized skills (Demmer, 2003). Private organizations have historically supported efforts for bereavement services within communities by providing financial grants and other types of donations (e.g., volunteer hours). Religious and spiritual

organizations may also be responsible for providing emotional and spiritual support sought by bereaved individuals. Private practitioners, medical personnel, and volunteers have also played a role in bereavement care. Collectively, these resources have implicitly and explicitly impacted society's awareness of bereavement by providing adequate services.

In general, hospices allocate an extremely low percentage of their budget for bereavement services (Foliart, Clausen, & Siljstrom, 2001; Rathbun, Denham, & McCarthy, 2003). Medicare mandates hospices to provide a minimum of 12 months of bereavement services to bereaved families as part of the per diem rate provided, not as a billable service (Demmer, 2003; Lattanzi-Licht, 1989). *Title 42—Public Health, Chapter IV of the Financing Administration, Department of Health and Human Services Sec. 418.204(c)* states that “bereavement counseling is a required hospice service but it is not reimbursable” (Department of Health and Human Services, 2001). The number of hospice patients is approximately 1.4 million (NHPCO, 2008), so the number of bereavement families qualifying for hospice bereavement services could well be over 1.4 million, as families are followed over 1-year period. Yet, no data currently exist to quantify these specific services.

#### *Efforts to Assess Bereavement Services*

Historically, bereavement research has focused on specific issues, symptoms, and reactions to a loss. Theory-based research has been minimal despite findings from studies such as that of Prigerson, (2004), Cherlin, Barry, Prigerson, Schulman-Green, Johnson-Hurzeler, Kasl and Bradley, (2007) that estimate that 10%-25% of people experiencing bereavement may have some type of complicated grieving process. This observed disparity in research contributes to misconceptions and myths about the multidimensional phenomena of bereavement. Regarding formalizing bereavement services, bereavement research remains a young discipline with few

studies documenting multidimensional perspectives of bereavement services in the United States. The delivery of bereavement services must be better understood.

*First National Bereavement Study in The United States*

Documented efforts to assess bereavement services in the United States date back to 1989 when Lattanzi-Licht completed the first national study of bereavement services by mailing a 2-page, 21-item survey to providers who were members of the National Hospice Organization (NHO). The survey was composed of both closed and open-ended questions with a total of 268 participants out of 439 initially contacted. The exploratory survey focused on different domains: development of bereavement services (length of time agency has been providing services), hospice size, coordination of services (who is coordinating bereavement services), discipline of bereavement coordinator, information on salaried and volunteer coordination, bereavement personnel (number of personnel), amount and type of bereavement staff training, services provided, service priorities, information about referrals to community providers, risk assessment, demographics of service recipients, identified obstacles in service provision, program funding, data collection and research, and identification of agency's needs.

Lattanzi-Licht's (1989) study documented the need to enhance general provision of bereavement services. Lattanzi-Licht elaborated on findings from Simson and Wilson (1986) regarding possible connections between size of hospices and delivery of bereavement services. Although Simson and Wilson's study did not primarily address bereavement services, it provided important information related to possible connections between size of a hospice and services offered such as bereavement. Related to this issue, Lattanzi-Licht quoted Simson and Wilson, stating that, "while all hospices provide some degree of bereavement support, new hospices often feel unable to undertake major bereavement service programs" (p. 22). There may be a

connection between type of hospice (private versus not-for-profit) and type and quantity of bereavement services offered to the public.

An interesting finding from Lattanzi-Licht's (1989) study was that few referrals (6%) were made to outside clinical providers. As the findings of this study revealed limited bereavement resources (e.g., staffing, programs, funding), the low number of referrals to outside psychotherapeutic services is interesting, and certainly more research needs to be done in this area to understand "the appropriateness of hospice involvement in intense grief therapy" (p. 24). No information was found regarding assessment of families that may be at high risk for complicated bereavement, but this was recommended.

Lattanzi-Licht (1989) also discussed problems with defining bereavement services by stating that bereavement services "vary widely and are often loosely defined" (p. 1). This phenomenon (lack of clear operational definitions) is also found in EOL (i.e., death, dying, palliation) care research. Such lack of clear operational definitions limits the advancement of research in this area (Berzoff & Silverman, 2004). This phenomenon was further impacted by the high number of hospices (94%) not participating in any research and the high number (60%) not collecting any bereavement data. Certainly, Lattanzi-Licht's study was a tremendous contribution to the bereavement field while at the same time generating additional research questions.

#### *Second National Bereavement Study in The United States*

In 2003 Demmer used a random sample of 450 (58% returned rate,  $n = 260$ ) provider members of the NHPCO from the United States to collect survey data regarding bereavement services in the United States. Demmer (2003) adapted Lattanzi-Licht's (1989) questionnaire to explore several domains within the 23-item survey: length of time bereavement services were

functioning, number of annual patient deaths and annual number of families served, types of services provided and number of families served, bereavement personnel information, bereavement staff training, priorities of bereavement services, assessment of bereavement needs of families, process of risk assessment, agencies' challenges when offering bereavement services, information about hospice funding, research efforts of the hospice agency, and recommendations to improve bereavement services.

Demmer (2003) addressed the current variability that exists as to what constitutes a bereavement program. Foliart et al. (2001) acknowledged that the lack of "state and federal standards on what constitutes a hospice bereavement program" (p. 328) has been a significant issue. This lack of standardization can have a direct impact on how, when, and who offers and provides bereavement services. Demmer enhanced the knowledge base in the area of bereavement services in the United States by providing updated information on bereavement services, staffing, training, services provided, issues, and obstacles. Among several findings, Demmer's study identified specific bereavement components provided by U.S. hospices: letters/notices of support groups and meetings, phone calls by bereavement personnel, literature/materials on grief, visits by bereavement personnel, memorial services, bereavement newsletters, children's camps, support group meetings, holiday grief programs, and referrals to outside therapists.

Demmer (2003) requested respondents to "estimate the average percentage of bereaved individuals who received services from their hospice" (p. 332). Multiple responses were possible. Of 12 services listed on the survey (including mailings, visits, workshops, support groups, referrals to outside providers, children's camps, memorial services) respondents estimated that 87% of bereaved families "were more likely" to receive letters or notices about

meetings or groups, 83% of bereaved families received phone calls, 81% received literature and materials on grief, and 55% received visits by bereavement personnel.

Demmer (2003) also asked respondents to prioritize bereavement services delivered in their hospice. Findings revealed that 35% of respondents identified “literature/mailings” as the first priority of their hospice, and 26% identified “visits” by bereavement personnel as first priority of their hospice. Of the respondents, 25% selected “literature/mailings” as the second most frequent priority, 30% of the respondents selected “support groups” together with “memorial service” (29%) as the third most frequent priority. Demmer concluded that hospices rated “literature/mailings,” “support groups,” and “memorial services” as top bereavement service priorities.

Demmer (2003) reported that respondents expressed a desire to provide more home visits and individual services but were limited in resources. Other findings from this study revealed specific obstacles when providing bereavement services by hospices, including lack of sufficient staff time (58% of respondents), funding pressures (38% of respondents), lack of personnel (31% of respondents), lack of interest of clients (14% of respondents), and lack of organizational support of bereavement services (10% of respondents).

#### *Other Bereavement Studies*

Two additional state-specific studies found in the research literature focused on assessing aspects of hospice bereavement services in the United States. The first assessed general provisions of bereavement services in California (Foliant et al., 2001). In this study, the researchers documented California’s bereavement support services, program content, staff training, and fees associated with provision of bereavement services. Additionally, the authors tested the hypothesis that the “content of bereavement programs is related to the size of the

hospice, with the largest hospices offering a wide array of support groups and workshops” (p. 462). Findings, related to the hypothesis, revealed that the content of services varied. Support groups and specific workshops, for example, were offered by hospices with a larger budget.

Also, the authors discussed the NHPCO’s (2000) draft of specific standards that defined or attempted to operationalize bereavement services. This included provision of bereavement services for a “minimum 13 months following the death of a patient and utilization of qualified staff and specifically trained volunteers” (Foliant et al., 2001, p. 462). The other three recommended standards by the NHPCO include having treatment plans for families and caregivers, assessing families and caregivers for bereavement needs, and bereavement programs providing bereavement support and education to their communities. As there are no state or federal standards regarding “what constitutes a bereavement program” (p. 462), the NHPCO’s standards only serve as recommended standards for bereavement services. This study was important in documenting the importance of standardizing bereavement services.

Another important (state-specific study) was conducted by Rathbun et al. (2003) and assessed Ohio’s compliance with the NHPCO’s Bereavement Standards. This was an important study because the NHPCO’s (2000) Bereavement Standards explicitly discuss documenting “quality and impact of bereavement services” (Rathbun et al., p. 448). Findings revealed that the 32 respondent hospices met all of the bereavement standards. Limitations of these state-specific studies were that only one state was sampled and they did not address key variables related to delivery of bereavement services to minority populations such as ethnicity, cultural variations, and language barriers. Other relevant information reviewed by Rathbun et al. (2003) related to findings from a meta-analysis that focused on therapeutic bereavement interventions. This revealed significant problems with previous bereavement research such as methodological issues

(e.g., small group samples, choosing ineffective assessment tools, lack of random assignment to groups); lack of a theoretical orientation basis; and insufficient follow-up data. The authors stated that, “little evaluative work has been done to discover whether hospice programs nationwide are compliant with these standards” (p. 448).

Another relevant and useful study by Ellifritt, Nelson, and Walsh (2003) provided information regarding issues of complicated bereavement. They developed a risk assessment tool, which was sent to 508 random hospice bereavement coordinators across the United States who registered with the NHPCO. Of the 508 surveys, 262 surveys were returned. Different professional disciplines were represented in the sample including social workers, nurses, chaplains, psychologists, and counselors. The participants were asked to rate an instrument composed of 19 factors each addressing potential signs and symptoms of complicated bereavement. The instrument was developed by one of the authors. Findings revealed that, “professional discipline is not important in assessing risk factors since all rated the most significant (risks) the same” (p. 119). Risk factors (of bereaved family members) most often selected by the participants included perceived lack of social support and poor coping skills of bereaved individuals. Findings, however, did not reveal how bereavement interventions may be different among the different disciplines or how the risk, when identified, was handled. This clinical issue may be an important aspect to explore in future research.

Ellifritt et al. (2003) discussed how early intervention in complicated bereavement cases may be cost-effective as it may prevent or decrease the use of healthcare resources (e.g., physician visits) and provide the necessary intervention to assist bereaved family members. These interventions may be in the form of a thorough psychosocial assessment of the family’s support system and coping skills, for example.

Researchers such as that of Cherlin et al. (2007) stated that 10%-25% of people with complicated bereavement issues access bereavement services. The benefits of bereavement services include decreasing possible distressful symptoms associated with the grieving process (e.g., isolation, feelings of despair, depression, sleep disturbances). Beem et al. (1998) discussed the benefits of bereavement counseling, particularly the prevention of more chronic and serious bereavement issues. Baohui et al. (2006) discussed the physical, mental, and social benefits of bereavement care. Their research focused on understanding the risk of complicated bereavement and enhancing the efficacy of clinical practice.

### *Hispanics and Bereavement*

#### *Death, Dying, and Bereavement Rituals of Hispanics*

Death and dying is an experience shared by all human beings. Nevertheless, each person will, undoubtedly, have different experiences and reactions to their own anticipated death or to the death of someone they know. Human beings ascribe to or develop meanings of various life experiences based on social constructs. The Hispanic community provides an example of how intrinsic end-of-life rituals and beliefs can remain intact despite high levels of acculturation. The intensity or level of the bereavement experience may vary regardless of cultural rituals and beliefs. However, acculturation does not always predict behavior. For example, Solis, Marks, Garcia, and Shelton (1990) discussed how access to healthcare, not acculturation, predicted the utilization of healthcare services among Mexican-Americans. Matsumara et al. (2002) stated that, “acculturation does not cause a complete conversion to the western model of end-of-life attitudes” (p. 538). Therefore, there may be different reasons for people’s experiences (Berger, 1998; Crawley et al., 2002; Gutiérrez, Yeakley, & Ortega, 2000; Hallenbeck & Goldstein, 1999; University of Washington Medical Center, 2006) and behaviors when facing the end of life and

bereavement. In the case of Hispanics, these variables may range from external (e.g., place of residence) to individualistic (e.g., country of origin, generational status, socioeconomic status, language proficiency) variables.

### *Attributes of Hispanic Families*

The central role of Hispanic families in decision-making should be mentioned as well as the concepts of *familismo* and *respeto*. Kwak and Haley (2005) mentioned that Hispanic families respond to a family-centered model of decision-making. *Familismo* is the “valuing, connecting to, and identifying with one’s large, extended family” (Doran & Downing-Hansen, 2006, p. 200). Family situations surrounding death “are often shared among three or four generations of relatives” (Falicov, 1998 as quoted by Doran and Downing Hansen, 2006, p. 200). Therefore, the sense of family is an important variable in Hispanic families.

*Respeto* is another common characteristic of Hispanics that impacts communication. Hispanics may not ask physicians, social workers, and/or nurses many questions, as the health care professionals are the “experts.” Hispanics may not question direct interventions and guidance from medical personnel in order to convey respect to the professional. Also, in general, Hispanics expect this respect to be reciprocated by being addressed as *Señor* (Mr.) or *Señora* (Mrs.).

Berger (1998) discussed common beliefs of Hispanics related to healthcare, such as not wanting to have medical situations disclosed, wishing not to be told the “truth” about medical conditions, and believing in the power of “God” and religion. Religion is an integral part of most Hispanic families and this relates both to the acceptance of the sick role and of pain as part of the life and the death process (University of Washington Medical Center, 2006). Hispanics may not immediately accept bereavement services, for example, as they expect to have

emotional grief and pain. *Sufrimiento* (suffering) is grounded in religious beliefs and may be common among Hispanics (Munet-Vilarò, 2004). Hispanics may have the cognitive awareness that interventions may exist to help them with intense grief responses but may not access or accept these interventions because physical, emotional, and existential (spiritual) pain is not perceived separately by Hispanics. Spiritual support and instilling hope may be an essential component to supporting Hispanics throughout the process of grief (Munet-Vilaro, 2004).

Other important beliefs and rituals of Hispanics, when death is approaching or has occurred, are the use of folk medicine (e.g., drinking special herbal teas), praying to “saints” and “God,” utilizing religious resources (e.g., priest), burning candles, and cleansing the deceased family member’s body (Gutierrez et al., 2000). *Ataque de Nervios* (attack of nerves) and *Susto* (fright) are both described in the *Diagnostic and Statistical Manual of Mental Disorders (DSM-IV-TR*, American Psychiatric Association, 2000), as normal behavioral reactions to stress or a specific traumatic event (e.g., death of a family member). During an *Ataque de Nervios*, the person may experience feeling out of control, while *Susto* has been defined as “an illness attributed to a frightening event that causes the soul to leave the body and results in unhappiness and sickness” (Sadock & Sadock, 2007, p. 524). Researchers, academicians, and practitioners alike have elaborated on these two culturally driven responses to traumatic events. Sadock and Sadock, for example, described specific symptoms such as aggression, fainting episodes, feeling out of control, suicidal gestures, dissociative experiences, appetite and sleep disturbances, extreme sadness, poor motivation, low self-worth, and somatic complaints that are associated with *Ataque de Nervios* and *Susto*.

The literature clearly points to the notion that Hispanics’ attitudes about death and bereavement are structured, to a large extent, by cultural heritage, religious practices, and the

family unit (Catlin, 2001; Oltjenbruns, 1998; University of Washington Medical Center, 2006). Furthermore, because nuances within cultural groups exist and communication strategies vary among cultural groups, researchers have attempted to provide guidelines that may frame work with Hispanics within EOL domains. Munet-Vilarò (2004), for example, provided practice guidelines for delivery of health care services to Hispanics. The importance of health care providers' cultural and linguistic competence, use of interpretation services, being aware of specific beliefs of Hispanic families, and being aware of different communication styles is discussed by the author.

### *Summary and Research Questions*

In summary, the research literature provides evidence that EOL care domains have been evolving in the past three decades. However, despite efforts and initiatives to advance the EOL care field, gaps in research continue to exist. One of the gaps relates to bereavement services specifically with Hispanics. Previous efforts (Demmer, 2003; Lattanzi-Licht, 1989) to assess the state of bereavement services in the United States have not considered and/or discussed ethnicity factors. It is unclear how many Hispanics are using hospice services in the United States overall because no clear standard mechanisms currently exist to track hospice use by Hispanics. Further, the NHPCO and the FHPC, for example, do not report specific statistics for bereavement hospice use by Hispanics. As a result, there are no clear statistics that report the number of Hispanics accessing bereavement services in the United States. In addition, little is known about the specific bereavement needs of this population.

The NHPCO (2008) reported that approximately 1.4 million people in the United States were enrolled in a hospice in 2006. Of the 1.2 million, 4.9% were reportedly Hispanics. Predictions by the U. S. Census Bureau (2001) indicate that Hispanics, with 96 million people,

will be the number one minority population in the United States by 2055. These statistics point to the need to develop new initiatives to understand specific needs of Hispanics in all areas where quality of life is an issue, including specific EOL care domains such as bereavement.

This exploratory study was driven by the documented gaps in the knowledge base in this area. This study is important because it may lead to a better understanding of the current state of bereavement needs and service provision to Hispanics and may lead to the development of practice initiatives. The study explored bereavement services offered to Hispanics by hospice agencies in the state of Florida.

There were several reasons for selecting Florida to explore this topic. In summary, Florida's Hispanic population, at over 3.5 million, represent 14.8% of the total U.S. Hispanic population and 16.8% of the total Hispanic population in Florida (U. S. Census, 2001). There is a need to explore and understand the general needs of this growing population. Another reason relates to the diversity of Florida's Hispanic population. This diversity is exhibited by having people from every Latin American country living in Florida. Hispanics in Florida are not homogeneous and differ in cultural beliefs, customs, socioeconomic systems, and educational levels. Yet another reason to focus on Florida is because of the limited information that exists regarding bereavement practices among Hispanics in Florida. A review of Florida's Department of Health's website, for example, did not yield any Community Health Assessment Resources Tool Sets (CHARTS) related to tracking of bereavement services. Such a knowledge gap combined with the diversity, heterogeneity, and total number of Hispanics in Florida point to the need to understand bereavement services with Hispanics in greater detail.

This study addressed the following research questions:

1. What are the characteristics of hospice organizations that provide bereavement services to Hispanics in Florida?
2. What bereavement services are offered to Hispanics by Florida hospices?
3. What do Florida's hospice bereavement coordinators identify as needs for bereaved Hispanics?
4. What challenges are faced by Florida's hospice bereavement coordinators in the provision of bereavement services to Hispanics?
5. What are the strengths identified in Florida hospices regarding bereavement services provided to Hispanics?

## CHAPTER 3

### METHODOLOGY

This section provides information on the methodology and procedures for this study. The research design, sampling strategy, instrumentation, detailed procedures for data collection, and Institutional Review Board (IRB) application for the study are included.

#### *Research Design*

The design used in this study was an exploratory research design. This design included neither random assignment nor control groups. The study's results are primarily descriptive in nature, as the purpose of the study was to collect and interpret information about the provision of bereavement services in Florida Hospices, including the current status of bereavement services being offered to Hispanics. A survey was created that specifically focused on service delivery and utilization, current challenges, and other issues relating to the creation and provision of bereavement services to Hispanics. I was the primary investigator (PI) and collected, analyzed, and interpreted the data obtained from the surveys.

Several methods of inquiry were considered for this study. After reviewing the research questions for this exploratory study, considering the various research methods that are currently available, and considering the limited research that has been generated in the area of bereavement practices with Hispanics, survey research was selected as the most appropriate method of inquiry.

## *Sampling Procedures*

### *Sample*

Nonprobability convenience sampling was used in this study. Nonprobability convenience sampling has been extensively used in research to explore and understand phenomena. Convenience sampling does not statistically represent larger populations and therefore limits generalizing findings. As research in the area of bereavement services with Hispanics is limited, this type of sampling technique was appropriate. Using a nonprobability convenience sample provided insight and clarification and allowed identification of specific bereavement services available to Hispanics in Florida. Furthermore, it allowed identification of gaps in bereavement services, which are discussed in chapter 4.

The sampling frame was all bereavement coordinators working in Florida hospices licensed by Florida's Agency for Health Care Administration (AHCA) and registered with the Florida Hospice and Palliative Care (FHPC) organization. Florida ranks third highest in the United States for hospice utilization (Connor et al., 2007), but bereavement services have not been thoroughly evaluated in this state. With 41 different hospice agencies serving the 67 counties in Florida, it seemed crucial to document and understand different efforts, challenges, and successes experienced by these agencies regarding bereavement care to Hispanics.

In order for respondents to be eligible to participate in this study, they had to self-identify as the person responsible for coordinating bereavement services for the respective hospice contacted by the investigator. Job titles varied and included bereavement counselor, bereavement coordinator, spiritual counselor, social worker, and/or counselor. On the initial contact, the PI requested to speak with the person who was coordinating bereavement services. The script for this initial contact has been included in Appendix A.

### *Recruitment*

The contact information for all of the registered hospices in Florida is listed on the FHPC website ([www.floridahospices.com](http://www.floridahospices.com)) and Florida's AHCA's website ([www.fdhc.state.fl.us/](http://www.fdhc.state.fl.us/)). There are 67 counties in Florida, and each county is served by at least one hospice agency. The total number of Florida hospice agencies registered with the FHPC was 41. These agencies often served more than one county and therefore when counting hospices by counties, the total number of hospices listed equaled 152.

For the purpose of this study, recruitment was accomplished by contacting all of the 41 hospice agencies registered with the FHPC and AHCA by telephone and electronic mail. The FHPC supported this study by informing all Florida Hospices Chief Executive Officers (CEOs) of the study and encouraged agencies to participate. After the University of Alabama's IRB Committee granted approval to conduct the research (Appendix B), the FHPC's Director sent an electronic mail, along with a brief biographical sketch of the PI, to all of the CEOs of Florida Hospices (Appendix C). This E-mail was sent at least 2 weeks prior to the PI's initial phone call to the bereavement coordinators.

During the initial phone call to the hospices, the PI requested to speak with the bereavement coordinator and/or bereavement services point of contact for each agency. When it was determined that a specific bereavement program provided services in other counties or locations, the PI attempted to obtain the contact information of any additional bereavement coordinators at those sites. This was accomplished by asking bereavement coordinators during the initial phone contact for the contact information of other bereavement coordinators working for the same agency but in a different city or county. Four respondents reported that they served multiple sites and one respondent reported that their agency had a different bereavement

coordinator at another site. In summary, all potential participants were provided with opportunities to participate in this study.

### *Procedures for Data Collection*

In this study, an Internet-based survey instrument was sent to all potential respondents ( $n = 41$ ). A formal request was made to The University of Alabama's IRB Committee, and approval was granted to proceed with the study (Appendix B).

After the IRB approval was granted, procedures and survey were pretested. This process will be discussed in greater detail under the "pretest" heading. After the pretest, telephone contacts began with all bereavement coordinators working in Florida hospices registered with FHPC and AHCA. A listing of the hospices can be found by accessing the FHPC's website at [www.floridahospices.org](http://www.floridahospices.org). A database (Appendix D) was kept with the name of the hospice, phone numbers, E-mail addresses, mailing address, and names of the bereavement coordinators. This helped to organize the contact information and avoided duplicate phone calls to agencies. This step was also necessary to verify the actual number of hospices that were going to be sampled.

The first contact was a phone call to hospice agencies. A request was made to speak with the bereavement coordinator or the person responsible for coordinating bereavement services (Appendix A). If the hospice agency did not offer bereavement services, the information was noted on the database sheet. A receptionist or phone operator typically answered the telephone calls and either connected the PI to the bereavement coordinator and/or provided the PI with a direct line to the bereavement coordinator. When connected to the appropriate individual, the PI introduced himself, explained the purpose for the phone call and the purpose of the proposed study, and informed them that more information about the study was going to be E-mailed (see

Appendix E) within 7 days of the phone call. This E-mail explained the purpose of the study, had an explanation of informed consent, and contained the hyperlink to access the survey via the Internet. The primary goal of the initial telephone contact was to verify contact information (address, E-Mail, phone number, etc.) for the hospice agency and obtain potential respondents' E-mail addresses in order to E-mail the procedures to participate in the study. Each hospice agency was assigned a number on the data sheet in order to keep track of communication.

Potential respondents were informed that participation in the study was voluntary and that their responses were confidential. The investigator did not have information about the respondents' computer's Internet Protocol (IP) address or any other method of connecting surveys to respondents. During the initial phone call, the potential respondents were provided with opportunities to ask questions about the study and were provided with the investigator's contact information (i.e., E-mail and telephone number) in the event that future questions emerged. After the initial phone call, the investigator sent a "Thank You" note via regular mail (see Appendix F) to potential respondents to thank them for their time and consideration to participate in the study. To thank them for their time, a \$2.00 food coupon, good at McDonalds Restaurants, was included with the "Thank You" card. All potential participants received this voucher to acknowledge their time and consideration to participate in the study.

Within 7 days of mailing the "Thank You" notes, an electronic mail (Appendix E) was sent to all potential respondents. The E-mail explained the purpose of the study and provided a hyperlink to the survey. The survey was created with SurveyMonkey, which is a world-wide-web-based survey company. Once the potential respondents connected to the survey via the hyperlink, details about the study including informed consent were displayed on the first page

(Appendix G). This E-mail also explained that there were no financial incentives for participating in the study and that participation was voluntary and confidential.

After 2 weeks of sending the first E-mail to the potential participants, a second E-mail (Appendix H) was sent to all potential respondents. The purpose of the second E-mail was twofold. First, respondents that completed the surveys were thanked for their cooperation and reminded that the results of the study were going to be E-mailed to all of the prospective respondents at the end of the study. The second goal of this E-mail was to encourage potential respondents who did not complete the survey to use the hyperlink to connect to the survey. Access to the Internet survey was closed 2 weeks after sending the last E-Mail reminder to participate.

Potential respondents were encouraged to complete the survey in one sitting. However, they were instructed that if they needed to close the survey and continue at a later time, that they had the opportunity to continue where they left off by clicking on the hyperlink that originally connected them to the survey. By clicking on the hyperlink, the website directly connected respondents to the survey on the SurveyMonkey website. Respondents were informed and reminded that in order to save their answers they needed to use the same computer to begin and end the survey, as the SurveyMonkey website remembered their computer's IP address. However, once they completed and submitted their answers, their computer's IP address was erased.

The investigator kept track of completed surveys by accessing the account on the website link provided by SurveyMonkey. Data analysis began the end of the fourth week of the initial E-mail sent to potential participants, at which time the survey was closed and the hyperlink was no longer accessible for the online survey.

### *Pretest Procedures*

The data collection process, including the survey instrument, was pretested with 4 hospice bereavement coordinators in California. Selection of these respondents commenced once IRB approval was obtained to conduct the study. The PI randomly selected four hospices in California from the California Hospice Foundation's (CHF) list accessed via the Internet ([www.hospicefoundation.info](http://www.hospicefoundation.info)). The sites for these four California hospices included the cities of Claremont, Monterey, Stockton, and Santa Maria. The bereavement coordinators from these hospices were contacted by telephone, and the previously discussed procedures were followed to pretest the entire process of data collection. As California has a large Hispanic population, it was expected that respondents pretesting the procedures and survey instrument were going to provide useful and relevant feedback. A different hyperlink for the pretest was created to avoid any confusion in data collection. This hyperlink was closed after completing the pretest.

The PI requested respondents who pretested the procedures to specifically review the survey for clarity, ease of reading, time it took to complete the survey, length of survey, ease of instructions, and formatting, and comment on the strengths and weaknesses of the survey. They were instructed and encouraged to read each question and share with the PI any comments and reactions to each question. The comments from the 4 respondents were considered, and changes were made to the survey as needed. The survey was not scored or analyzed.

The survey was created specifically for this study. Several authors have discussed different criteria to evaluate surveys. The criteria by Fink and Kosecoff (1989) and Nardi (2006) were considered for the pretest of the survey. The following criteria from these authors were used:

- Did the survey provide required information to the respondents to answer the questions?
- Did the survey have any ambiguous words, terms, or sentences?
- Did the questions flow well?
- Were the survey procedures clear and conducive to being used by other researchers to collect information in the same manner?
- How long did it take for participants to complete the survey?
- Was the formatting of the survey acceptable?

Participants completing the pretest process were provided with these criteria. These participants were asked to rate the survey on these criteria and also identify the strengths and weaknesses of the survey measure. Feedback from these respondents was considered, and changes were made in the amount of time it took to complete the survey, which was changed from 20 minutes to 30 minutes. Also, at least one respondent reported that open-ended categories needed to be included in certain questions. This was easily accomplished by adding an “Other, please specify” or “Comments” boxes to relevant questions.

Respondents participating in the pretest were asked to rate the survey on the criteria by Fink and Kosecoff (1989) and Nardi (2006) listed previously. Participants were asked to rate questions by using the following scale: *Strongly Agree*, *Agree*, *Neutral*, *Disagree*, and *Strongly Disagree*. Collapsing these categories into *Agree* and *Disagree* revealed that for the first evaluation criterion, “Did the survey provide required information to answer the questions?” 3 (75%) respondents indicated *Agree*. For the criterion “Did the survey have any ambiguous words or sentences?” all 4 (100%) of the respondents selected *Disagree*. For the criterion “The questions flow well” all 4 (100%) of the respondents reported *Agree*. For the criterion “The

survey procedures are clear and conducive to being used by other researchers to collect information in the same manner” 3 (75%) of the respondents indicated, *Agree*. For the criterion “The length of the survey is appropriate for the information that is being collected,” all 4 (100%) of the respondents reported *Agree*. For the last criterion, “The formatting of the survey is acceptable,” all 4 (100%) respondents indicated *Agree*.

Appendix I depicts the pretest survey with specific instructions. A “thank you” letter (Appendix J) was mailed to the respondents that participated in the pretest.

### *Survey Instrument*

The exploratory survey (Appendix K) for this study was created from a review of the EOL and bereavement care research literature and the PI’s practice experience as a hospice/bereavement social worker. The 18-page survey had six different sections, and specific questions were written to support and further operationalize each content area. The survey for this study had a total of 66 questions, of which 16 were adapted with permission (Appendix L) from Demmer’s (2003) 23-item Survey of Bereavement Services.

The survey used in this study had two general domains (factual information about the agency and perceptions of bereavement coordinators) with different sections for each domain. There was also a small demographic section at the end that collected information about the respondents. The first domain had two sections that collected factual information about the agency’s general characteristics and bereavement services offered at the respondents’ agencies. The first section of this domain requested information on characteristics of the agency and was dichotomized into three subsections: hospice agency background, bereavement care, and bereavement training for staff. The subsection for hospice agency background had 12 questions including type and status of hospice agency, counties served, type of hospice auspices, location

of the agency, census, budget, payment sources, Medicare certification status, and types of accreditation. Respondents were asked to respond to these questions by selecting answers or answering open-ended questions. For example, respondents were asked to select payment sources accepted by their hospice program. They were asked to select from responses such as “Medicare,” “Medicaid,” and “Private Insurance.” An example of one of the open-ended questions in this section was “How many counties are served by your hospice agency?”

The second subsection had 17 questions and explored bereavement care services. Questions included length of time the agency had been providing bereavement services, type of bereavement care services (i.e., full-service, assessment and referral only), cost to families, bereavement census, percentage of census that spoke Spanish, characteristics of bereavement staff (type of profession, number of professionals including volunteers, number of bereavement staff who spoke Spanish), specialized training offered by the agencies, and agencies’ support for continuing education. Respondents were asked to select preselected answers from drop-down menus, write in answers, estimate census and agency staff’s composition, and estimate fees charged (if any) for bereavement services. For example, to determine an estimated number of individuals and families served by their bereavement program in the past year, respondents were asked to select from the drop down menu for “Individuals” and from the drop down menu for “Families” and select one of the categories (1-20, 21-40, 41-60, 61-80, 81-100, 100+).

The third and last subsection explored training available to bereavement staff. This section had four questions and requested respondents to comment on the number of annual training hours bereavement staff received, comment on specialized bereavement training, identify any specific training to work with different ethnic populations, and identify any financial support provided by the agency to attend training. All of these questions asked respondents to

select answers. For example, to determine if the bereavement staff received specific training on how to work with Hispanics, respondents were asked to select *Yes* or *No*.

Section two of the survey explored specific characteristics of bereavement services for Hispanics. This section had nine questions and inquired about referrals of Hispanic individuals/families to community resources. Also, respondents were asked to rank the top three community resources most often used with Hispanic clients. Other questions in this section included querying respondents about the agencies' bereavement assessment process, identifying the types of bereavement services the agencies offered, identifying the three most frequently offered bereavement services to both English- and Spanish-speaking clients, identifying all available resources the agency had to communicate with Spanish-speaking clients, responding to funding sources for available and needed interpretation services, and querying if undocumented families/individuals had access to bereavement services at the agency. The questions in this section were primarily check-off items with *yes* and *no* answers, and prioritizing community resources. The last question was an open-ended question asking bereavement coordinators to comment on their perceptions about any related bereavement needs of Hispanics in their area.

The second domain of the survey instrument began with section three of the survey and explored perceptions of bereavement coordinators in three different areas. The first area, bereavement needs of Hispanics, was composed of four questions including the opinions of respondents on the most common bereavement needs of Hispanics, the types of bereavement services needed by Hispanics, and the identification of gaps when offering bereavement services to Hispanics. The questions on section three included check-off items, listing, and prioritizing.

Section four, under the second domain, explored perceptions of bereavement coordinators on the challenges faced by hospice agencies in the provision of bereavement services to

Hispanics. This section, composed of four questions, focused on the identification of specific difficulties faced by Florida hospices and bereavement services when offering services to Hispanics. This section also requested participants to identify the greatest obstacles faced by their agencies when delivering bereavement services to Hispanics, as well as identify roadblocks to preventing the advancement of bereavement services to Hispanics. The structure of these questions included fill-in answers, check-off items, and prioritizing lists.

Section five under the second domain explored the strengths of the agency related to hospice and bereavement service delivery. This section, composed of three questions, focused on identifying strengths of both hospice and bereavement services, and identifying specific strengths when offering bereavement services to Hispanics. Respondents were asked to identify and prioritize strengths.

The last section of the questionnaire (section six) was composed of 13 demographic questions related to the respondents' characteristics. These questions included the respondents' age, gender, professional title, employment status, and professional discipline, Spanish-speaking knowledge, educational level, race, ethnic background, religious affiliation, and length of time they had worked in hospice. The last question, an open-ended question, prompted respondents to provide any additional comments related to the topic of bereavement services with Hispanics or anything else they wished to say about the study. The majority of these items requested participants to write in the answers.

### *Data Analysis*

This section will address data analyses that served to provide a greater understanding of what bereavement services were being offered to Hispanics in Florida at the time of the study.

The analyses were selected with the goal of answering the study's research questions presented earlier.

Descriptive statistics were used to present the data generated from the surveys. Descriptive statistics allow “researchers to summarize and organize data in an effective and meaningful way. They provide tools for describing collections of statistical observations and reducing information to an understandable form” (Frankfort-Nachmias & Nachmias, 1999, p. 321). Demographic variables were presented with descriptive statistics to enhance the understanding of the population's sample. Specifically, the mean, range, minimum and maximum values, frequency of responses, and percentages were computed as appropriate. Because of the exploratory nature of this study there were no hypotheses to be tested and therefore no inferential statistics were conducted. The format for presenting results was modeled after Demmer's (2003) exploratory study, which primarily reported percentages and frequencies. It was determined that these basic measurements provided an accurate representation of the data explored in this study. In addition, a larger sample would be required for inferential statistics.

As the respondents had opportunities to write in comments to many of the questions on the survey, open-ended responses were analyzed in aggregate form. These responses were transferred into a Word document to ease the content analyses process of piling, sorting, and categorizing responses. Word for Mac 2004 and Mac software were used as they contained several tools conducive to quantifying words/concepts (e.g., *find next*, *Spotlight*). The categories created from piling and sorting the open-ended responses were presented in both a table format and providing the exact responses of the narrative answers. The tables with all of the open-ended responses have been included in Appendix M. These responses are presented in the Discussion section.

### *Protection of Human Subjects*

Prior to commencing the study and collecting data, a proposal was presented to The University of Alabama's IRB for approval. The IRB proposal had specific sections including Protection of Human Subjects, Informed Consent Form, the study's benefits and risks of participation, as well as the limitations and gains of the proposed study. As stated previously, the IRB's approval is found in Appendix B.

## CHAPTER 4

### RESULTS

The purpose of this exploratory study was to examine and document current bereavement services for Hispanics in Florida. The study explored five research questions via an Internet-based survey created specifically for this study. From the total number of Florida Hospices ( $n = 41$ ) registered with the FHPC and the FAHCA, 30 (73.2%) were represented in the total sample. This chapter describes the results of the survey beginning with the first section identified as factual information. Within this first section, descriptive characteristics of the respondents are reported, followed by the characteristics of the hospice agencies, specific characteristics of the bereavement departments, and bereavement training for staff. The second section reports the perceptions of respondents about the bereavement services for Hispanics, bereavement needs of Hispanics, challenges encountered by hospice agencies when delivering hospice and bereavement services, and strengths of hospice agencies related to hospice and bereavement service delivery. The last section reports open-ended comments reported by the respondents related to the topic of bereavement services with Hispanics.

#### *Characteristics of Respondents*

Table 1 shows respondents' age, gender, race, ethnicity, religion, professional title, employment status, level of education, professional discipline, length of time working in end-of-life care, and length of time working in bereavement care at their agencies. Most respondents were female ( $n = 24$ , 85.7%) with a mean age of 51 and reported being Caucasian ( $n = 25$ , 89.3%), Christian ( $n = 24$ , 92.3%), and non-Spanish speakers.

Table 1

*Characteristics of Respondents*

Variables	<i>n</i>	%
Age ( <i>n</i> = 26)		
62-68	5	19.2
51-61	10	38.5
39-50	5	19.2
20-38	6	23.1
Fluent Spanish Speaker ( <i>n</i> = 28)		
No	15	53.6
Some	10	35.7
Yes	3	10.7
Discipline (multiple responses possible, <i>n</i> = 21)		
Social Work	14	66.7
Other (counselors, art therapy, family Therapy)	12	57.1
Psychology	5	23.8
Religion/Theology	4	19.0

Most respondents reported being managers and/or directors (*n* = 21, 75%) of their bereavement programs working full time (*n* = 26, 93.0%) with masters degrees (*n* = 23, 85.2%) and indicated that they had been working in end-of-life care services (*n* = 22, 78.6%) and bereavement services (*n* = 18, 64.3%) longer than 5 years. Social workers were overrepresented in the sample.

### *Characteristics of the Hospice Agencies*

Of the 67 total counties in Florida, 44 (66%) were represented. The largest representation was found in South and North Florida (Table 2) with the exception of the Panhandle area of the State. Counties in Florida's Panhandle were underrepresented in this study. Every geographic region of Florida was represented in the sample. Most of the agencies used the word *Hospice* in the name of the agency ( $n = 22$ , 84.6%), and few ( $n = 4$ , 15.4%) used the words *palliative care* in addition to *hospice*. Many were freestanding ( $n = 20$ , 83.3%), whereas the others were hospital based ( $n = 10$ , 41.7%), skilled-nursing facility-based ( $n = 6$ , 25.0%), and not for-profit ( $n = 23$ , 85.2%). Most agencies ( $n = 21$ , 75%) had been providing hospice services for at least 20 years. Over 65% of respondents ( $n = 17$ ) reported that the daily hospice census was between 0-500, with the rest ( $n = 9$ , 34.6%) reporting a daily census over 501. Although the majority ( $n = 14$ , 52%) reported not knowing the annual hospice budget, 44% ( $n = 12$ ) reported a hospice budget of at least \$1 million.

Regarding the types of payment accepted by hospices, there were 28 respondents, and all reported that Medicare and Medicaid were accepted as payment types. Most respondents reported that their hospice agencies are Medicare certified ( $n = 25$ , 89.3%), with only 3 (10.7%) respondents reporting they did not know certification status. Private insurance and private pay were also reported as payment sources by over 93% of the respondents. Although all 24 respondents reported that Medicare was the most common type of payment source for hospice services, 4 (16.7%) respondents selected a combination of Medicare and Medicaid. Accreditation by the Accreditation Commission for Health Care (ACHC) and the Joint Commission Accreditation for Health Care Organizations (JCAHO) have been earned by many hospice agencies (Table 2).

Table 2

*Characteristics of Hospice Agencies*

Variables	<i>n</i>	%
Location of Agencies by Counties ( <i>n</i> = 44)		
North Florida	17	38.6
South Florida	15	34.1
Central Florida	11	25.0
Panhandle	1	2.3
Accreditations of Hospice Agencies (multiple responses possible, <i>n</i> = 28)		
Accreditation commission for health care	10	35.7
Unknown	10	35.7
The joint commission on the accreditation of healthcare organizations	9	32.1
Community health accreditation program	4	14.3
Not accredited	2	7.1

*Characteristics of Bereavement Services*

Table 3 depicts the characteristics of bereavement services reported by the respondents. Results show that all (*n* = 30) hospice agencies offered bereavement services to families and community members. Regarding fees, 26 respondents (86.7%) reported that services were free of charge, and 4 (13.3%) reported that agencies requested donations from families. Fifty percent of the respondents indicated that their hospice agencies had been offering bereavement services for the past 19-27 years, and 82% offered these services to families for a minimum of 13 months after a patient's death. The top three represented professions were social work (*n* = 134),

pastoral ( $n = 112$ ), and counseling ( $n = 87$ ), with a total of 159 volunteers being reported across Florida. The majority of respondents ( $n = 15$ , 68.2%) reported having 1-2 fluent Spanish-speaking staff, and the rest ( $n = 7$ , 31.8%) reported having 3-10 fluent Spanish-speaking staff. Similarly, few volunteers spoke fluent Spanish (Table 3).

The number of individuals and families served by hospice bereavement services was estimated by most of the respondents to be more than 100 individuals at any given time. Less than 10% of these recipients were Hispanic (Table 3).

Most respondents (between 82% and 96%) reported that their bereavement agencies engaged in outreach activities with religious/spiritual organizations ( $n = 23$ , 82.1%). Most reported that all hospice patients ( $n = 23$ , 85.2%) and family members ( $n = 24$ , 88.9%) received a bereavement needs assessment, reported that their bereavement programs had standardized bereavement care plans ( $n = 25$ , 86.2%), and reported that their bereavement programs provided bereavement education and supportive services to their local community ( $n = 29$ , 96.7%).

Table 3

*Characteristics of Bereavement Services*

Variables	<i>n</i>	%
Number of Years Agency Has Been Offering Bereavement Services ( <i>n</i> = 28)		
28-36	5	17.9
19-27	14	50.0
1-18	9	32.1
Minimum Number of Months Bereavement Services are Offered ( <i>n</i> = 28)		
13 or longer	23	82.1
1-12	5	17.9
Estimated Percentage of Hispanic Clients ( <i>n</i> = 27)		
21% or more	4	14.8
11-20%	8	29.6
0-10%	15	55.6
Number of Bereavement Volunteers ( <i>n</i> = 25)		
21-30	5	20.0
11-20	8	32.0
1-10	12	48.0
Number of Fluent Spanish-speaking Bereavement Volunteers ( <i>n</i> = 16)		
3 or more	6	37.5
1-2	10	62.3

### *Bereavement Training for Staff*

Most of the respondents ( $n = 19$ , 65.5%) indicated that their agencies offered specialized training (e.g., training on how to work with ethnic minority populations) to bereavement personnel. The majority 58% ( $n = 17$ ) of respondents reported that bereavement staff received an average of 16 hours or less of specialized training, 9 respondents (31.3%) reported an average of 17 hours or more of specialized training, and 3 (10.3%) respondents indicated the question was not applicable. However, for most respondents ( $n = 20$ , 71%), this type of training did not specifically include training on how to work with Hispanics. Close to 90% ( $n = 26$ ) of the respondents reported that financial support was provided for continuing education.

### *Characteristics of Bereavement Services for Hispanics*

Close to 59% ( $n = 17$ ) of respondents reported that their bereavement programs had a specific process for identifying high-risk bereaved Hispanics. Most ( $n = 19$ , 67.9%) of the respondents reported that bereavement services were offered to undocumented Hispanics. When communicating with clients identified as having Limited English Proficiency (LEP), the top three communication resources used were bilingual bereavement staff ( $n = 21$ , 72.4%), bilingual staff from other departments ( $n = 18$ , 62.1%), and family members ( $n = 17$ , 58.6%).

Other results indicate that most Hispanic families are referred to community services such as religious organizations (Table 4). Although a variety of bereavement services were offered to Hispanics by hospice agencies (Table 5), the most common way to deliver bereavement services to Spanish-speaking clients was phone calls (Table 6).

Table 4

*Most Common Community Referrals Used With Hispanics (n = 21)*

Variables	<i>n</i>	%
Religious organizations	8	38.1
Community therapists/counselors	8	38.1
Support groups	4	19.0
Mental health center	1	4.8

Table 5

*Bereavement Services Offered to Bereaved Hispanics (multiple responses possible)*

Variables	<i>n</i>	%
Counseling ( <i>n</i> = 29)	29	100.0
Phone calls ( <i>n</i> = 29)	29	100.0
Visits by bereavement personnel ( <i>n</i> = 28)	28	100.0
Memorial services ( <i>n</i> =29)	28	96.6
Spiritual counseling ( <i>n</i> = 28)	27	96.4
Support groups ( <i>n</i> = 28)	27	96.4
Letters ( <i>n</i> = 28)	26	92.9
Literature/printed materials ( <i>n</i> = 28)	26	92.9
Referrals to outside resources ( <i>n</i> = 27)	26	96.3
Bereavement newsletters ( <i>n</i> = 24)	14	58.3

Table 6

*Most Common Bereavement Services Offered to Spanish-Speaking Clients (n = 28)*

Variables	<i>n</i>	%
Phone calls	7	25.0
Support groups	6	21.4
Counseling	4	14.3
Visits by bereavement personnel	3	10.7
Letters	3	10.7
Literature/printed materials	2	7.1
Referrals to outside resources	2	7.1
Bereavement newsletter	1	3.6

In contrast, most respondents reported that English-speaking clients were offered counseling services in addition to phone calls (Table 7). Only one third of the respondents reported that their annual hospice budget included interpretation services, whereas other respondents ( $n = 8$ , 29.6%) reported either not knowing or indicated that the question was not applicable ( $n = 9$ , 33.3%).

Table 7

*Most Common Bereavement Services Offered to English-Speaking Clients (n = 28)*

Variables	<i>n</i>	%
Phone calls	7	25.0
Support groups	7	25.0
Counseling	6	21.4
Letters	3	10.7
Visits by bereavement personnel	2	7.1
Literature/printed materials	2	7.1
Bereavement newsletters	1	3.6

*Perceptions of Bereavement Needs Specific to Hispanics*

Respondents identified language needs, lack of information about available services, and cultural issues as top bereavement needs for Hispanics (Table 8). To further explore specific bereavement needs of Hispanics in Florida, respondents were asked to answer an open-ended question regarding their perceptions related to bereavement needs of Hispanics in their communities. Of the 30 respondents, 16 (53.3%) provided in-depth responses, which are found in Appendix M. Thematic analysis revealed that bereavement coordinators identified cultural issues and language and communication challenges as common bereavement needs of Hispanics.

Table 8

*Perceived Bereavement Needs of Hispanics (multiple responses possible)*

Variables	<i>n</i>	%
Language needs ( <i>n</i> = 29)	19	65.5
Information about available services ( <i>n</i> = 29)	15	51.7
Cultural issues ( <i>n</i> = 27)	12	44.4
Financial needs ( <i>n</i> = 28)	10	35.7
Support system needs ( <i>n</i> = 27)	5	18.5

The top three bereavement services believed to be needed by Hispanics were language/culture concordant services, individual/group support, and home-based counseling (Table 9). Further, respondents identified language, cultural barriers, and information/marketing as the most important bereavement service-delivery gaps in the provision of bereavement services to Hispanics. The complete document, containing the open-ended responses, is listed in Appendix M.

Table 9

*Bereavement Services Needed for Hispanics (n = 26)*

Variables	<i>n</i>	%
Language/culture concordant services/information	15	57.7
Individual/group counseling services	6	23.1
Home-based counseling	2	7.7
Education	2	7.7
Spiritual services	1	3.8

Finally, bereavement coordinators reported that without the limitations of time and money, their hospices would offer several bereavement services. These services would include groups ( $n = 23$ , 82.1%), educational programs ( $n = 23$ , 82.1%), providing additional resources ( $n = 21$ , 75%), individual counseling ( $n = 20$ , 71.4%), regular home visits ( $n = 17$ , 60.7%), mail-outs ( $n = 16$ , 57.1%), and interpretation/translation services ( $n = 15$ , 53.6%).

*Perceived Agency's Challenges in Delivery of Hospice and Bereavement Services to Hispanics*

Most respondents identified language barriers as the top challenge preventing adequate provision of bereavement services to Hispanics in Florida. Cultural barriers were identified as the second most common challenge by 9 of the respondents (Table 10).

Table 10

*Perceived Agencies' Challenges in the Delivery of Bereavement Services to Hispanics (multiple responses possible,  $n = 28$ )*

Variables	<i>n</i>	%
Language barriers	13	46.4
Cultural barriers	9	32.1
Other (limited media advertisement/ financial resources, marketing challenges, accurate census information, lack of specialized staff)	7	25.0
Public prejudice/ignorance	3	10.7

Most respondents identified not having Spanish-speaking personnel, complexity/difficulty defining bereavement services for Hispanics, and bereavement personnel's limited understanding of cultural competence as the greatest obstacles when delivering bereavement services to Hispanics (Table 11).

Table 11

*Perceived Agencies' Obstacles in the Delivery of Bereavement Services to Hispanics (n = 26)*

Variables	<i>n</i>	%
Lack of Spanish-speaking personnel	22	84.6
Complexity/difficulty defining bereavement services for Hispanics	11	42.3
Limited understanding on cultural competence	11	42.3
Insufficient funding	9	34.6
Lack of interpretation services	8	30.8
Insufficient training of staff	5	19.2
Lack of organizational support	3	11.5
Staff or volunteers stress or burnout	3	11.5

Table 12 shows that the most important challenges believed to be experienced by hospices related to difficulty reaching minority populations, competition with other hospices, difficulty hiring adequate staff, and inadequate funding.

Table 12

*Perceived Challenges Encountered by Hospices (multiple responses possible, n = 28)*

Variables	<i>n</i>	%
Difficult reaching minority populations	21	75.0
Competition with other hospices in the area	20	71.4
Difficulty hiring adequate staff	17	60.7
Inadequate funding	16	57.1
Inadequate staffing	15	53.6
Burnout among personnel	14	50.0
Audits	12	42.9
Low census	11	39.3
Low salaries	10	35.7
Interagency politics/red-tape	10	35.7
Problems with reimbursements	9	32.1

Regarding specific challenges experienced by bereavement services, most respondents identified difficulty reaching minority populations, inadequate funding, and inadequate staffing as the most important challenges (Table 13).

Table 13

*Perceived Challenges Encountered by Bereavement Services (multiple responses possible)*

Variables	<i>n</i>	%
Difficult reaching minority populations ( <i>n</i> = 29)	23	79.3
Inadequate funding ( <i>n</i> = 29)	16	55.2
Inadequate staffing ( <i>n</i> = 29)	13	44.8
Burnout among personnel ( <i>n</i> = 28)	12	42.9
Difficulty hiring adequate staff ( <i>n</i> = 28)	11	39.3
Competition with other hospices in the area ( <i>n</i> = 28)	10	35.7
Low salaries ( <i>n</i> = 28)	10	35.7
Audits ( <i>n</i> = 28)	7	25.0
Problems with reimbursements ( <i>n</i> = 27)	4	14.8
Low census ( <i>n</i> = 28)	4	14.3
Interagency politics/red-tape ( <i>n</i> = 28)	4	14.3

*Perceived Strengths of Hospice and Bereavement Services*

The majority of the respondents believed that the most important strength for their hospice services and also their bereavement services was the specific services offered to individuals (Table 14). Results also revealed that when offering bereavement services to Hispanics, 48% (*n* = 12) of respondents identified and rated culturally congruent services/ bilingual staff as an extremely important strength, followed by 32% (*n* = 8) for “services,” and 20% for “personnel.”

Table 14

*Perceived Strengths of Hospice and Bereavement Services*

Variables	<i>n</i>	%
Strengths of hospice services ( <i>n</i> = 25)		
Services offered	11	44.0
Personnel	9	36.0
Core Values	3	12.0
Strengths of bereavement services ( <i>n</i> = 27)		
Services offered	19	70.4
Personnel	8	29.7

## CHAPTER 5

### DISCUSSION

In direct response to the growing imperative to understand the bereavement needs of Hispanics, this exploratory study aimed to enhance the general knowledge about bereavement services provided to this population. The primary objective of this exploratory study was to address the paucity of research in this area and augment efforts to decrease healthcare disparities among minorities. As the State of Florida is considered the gateway to and from Latin America, it was targeted for the sample. All Florida hospices registered with FHCA and FHPC were included in the study and their bereavement coordinators were asked to participate in the study. From the 41 potential participants, 30 (73.2%) completed an Internet-based survey.

In this chapter, the results of this study are summarized and discussed. Current standards of bereavement practice will be discussed within the context and findings of this exploratory research study. Next, the implications and significance of the characteristics of Florida hospice agencies will be addressed including characteristics of the respondents, characteristics of hospice services, characteristics of bereavement services, financing of hospice/bereavement services, census, and personnel training. Specifically, the discussion will focus on hospice agencies' response to their perceived bereavement needs of Hispanics. The last section will discuss the study's limitations, recommendations for future research, social work implications, and conclusions.

### *Current State of Bereavement Services for Hispanics*

The hospice movement has gained much attention over the past 20 years. For instance, the number of hospice agencies in the United States continues to grow annually. The benefits of hospice both to the patient, family, and society, in general, have been recognized and are generally supported by national, state, and local governments. As an illustration, the Medicare Hospice Benefit has supported and funded hospice services since its enactment in 1982. Unfortunately, bereavement services, embedded within hospice services, have not evolved in relationship to the exponential growth that hospice services have experienced throughout the years.

There may be different reasons for the lack of substantial attention that bereavement services have historically received in the United States. Lattanzi-Licht (1989) first mentioned the term *poor stepchild* to describe bereavement services found within hospice services. In other words, hospice bereavement services may not have become an integral component of hospice services. Furthermore, hospice bereavement services have not received the attention, funding, and academic focus needed to move this field forward. It is unfortunate that, in general, most bereavement services have been perceived by hospice agencies as ad hoc hospice services without clear guidelines and standards. Overall, bereavement programs have not been formally evaluated to determine, for instance, their effectiveness in providing services to the general public (Rathbun et al., 2003). Furthermore, the functions and processes of hospice bereavement programs have been insufficiently chronicled in the literature.

The good news is that there appears to be interest among end-of-life care scholars to enhance the knowledge base in this area. Researchers (Berzoff & Silverman, 2004; Demmer, 2003; Lattanzi-Licht, 1989) have raised concerns about the lack of structure and lack of practice

guidelines characterizing bereavement services. Questions being raised by these leaders have the potential to establish research, practice, and policy priorities that may assist in moving beyond a basic understanding of bereavement to actually focusing on bereavement outcomes and establishing specific practice guidelines. This will require differentiating between hospice agencies' perceived needs from actual needs. An initial step in this differentiation process is to have an accurate general account of agencies' bereavement census.

Sixty-five percent of respondents in this study estimated that the annual census for hospice services was in the range of 60 to 1,500 clients. It is interesting to note that Demmer (2003) reported deaths per year for hospice services as opposed to annual census of hospice agencies. This current study used the variable of annual census of hospice services to conceptualize the number of potential individuals and families eligible for bereavement services. In effect, the process of bereavement may include the patient and commence prior to the patient's death.

A study by Foliart et al. (2001) of California's bereavement services reported a median census of 30 hospice patients, whereas the median census for Florida hospices was 372.50. Comparing California and Florida census values is noteworthy, as they illustrate and validate the increase of hospice census reported by various agencies across the United States (NHPCO, 2008). The relationship between high census and bereavement services relates to access and availability of bereavement services. In other words, the potential exists for hospice bereavement services to also experience high census. In this study, most respondents believed that their agencies were providing bereavement services to more than 100 individuals and families at a given time. The exact number is unknown even from this study, as the respondents were asked to provide an estimate only.

From the reported overall census of hospice bereavement services, most respondents estimated that Hispanics comprised at least 10% of their census, with 11%-20% being the second most selected category. It is possible that larger bereavement programs with a higher census may even have more Hispanic clients. Consequently, as reported by most of the respondents, all hospice patients and all significant family members or caregivers received a bereavement needs assessment along with a standardized bereavement care plan. The exact number of individuals and families qualifying or requesting additional bereavement services remains unknown, as it was not explored throughout the survey.

In this study, the specific number of Hispanics participating in bereavement services was unknown. Participants did, however, estimate the percentages of their census that in their opinion were Hispanic. From these estimates, it appears that the number of Hispanics eligible for bereavement services may be greater than perceived by respondents. For instance, some respondents reported that 10% of their census was Hispanic, which translates to 10 Hispanic clients for every 100 in the total census. In general, hospices reporting a high census may also have a higher number of Hispanic clients.

Unfortunately, as previously mentioned, to date there are no existing mechanisms in the United States for collecting this demographic information about Hispanic clients. Additionally, efforts by nationally recognized agencies, such as the NHPCO, have addressed the need for hospice bereavement practice guidelines (NHPCO, 2001). In fact, the NHPCO has published a section of its hospice care guidelines explicitly addressing bereavement standards. Findings of this current study revealed that most of the respondents in Florida believed that their hospice agencies were compliant with the NHPCO's recommended guidelines of bereavement care. Specifically, most reported that their agencies offered bereavement services longer than 12

months. Likewise, respondents indicated that their agencies assessed for grief and bereavement needs of all patients and family members, completed screenings to identify high-risk individuals and families, and developed care plans to identify psychosocial needs. These findings parallel results of one previous study (Rathbun et al., 2003). A need exists across the country to look at hospice agencies' compliance with the NHPCO's recommended bereavement standards. This type of effort may be the impetus to formalize these recommendations by advocating for concrete policies that are not only conceptually useful but also functional in practice.

As previously discussed, clarifying the actual versus perceived number of Hispanics being offered and receiving bereavement services is needed before even attempting to address their needs in the areas of practice, research, and policy. Quantifying the number of Hispanics receiving or in potential need of bereavement services may impact hospice agencies' acquisition of resources required to meet different psychosocial needs of Hispanics.

#### *Characteristics of Respondents*

In Florida, most of the bereavement coordinators/managers reported being older, White, female, with master's degrees, in the profession of social work, full-time employees, and working in the field of end-of-life care longer than 5 years. As observed in Florida, female social workers were overrepresented in the sample. Similarly, women have historically been overrepresented in social work (NASW, 2003), and this was certainly evident in this study. The advanced degree, combined with the length of work in end-of-life care, may suggest a committed core of professionals having appropriate levels of job satisfaction with low levels of burnout. It is interesting to note that despite having several opportunities throughout the survey to address issues of burnout, respondents did not identify, select, or comment on this issue in detail.

The general characteristics of the respondents were fairly homogeneous. Regarding their proficiency in speaking Spanish, for example, only 35% of respondents reported speaking “some” Spanish, with over 50% reporting that they did not speak Spanish at all. Ethnic variation among hospice bereavement personnel was not explored in previous national bereavement studies, however the lack of ethnic diversity of social workers in the United States has been previously addressed by the NASW and Center for Workforce Studies (National Association of Social Workers and the Center for Workforce Studies, 2006).

The NASW (2006) reported that only 4% of licensed social workers in the United States are Hispanics, suggesting the need, at least generally, to increase the number of Hispanic social workers. Moreover, diversifying the ethnic composition of social workers may directly impact the psychosocial bereavement service outcomes of Hispanics (Torres, Cabassa, Zayas, & Alvarez-Sanchez, 2008). Certainly, the findings of this study seem to support the notion that a need exists to increase the number of hospice/bereavement bilingual personnel in Florida. However, the effect of augmenting the number of bilingual hospice/bereavement personnel on bereavement service utilization by Hispanics requires further attention in future studies.

Most respondents indicated that only one fluent Spanish-speaking staff member was available to their bereavement services. No other studies found in the literature have explored this specific issue; therefore, comparison with previous studies is not possible at this time. This is of great concern because when clients with LEP request bereavement services, there may not be sufficient personnel that are fluent in Spanish to provide needed services. Considering that only 4% of licensed clinical social workers in the United States are reportedly Hispanic (NASW) and the majority of hospice/bereavement providers of psychosocial services are social workers, a need seems to exist to augment the Hispanic social work force in this area.

It is interesting to note that in this study respondents did not report volunteers as key players in augmenting language services. The majority of the respondents reported that there were less than 10 volunteers available to support bereavement services at their site. Parallel to this, most respondents indicated that their bereavement programs had only one volunteer who spoke fluent Spanish. When the categories are collapsed, this distinction becomes even more noteworthy, with 75% of the 16 respondents indicating that they had three or less fluent Spanish-speaking volunteers available to support their bereavement services. Therefore, hospices in Florida may consider implementing strategies to first assess their agencies' language needs followed by implementing specific interventions to address identified needs. Multisystemic needs assessments, that include families, may assist in clarifying perceived language needs versus actual language needs.

In Florida, most of the bilingual bereavement personnel were either working as part of the hospice/bereavement team or were affiliated with other departments at their agencies. Also, many respondents reported that family members have been used as interpreters. This is an interesting variable to explore in future studies to determine if the request to use family members to interpret is initiated by family members themselves or bereavement personnel. It might be the case that families that have established a strong sense of *Respeto* and rapport with a specific hospice care provider may feel more comfortable continuing with that relationship throughout the bereavement process and may use a bilingual family member to interpret.

In this study, interpretation services were funded through the hospice agencies' budget. Yet, as reported by most respondents, "bilingual bereavement staff" was the number one resource available for communicating with Spanish-speaking clients. The processes that bereavement personnel use to identify the need for an interpreter should be explored further. The

mandate by the United States Congress that directed the Office of Minority Health in 1994 under Public Law 101-527 “to develop the capacity of health care professionals to address the cultural and linguistic barriers to health care delivery and increase access to health care for limited English-proficient people” (p. 1) has, generally, been followed by hospice bereavement programs in Florida. Agencies have been able to address some of the cultural and linguistic barriers by allocating part of their budget to support personnel with continuing education and securing language resources (e.g., interpreters). However, more research is necessary to identify ways to further narrow cultural and linguistic barriers. In addition, there seems to be a need to address the National Standards on Culturally and Linguistically Appropriate Services (CLAS) recommended in 2001 by the Department of Health and Human Services (2001). CLAS standards, developed to address access to care, quality of care, and health outcomes have been separated into three different areas, including (1) Culturally Competent Care, (2) Language Access Services, and (3) Organizational Supports for Cultural Competence. Organizations receiving federal funds are mandated to follow these CLAS standards. A need seems to exist to continue enhancing the cultural and linguistic capacity of health care providers in Florida, and across the United States, to continue decreasing healthcare disparities among minorities.

Meeting the bereavement needs of Hispanics begins with cultural sensitivity of hospice bereavement service providers. Congruent with Demmer’s (2003) findings, in this study the majority of the respondents indicated that bereavement personnel received specialized training, with the majority of respondents indicating spending between 9 and 16 hours annually in specialized training. Also, the majority of Florida hospices are financially supporting their staff’s continuing education. Despite this type of support, over 70% of respondents indicated that bereavement personnel did not receive specific training on how to work with Hispanics. As

previously discussed, respondents consistently reported the need to address cultural issues when working with Hispanics, however their educational needs may require additional attention and support. Accessing cultural competence training offered by the NASW and reviewing the NASW's standards for EOL care may be helpful to hospice personnel working with Hispanics.

### *Characteristics of Bereavement Services*

Respondents reported that the majority of the professionals providing bereavement services in Florida were social workers, followed by chaplains, counselors, and nurses. Only one psychologist was reported as being a part of the bereavement team. Comparatively, these results parallel Demmer's (2003) results. The total number of volunteers, however, outnumbered all of the represented professions, with a total of 159 volunteers. Despite the report by the Hospice Foundation of America (n.d.) that there are over 400,000 hospice volunteers throughout the United States, there are no specific statistics on volunteers being tracked and/or reported specifically for bereavement services (HFA, 2008, personal communication). Therefore, the number of specific volunteers being used for bereavement services in the United States is currently unknown and undocumented.

All respondents reported that bereavement services were offered at their agencies, and the majority reported that their agencies have been offering bereavement services for many years, with some reporting over 27 years of service. This translates to the majority of Florida Hospices providing some sort of bereavement service as early as 1981. This was not a surprising result because of the mandate that Medicare-funded hospices offer bereavement services. Incidentally, several questions on the survey implicitly requested information from respondents that indirectly addressed the NHPCO's five overarching standards of practice for hospice programs. Similar to the results of a study by Rathbun et al. (2003) with hospices in Ohio, Florida hospices seemed to

meet most of the NHPCO standards. This may denote a strong movement and awareness in Florida among hospice and bereavement services to focus on quality of care.

Lattanzi-Licht (1989) and Demmer (2003) described bereavement services within hospice services as the poor stepchild of hospice services. Furthermore, on a national level, there is lack of “substantive work related to bereavement program evaluation...Little attention has been paid to documenting the quality and impact of hospice bereavement programs” (Rathbun et al., 2003, p. 448). The poor stepchild analogy will be important to keep in mind when the specific bereavement services offered at agencies are later discussed. However, in this section, one conclusion or expectation would be that if a program has been in place for 27 years or longer, a clear process of quantifying bereavement services and understanding the major intricacies of service delivery would exist. However, findings from this study did not support this expectation.

Given Medicare guidelines, it is not surprising that respondents reported that their agencies were providing some type of bereavement service. Furthermore, most respondents indicated, that their agencies provided a minimum of 13 months of bereavement services, and 7 respondents reported providing bereavement services for a period of 15 months or longer. This was a somewhat surprising result, as Medicare mandates offering bereavement services for a total of 12 months. However, the NHPCO has specifically addressed in their guidelines that agencies need to provide bereavement care for a period of 13 months.

Most of the respondents indicated that bereavement services were provided to anyone related to the patient (including friends) and anyone from the community regardless of connection to the hospice agency. Provision of bereavement services to individuals, families, and the community at large is one of the five standards for hospice and palliative care programs

recommended by the NHPCO. All of the respondents reported that their agencies provided supportive services to their communities and further elaborated that bereavement services were free of charge. However, the response of some respondents indicated that agencies are charging small fees for special events such as weekend retreats and children's groups. This is not surprising; as discussed earlier, Medicare does not allow for direct billing for bereavement services. Therefore, special events related to bereavement services (e.g., retreats, weekend seminars) must be privately funded or supported from the hospice budget (Foliant et al., 2001).

Regarding financial matters, over 50% of respondents reported not knowing the annual budget for their hospice agency. Because this variable was not explored further, it is difficult to ascertain the precise impact this may have on hospice programs. In particular, exploring bereavement coordinators' funds/monies-request practices may be associated with knowledge of the annual hospice budget. The implication of knowing the annual hospice budget may be directly connected to the type and quantity of bereavement services offered to the general public. Knowledge of the agency's budget may also be associated with securing resources for minority populations such as interpretation services. Close to one half of the respondents in this study reported that their hospice had an annual budget of over \$1 million.

Respondents indicated that Florida hospice agencies accepted various types of payment sources including Medicare, Medicaid, private insurance, and private pay. However, Medicare continues to be the primary funding source for hospice services. Only 4 (16.7%) respondents also reported that Medicaid was the type of payment most often used at their agencies. These were expected findings because Medicare has been the primary funding type of hospices since the enactment of the Medicare Benefit Act in 1983 and because the patient population is primarily over the age of 65. Additionally, Florida's Medicaid hospice benefit mirrors

Medicare's guidelines, and therefore the benefits are similar. Specifically, in 2007 over 7,000 individuals received hospice services through the Florida Medicaid Hospice Benefit (The Hospice of The Florida Suncoast, 2007).

As previously discussed, it is essential to determine the Medicare status of agencies because bereavement services are embedded within hospice services, and unlike ancillary services (e.g., social work services, medical evaluations, nursing care), bereavement services are not able to bill Medicare and/or Medicaid. In Florida, the Medicaid Hospice Benefit explicitly states, "Although bereavement counseling is a required hospice service, it is not reimbursed by Medicaid" (Agency for Health Care Administration, 2005, p. 2-2,) and not directly billed by Medicare.

Bereavement services, however, must be offered by hospice agencies, as they are a part of the Medicare regulations process, in addition to being part of the recommended guidelines from the JCAHO and the NHPCO. In this study most of the respondents (89%) reported that their hospice agencies were Medicare certified. Responses alluded to specific accreditations of hospice agencies, and one third of the respondents did not know the types of accreditation held by their hospice agencies, whereas other respondents reported accreditations by ACHC, JCAHO, and the Community Health Care Accreditation Program (CHAP). The type and quantity of bereavement services offered to Hispanics may be associated with staff's knowledge of their agencies accreditations. For instance, not knowing the types of accreditation held by hospice agencies may be related to types of funding sought and secured by hospice agencies. In such cases, limited knowledge of an agency's infrastructure may be associated with low grant and funds acquisition.

### *Perceived Bereavement Service Needs of Hispanics*

Lattanzi-Licht (1989), as quoted in Demmer (2003), reinforced the need to “match service priorities with actual delivery of services” (p. 338). As indicated by most respondents in this current study, Florida hospices are generally matching identified priorities with service delivery. For example, most respondents in this study reported that the top two bereavement services needed by Hispanics were language/culture concordant services/information and individual/group counseling services. Further, the majority of respondents reported that the most important bereavement needs of Hispanics were language and information about available services needs. Consequently, the most frequent bereavement services offered to Hispanics were phone calls, support groups, and counseling.

Respondents reported that the most common bereavement needs of Hispanics in Florida were language needs, cultural-related needs, financial needs, and support system needs. Respondents repeatedly identified these needs, especially language and cultural barriers, throughout the survey. Language needs was the most commonly identified need and most commonly identified barrier to service delivery. Several respondents indicated on the open-ended responses that, “Hispanics need language specific grief educational/written materials,” “Counseling in their own language,” “Free in-home or local Spanish Speaking counseling,” “Culturally appropriate care in Spanish,” and “Support groups conducted in Spanish.” It is important to highlight that Florida hospices are generally providing bereavement services to Hispanics by utilizing both hospice agencies’ resources and community resources.

The low percentage of bilingual personnel and volunteers available to provide services in Spanish may prompt hospice bereavement services personnel to access community services to meet the bereavement needs of Hispanics. In this study, most respondents indicated that their

agencies referred Hispanics to community agencies for counseling and support services. In Florida, most of the direct bereavement needs of Hispanics were being met outside of the hospice bereavement agencies by religious organizations and community therapists/counselors. In fact, one respondent stated that in their community “Hispanic families usually rely on church and extended family members for support.”

Most of the respondents indicated that their agencies engaged in outreach activities with religious organizations. One respondent indicated that their hospice agency has a “Hispanic Community Liaison that works with Hispanic churches as well as other organizations.” This was not further explored in this study, but it is worth considering in future studies. As the majority (76%) of Hispanics in the United States are Catholic (United States Conference of Catholic Bishops, n.d.), perhaps outreach and referrals to religious organizations is meeting, to a minimum, the religious and/or spiritual needs of bereaved Spanish-speaking clients. These types of organizations may continue to be a support service to individuals/families in Florida. This would be another important variable to further understand and explore in future research. It is possible that religious organizations are not only meeting the religious needs of Spanish-speaking people, but other psychosocial needs as well. Exploring the types of referrals these religious leaders are experiencing and their competency level in the provision of bereavement counseling is necessary.

Most respondents indicated that their bereavement program engaged in education and supportive services in their local communities thereby meeting another NHPCO standard. This may be through local workshops, community presentations, and volunteer activities to address topics of interest such as discussing hospice and bereavement services, and the process of grief and loss. These community outreach efforts, combined with the support of religious agencies

and other grass-roots interventions, have the potential to narrow language gaps existing in most Florida hospice bereavement programs.

There is evidence, for example, that grass-roots efforts to enhance Hispanics' knowledge and understanding of hospice services are effective and should be considered when working with Hispanics. This was found in findings from a study conducted in 2002 in Florida by Hospice By The Sea. They increased the percentage of Hispanic patients from 1.5% to 5.78% by conducting focus groups with Hispanics, and contacting over 14 thousand Hispanics during community events, meetings, and presentations to discuss hospice services (Robert Wood Johnson Foundation, 2006). These community interventions resulted in close to 3,000 Hispanics participating in pre and posttest questionnaires to determine if these community outreach events had an impact on participants' knowledge of hospice services. Results showed a significant increase in participants' knowledge and understanding of hospice services after participating in these outreach community events. Researchers (Balcazar et al., 2006; McElmurry, Park & Buseh, 2003) have discussed the impact that community outreach has on Hispanics. Specifically, these researchers have discussed developing an infrastructure of community health advocates that can bridge services to Hispanics and also serve as interpreters.

The belief by most respondents that Hispanics had "support system needs" is important to highlight because *Familismo* has been extensively mentioned in the literature as a significant value of Hispanic families (Chong, 2002; Guitierrez et al., 2000). However, there may be an erroneous perception and a general fallacy that this belief means that they take care of their own and may not need formal and/or informal support systems. Thus, it is imperative that the bereavement needs of Hispanics are understood from an ecological perspective, considering the person-in-environment along with variables such as levels of acculturation and assimilation.

From the open-ended responses in the survey, respondents frequently commented on the importance of being aware of cultural variations among Hispanics, the importance of providing culturally sensitive services, and operationalizing culturally appropriate bereavement services for Hispanics. Bereavement coordinators in Florida identified that cultural issues such as Hispanics' limited English proficiency, lack of bilingual/bicultural hospice personnel, challenges with acculturation/assimilation, and distrust of formal agencies may be connected to offering and actual delivery of bereavement service to Hispanics. A previous study by Wilson et al. (2005) on the issue of language-concordant services showed that language-concordant physicians diminished language barriers but did not eliminate them, suggesting that cultural factors are also important. Conversely, matching healthcare providers' ethnicities to those of consumers leads to overall improvement in treatment outcomes (U.S. DHSS, OPHS, 2001). These studies point to the importance of not perceiving Hispanics as homogeneous and considering other variables, besides language, when attempting to conceptualize and understand their bereavement needs.

Further research is needed to understand the complexities regarding the decision of Hispanics to access or not access bereavement services. Factors such as cultural dynamics (e.g., religion), limited awareness of hospice benefits (Randall & Csikai, 2003), and familial attributes (e.g., *familismo*) may serve as variables of interest in future studies. In this study, various respondents elaborated on possible cultural and familial dynamics that influence Hispanics' decisions to access bereavement services. For example, one of the respondents reported that, "Hispanic families tend to refuse some of the bereavement services stating that they wanted to 'keep it within the family' rather than seeking outside professional help." Other respondents stated, "Hispanics are reluctant to accept support outside of the family and church," and "The culture often does not want or accept assistance offered." It is important to mention that in this

study, hospice agencies appear to be providing the needed bereavement services according to the perceptions the bereavement coordinators targeted in this study. However, the actual bereavement needs of Hispanics are unclear, as the voices of bereaved Hispanics were not included in this study. It is possible that Hispanics may, generally, prefer to seek assistance from the church and/or family members to cope with grief. Also, it is possible that Hispanics may not be emotionally prepared to accept the death of their family member and may not reach out for bereavement services. For these reasons, outreach may be needed, perhaps in Spanish, to Hispanic families after the death of a family member. Outreach services may range from reviewing/reminding Hispanic families of bereavement services available to them to counseling and/or referrals to community resource

#### *Limitations of the Study*

There are several limitations of this study that need to be considered when interpreting the results. The primary limitation is the small sample size of bereavement services in one state. It is, thus, not representative of all bereavement programs in all states. This study focused on perceptions of respondents, which is a limitation as they were not asked about their actual contact with bereaved Hispanics and were not explicitly asked how much involvement they have had with direct patient care. This may be a limitation because some of the bereavement coordinators may have reported second-hand information rather than their own experiences. It may have been helpful to sample all bereavement personnel and individuals who provided bereavement support, not strictly the coordinators.

As indicated in the results section, respondents reported that their hospice agencies were composed of various disciplines, including volunteers. These professionals may have been able to provide additional information, different perspectives and experiences, and different

perceptions regarding the bereavement needs of Hispanics in Florida. Future studies may want to consider sampling every hospice and bereavement staff member to obtain richer data.

There is a need to enhance the measures used in this study and, specifically, address perceived versus the actual bereavement needs of Hispanics. Including bereaved Hispanics in the methodology would be essential to accomplish this goal. Focus groups and qualitative interviews with Hispanics (and bereavement personnel) may provide the necessary data to continue exploring this phenomenon in greater depth. Furthermore, future research in this area should consider a nationally representative sample. States across the country with high percentages of Hispanics may benefit from learning about the bereavement needs of this population and continue tailoring interventions to meet the actual needs of their local population.

Another limitation of this study was using only the internet-based survey to collect information. Despite the good response rate (73%), perhaps using multiple methods of data collection may have increased the response rate. Future researchers may consider using a combination of Internet and regular mail surveys along with different measures, such as qualitative and/or mixed-methods. In addition, using a survey does not capture the actual experiences of bereavement coordinators with regard to the bereavement needs of Hispanics. Therefore, in-depth qualitative interviews with hospice/bereavement personnel and bereaved Hispanics may be useful in capturing these experiences.

The focus of this study was explicitly on Hispanics. By not asking questions regarding other minorities the usefulness of the findings are not applicable to other minority groups. Other minority groups may experience similar challenges and roadblocks when accessing bereavement services that are not only language based but also that are culturally, socioeconomically, and socially based. For example, minority groups may experience access issues by not having

reliable transportation or telephones or living in rural settings. Perhaps there are issues of prejudice, as reported by one respondent, and discrimination that impact provider-client relationships. There may be more similarities than differences when minority groups are considered in research, and focusing on these similarities may be essential to developing policies and intervention strategies for minority groups who are not accessing bereavement services. For example, language and cultural barriers are shared among different minority groups. Furthermore, the survey instrument would need further revisions to reflect the bereavement needs of other minority groups. Specifically, there is a need to use unambiguous terms and words in future survey instruments.

Although the words *offer* and *provide* were used interchangeably throughout the survey, there seems to exist a need to clarify these words, as semantically they may be too similar but yet could be perceived differently. For instance, respondents may have reported that their agencies provided bereavement services when actually what they were doing was merely offering services. Using the word *offer* implies that the service may be accepted or rejected, whereas using the word *provide* implies the actual delivery of services. With this in mind, future researchers need to focus on clearly operationalizing terms to avoid using biased and/or unclear terms.

Another example of a wording problem may be that for Hispanics, the word “Hospice (*hospicio*) is negatively associated as a place where either abandoned, poor, elderly people, or orphans are cared for” (Robert Wood Johnson Foundation, 2008, p. 1). The confusion brought about by the word *hospice* is shared not only by Hispanics but also by the general population as described by the NHPCO when they reported in 1999 that 80% of individuals in their study did not know the meaning of the word *hospice* (NHPCO, 1999). Despite realignment and merging

movements of hospice agencies in the United States (Connor, 1998), most Florida hospices continue to use the term *hospice* to describe their agencies. The term *palliative care* was only reported by 4 of the 22 respondents. This is interesting in that there may be confusion regarding the use of the word *hospice* for Hispanics and reluctance to access hospice/bereavement services.

### *Future Research*

Provision of bereavement care for Hispanics is a complex phenomenon comprised of different psychosocial variables. Social workers can individually or collectively use the results of this study to further understand bereavement services with Hispanics. Understanding the psychosocial needs that religious organizations meet for Hispanics is an area that requires further exploration. Recommendations have been made to explore the role of Catholic churches in educating Hispanics about hospice services (Randall & Csikai, 2003), in addition to grass-roots efforts by conducting community education to explain benefits of hospice services (Robert Wood Johnson Foundation, 2006). Additionally, it is recommended that the education level, competency level, and comfort level of religious representatives be explored when they attend to the psychosocial bereavement needs of individuals/families (Lount & Hargie, 1998; O’Kane & Miller, 2001).

Also, it is imperative to explore and understand the bereavement needs of Hispanics, as different variables may impact Hispanics’ perceptions of hospice and bereavement service utilization (Robert Wood Johnson Foundation, 2006). In order to understand these phenomena, qualitative methods of inquiry may elucidate the actual process followed by bereavement programs when referring Hispanics to religious organizations and, in turn, understand their process of accepting referrals from community agencies.

Findings from this study may facilitate the identification of new areas of inquiry related to bereavement services with Hispanics. Specifically, social work researchers and practitioners could use findings to explore and develop new research questions leading to a greater understanding of the complexity of bereavement services with Hispanics. These questions may lead to the use of different methodologies to test hypotheses and to increase the knowledge base in this area. For instance, it would be beneficial to understand if specific characteristics of hospice organizations (e.g., size, budget) predict utilization of bereavement services by Hispanics (Foliart et al., 2001). Also, it would be relevant to determine if any relationships exist between characteristics of providers and the rate of accepting bereavement services by Hispanics.

Research efforts should also focus on developing a process for collecting bereavement data. As previously discussed, bereavement data is not being collected by CHARTS in Florida. No tracking methods are currently found in the literature to account for the number of Hispanics served by hospice bereavement services. It would be important, for example, to develop national minimum data sets to track bereavement service utilization by Hispanics. Quantifying these services will lead to clarifying the actual needs of bereavement recipients and specifically challenge perceived needs. More importantly, quantifying these services could lead to increased funding from community, state, and federal agencies.

The small nonrepresentative sample of this study prevents generalizing results. Future studies may consider a national random sample of bereavement coordinators in conjunction with other bereavement personnel (e.g., nurses, counselors, physicians). These potential participants may be obtained from the NHPCO by requesting their assistance in disseminating the survey.

The NHPCO has participated in previous national bereavement surveys (Demmer, 2003), and their cooperation would be likely.

### *Social Work Implications*

The findings of this study have direct implications for the delivery of social work services to bereaved Hispanics. The study revealed several gaps in service delivery that social workers can address by advocating for and with Hispanic clients. Throughout the study, “Spanish-tailored” bereavement services frequently emerged as a service needed by Hispanics. However, in order to provide effective bereavement services to Hispanics, agencies must have trained personnel who are not only proficient in Spanish but also who are bicultural. Certain cultural variables must be considered when providing bereavement services to Hispanics. Thus, cultural interpreters can be used by social workers to enhance delivery of bereavement services to this population. However, Solis and colleagues (1990) indicated that access to services, not acculturation, predicts utilization of services. Therefore, social workers must focus their attention on access challenges such as lack of transportation and/or not having a telephone, and clarifying misconceptions about bereavement services, as many Hispanics may believe that they will be charged for the service.

Some of these challenges can be addressed on a policy level by advocating for the needs of Hispanics with local and state governments. For example, social workers, with the support of their local NASW chapters, can engage in community assessment efforts to identify and create a core group of bilingual volunteers. Social workers can work with religious organizations alongside local and state NASW chapters to create language banks for hospices to use as resources when working with Hispanics with LEP. Continuing education opportunities can be

developed by social workers via webinars and presenting relevant topics at local venues and conferences.

Because a main theoretical perspective of the social work profession is the person-in-environment and systems dynamic, social work practitioners may utilize findings of this study to identify how to best meet the psychosocial needs of this population. Social workers can map resources available in an individual and/or family's community and identify macro and micro resources and support systems that may be useful. This type of mapping has the potential to have a systemic impact on the individual and the environment. Investing the time and energy to engage in outreach efforts with bereaved Hispanics may impact informal and formal means of communication. Hispanics may serve as informal representatives of the hospice philosophy by discussing their hospice experiences with family members, friends, and community organizations (e.g., religious organizations).

Hospice By The Sea was able to increase their percentage of Hispanic clients from 1.5% to 5.78% by engaging in outreach and education efforts (Robert Wood Johnson Foundation, 2006). They used focus groups with various Hispanics from the local area to examine their needs and provided education on the hospice philosophy and services. In order to provide effective bereavement services to Hispanics, social workers must engage in different types of outreach activities such as networking with religious organizations, and using the local media as a means of communication. Social workers must be mindful of using a strength's perspective and should focus on prevention (i.e., complicated grief) efforts rather than reaction-based services.

Other outreach efforts may take place in local community programs through staff's attendance at special meetings and/or events with a focus on meeting the needs of Hispanics. In

order to provide social work services to bereaved Hispanics, a sense of mutual respect must exist between Hispanics and the provider of bereavement services. Findings from the 2003 study of Hospice By The Sea's outreach efforts, and published by the Robert Wood Johnson Foundation in 2006, need to be considered by other bereavement agencies in Florida. Using the media, engaging in mutual relationships with religious/spiritual organizations, and most importantly being visible in the community would be essential. Participating in local Hispanic events to establish trust and rapport with local Hispanic leaders is recommended.

Perhaps the most significant practice implication of this study is that social workers should be aware that Hispanics, in general, experience cultural and language barriers preventing them from obtaining access to bereavement services. Social workers providing bereavement services need to understand and incorporate into their practice the NASW's Standards for Cultural Competence, and the national standards on CLAS recommended by the United States Department of Health and Human Services' Office of Minority Health (2001). Also, social workers should challenge the misconception that all Hispanics rely on their families for support and, because of their sense of collectivism, may not need additional support during periods of bereavement. Again, access to services may predict Hispanic utilization of services (Solis et al., 1990).

Macro and micro policies at the federal and state levels need to be generated to enhance delivery of bereavement services to Hispanics. Social workers can assist by advocating for new policies directed at narrowing the bereavement disparities that Hispanics experience. These efforts need to be driven by a solid and clear understanding of the needs of this population. Specifically, new policies are needed to support direct reimbursement for bereavement services.

This may open the doors to accessing and having available interpreter services and eventually a more diversified bereavement core of professionals who are bicultural and bilingual.

### *Conclusions*

The current state of bereavement services available to Hispanics in the United States is unknown and undocumented. The specific bereavement needs have not been explored and addressed in research, policy, and/or practice venues. This study aimed to explore hospice bereavement services for Hispanics in Florida and to thereby chronicle an initial effort to understand the needs of this growing population.

As with any areas of deductive inquiry, methodological and structural recommendations are often identified. In this study, recommendations to enhance the methodology of the study and extend the sample to all bereavement health care providers in future studies were offered. The positive aspects of this study, including the high response rate, support from the Florida Hospice and Palliative Care organization, identification of the most important bereavement needs of Hispanics, and identification of interventions to bridge the gap in solidifying services to Hispanics were seen. The efforts initiated by the NHPCO to standardize bereavement programs and develop tracking mechanisms to quantify service utilization by Hispanics should be continued.

Social workers have the knowledge and expertise to analyze, formulate, and advocate for improved health care policies that focus on the bereavement needs of this population, and to develop new interventions to bridge practice gaps. Research studies such as the study presented here can be a tool to enhance the initial state of hospice bereavement services to Hispanics. Findings from this study may lead to eventually creating new interventions whereby the

bereavement needs of Hispanics are addressed at different venues from local to state to national levels.

## REFERENCES

- Adams, C. E., Horn, K., & Bader, J. (2006). Hispanic access to hospice services in a predominantly Hispanic community. *American Journal of Palliative Care, 23*, 9-16.
- Administration on Aging. (2008). *Statistics on the aging population*. Retrieved January 6, 2008, from <http://www.aoa.gov/prof/Statistics/statistics.asp>
- Agency for Healthcare Administration. (2005). *Florida medicaid: Hospice services coverage and limitations handbook*. Retrieved September 18, 2008, from [www.baccinc.org/medi/CD\\_April\\_2005/Provider\\_Handbooks/Medicaid\\_Coverage\\_and\\_Limitations\\_Handbooks/Hospice\\_Services\\_Updated\\_January\\_2005.pdf](http://www.baccinc.org/medi/CD_April_2005/Provider_Handbooks/Medicaid_Coverage_and_Limitations_Handbooks/Hospice_Services_Updated_January_2005.pdf)
- Allumbaugh, D. L., & Hoyt, W. T. (1999). Effectiveness of grief therapy: A meta analysis. *Journal of Counseling Psychology, 46*, 370-380.
- American Psychiatric Association. (2000). *Diagnostic and statistical manual of mental disorders (DSM-IV-R, 5<sup>th</sup> ed., rev.)*. Washington, DC: American Psychological Association.
- Baker, D. W., Hayes, R., & Fortier, J. P. (1998). Interpreter use and satisfaction with interpersonal aspects of care for Spanish-speaking patients. *Medical Care, 36*, 1461-1470.
- Balcazar, H., Alvarado, M., Hollen, M. L., Gonzalez-Cruz, Y., Hughes, O., Vazquez, E., et al. (2006). Salud para su corazon-NCLR: A comprehensive promotora outreach program to promote heart-healthy behaviors among Hispanics. *Health Promotion Practice, 7*, 68-77.
- Baohui, Z., El-Jawahri, A., & Prigerson, H. G. (2006). Update on bereavement research: Evidence-based guidelines for the diagnosis and treatment of complicated bereavement. *Journal of Palliative Medicine, 9*, 1188-1203.
- Bass, D. M., & Bowman, K. (1990). The transition from caregiving to bereavement: The relationship of care-related strain and adjustment to death. *Gerontologist, 30*, 35-42.
- Beem, E. E., Eurelings-Bonteloe, E. H., Cleiren, M., & Garsen, B. (1998). Workshops to support the bereavement process. *Patient Education and Counseling, 34*, 53-62.
- Berger, J. T. (1998). Culture and ethnicity in clinical care. *Archives of Internal Medicine, 158*, 2085-2089.

- Berzoff, J., & Silverman, P. R. (2004). *Living with dying: A handbook for end-of-life healthcare practitioners. Appendix 2: Potential areas for research in end-of-life (EOL) care*. New York, NY: Columbia University Press.
- Bonanno, G. A., & Kaltman, S. (1999). Toward an integrative perspective on bereavement. *Psychological Bulletin, 125*, 760-776.
- Bowlby, J., & Parkes, C. M. (1970). Separation and loss within the family. In E. J. Anthony (Ed.), *The child in his family* (pp. 197-216). New York: Basic Books.
- Bulkin, W., & Lukashok, H. (1988). Rx for dying: The case for hospice. *New England Journal of Medicine, 318*, 376-378.
- Catlin, G. (2001). The role of culture in grief. *The Journal of Social Psychology, 133*(2), 173-184.
- Centers for Disease Control. (2005). *Hispanic or Latino populations*. Retrieved September 6, 2005, from <http://www.cdc.gov/omh/Populations/HL/hl.htm>
- Cherlin, E. J., Barry, C. L., Prigerson, H. G., Schulman-Green, D., Johnson-Hurzeler, J., Kasl, S. V., & Bradley, E. H. (2007). Bereavement services for family caregivers: How often used, why, and why not. *Journal of Palliative Medicine, 10*, 148-158.
- Chong, N. (2002). *The Latino patient: A cultural guide for healthcare providers*. Yarmouth, ME: Intercultural Press.
- Colón, M. (2005). Hospice and Latinos: A review of the literature. *Journal of Social Work in End of Life and Palliative Care, 2*, 27-43.
- Colón, M., & Lyke, J. (2003). Comparison of hospice use and demographics among European Americans, African Americans, and Latinos. *American Journal of Hospice & Palliative Care, 20*, 182-190.
- Connor, S. R. (1998). *Hospice: Practice, pitfalls, and promise*. New York: Taylor & Francis.
- Connor, S. R., Elwert, F., Spence, C., & Christakis, N. A. (2007). Geographic variation in hospice use in the United States in 2002. *Journal of Pain and Symptom Management, 34*, 277-285.
- Connor, S. R., Tecca, M., Lund-Person, J., & Teno, J. (2004). Measuring hospice care: The national hospice and palliative care organization national hospice data set. *Journal of Pain and Symptom Management, 28*, 316-328.
- Crawley, L. M., Marshall, P. A., Lo, B., & Koenig, B. (2002). Strategies for culturally effective end-of-life care. *Annals of Internal Medicine, 136*, 673-679.

- Csikai, E. (2006). Bereaved hospice caregivers' perceptions of the end-of-life care communication process and the involvement of health care professionals. *Journal of Palliative Medicine, 9*, 1300-1309.
- Demmer, C. (2003). A national survey of hospice bereavement services. *Omega, 47*, 327-341.
- Department of Health and Human Services. (2001). Title 42-Public Health. Chapter IV—Health Care Financing Administration, Part 418-Hospice Care. Retrieved February 2, 2008, from [www.access.gpo.gov/cgi-bin/fcfrassemble.cgi?title=200142](http://www.access.gpo.gov/cgi-bin/fcfrassemble.cgi?title=200142)
- Doran, G., & Downing-Hansen, N. (2006). Constructions of Mexican American family grief after the death of a child: An exploratory study. *Cultural Diversity of Ethnic Minority Psychology, 12*(2), 199-211.
- Ellifritt, J., Nelson, K. A., & Walsh, D. (2003). Complicated bereavement: A national study survey of potential risk factors. *American Journal of Hospice & Palliative Care, 20*, 114-120.
- Falicov, C. J. (1998). *Latino families in therapy: A guide to multicultural practice*. New York: Guilford.
- Fink, A., Kosecoff, J. (1989). *How to conduct surveys: A step-by-step guide*. Newbury Park, CA: Sage.
- Foliart, D. E., Clausen, M., & Siljeström, C. (2001). Bereavement practices among California hospices: Results of a statewide survey. *Death Studies, 25*, 461-467.
- Forte, A. L., Hill, M., Pazder, R., & Freudtner, C. (2004). Bereavement care interventions: A systematic review. *BMC Palliative Care, 3*, 1-14.
- Frankfort-Nachmias, C., & Nachmias, D. (1999). *Research methods in the social sciences*. New York: Worth Publishers and St. Martin's Press.
- Gordon, A. K. (1996). Hospice and minorities: A national study of organizational access and practice. *The Hospice Journal, 11*, 49-70.
- Gutiérrez, L., Yeakley, A., & Ortega, R. (2000). Educating students for social work with Latinos: Issues for the new millennium. *Journal of Social Work Education, 36*, 541-557.
- Hallenbeck, J., & Goldstein, M. K. (1999). Decisions at the end of life: Cultural considerations beyond medical ethics. *Generations, 23*, 24-29.
- Hospice Foundation of America. (n.d.). *Be a Hospice Volunteer*. Retrieved November 30, 2008, from <http://www.hospicefoundation.org/hospiceInfo/volunteer.asp>

- The Hospice of the Florida Suncoast. (2007). *Preserve the Hospice Medicaid Benefit*. Retrieved September 18, 2008, from [http://www.thehospice.org/help/voice/preserve\\_medicaid.asp](http://www.thehospice.org/help/voice/preserve_medicaid.asp)
- Kubler-Ross, E. (1969). *On death and dying*. Toronto, Canada: Macmillan.
- Kwak, J., & Haley, W. E. (2005). Current research findings on end-of-life decision among racially or ethnically diverse groups. *The Gerontologist, 45*, 634-641.
- Lackan, N. A., Ostir, G. V., Freeman, J. L., Kuo, Y., Zhang, D. D., & Goodwin, J. S. (2004). Hospice use by Hispanic and non-Hispanic white cancer decedents. *Health Services Research, 39*, 969-986.
- Lattanzi-Licht, M. E. (1989). Bereavement services: Practice and problems. *Hospice Journal, 5*, 1-28.
- Lount, M., & Hargie, O. (1998). Preparation for the priesthood: A training needs analysis. *Journal of Vocational Education and Training, 50*, 61-77.
- Marrone, R. (1999). Dying, mourning, and spirituality: A psychological perspective. *Death Studies, 23*, 495-519.
- Matsumara, S., Bito, S., Liu, H., Kahn, K., Fukuhara, S., Kagawa-Singer, M., & Wenger, N. (2002). Acculturation of attitudes toward end-of-life care: A cross-cultural survey of Japanese Americans and Japanese. *Journal of General Internal Medicine, 17*, 531-539.
- McElmurry, B. J., Park, G. P., & Buseh, A. G. (2003). The nurse-community health advocate team for urban immigrant primary health care. *Journal of Nursing Scholarship, 35*, 275-281.
- Minino, A. M., Heron, M. P., Murphy, S. L., & Kochanek, K. D. (2007). Deaths: Final data for 2004. *National Vital Statistics Reports, 55*(19), 1-120.
- Munet-Vilarò, F. (2004). Delivery of culturally competent care to children with cancer and their families: The Latino experience. *Journal of Pediatric Oncology Nursing, 21*, 251-258.
- Nardi, P. M. (2006). *Doing survey research: A guide to quantitative methods* (2nd ed.). New York: Allyn & Bacon.
- National Association of Social Workers (NASW). (2003). Practice Research Network (PRN) project. Retrieved December 8, 2008, from <https://www.socialworkers.org/naswprn/surveyTwo/Datagram2.pdf>
- National Association of Social Workers. (n.d.). *End of life care standards. NASW standards for social work practice in palliative & end of life care*. Retrieved November 24, 2006, from <http://www.socialworkers.org/practice/bereavement/standards/default.asp>

- National Hospice and Palliative Care Organization [NHPCO]. (1999). *Public opinion survey*. Retrieved November 12, 2008, from <[www.nhpc.org](http://www.nhpc.org)>.
- National Hospice and Palliative Care Organization [NHPCO]: (2000). *Standards of practice for hospice programs*. Alexandria, VA: National Hospice and Palliative Care Organization.
- National Hospice and Palliative Care Organization [NHPCO]. (2001). *Facts and figures on hospice care in America*. Retrieved September 18, 2008, from <http://www.kued.org/productions/journey/how/factsheet0101.pdf>
- National Hospice and Palliative Care Organization [NHPCO]. (2008). *Patients served by hospice each year*. Retrieved February 13, 2009, from [http://www.nhpc.org/files/public/Statistics\\_Research/NHPCO\\_facts-and-figures\\_2008.pdf](http://www.nhpc.org/files/public/Statistics_Research/NHPCO_facts-and-figures_2008.pdf)
- National Association of Social Workers and the Center for Workforce Studies. (2006). *Assuring the sufficiency of a frontline workforce: A national study of licensed social workers*. Retrieved November 29, 2008, from [http://workforce.socialworkers.org/studies/nasw\\_06\\_execsummary.pdf](http://workforce.socialworkers.org/studies/nasw_06_execsummary.pdf)
- Office of Management and Budget. (1978). *Directive no. 15: Race and ethnic standards for federal statistics and administrative reporting. Statistical Policy Handbook*. Washington, DC: Department of Commerce, Office of Federal Statistical Policy and Standards.
- O’Kane, S., & Miller, R. (2001). An investigation into the counseling-type work of Roman Catholic priests: A survey of one diocese in northern Ireland. *British Journal of Guidance & Counseling*, 29, 323-335.
- Oltjenbruns, K. A. (1998). Ethnicity and the grief response: Mexican American versus Anglo American college students. *Death Studies*, 22(2), 141-155.
- O’Mara, A. M., & Arenella, C. (2001). Minority representation, prevalence of symptoms, and utilization of services in a large metropolitan hospice. *Journal of Pain & Symptom Management*, 21, 290-297.
- Pawling-Kaplan, M., & O’Connor, P. (1989). Hospice care for minorities: An analysis of a hospital-based inner city palliative care service. *American Journal of Hospice Care*, 6, 13-21.
- Prigerson, H. G. (2004). Complicated grief: When the path of adjustment leads to a dead-end. *Bereavement Care*, 23, 38-40.
- Ramirez, R. R. (2004). *We the people: Hispanics in the United States: Census 2000 Special Reports*. Washington, DC: U.S. Census Bureau.
- 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.

- Rando, T. A. (1985). Bereaved parents: Particular difficulties, unique factors, and treatment issues. *Social work, 30*, 19-24.
- Rathbun, A., Denham, S. A., & McCarthy, C. C. 2003. The Ohio hospice bereavement study: Meeting NHPCO standards. *American Journal of Hospice & Palliative Care, 20*, 448-458.
- Robert Wood Johnson Foundation. (2006). *Florida hospice uses grant to improve outreach, service to Hispanics*. Retrieved January 17, 2008, from <http://www.rwjf.org/reports/grr/046134.htm>
- Rothaupt, J. W. (2007). A literature review of western bereavement theory: From decathecting to continuing bonds. *The Family Journal: Counseling and Therapy for Couples and Families, 15*, 6-15.
- Sadock, B. J., & Sadock, V. A. (2007). *Synopsis of Psychiatry* (10<sup>th</sup> ed.). Philadelphia, PA: Lippincott Williams & Wilkins.
- Schonwetter, R. (2006). Hospice and palliative medicine: Ten years has made a difference. *Journal of Palliative Medicine, 9*, 236-238.
- Schulz, R., & Beach, S. R. (1999). Caregiving as a risk factor for mortality: The caregiver health effects study. *Journal of the American Medical Association, 282*, 2215-2219.
- Shrank, W. H., Kutner, J. S., Richardson, T., Mularski, R. A., Fischer, S., & Kagawa-Singer, M. (2005). Focus group findings about the influence of culture on communication preferences in end-of-life care. *Journal of General Internal Medicine, 20*, 703-709.
- Simson, S., & Wilson, L. B. (1986). Strategies for success: An examination of the organizational development of early hospice programs. *The Hospice Journal, 2*(2), 19-39.
- Solis, J. M., Marks, G., Garcia, M., & Shelton, D. (1990). Acculturation, access to care, and use of preventive services by Hispanics: Findings from HHANES 1982-84. *American Journal of Public Health, 80*, 11-19.
- Stroebe, W., & Stroebe, M. S. (1987). *Bereavement and health*. Cambridge, England: Cambridge University Press.
- Torres, L. R., Cabassa, L. J., Zayas, L. H., & Alvarez-Sanchez, T. (2008). Assessing psychosocial stressors among Hispanic outpatients: Does clinical ethnicity matter? *Psychiatric Services, 59*, 690-692.
- U.S. Census Bureau. (2001). Population by race and Hispanic or Latino origin, for all ages and for 18 years and over, for the United States: 2000. Retrieved January 15, 2007, from <http://www.census.gov/population/cen2000/phc-t1/tab01.txt>

- U.S. Census Bureau. (n.d.). *U.S. Hispanic population surpasses 45 million: Now 15 percent of total*. Retrieved January 6, 2009, from <http://www.census.gov/Press-Release/www/releases/archives/population /011910.html>
- United States Conference of Catholic Bishops. (n.d.). Cultural Diversity in the Church. Retrieved September 21, 2008, from <http://www.nccbuscc.org/hispanicaffairs/demo.shtml>
- U.S. Department of Health and Human Services. (2001). *Mental health: Culture, race, and ethnicity—A supplement to mental health: A report of the Surgeon General*. Rockville, MD: U.S. Department of Health and Human Services, Substance Abuse and Mental Health Services Administration, Center for Mental Health Services.
- U.S. Department of Health and Human Services, OPHS Office of Minority Health. (2001). *National standards for culturally and linguistically appropriate services in health care. final report*. Retrieved November 29, 2008, from <http://www.omhrc.gov/assets/pdf/checked/finalreport.pdf>
- University of Washington Medical Center. (2006). End-of-life care: The Latino culture. Retrieved February 13, 2006, from <http://depts.washington.edu/pfes/culturesclues.html>
- Vallerand, A. H. (2003). The unequal burden of pain: Confronting racial and ethnic disparities in pain. *Pain Medicine, 4*, 277-294.
- Waldrop, D. P. (2007). Caregiver grief in terminal illness and bereavement: A mixed methods study. *Health and Social Work, 32*, 197-206.
- Walsh, F., & McGoldrick, M. (2004). Loss and the family: A systemic perspective. In F. Walsh & M. McGoldrick (Eds.), *Living beyond loss: Death in the family* (pp. 182-212). New York: W. W. Norton.
- Weissman, D. E., Gordon, D., & Bidar-Sielaff, S. (2004). Cultural aspects of pain management. *Journal of Palliative Medicine, 7*, 715-718.
- Werth, J. L., & Blevins, D. (2002). Public policy and end-of-life care. *The American Behavioral Scientist, 46*, 401-426.
- Wilson, E., Chen, A. H., Grumbach, K., Wang, F., & Fernandez, A. (2005). Effects of limited English proficiency and physician language on health care comprehension. *Journal of General Internal Medicine, 20*, 800-806.
- Worden, W. J. (1982). *Grief counseling and grief therapy: A handbook for the mental health practitioner*. New York: Springer.
- Wortman, C. B., & Silver, R. C. (1989). The myths of coping with loss. *Journal of Consulting and Clinical Psychology, 57*, 349-357.
- Zecracki, K., & Stancin, T. (2007). Cultural considerations in facilitating coping to a father's illness and bereavement in a Latino child. *Clinical Case Studies, 6*, 3-16.

## APPENDIXES

APPENDIX A

INITIAL TELEPHONE CONTACT WITH HOSPICE AGENCY SCRIPT

*Script:*

“Good morning, my name is Pablo Arriaza and I am looking for the bereavement counselor or the person in charge of bereavement services”

“Hello (Name of bereavement coordinator), my name is Pablo Arriaza and I am a doctoral candidate in social work at The University of Alabama. I am interested in understanding bereavement services with Hispanics in Florida and therefore I am conducting a study that will focus on the needs of this population”

“I am calling all Florida hospices registered with the Florida Hospice and Palliative Care Organization to speak with bereavement coordinators. I would like to send you additional information about the study in order for you to make a decision about your participation. Your participation is strictly voluntary. Your participation requires you to complete an online survey about your perception regarding the bereavement needs of Hispanics. The survey should take you approximately 20 minutes to complete.”

Agreement to receive the information: “Thank you for your time and consideration. Do you have any questions at this time? May I please have your E-mail address where I can send you the study’s information, informed consent, and hyperlink to connect to the study? Also, I would like to have your Agency’s mailing address and your name (if you wish) to send you a thank letter for your consideration in participating in the study. You will be receiving the information in the next seven days via E-mail.”

“May I ask you if your organization provides bereavement services in other counties/cities?” If the answer is “yes”, the PI will attempt to obtain the contact information for any additional bereavement coordinators working for the same agency but in a different county/city.”

If you have any questions about the study or feel uneasy about your participation, you may contact me, Pablo Arriaza at (205)-394-3256 or the supervisors of this study Dr. Ellen Csikai, or Dr. Jordan Kosberg at (205)-348-3924. If you have any questions and/or concerns about your rights as a participant in this research study please contact The University of Alabama’s Research Compliance Officer, Ms. Tanta Myles at [cmyles@fa.ua.edu](mailto:cmyles@fa.ua.edu) or (205)-348-5152.

Does not agree to receive the information: “Thank you for your time. If you decide to receive the information, please let me know by calling me at 205-394-3256 or via E-mail at [arria001@bama.ua.edu](mailto:arria001@bama.ua.edu). Thank you. Have a good day.”

APPENDIX B  
INSTITUTIONAL REVIEW BOARD APPROVAL

Office for Research    May 28, 2008  
Office of the Director of  
Research Compliance



Pablo Arriaza, MSW, LCSW  
School of Social Work  
Box 870314

Re: IRB # EX-08-CM-052 "Bereavement Services for Hispanics: An  
Exploratory Study of Florida Hospices"

Dear Mr. Arriaza:

The University of Alabama Institutional Review Board has granted approval for your proposed research.

Your protocol has been given exempt approval according to 45 CFR part 46.101(b) (2) as outlined below:

- (2) Research involving the use of educational tests (cognitive, diagnostic, aptitude, achievement), survey procedures, interview procedures or observation of public behavior, unless:
- (i) information obtained is recorded in such a manner that human subjects can be identified, directly or through identifiers linked to the subjects; and
  - (ii) any disclosure of the human subjects' responses outside the research could reasonably place the subjects at risk of criminal or civil liability or be damaging to the subjects' financial standing, employability, or reputation.

Should you need to submit any further correspondence regarding this proposal, please include the assigned IRB application number. Please use reproductions of the IRB approved informed consent form to obtain consent from your participants.

Good luck with your research.

Sincerely,

A large black rectangular box redacting the signature of the Director of Research Compliance.

Director of Research Compliance & Research Compliance Officer  
Office of Research Compliance  
The University of Alabama



APPENDIX C

E-MAIL FROM FHPC TO FLORIDA HOSPICES' CEO'S

**Paul Ledford <Paul@floridahospices.org>**

To: Pablo Arriaza <pabloarriaza@gmail.com>, Pablo Arriaza <arria001@bama.ua.edu>

Hi Pablo, This email went out this morning to my board (CEOs). Let me know if you need my assistance.

Best wishes on the research! Paul **From:** Paul Ledford **Sent:** Thursday, June 26, 2008 10:52 AM

Dear FHC Board of Directors, FHPC periodically coordinates with doctoral candidates and researchers who are researching end-of-life issues. Recently, I have been working with Pablo Arriaza, LCSW (AL & FL), a candidate for a Doctor of Philosophy in Social Work, at the School of Social Work, University of Alabama, as he prepares to research the bereavement needs of, and services provided to, Hispanics in Florida. Under the guidance of Jordan Kosberg, Ph.D Co-Chair, Ellen Csikai, Ph.D Co-Chair, Shadi Martin, Ph.D, Rebecca Allen, Ph.D, Linda Dunn, DSN, RN, Mr. Arriaza has prepared a detailed 88-page plan for the research. The study will address the following research questions: 1) What are the characteristics of hospice organizations that provide bereavement services to Hispanics in Florida? 2) What bereavement services are offered to Hispanics by Florida hospices? 3) What do Florida's hospice bereavement coordinators identify as needs for bereaved Hispanics? 4) What challenges are faced by Florida's hospice bereavement coordinators in the provision of bereavement services to Hispanics? 5) What are the strengths identified in Florida hospices regarding bereavement services provided to Hispanics? How your program can participate: Mr. Arriaza will begin with an initial phone call to the bereavement coordinator of each of Florida's hospice programs within the next few weeks, followed by on-line survey(s) using "surveymonkey." All of the data gathered during the course of the research will be strictly confidential, and the questions/surveys are not time-intensive. I have placed a short bio for Mr. Arriaza, below my signature block. **I am asking you to please let the bereavement coordinator in your hospice program know that Mr. Arriaza will be calling them within the next few weeks, and ask for your cooperation in this research.**

Thank you, **Paul A. Ledford, Executive Director**

Florida Hospices and Palliative Care 2000 Apalachee Parkway, Suite 200

Tallahassee, FL 32301 850.878.2632 (office)

850.878.5688 (fax)

877.783.1922 (toll free)

850.321.4617 (cell)

Florida's Advocate for Quality End-of-Life Care

Pablo Arriaza, LCSW  
Doctoral Candidate  
School of Social Work  
The University of Alabama

Please allow me to introduce myself. My name is Pablo Arriaza and I am currently a doctoral candidate in the School of Social Work at The University of Alabama. I have been practicing social work for 16 years and hold Clinical Social Work Licenses in both Florida and in Alabama. My previous experience as a hospice and bereavement social worker in Florida prompted my current interest in focusing my research on the bereavement needs of Hispanics. In order to better understand the current state of bereavement service provision to Hispanics, I have created a survey to obtain a comprehensive overview of these services from the perspective of bereavement coordinators.

In the next few days, I will be attempting to contact you via telephone to discuss my study with you and provide you with opportunities to participate in this study. I thank you in advance for considering participating, and assisting me in collecting information that may be translated into policy and practice. I will close this brief introduction by applauding your commitment to serve individuals/families facing end of life matters. I look forward to speaking with you and thank you again for your time.

Pablo

APPENDIX D  
DATABASE SHEET

	<b>Bev. Coord.</b>	<b>Hosp.</b>	<b>Cit y</b>	<b>County</b>	<b>Pho ne</b>	<b>OK to call</b>	<b>Address</b>	<b>Email</b>	<b>Date of Phone Call</b>	<b>“Thank you” card mail date</b>	<b>1<sup>st</sup> E-mail date</b>	<b>Two Weeks Date from 1<sup>st</sup> E-mail</b>	<b>Remin der E-mail Date</b>	<b>Two Weeks Date From Rem. E-mail</b>
<b>1</b>														
<b>2 . . . . 5 3</b>														

APPENDIX E

TEXT FOR INVITATION E-MAIL

Hello, this is Pablo and I have recently spoken with you about considering participating in an online survey about bereavement services for Hispanics. I am a doctoral candidate at the University of Alabama's school of social work and I am interested in learning more about bereavement services with Hispanics. Information collected from this online survey will allow me to complete my dissertation and disseminate the findings to other professionals via academic journals and professional presentations. Additionally, I will E-mail you the results and findings of this study once the study has been completed.

You can access the online survey (created with *SurveyMonkey*), by clicking on the following link:

[http://www.surveymonkey.com/s.aspx?sm=j6IhmJkht4HC\\_2fH8nrPY3CA\\_3d\\_3d](http://www.surveymonkey.com/s.aspx?sm=j6IhmJkht4HC_2fH8nrPY3CA_3d_3d)

The above link will take you directly to the first page of the online survey, which has detailed information about the study, informed consent, and your rights as a participant.

Your participation is voluntary and your responses will remain confidential. I will be the only person analyzing the information collected from the surveys. Any identifiable information (i.e. gender of providers) will be presented in aggregate form.

I encourage you to complete the survey in one sitting. You can exit the survey and return to complete it where you left off as long as you use the same computer. I will not have access to your computer's Internet Protocol (IP) address. Also, you will have the option to go back to correct any answers you have previously answered. Once you complete the survey and click on the icon labeled "Done" the web page will automatically close and your answers will be submitted.

Again, the link to access the online survey is:

[http://www.surveymonkey.com/s.aspx?sm=j6IhmJkht4HC\\_2fH8nrPY3CA\\_3d\\_3d](http://www.surveymonkey.com/s.aspx?sm=j6IhmJkht4HC_2fH8nrPY3CA_3d_3d)

If you have any questions about the study or feel uneasy about your participation, you may contact me, Pablo Arriaza at (205)-394-3256 or the supervisors of this study Dr. Ellen Csikai, or Dr. Jordan Kosberg at (205)-348-3924. If you have any questions and/or concerns about your rights as a participant in this research study please contact The University of Alabama's Research Compliance Officer, Ms. Tanta Myles at [cmyles@fa.ua.edu](mailto:cmyles@fa.ua.edu) or (205)-348-5152. If you have any questions regarding the online website you can go to [www.surveymonkey.com](http://www.surveymonkey.com)

Thank you again for your participation.

Respectfully,

Pablo Arriaza, LCSW  
Doctoral Candidate  
The University of Alabama  
School of Social Work  
205-394-3256  
[arria001@bama.ua.edu](mailto:arria001@bama.ua.edu)

APPENDIX F

“THANK YOU” NOTE (VIA REGULAR MAIL)

May 2008

Dear \_\_\_\_\_ (Bereavement Coordinator),

I wanted to thank you for speaking with me on (include date of initial phone call) regarding the study that I am conducting in Florida about the bereavement needs of Hispanics. I appreciate your time and your consideration to participate in this study. My goal is to enhance bereavement services to Hispanics by initially understanding what bereavement services are currently available to them and later linking my research findings with practice and policy efforts. In the next couple of days you will be receiving an E-mail with detailed information about the study and informed consent. The E-mail will have a link to the online survey that we spoke about. You are free to access the survey at this time by using your Internet browser and typing: [http://www.surveymonkey.com/s.aspx?sm=j6IhmJkht4HC\\_2fH8nrPY3CA\\_3d\\_3d](http://www.surveymonkey.com/s.aspx?sm=j6IhmJkht4HC_2fH8nrPY3CA_3d_3d)

Thank you so much for your consideration to share your professional thoughts, wisdom, and experiences related to provision of bereavement services to Hispanics. If you have any questions about the study or feel uneasy about your participation, you may contact me, Pablo Arriaza at (205)-394-3256 or the supervisors of this study Dr. Ellen Csikai, or Dr. Jordan Kosberg at (205)-348-3924. If you have any questions and/or concerns about your rights as a participant in this research study please contact The University of Alabama's Research Compliance Officer, Ms. Tanta Myles at [cmyles@fa.ua.edu](mailto:cmyles@fa.ua.edu) or (205)-348-5152. To thank you for your time, I am enclosing a \$2.00 coupon that you or someone else can use at Mcdonalds. Thank you again for your assistance and participation.

Respectfully,

Pablo Arriaza, LCSW,  
Doctoral Candidate  
The University of Alabama  
School of Social Work

APPENDIX G

FIRST SCREEN PAGE OF ONLINE SURVEY,  
EXPLANATION OF STUDY, AND INFORMED CONSENT

Hello, my name is Pablo Arriaza, I am a Florida Licensed Clinical Social Worker and a doctoral candidate in the "School of Social Work" at The University of Alabama. I am conducting an internet-based survey research about bereavement services available to Hispanics in the State of Florida. The purpose of this study is to gain a better understanding, from bereavement coordinators, of the bereavement needs of Hispanics. You were chosen to participate in this study because you currently work as a hospice bereavement coordinator or you are the person responsible for coordinating bereavement services at your hospice.

Your participation is voluntary, your answers will be confidential, and the information obtained from all of the surveys will be analyzed in aggregate, not individually, and only handled by me (the investigator). You can discontinue participation at any point without penalty by closing the survey and/or contacting me directly at the contact information found below. The total number of participants is estimated to be 53. The survey should take approximately 20 minutes or less to complete. You are encouraged to complete the survey all at once. Each section of the survey has explicit directions to follow to answer questions. You can stop and save your answers and return to the survey at a later time to complete it if needed. To do this, you must use the same computer you initially began the survey on in order for the website to remember where you left off. You will be able to go back and correct any answers but once you click "Done" on the last page, your answers will be submitted and your web page will automatically close and your computer's Internet Protocol (IP) address will not be collected.

There should be no significant risks to completing the survey and your employer will not have access to individual responses. If you have any questions about the study or feel uneasy about your participation, you may contact me, Pablo Arriaza at (205)-394-3256 or the supervisors of this study Dr. Ellen Csikai, or Dr. Jordan Kosberg at (205)-348-3924. If you have any questions and/or concerns about your rights as a participant in this research study please contact The University of Alabama's Research Compliance Officer, Ms. Tanta Myles at [cmyles@fa.ua.edu](mailto:cmyles@fa.ua.edu) or (205)-348-5152. Although benefits cannot be promised in research, it is possible that the results of this study may lead to the development of interventions designed to enhance the delivery of bereavement services to Hispanics. Results will be E-mailed to you and results may be presented at local, national, and international conferences and published in academic journals.

By clicking the "NEXT" icon below, you are freely consenting to participate in this study, stating you understand that your name will in no way be associated with your responses, and that you understand your rights as a participant. To thank you for your time, a \$2.00 coupon to use at MacDonaldis' Restaurants will be mailed to you. Thank you for your participation and your willingness to help me understand bereavement services with Hispanics. I appreciate your time in sharing your knowledge and experiences with me. Thank you. Pablo

Pablo Arriaza, LCSW  
Doctoral Candidate

APPENDIX H

THANK YOU E-MAIL AND REMINDER TO COMPLETE SURVEY

May 2008

Dear (Name of bereavement coordinator),

Thank you for taking the time to speak with me on (include day of first phone call) regarding your participation in a research study that explores the bereavement services with Hispanics. I have recently E-mailed prospective participants a letter explaining the purpose of the study. The E-mail also included a direct link to the online survey. If you have completed the survey, thank you very much. If you received the E-mail and have not completed the online survey, I would like to remind you that the survey remains available online and you can still participate. If you did not receive the E-mail and would like to participate, please contact me at (205)-394-3256, E-mail me at [arria001@bama.ua.edu](mailto:arria001@bama.ua.edu) or use the following hyperlink to connect to the survey online:

[http://www.surveymonkey.com/s.aspx?sm=j6IhmJkht4HC\\_2fH8nrPY3CA\\_3d](http://www.surveymonkey.com/s.aspx?sm=j6IhmJkht4HC_2fH8nrPY3CA_3d)

Your participation is important to furthering the knowledge about the bereavement needs and services provided to Hispanics. If you have any questions about the study or feel uneasy about your participation, you may contact me, Pablo Arriaza at (205)-394-3256 or the supervisors of this study Dr. Ellen Csikai, or Dr. Jordan Kosberg at (205)-348-3924. If you have any questions and/or concerns about your rights as a participant in this research study please contact The University of Alabama's Research Compliance Officer, Ms. Tanta Myles at [cmyles@fa.ua.edu](mailto:cmyles@fa.ua.edu) or (205)-348-5152. Thank you again and have a good day.

Sincerely,

Pablo Arriaza, LCSW  
Doctoral Candidate  
The University of Alabama  
School of Social Work

APPENDIX I  
PRETEST SURVEY INSTRUMENT

The following hyperlink directed the participants to the online Pretest survey  
[http://www.surveymonkey.com/s.aspx?sm=hsSiu7CU6tjYDaU3buBI2w\\_3d\\_3d](http://www.surveymonkey.com/s.aspx?sm=hsSiu7CU6tjYDaU3buBI2w_3d_3d)

The following 11 pages are copies of the online pretest survey.

## 2. Introduction and Informed Consent

Hello, my name is Pablo Arriaza, I am a Florida Licensed Clinical Social Worker and a doctoral candidate in the "School of Social Work" at The University of Alabama. I am conducting an internet-based survey research about bereavement services available to Hispanics in the State of Florida. The purpose of this study is to gain a better understanding, from bereavement coordinators, of the bereavement needs of Hispanics. You were chosen to participate in this study because you currently work as a hospice bereavement coordinator or you are the person responsible for coordinating bereavement services at your hospice.

Your participation is voluntary, your answers will be confidential, and the information obtained from all of the surveys will be analyzed in aggregate, not individually, and only handled by me (the investigator). You can discontinue participation at any point without penalty by closing the survey and/or contacting me directly at the contact information found below. The total number of participants is estimated to be 53.

The survey should take approximately 20 minutes or less to complete. You are encouraged to complete the survey all at once. Each section of the survey has explicit directions to follow to answer questions. You can stop and save your answers and return to the survey at a later time to complete it if needed. To do this, you must use the same computer you initially began the survey on in order for the website to remember where you left off. You will be able to go back and correct any answers but once you click "Done" on the last page, your answers will be submitted and your web page will automatically close and your computer's Internet Protocol (IP) address will not be collected.

There should be no significant risks to completing the survey and your employer will not have access to individual responses. If you have any questions about the study or feel uneasy about your participation, you may contact me, Pablo Arriaza at (205)-394-3256 or the supervisors of this study Dr. Ellen Csikai, or Dr. Jordan Kosberg at (205)-348-3924. If you have any questions and/or concerns about your rights as a participant in this research study please contact The University of Alabama's Research Compliance Officer, Ms. Tanta Myles at [cmyles@fa.ua.edu](mailto:cmyles@fa.ua.edu) or (205)-348-5152.

Although benefits cannot be promised in research, it is possible that the results of this study may lead to the development of interventions designed to enhance the delivery of bereavement services to Hispanics. Results will be E-mailed to you and results may be presented at local, national, and international conferences and published in academic journals.

By clicking the "NEXT" icon below, you are freely consenting to participate in this study, stating you understand that your name will in no way be associated with your responses, and that you understand your rights as a participant. To thank you for your time, a \$2.00 coupon to use at MacDonald's Restaurants will be mailed to you.

Thank you for your participation and your willingness to help me understand bereavement services with Hispanics. I appreciate your time in sharing your knowledge and experiences with me. Thank you. Pablo

Pablo Arriaza, LCSW  
Doctoral Candidate

## 1. INSTRUCTIONS FOR PRE-TESTING THE SURVEY

Dear bereavement coordinator. First of all, thank you for talking to me over the phone and accepting this opportunity to assist me in pre-testing this survey instrument which has been created by reviewing the literature, adapting a previous survey by Dr. Craig Demmer (2003) and my previous professional experience as a hospice and bereavement social worker in Florida. I am a doctoral candidate in Social Work at The University of Alabama. For my dissertation, I will be collecting information from bereavement coordinators in Florida regarding provision of bereavement services to Hispanics. Please note that the word "Hispanic" will be used as it is commonly used in Florida. People from Latin American and/or European descent may use different labels to classify themselves. Therefore, keep in mind that in other areas of the United States some people may use words such as "Latino", "Latina", "Spanish-speaking", "Chicano", "Chicana", and "Latino Americano" to describe their ethnicity and/or cultural background.

Pre-testing the survey is an essential step in this research study. In order to standardize the survey and enhance its utility and efficacy, I need objective feedback from experienced professionals like you. Your feedback, suggestions, and comments will be collected in order to make any necessary adjustments to the survey prior to sending it to bereavement coordinators in Florida. You are one of four bereavement coordinators in California that will take part in pre-testing the survey.

It may take you approximately 20-30 minutes to go through the survey and review its content for strengths and weaknesses. Please note that each question has either a comment box or a place for you to provide any comments related to the question. You do not have to complete the survey instead read the questions and go through the survey as if you were going to answer the questions. Please record the time that it takes to complete the survey. You can do this by first going through the survey as if you were going to complete it and then return to it in order to provide feedback on each question.

Please provide your opinion to the overall structure of each question, the ease of readability, note any ambiguous words, confusing terms, or anything you may want to share with me to enhance the final product. Your participation and comments will remain confidential.

At the end of the survey, there is a general "Comments" box. You can use this box to elaborate on your reactions to the survey and provide additional feedback. A rating scale and open-ended questions to this rating scale follows the "Comments" box.

I thank you for your time and willingness to assist me with this research study. I will E-mail you the final product once I have made the necessary changes. To thank you for your time, a \$2.00 McDonald's food coupon will be mailed to you. The following page will display the first page of the survey that prospective bereavement coordinators in Florida will see. If you have any questions about the study or feel uneasy about your participation, you may contact me, Pablo Arriaza at (205)-394-3256 or the supervisors of this study Dr. Ellen Csikai, or Dr. Jordan Kosberg at (205)-348-3924. If you have any questions and/or concerns about your rights as a participant in this research study please contact The University of Alabama's Research Compliance Officer, Ms. Tanta Myles at [cmyles@fa.ua.edu](mailto:cmyles@fa.ua.edu) or (205)-348-5152. Please note that all of the informed consent content on the following page also applies to you. Please read the next page carefully and contact me with any questions you may have. Your participation is voluntary and you can stop participating at any time without penalty. The survey will be closed for access on July 4, 2008.

Thank you

### 3. Bereavement Care

The following section contains items related to bereavement services at your agency. Please check or write in your responses for each question in the spaces provided.

#### 1. Does your agency offer bereavement services?

Yes  No

Other (please specify)

#### 2. How long has your agency been offering bereavement services?

#### 3. Who is eligible for bereavement services at your agency?

- All bereaved family members that have lost someone serviced by our hospice  
 Only bereaved family members identified as "high risk"  
 Anyone from the community regardless of having any connection to the agency

Other (please specify)

#### 4. What is the minimum length of time (in months) that bereavement services are offered for a your agency?

Length of time  Months

Other (please specify)

#### 5. How would you best describe the bereavement services at your agency?

- Full service (available for home visits, individual/family counseling, mailings/letters, memorial services, spiritual support, etc)  
 Assessment and referral only

Other (please specify)

#### 6. What is the cost to families that accept bereavement services?

- The agency does not charge for bereavement services  
 The agency asks for donations from families served  
 The agency asks for donations from the community

Other (please specify)

#### 7. If there is a charge for some of the bereavement services, please specify the type of service(s) and approximate fee. If all bereavement services are free of charge, please place an asterisk (\*) in the space provided. Thank you.

	Approximate Fee	Sliding Scale Available?	Open to the Community
Support Groups	<input type="text"/>	<input type="text"/>	<input type="text"/>
Counseling	<input type="text"/>	<input type="text"/>	<input type="text"/>
Other	<input type="text"/>	<input type="text"/>	<input type="text"/>
Other	<input type="text"/>	<input type="text"/>	<input type="text"/>

Please place an asterisk (\*) in the box below if all bereavement services are free of charge

8. From the drop-down menus, please estimate the number of individuals and/or families serviced last year by your bereavement program.

# of Individuals/families

# of Individuals

# of Families

Other (please specify)

9. From your agency's annual bereavement census, please estimate the percentage of clients that you believe were Hispanic?

% of Hispanic Clients

% of Hispanic clients

Other (please specify)

10. Please select from the drop-down menus, the number of professionals that provide bereavement services at your agency.

Number of Professionals

Social Workers

Nurses

Counselors

Psychologists

Chaplains

Physicians

11. Of the total number of bereavement program staff, how many speak fluent Spanish?

Bereavement Staff that Speak Fluent Spanish

Bereavement Program

Other (please specify)

12. What is the total number of volunteers for your bereavement program?

Number of Bereavement Volunteers

Bereavement Program

Other (please specify)

13. Of the total number of volunteers for your bereavement program, how many speak fluent Spanish?

Number of Volunteers that speak Fluent Spanish

Bereavement Program

Other (please specify)

14. Does your bereavement program engage in outreach activities with religious and/or spiritual organizations?

Yes  No

Other (please specify)

15. In your bereavement program, who receives a grief/bereavement needs assessment? (select all that apply)

All hospice patients

All significant family members and caregivers

No grief or bereavement assessment is done

Other (please explain)

16. Does your bereavement program have standardized bereavement care plans that are used for individuals/families accepting bereavement services?

Yes  No

PILOT STUDY RESPONDENT'S COMMENTS:

  

17. Does your bereavement program provide bereavement education and supportive services to the local community? (i.e. presentations to schools or healthcare facilities?)

Yes  No

Other (please specify)

  

#### 4. Bereavement Training for Staff

1. Does the agency offer any specialized bereavement training (i.e. working with different ethnic populations) to the bereavement staff?

Yes  No

If "yes" please provide types of training offered:

  

2. What is the average number of hours of annual general training that bereavement staff receive at the agency?

8 hours or less  9-16 hours  17 hours or more  N/A

Other (please specify)

  

3. Does the bereavement staff receive specific training on how to work with Hispanics?

Yes  No

Other (please specify)

  

4. Does your agency provide any financial support for staff to attend continuing education (i.e. trainings/seminars/workshops/conferences)?

Yes  No

Other (please specify)

**5. Section 2: BEREAVEMENT SERVICES FOR HISPANICS**

**1. Does your bereavement program refer Hispanic individuals/families to community services to supplement bereavement services offered by your agency?**

Yes       No       I don't know

Other (please specify)

**2. If your bereavement program refers bereaved Hispanic individuals/families to community resources, what are the top three community resources most often used?**

Referrals to community resources

#1 referral source

#2 referral source

#3 referral source

Other (please specify)

**3. Does your program use a process for identifying "high risk" Hispanic individuals/families?**

Yes       No

If "yes" please comment on the process used:

**4. For each bereavement service listed below, please select "Yes", "No", or "N/A" to indicate which services are offered to Hispanic clients.**

	Yes	No	N/A
Counseling	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Support Groups	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Memorial Services	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Spiritual Counseling	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Phone Calls	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Visits by bereavement personnel	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Letters	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Literature/printed materials	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Bereavement newsletters	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Referrals to Outside resources	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Other (please specify)

**5. Please select the 3 most frequently offered bereavement services at your agency to both English and Spanish-speaking clients.**

	Spanish-Speaking Clients	English-Speaking Clients
1	<input type="text"/> <input type="button" value="↑"/> <input type="button" value="↓"/>	<input type="text"/> <input type="button" value="↑"/> <input type="button" value="↓"/>
2	<input type="text"/> <input type="button" value="↑"/> <input type="button" value="↓"/>	<input type="text"/> <input type="button" value="↑"/> <input type="button" value="↓"/>
3	<input type="text"/> <input type="button" value="↑"/> <input type="button" value="↓"/>	<input type="text"/> <input type="button" value="↑"/> <input type="button" value="↓"/>

Other (please specify)

**6. How does your bereavement staff communicate with families that speak Spanish and have limited English proficiency? (Select all that apply)**

Use bilingual bereavement staff  
 Use bilingual staff available (who are not a part of the bereavement team)  
 Use family members  
 Use hospice volunteers  
 Use volunteers outside of our hospice agency (from the community)  
 Use telephone language interpreting services  
 Referral to Spanish-speaking resources  
 Use Internet language interpreting services

Other (please specify):

**7. How are interpretation services funded? (Select all that apply)**

Annual hospice budget  
 Agency receives donations specifically for interpretation services  
 Volunteers from the community offer their services free of charge  
 Bill to Medicare/Medicaid and/or other insurance companies  
 Family is billed  
 I don't know  
 N/A

Other (please specify):

**8. Please comment on any related bereavement needs specific to Hispanics in your community.**

**9. Does your bereavement program offer bereavement services to undocumented Hispanic individuals/families?**

Yes       No       I don't know

Comments:

**6. Section 3: Bereavement Needs of Hispanics**

In this section, please provide your opinions regarding the bereavement needs of Hispanics.

**1. In your opinion, what are the most common bereavement needs of Hispanics? Rate each of these needs according to "High", "Medium", or "Low" needs.**

	High level of need	Medium level of need	Low level of need
Language needs	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Financial needs	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Support system needs (limited availability of friends/family)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Information about available services	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Cultural issues (such as acculturation)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Other (please specify):

**2. Please identify and prioritize the top 3 bereavement services that you believe are needed by Hispanics. (1=top priority, 2=less priority, 3=least priority)**

#1

#2

#3

PILOT STUDY RESPONDENT'S COMMENTS:

**3. Please identify and prioritize the top 3 service-delivery gaps in the provision of bereavement services to Hispanics at your agency. (1=top priority, 2=less priority, 3=least priority)**

#1

#2

#3

PILOT STUDY RESPONDENT'S COMMENTS:

4. As this is a study about Hispanics and bereavement services, please select the types of bereavement services your agency would offer to Hispanics if time and money were not limitations. (Select all that apply)

- Groups
- Regular home visits
- Individual counseling
- Educational programs
- Mail outs
- Additional resources (i.e. books, videos, pamphlets in Spanish)
- Interpretation/translation resources

Other (please specify)

  

#### 7. Section 4: Challenges for the agency in the delivery of hospice and bereave...

In this section, please answer questions related to the challenges of the agency in delivering hospice and bereavement services in general and specifically to Hispanics.

1. In your opinion, what challenge(s) exist in Florida that prevents the advancement of bereavement services to Hispanics?

  

2. Please select the items that in your opinion, are the greatest difficulties or obstacles encountered in the delivery of bereavement services to Hispanics (select all that apply).

- Lack of Spanish-speaking personnel
- Lack of interpretation services
- Insufficient funding
- Lack of organizational support
- Insufficient training of staff
- Complexity/difficulty in defining bereavement services for Hispanics
- Staff or volunteers stress or burnout
- Limited understanding on cultural competence

Other (please specify)

3. The following table lists some challenges that HOSPICE agencies sometimes encounter. Select your response according to the scale provided (1=Not Very Important, 2=Less important, 3=Neutral, 4=Important, 5=Extremely Important)

	1= Not Very Important	2= Less Important	3= Neutral	4=Important	5=Extremely Important
Audits	<input type="radio"/>				
Competition with other hospices in the area	<input type="radio"/>				
Inadequate funding	<input type="radio"/>				
Difficulty reaching minority populations	<input type="radio"/>				
Inadequate staffing	<input type="radio"/>				
Low Census	<input type="radio"/>				
Difficulty hiring adequate staff	<input type="radio"/>				
Low salaries	<input type="radio"/>				
Burnout among personnel	<input type="radio"/>				
Problems with reimbursements	<input type="radio"/>				
Inter-agency politics/red-tape	<input type="radio"/>				
Other (please specify)	<input type="text"/>				

4. The following table lists some challenges that BEREAVEMENT programs sometimes encounter. Select your response according to the scale provided (1=Not Very important, 2=Less Important, 3=Neutral, 4=Important, 5=Extremely Important)

	1=Not Very Important	2=Less Important	3= Neutral	4=Important	5=Extremely Important
Audits	<input type="radio"/>				
Competition with other hospices in the area	<input type="radio"/>				
Inadequate funding	<input type="radio"/>				
Difficulty reaching minority populations	<input type="radio"/>				
Inadequate staffing	<input type="radio"/>				
Low census	<input type="radio"/>				
Difficulty hiring adequate staff	<input type="radio"/>				
Low salaries	<input type="radio"/>				
Burnout among personnel	<input type="radio"/>				
Problems with reimbursements	<input type="radio"/>				
Inter-agency politics/red-tape	<input type="radio"/>				
Other (please specify)	<input type="text"/>				

## 8. Section 5: Strengths of Agency Related to Hospice and Bereavement Service D...

In this section please provide your opinions regarding the strengths of your agency related to hospice and bereavement service delivery.

1. In your opinion, what are the top 3 strengths of HOSPICE services at your agency. Please list them in order of importance with #1=Extremely Important Strength, #2=Important Strength, #3=Less Important.

#1=Extremely Important Strength

#2=Important Strength

#3=Less Important

I can't think of any (Write "N/A")

PILOT STUDY RESPONDENT'S COMMENTS:

2. In your opinion, what are the top 3 strengths of BEREAVEMENT services at your agency. Please list them in order of importance with #1=Extremely Important, #2=Important, #3=Less Important.

#1=Extremely Important Strength

#2=Important Strength

#3=Less Important

I can't think of any (Write "N/A")

PILOT STUDY RESPONDENT'S COMMENTS:

3. In your opinion, what are the top 3 strengths of your BEREAVEMENT department when offering services to Hispanics. Please list them in order of importance with #1=Extremely Important, #2=Important, #3=Less Important.

#1=Extremely Important Strength

#2=Important Strength

#3=Less Important

I can't think of any (Write "N/A")

PILOT STUDY RESPONDENT'S COMMENTS:

## 9. Hospice Agency Background

This section contains items regarding your hospice agency. Please check your response(s) or write in your answers. Thank you.

1. The official name of your agency includes the word(s):

- Hospice  Palliative Care  Hospice and Palliative Care

Other (please specify)

  

2. Please select the correct category for your hospice (select all that apply).

- Freestanding  Hospital-based  Skilled nursing facility-based  Home health agency-based

Other (please specify)

  

3. Please select the most appropriate category regarding your agency:

- For-profit  Not for-profit  I don't know

Other (please specify)

  

4. Where, in Florida, is the agency located (city and/or county)?

5. How many counties are serviced by your hospice agency? Please write in counties if possible.

6. How long has the agency been providing hospice services?

- Less than 5 years  5-10 years  11-15 years  16-20 years  Over 20 years

Other (please specify)

**7. What is an approximate daily hospice/palliative care census of your agency? Please include all patients (outpatient, inpatient, extended care facilities, home-based, etc) enrolled in hospice (do not include bereavement care)**

\_\_\_\_\_

**8. What is the annual budget for your hospice program?**

Less than \$99,000

\$100,000-\$999,999

More than \$1,000,000

I don't know

Other (please specify)

\_\_\_\_\_

**9. Please select all the payment sources that are accepted by your hospice program**

Medicare

Medicaid

Private Insurance

Private Pay

Other (please specify)

\_\_\_\_\_

**10. In your opinion, what payment source is most often used for hospice/palliative care services at your agency? (do not include bereavement care)**

Medicare

Medicaid

Private Insurance

Private Pay

Other (please specify)

\_\_\_\_\_

**11. Is the agency presently Medicare-certified?**

Yes

No

I don't know

Other (please specify)

\_\_\_\_\_

**12. Please select the types of accreditations that the agency currently holds.**

ACHC (Accreditation Commission for Health Care)

CHAP (Community Health Accreditation Program)

JCAHO (The Joint Commission on the Accreditation of Healthcare Organizations)

CARF (Commission on Accreditation of Rehabilitation Facilities)

Not accredited

I don't know

Other (please specify)

\_\_\_\_\_

## 10. Section 6: Respondent Background Information

In this section, please answer the following questions pertaining to yourself.

### 1. What is your professional title within your agency?

Professional Title:

PILOT STUDY RESPONDENT'S COMMENTS:

### 2. What is your employment status? (select all that apply)

Full-time  Part-time  Volunteer

Other/Comments:

### 3. What is your discipline?

Social work  Psychology  Nursing  Religion/theology

Other (please specify)

### 4. From the drop-down menu, please indicate how long have you been involved in the delivery of bereavement services at your agency?

PILOT STUDY RESPONDENT'S COMMENTS:

### 5. How long have you worked in end-of-life care?

PILOT STUDY RESPONDENT'S COMMENTS:

### 6. Do you speak Spanish?

Yes  No  Some

PILOT STUDY RESPONDENT'S COMMENTS:

### 7. What is your highest completed level of education?

Ph.D.  Masters Degree  Bachelors Degree  Associates Degree  High School Diploma

PILOT STUDY RESPONDENT'S COMMENTS:

### 8. What is your gender?

Female  Male

PILOT STUDY RESPONDENT'S COMMENTS:

### 9. What is your race?

### 10. What is your ethnic background?

### 11. What is your age?

### 12. What is your religious affiliation?

13. Please use the space below to provide any additional comments regarding the topic of bereavement services with Hispanics and/or anything else you may wish to express: (FOR PILOT STUDY RESPONDENTS, PLEASE PROVIDE ANY ADDITIONAL COMMENTS THAT MAY BE HELPFUL IN IMPROVING THIS SURVEY. PLEASE COMMENT ON THE STRENGTHS AND WEAKNESSES OF THE SURVEY. THANK YOU!) PLEASE SEE THE LAST THREE QUESTIONS (14-16) BELOW.

14. How long did it take to complete the survey?

15. FOR PILOT STUDY RESPONDENTS  
Please rate the survey on the following:

	Strongly Agree	Agree	Neutral	Disagree	Strongly Disagree
The survey has the required information for respondents to answer questions.	<input type="radio"/>				
The survey does not have any ambiguous words, terms, sentences.	<input type="radio"/>				
The questions flow well	<input type="radio"/>				
The survey procedures are clear and conducive to being used by other researchers to collect information in the same manner.	<input type="radio"/>				
The length of the survey is appropriate for the information that is being collected.	<input type="radio"/>				
The formatting of the survey is acceptable.	<input type="radio"/>				

16. In this last section, please elaborate on any of the previous rating scale questions.

The survey has the required information for respondents to answer questions.	<hr/>
The survey does not have any ambiguous words, terms, sentences.	<hr/>
The questions flow well	<hr/>
The survey procedures are clear and conducive to being used by other researchers to collect information in the same manner.	<hr/>
The length of the survey is appropriate for the information that is being collected.	<hr/>
The formatting of the survey is acceptable.	<hr/>

APPENDIX J

“THANK YOU” LETTER TO PRETEST PARTICIPANTS

Dear (Name of the participant),

I would like to formally thank you for taking time from your busy schedule to assist me in revising the survey instrument that I will use in dissertation research. Pretesting the instrument and the process of data collection is extremely important in order to avoid any unnecessary steps and decrease bias. I could not have completed this survey without your participation and objective feedback. Your self-less participation has provided me with an opportunity to develop a survey tool that may be used in future research in the area of bereavement services to Hispanics. My goal is to continue enhancing bereavement service delivery to Hispanics and other minorities in the United States as well as worldwide. As previously discussed, I am enclosing the final product for your review. If you become interested in using the survey in research, please feel free to contact me at (205)-394-3256 or via E-mail at [pabloarriaza@gmail.com](mailto:pabloarriaza@gmail.com) to provide you with the necessary release and permission to use it. Thank you again for your support and your guidance.

Sincerely,

Pablo Arriaza, LCSW  
Doctoral Candidate, School of Social Work  
The University of Alabama

APPENDIX K  
SURVEY INSTRUMENT

The following hyperlink directed the reader to the online survey:

[http://www.surveymonkey.com/s.aspx?sm=j6IhmJkht4HC\\_2fH8nrPY3CA\\_3d\\_3d](http://www.surveymonkey.com/s.aspx?sm=j6IhmJkht4HC_2fH8nrPY3CA_3d_3d)

The following 10 pages are copies of the online survey.

## 1. Introduction and Informed Consent

Hello, my name is Pablo Arriaza, I am a Florida Licensed Clinical Social Worker and a doctoral candidate in the "School of Social Work" at The University of Alabama. I am conducting an internet-based survey research about bereavement services available to Hispanics in the State of Florida. The purpose of this study is to gain a better understanding, from bereavement coordinators, of the bereavement needs of Hispanics. You were chosen to participate in this study because you currently work as a hospice bereavement coordinator or you are the person responsible for coordinating bereavement services at your hospice.

Your participation is voluntary, your answers will be confidential, and the information obtained from all of the surveys will be analyzed in aggregate, not individually, and only handled by me (the investigator). You can discontinue participation at any point without penalty by closing the survey and/or contacting me directly at the contact information found below. The total number of participants is estimated to be 41.

The survey should take approximately 25-30 minutes or less to complete. You are encouraged to complete the survey all at once. Each section of the survey has explicit directions to follow to answer questions. You can stop and save your answers and return to the survey at a later time to complete it if needed. To do this, you must use the same computer you initially began the survey on in order for the website to remember where you left off. You will be able to go back and correct any answers but once you click "Done" on the last page, your answers will be submitted and your web page will automatically close and your computer's Internet Protocol (IP) address will not be collected.

There should be no significant risks to completing the survey and your employer will not have access to individual responses. If you have any questions about the study or feel uneasy about your participation, you may contact me, Pablo Arriaza at (205)-394-3256 or the supervisors of this study Dr. Ellen Csikai, or Dr. Jordan Kosberg at (205)-348-3924. If you have any questions and/or concerns about your rights as a participant in this research study please contact The University of Alabama's Research Compliance Officer, Ms. Tanta Myles at [cmyles@fa.ua.edu](mailto:cmyles@fa.ua.edu) or (205)-348-5152.

Although benefits cannot be promised in research, it is possible that the results of this study may lead to the development of interventions designed to enhance the delivery of bereavement services to Hispanics. Results will be E-mailed to you and results may be presented at local, national, and international conferences and published in academic journals.

By clicking the "NEXT" icon below, you are freely consenting to participate in this study, stating you understand that your name will in no way be associated with your responses, and that you understand your rights as a participant. To thank you for your time, a \$2.00 coupon to use at MacDonalds' Restaurants will be mailed to you.

Thank you for your participation and your willingness to help me understand bereavement services with Hispanics. I appreciate your time in sharing your knowledge and experiences with me. Thank you. Pablo

Pablo Arriaza, LCSW  
Doctoral Candidate

## 2. Bereavement Care

The following section contains items related to bereavement services at your agency. Please check or write in your responses for each question in the spaces provided.

### 1. Does your agency offer bereavement services?

Yes  No

Other (please specify)

### 2. How long has your agency been offering bereavement services?

### 3. Who is eligible for bereavement services at your agency?

All bereaved family members that have lost someone serviced by our hospice

Only bereaved family members identified as "high risk"

Anyone from the community regardless of having any connection to the agency

Other (please specify)

### 4. What is the minimum length of time (in months) that bereavement services are offered for at your agency?

Months

Length of time

### 5. How would you best describe the bereavement services at your agency?

Full service (available for home visits, individual/family counseling, mailings/letters, memorial services, spiritual support, etc)

Assessment and referral only

Other (please specify)

**6. What is the cost to families that accept bereavement services?**

- The agency does not charge for bereavement services
- The agency asks for donations from families served
- The agency asks for donations from the community

Other (please specify)

**7. If there is a charge for some of the bereavement services, please specify the type of service(s) and approximate fee. If all bereavement services are free of charge, please place an asterisk (\*) in the space provided. Thank you.**

	Approximate Fee	Sliding Scale Available?	Open to the Community
Support Groups	<input type="text"/>	<input type="text"/>	<input type="text"/>
Counseling	<input type="text"/>	<input type="text"/>	<input type="text"/>
Other	<input type="text"/>	<input type="text"/>	<input type="text"/>
Other	<input type="text"/>	<input type="text"/>	<input type="text"/>

Please place an asterisk (\*) in the box below if all bereavement services are free of charge

**8. From the drop-down menus, please estimate the number of individuals and/or families serviced last year by your bereavement program.**

# of Individuals/families	# of individuals	# of families
<input type="text"/>	<input type="text"/>	<input type="text"/>

**9. From your agency's annual bereavement census, please estimate the percentage of clients that you believe were Hispanic?**

% of Hispanic Clients
<input type="text"/>

**10. Please select from the drop-down menus, the number of professionals that provide bereavement services at your agency.**

Number of Professionals	
Social Workers	<input type="text"/>
Nurses	<input type="text"/>
Counselors	<input type="text"/>
Psychologists	<input type="text"/>
Chaplains	<input type="text"/>
Physicians	<input type="text"/>
Volunteers	<input type="text"/>
Other Personnel:	<input type="text"/>

**11. Of the total number of bereavement program staff, how many speak fluent Spanish?**

Bereavement Staff that Speak Fluent Spanish	
Bereavement Program	<input type="text"/>

**12. What is the total number of volunteers for your bereavement program?**

Number of Bereavement Volunteers	
Bereavement Program	<input type="text"/>

**13. Of the total number of volunteers for your bereavement program, how many speak fluent Spanish?**

Number of Volunteers that speak Fluent Spanish	
Bereavement Program	<input type="text"/>

**14. Does your bereavement program engage in outreach activities with religious and/or spiritual organizations?**

- Yes
- No

15. In your bereavement program, who receives a grief/bereavement needs assessment? (select all that apply)

- All hospice patients
- All significant family members and caregivers
- No grief or bereavement assessment is done

Other (please explain)

16. Does your bereavement program have standardized bereavement care plans that are used for individuals/families accepting bereavement services?

- Yes       No

17. Does your bereavement program provide bereavement education and supportive services to the local community? (i.e. presentations to schools or healthcare facilities?)

- Yes       No

### 3. Bereavement Training for Staff

1. Does the agency offer any specialized bereavement training (i.e. working with different ethnic populations) to the bereavement staff?

- Yes       No

If "yes" please provide types of training offered:

2. What is the average number of hours of annual general training that bereavement staff receive at the agency?

- 8 hours or less       9-16 hours       17 hours or more       N/A

3. Does the bereavement staff receive specific training on how to work with Hispanics?

- Yes       No

4. Does your agency provide any financial support for staff to attend continuing education (i.e. trainings/seminars/workshops/conferences)?

- Yes       No

**4. Section 2: BEREAVEMENT SERVICES FOR HISPANICS**

1. Does your bereavement program refer Hispanic individuals/families to community services to supplement bereavement services offered by your agency?

- Yes       No       I don't know

2. If your bereavement program refers bereaved Hispanic individuals/families to community resources, what are the top three community resources most often used?

Referrals to community resources

#1 referral source

#2 referral source

#3 referral source

Other (please specify)

3. Does your program use a process for identifying "high risk" Hispanic individuals/families?

- Yes       No

If "yes" please comment on the process used:

4. For each bereavement service listed below, please select "Yes", "No", or "N/A" to indicate which services are offered to Hispanic clients.

	Yes	No	N/A
Counseling	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Support Groups	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Memorial Services	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Spiritual Counseling	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Phone Calls	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Visits by bereavement personnel	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Letters	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Literature/printed materials	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Bereavement newsletters	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Referrals to Outside resources	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

5. Please select the 3 most frequently offered bereavement services at your agency to both English and Spanish-speaking clients.

	Spanish-Speaking Clients	English-Speaking Clients
1	<input type="text" value=""/> <input type="button" value="v"/>	<input type="text" value=""/> <input type="button" value="v"/>
2	<input type="text" value=""/> <input type="button" value="v"/>	<input type="text" value=""/> <input type="button" value="v"/>
3	<input type="text" value=""/> <input type="button" value="v"/>	<input type="text" value=""/> <input type="button" value="v"/>

6. How does your bereavement staff communicate with families that speak Spanish and have limited English proficiency? (Select all that apply)

- Use bilingual bereavement staff
- Use bilingual staff available (who are not a part of the bereavement team)
- Use family members
- Use hospice volunteers
- Use volunteers outside of our hospice agency (from the community)
- Use telephone language interpreting services
- Referral to Spanish-speaking resources
- Use internet language interpreting services

Other (please specify)

**7. How are interpretation services funded? (Select all that apply)**

- Annual hospice budget
- Agency receives donations specifically for interpretation services
- Volunteers from the community offer their services free of charge
- Bill to Medicare/Medicaid and/or other insurance companies
- Family is billed
- I don't know
- N/A

Other (please specify)

**8. Please comment on any related bereavement needs specific to Hispanics in your community.**

**9. Does your bereavement program offer bereavement services to undocumented Hispanic individuals/families?**

- Yes
  No
  I don't know

Comments:

**5. Section 3: Bereavement Needs of Hispanics**

In this section, please provide your opinions regarding the bereavement needs of Hispanics.

**1. In your opinion, what are the most common bereavement needs of Hispanics? Rate each of these needs according to "High", "Medium", or "Low" needs.**

	High level of need	Medium level of need	Low level of need
Language needs	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Financial needs	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Support system needs (limited availability of friends/family)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Information about available services	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Cultural issues (such as acculturation)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

**2. Please identify and prioritize the top 3 bereavement services that you believe are needed by Hispanics. (1=top priority, 2=less priority, 3=least priority)**

#1

#2

#3

**3. Please identify and prioritize the top 3 service-delivery gaps in the provision of bereavement services to Hispanics at your agency. (1=top priority, 2=less priority, 3=least priority)**

#1

#2

#3

**4. As this is a study about Hispanics and bereavement services, please select the types of bereavement services your agency would offer to Hispanics if time and money were not limitations. (Select all that apply)**

- Groups
- Regular home visits
- Individual counseling
- Educational programs
- Mail outs
- Additional resources (i.e. books, videos, pamphlets in Spanish)
- Interpretation/translation resources

Other (please specify)

## 6. Section 4: Challenges for the agency in the delivery of hospice and bereave...

In this section, please answer questions related to the challenges of the agency in delivering hospice and bereavement services in general and specifically to Hispanics.

1. In your opinion, what challenge(s) exist in Florida that prevents the advancement of bereavement services to Hispanics?

2. Please select the items that in your opinion, are the greatest difficulties or obstacles encountered in the delivery of bereavement services to Hispanics (select all that apply).

- Lack of Spanish-speaking personnel
- Lack of interpretation services
- Insufficient funding
- Lack of organizational support
- Insufficient training of staff
- Complexity/difficulty in defining bereavement services for Hispanics
- Staff or volunteers stress or burnout
- Limited understanding on cultural competence

Other (please specify)

3. The following table lists some challenges that HOSPICE agencies sometimes encounter. Select your response according to the scale provided (1=Not Very Important, 2=Less important, 3=Neutral, 4=Important, 5=Extremely Important)

	1=Not Very Important	2=Less Important	3=Neutral	4=Important	5=Extremely Important
Audits	<input type="radio"/>				
Competition with other hospices in the area	<input type="radio"/>				
Inadequate funding	<input type="radio"/>				
Difficulty reaching minority populations	<input type="radio"/>				
Inadequate staffing	<input type="radio"/>				
Low Census	<input type="radio"/>				
Difficulty hiring adequate staff	<input type="radio"/>				
Low salaries	<input type="radio"/>				
Burnout among personnel	<input type="radio"/>				
Problems with reimbursements	<input type="radio"/>				
Inter-agency politics/red-tape	<input type="radio"/>				

4. The following table lists some challenges that BEREAVEMENT programs sometimes encounter. Select your response according to the scale provided (1=Not Very important, 2=Less Important, 3=Neutral, 4=Important, 5=Extremely Important)

	1=Not Very Important	2=Less Important	3=Neutral	4=Important	5=Extremely Important
Audits	<input type="radio"/>				
Competition with other hospices in the area	<input type="radio"/>				
Inadequate funding	<input type="radio"/>				
Difficulty reaching minority populations	<input type="radio"/>				
Inadequate staffing	<input type="radio"/>				
Low census	<input type="radio"/>				
Difficulty hiring adequate staff	<input type="radio"/>				
Low salaries	<input type="radio"/>				
Burnout among personnel	<input type="radio"/>				
Problems with reimbursements	<input type="radio"/>				
Inter-agency politics/red-tape	<input type="radio"/>				

## 7. Section 5: Strengths of Agency Related to Hospice and Bereavement Service D...

In this section please provide your opinions regarding the strengths of your agency related to hospice and bereavement service delivery.

**1. In your opinion, what are the top 3 strengths of HOSPICE services at your agency. Please list them in order of importance with #1=Extremely Important Strength, #2=Important Strength, #3=Less Important.**

#1=Extremely Important Strength	<input type="text"/>
#2=Important Strength	<input type="text"/>
#3=Less Important	<input type="text"/>
I can't think of any (Write "N/A")	<input type="text"/>

**2. In your opinion, what are the top 3 strengths of BEREAVEMENT services at your agency. Please list them in order of importance with #1=Extremely Important, #2=Important, #3=Less Important.**

#1=Extremely Important Strength	<input type="text"/>
#2=Important Strength	<input type="text"/>
#3=Less Important	<input type="text"/>
I can't think of any (Write "N/A")	<input type="text"/>

**3. In your opinion, what are the top 3 strengths of your BEREAVEMENT department when offering services to Hispanics. Please list them in order of importance with #1=Extremely Important, #2=Important, #3=Less important.**

#1=Extremely Important Strength	<input type="text"/>
#2=Important Strength	<input type="text"/>
#3=Less Important	<input type="text"/>
I can't think of any (Write "N/A")	<input type="text"/>

## 8. Hospice Agency Background

This section contains items regarding your hospice agency. Please check your response(s) or write in your answers. Thank you.

**1. The official name of your agency includes the word(s):**

- Hospice       Palliative Care       Hospice and Palliative Care

Other (please specify)

**2. Please select the correct category for your hospice (select all that apply).**

- Freestanding       Hospital-based       Skilled nursing facility-based       Home health agency-based

Other (please specify)

**3. Please select the most appropriate category regarding your agency:**

- For-profit       Not for-profit       I don't know

Other (please specify)

**4. Where, in Florida, is the agency located (city and/or county)?**

**5. How many counties are serviced by your hospice agency? Please list counties if possible.**

**6. How long has the agency been providing hospice services?**

- Less than 5 years       5-10 years       11-15 years       16-20 years       Over 20 years

**7. What is an approximate daily hospice/palliative care census of your agency? Please include all patients (outpatient, inpatient, extended care facilities, home-based, etc) enrolled in hospice (do not include bereavement care)**

**8. What is the annual budget for your hospice program?**

- Less than \$99,000       \$100,000-\$999,999       More than \$1,000,000       I don't know

**9. Please select all the payment sources that are accepted by your hospice program**

- Medicare       Medicaid       Private Insurance       Private Pay

Other (please specify)

**10. In your opinion, what payment source is most often used for hospice/palliative care services at your agency? (do not include bereavement care)**

- Medicare       Medicaid       Private Insurance       Private Pay

Other (please specify)

**11. Is the agency presently Medicare-certified?**

- Yes       No       I don't know

**12. Please select the types of accreditations that the agency currently holds.**

- ACHC (Accreditation Commission for Health Care)  
 CHAP (Community Health Accreditation Program)  
 JCAHO (The Joint Commission on the Accreditation of Healthcare Organizations)  
 CARF (Commission on Accreditation of Rehabilitation Facilities)  
 Not accredited  
 I don't know

Other (please specify)

**9. Section 6: Respondent Background Information**

In this section, please answer the following questions pertaining to yourself.

**1. What is your professional title within your agency?**

**2. What is your employment status? (select all that apply)**

- Full-time     Part-time     Volunteer

Other/Comments:

**3. What is your discipline?**

- Social work     Psychology     Nursing     Religion/theology

Other (please specify)

**4. From the drop-down menu, please indicate how long have you been involved in the delivery of bereavement services at your agency?**

**5. How long have you worked in end-of-life care?**

**6. Do you speak Spanish?**

- Yes       No       Some

Comments:

**7. What is your highest completed level of education?**

- Ph.D       Masters Degree       Bachelors Degree       Associates Degree       High School Diploma

**8. What is your gender?**

Female  Male

**9. What is your race?**

**10. What is your ethnic background?**

**11. What is your age?**

**12. What is your religious affiliation?**

**13. Please use the space below to provide any additional comments regarding the topic of bereavement services with Hispanics and/or anything else you may wish to express:**

APPENDIX L

PERMISSION TO USE AND ADAPT DR. DEMMER'S SURVEY

**Date:** Fri, 1 Feb 2008 11:57:41 -0700  
**From:** [Pablo Arriaza <arria001@bama.ua.edu>](mailto:arria001@bama.ua.edu)  
**To:** [CRAIG DEMMER <CRAIG.DEMMER@lehman.cuny.edu>](mailto:CRAIG.DEMMER@lehman.cuny.edu)  
**Subject:** Using bereavement survey

Dr. Demmer, I hope you remember me...it has been a while since we last communicated. This is Pablo, completing my Ph.D in social work at the University of Alabama. I am looking at provision of bereavement services to Latinos in Florida. You were very kind to send me your survey and I never asked you if it would be OK for me to use your survey. Many of the questions from your survey apply directly to my study and certainly don't want to reinvent the wheel. Please let me know if I have your permission to use your survey and use the questions from it. I will certainly cite your work. Thank you again for your support.

Pablo

Pablo Arriaza, LCSW  
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**From:** [CRAIG DEMMER <CRAIG.DEMMER@lehman.cuny.edu>](mailto:CRAIG.DEMMER@lehman.cuny.edu)  
**To:** [Pablo Arriaza <arria001@bama.ua.edu>](mailto:arria001@bama.ua.edu)  
**Subject:** Re: Using bereavement survey

Hi Pablo

Yes I give you permission to use my survey. Hope all is well.  
Best,  
CD

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APPENDIX M  
RESPONSES TO THE OPEN-ENDED QUESTIONS

Open-Ended Responses For Survey Question 14, Section 1-2: *In your bereavement program, who receives a grief/bereavement needs assessment?*

Anticipatory grief and after death assessments for loved ones  
In bereavement, all individuals who request and receive bereavement & community grief counseling services  
Family members if requested or if the counseling while working with the patient sees that there is a family member in need of counseling will request counseling support for that family member  
Identified primary caregiver and any other that the social worker thinks might need this service. Usually there is one bereaved identified for assessment and services, but there can be more.  
Community referrals  
Primary caregiver of patient  
Screen community clients over the phone

Open-Ended Responses for Survey Question 1 Section 1- 3: *Does your agency offer any specialized bereavement training?*

Cultural competency  
Seminars off site  
Panel discussion, educational handouts “winks”, in-services  
Working with people after traumatic loss, working with children, complicated mourning, etc.  
Agency has some training re: ethnic populations not specific to bereavement  
Religious and cultural  
Informal in-services only re: cultural diversity  
In-services  
We provide a diversity sensitivity educational program for the staff and volunteers  
Children, Jewish  
Cultural diversity  
Cultural sensitivity, grief with respect to different religions  
Cultural diversity and grief  
ELNEC Training, Florida Hospices & NHPCO trainings  
Workshops as they are available for ethnic populations, alternative life styles, violent and traumatic loss, parental loss, etc.  
Cultural diversity including Jewish and Muslim

Open-Ended Responses for Survey Question 1, Section 2: *If your bereavement program refers bereaved Hispanic individuals/families to community resources, what are the top three community resources most often used?*

Financial assistance programs. We refer based on assessment and then need, difficult to pick top three as it varies based on client  
Social services  
We have local Children’s Bereavement Center, which provides support groups for children and their parents. Also, we refer to the local chapter of Compassionate Friends, for bereaved parents. Catholic charities

Open-Ended Responses for Survey Question 3, Section 2: *Does your program use a process for identifying “high risk” Hispanic individuals/families?*

Bereavement assessment by Primary degreed SW of all loved ones-Early Bereavement contacted 1<sup>st</sup> wk  
All bereaved are evaluated using the same assessment tool  
High risk factors are considered for each client but not based on gender or ethnicity  
All clients receive the same assessment, regardless of ethnic background  
We identify all “high risk” individuals regardless of their ethnicity  
All bereaved individuals are assessed for “high risk” by the counselors and social workers, during the care of the patient. Their findings are reported in the psychosocial evaluations and visit notes.  
Risk assessment survey  
A list of high risk indicators such as number of losses in the past two years, drugs or alcohol use, sudden death, age, number of years married, support system, etc.  
High risk is used for every assessment  
All bereaved are assessed for high risk needs  
Every survivor is assessed for risk level, this is not dependent upon culture, race, ethnicity, etc.  
We would use the same process we use for identifying high risk in other ethnic groups but conducted by a Spanish speaking counselor  
Same criteria is used to identify all clients, not necessarily Hispanic in nature  
Assessment tool with specific indicators of high risk  
This process is used for all high risk bereaved, not just Hispanic. The field SW assesses this through out care  
Initial bereavement risk assessment done on admission and yearly updates  
It is what we use for all families

Open-Ended Responses for Survey Question 8, Section 2: *Please comment on any related bereavement needs specific to Hispanics in your community.*

The most important need is to provide them with a sense of understanding cultural/spiritual background  
Hispanic families tend to refuse some of our bereavement services, stating that they would rather “keep it within the family” than seek outside professional help/assistance  
None  
Bilingual support groups in the area are limited and often not well attended despite who the sponsoring agency is  
A safe place to express their mourning, and to be heard  
Adult children tend to adopt a very protective nature of their elderly family members; Hispanics don’t often seeking out services on their own. They tend to be responsive to services offered but don’t actively seek services themselves.  
My experience has been that Hispanic individuals do not access grief support services offered to them.  
We are just now addressing the needs of the Latino community. We are this time translating all the forms we have to Spanish (internally). We have just hired a Latino Bereavement Counselor who is bi-lingual. We will also create a support group for Spanish-speaking individuals in two months. We have made great strides these past few months in providing information, education, and counseling to the Latino community about Hospice services.  
Coping with having placed their loved one in a nursing home due to lack of caregiver at home

We offer the same service to both Hispanics and non-Hispanics alike.  
Families need assistance with final arrangements. There are no resources for this service in our community for cremation or burial.

There is a gap in all mental health resources in Osceola county and south Orlando – both Spanish and English speaking. Our Osceola county bereavement counselor does not speak Spanish, so Spanish speaking clients must travel to our office for counseling in Spanish. We do offer field visits from a Spanish speaking bereavement counselor in East Orlando. Our office is located approximately an hour from Osceola County.

In our community, the Hispanic families usually rely on church and extended family members for support

We have a Hispanic Community Liaison that works with the Hispanic churches as well as other organizations. She educates them on our services available and provides them with Spanish literature from the bereavement department.

A community needs assessment has not been conducted

Limited local family

Open-Ended Responses for Survey Question 4, Section 3: *As this is a study about Hispanics and bereavement services, please select the types of bereavement services your agency would offer to Hispanics if time and money were not limitations.*

All other services are currently offered, individual counseling would be helpful for Hispanics and non Hispanics

With the exception of routine home visits & resources in Spanish, all the above are available to every family member of our patients. However, if they cannot speak English, the services are extremely limited unless there was a funding source to bridge this gap

We are able to meet the need for individual counseling and group support with our Hispanic population through 1 full time Bi-Lingual Bereavement Counselor. But we could use more resources regarding written materials for this population

Children's Play and Sand Tray Therapy and children's bereavement camps

These services are offered at this time

Annual memorial services and research into why Hispanics do not take advantage of services offered

We provide all our services to Hispanics

Open-Ended Responses for Survey Question 2, Section 3: <i>Please identify and prioritize the top 3 bereavement services that you believe are needed by Hispanics (1=top priority, 2=less priority, 3=least priority)</i>		
Top Priority Responses	Less Priority Responses	Least Priority Responses
Support groups conducted in Spanish Spiritual Visits More Hispanic Volunteers Information about grief and mourning Literature available in Spanish Culturally appropriate care in Spanish served at locations they would be comfortable going Language specific grief education written materials Counseling support To avail themselves of our services Bereavement counseling Counseling Counseling in their own language Support groups Individual Support Information about available services Free in-home or local Spanish speaking counseling Information about available services Culturally appropriate support Hispanic speaking support group Education Counseling language specific specific	Individual sessions Supportive counseling (ind. or family) Calls Ongoing support/counseling Knowledge on the benefits of grief counseling Knowledge of the availability of these services Transportation for accessing community services Referrals for Immigration services To allow us to be in support for them Family counseling Support group counseling Help in understanding American ways in relation to aggressive treatment Printed material on bereavement Group support Language needs Written resources in Spanish – grief literature for both therapists and bereaved clients Cultural issues Information about services Better doctor referral for Hispanics in need as well as referring earlier other than when imminent Support groups Support groups –language specific	Understanding of their culture Literature Literature Support groups BV support groups for Hispanics Grief information Education about Hospice Mission and services Community support Information resources Financial needs Social support for immigrants whose families are abroad Financial needs Means and transportation to access services Educating and reaching the community especially the no cost service we provide Individual counseling Referrals to community agencies Literature in Spanish Financial Printed material

Open-Ended Responses for Survey Question 2, Section 3, Continued: <i>Please identify and prioritize the top 3 bereavement services that you believe are needed by Hispanics (1=top priority, 2=less priority, 3=least priority)</i>	
Top Priority	Less Priority
To have a counselor who speaks their language and understands their culture Spanish speaking grief specialist Support group More Spanish speaking bereavement professionals	Groups of Spanish speaking individuals Spiritual support Spanish speaking support groups

Open-Ended Responses for Survey Question 3, Section 3: <i>Please identify and prioritize the top 3 service-delivery gaps in the provision of bereavement services to Hispanics at your agency (1=top priority, 2=less priority, 3=least priority)</i>		
Top Priority Responses	Less Priority Responses	Least Priority Responses
Need more participation of Spanish speaking individuals	Attempt to reach bereaved Hispanic individuals	More contacts in the community
Language barriers	Distance	Limited resources
None	None	None enough referral sources
Group structures or times that are more attractive	Not enough bilingual employees and volunteers	Lack of community resources
Lack of understanding regarding culture	Additional bilingual bereavement staff	Transportation
All the above	Having sufficient bilingual staff members	Financial support for final arrangements
Language specific grief education written materials	We need more Spanish speaking counselors	Financial needs
Having all program literature produced in Spanish	Spanish literature	Marketing our services to the Spanish speaking population
Not all of our bereavement literature is in Spanish	Educational programs/material	Need to do better job understanding why Hispanics do not take advantage of services that are available
Bi-lingual staff to serve the Latinos	Cultural diversity	Information about services
Demand is higher than availability of staff	Enough Spanish speaking personnel	Distance
Language	Acceptance of services	Literature in Spanish
Spanish speaking support groups	Information about available services	Same as above
Language	Spanish language grief literature	
Language needs	Need to better understand cultural differences	
No in-home Spanish speaking services offered in Osceola County or South Orlando	Cultural understanding	
Need more bilingual professional staff	Not having Hispanic speaking staff in each discipline of our service	
Language	Location	
Educating community	Groups of Spanish speaking individuals	
Language barriers	Access to social service agencies	
No. of Spanish speaking counselors available	Same as above	
We have no bilingual counselors		
Spanish speaking grief specialist		
Knowledge of the different Spanish languages		
Same as above		

Open-Ended Responses for Survey Question 1, Section 4 *In your opinion, what challenges exist in Florida that prevents the advancement of bereavement services to Hispanics?*

I don't know of any challenges. Like with other populations, participation is voluntary  
Language barrier between therapist and bereaved family/individual.  
Prejudice  
Not enough advertisement of services in Hispanic newspapers  
Ignorance on the part of policy makers and individuals regarding the culture  
Services are often available based on the % make-up in a given community. The smaller the % the less priority it takes, in bringing all types of services to a population, especially when there seems to be less money available supporting social service efforts.  
Non-Spanish speaking care providers  
#1 = Lack of Spanish-speaking personnel in the field of Bereavement  
Language barriers are the most prevalent challenges  
The Hispanics reluctance to avail themselves of our services. Since there is no translation for the word "hospice" we are sometimes at a loss to make our services known in the Hispanic community  
Their knowledge of the services that are available to them in the community  
Lack of awareness of the need. Lack of knowledge about the numbers that exist. Lack of education and comfort level on how to proceed with a plan to market this population. Lack of funds to invest in an Outreach Program for this population. Lack of staff to specialize in this effort.  
General acceptance of counseling services by Hispanics  
Distrust of outside agencies  
Language and cultural competency  
A lack of understanding what bereavement is and how one works through their loss  
Language  
Not enough bilingual personnel  
The Spanish speaking population is growing faster than the agency, which prevents us from hiring an additional Spanish speaking counselor  
Language barrier and limited understanding regarding the culture as it relates to bereavement  
Not enough clients to work with in our area whether it be from lack of education, to denial of bereavement services, or lack of referral sources  
Language barriers, delivery of services and Hispanic clients tending to keep issues at home  
Lack of Spanish speaking counselors  
A lack of bilingual social workers  
Lack of Spanish speaking social workers and counselors  
Cultural issues of self-reliance yet without family support. Fear of stranger invasion of personal life.  
Lack of financial resources  
Are they aware of hospice and the benefits of using

Open-Ended Responses for Survey Question 2, Section 4: *Please select the items that in your opinion are the greatest difficulties or obstacles encountered in the delivery of bereavement services to Hispanics.*

Prejudice

I believe the bereavement services can be duplicated for the Latino community. Transportation is always an issue

Reluctance to accept supports outside of the family and church

None of the above applies. We have the services set up to serve this population but not enough referrals who take advantage of additional support outside of our standard mailings

The culture often does not want or accept assistance offered

Utilization of hospice by Hispanics

Open-Ended Responses for Survey Question 1, Section 5: <i>In your opinion, what are the top 3 strengths of Hospice services at your agency. Please list them in order of importance with #1=Extremely Important Strength, #2=Important Strength, #3=Less Important</i>		
Extremely Important Strength	Important Strength	Less Important Strength
Provision of comfort in a supportive environment Services available to all 4 physicians on staff Multicultural staff Our availability to the community and investment in the community Employees commitment to mission and providing quality care at the EOL Quality of service (recognized nationally) Core Value: Patients and Families come first”..quality palliative care and pain management Hospice services are offered to all individuals without regard to ability to pay for them The staff believes in the mission of Hospice Caring compassionate staff Bedside crisis care and nursing Services that are offered Reputation of great care given by highly trained staff Timely, ompassionate care Good staff	Empathy and validation of grief related feelings Team oriented approached to all patients Educated workers – degreed staff Several services available to community without the need to be served by hospice Above and beyond services (i.e. complementary therapies) N/A Dedicated staff Multidisciplinary Team Approach The agency has high standards for customer service The staff is dedicated and believes the work is a “calling” Knowledgeable intelligent staff Chaplains Size of our Hospice Bereavement care Quality staff High Quality personnel Open access to all Excellent reputation Excellent pain management Service to anyone, regardless of ability to pay	More of the above Non-for-profit hospice 24/7 on call coverage No charge for services, such as groups, children camp, community responses after a trauma or loss A true team effort N/A Quick enrollment after referral Not-for-profit status: Services are based on medical need and are provided regardless o ability to pay, age, race, creed, sex, lifestyle or illness—provides an average of \$4million in charity care annually Staff members are compassionate caregivers Monetary compensation Reliability Social worker N/A Hospice houses Good symptom management Compassionate care for employees Large well funded Dedicated individuals

Open-Ended Responses for Survey Question 1, Section 5, Continued: *In your opinion, what are the top 3 strengths of Hospice services at your agency. Please list them in order of importance with #1=Extremely Important Strength, #2=Important Strength, #3=Less Important*

Extremely Important Strength	Important Strength	Less Important Strength
<p>Good community connections  Our level of care  Patient and family centered  Experienced counselors, nurses, doctors, chaplains  24 hour availability of staff and services regardless of income or ability to pay  Well trained and educated staff  Bereavement programs  The care the staff gives patients and family</p>	<p>Experienced compassionate staff  Facilities  Volunteer and outreach programs  Job knowledge and skill</p>	<p>Provide services that other area Hospices do not  Supportive management for specialty services/complementary therapies  Staff who work well with each other  Community support  N/A  Flexibility in schedules</p>

Open-Ended Responses for Survey Question 2, Section 5: <i>In your opinion, what are the top 3 strengths of Bereavement services at your agency. Please list them in order of importance with #1=Extremely Important Strength, #2=Important Strength, #3=Less Important</i>		
Extremely Important Strength	Important Strength	Less Important Strength
Provision of comfort in a supportive environment	Empathy and validation of feelings	More of the above
Free counseling services to hospice families	Same services offered to community for donation	Individual, family, and group services available
Free of charge – full spectrum of services	Degreed grief workers on staff	On call staff
Extensive mailing and resource provision to hospice an non hospice families	Grief education and support group participation available to hospice and non hospice families	Our services are accessible to anyone in the community
Above and beyond services (Children’s grief center/camp, traumatic loss program)	All staff are masters level and licensed counselors with special training in bereavement interventions	Strong team
Committed qualified counselors	An array of services offered (individual, group, seminars, camp, letters, memorials)	Mailings, surveys
Flexibility to meet client needs	Variety of services offered	Bereavement care begins with the admission of the patient
Contact and assessment of all bereaved family members; Individual (in-home) counseling offered	Additional Community Services (Group Support; Memorial Services; Camps, Family Retreat, Adult Retreat; Children’s Grief Support group model)	Children’s Play and Sand Tray Therapy program
Bereavement services are without cost to family members and friends of hospice patients	Services are offered without regard to ethnicity or religious preference.	Staff is eager to increase their skills to better serve their clients
One-on-one counseling	Small support groups	Assistance with funeral services/chaplain services
Provide the same level of care to the Hispanic population that is provided to the general population	Provide literature to the families in Spanish	Printed materials
Staff experience a high degree of job satisfaction	Staff is dedicated to facilitating the healing process for others	Commitment and longevity of staff
Written information for families in the language of choice	Compassionate staff	A full range of support services/programs
Printed material	Wide Range of group locations and times	Compassionate care for employees
	Having staff trained in bereavement	Need more bilingual staff
		Staff open to expanding the bereavement program
		Building a great community bereavement program and providing education to facilities and the community
		Support for caregivers as well as bereaved
		Physical plant availability

Open-Ended Responses for Survey Question 2, Section 5, Continued: <i>In your opinion, what are the top 3 strengths of Bereavement services at your agency. Please list them in order of importance with #1=Extremely Important Strength, #2=Important Strength, #3=Less Important</i>		
Extremely Important Strength	Important Strength	Less Important Strength
Follows families for 15 months Children's Bereavement Center Quality staff Free bereavement services for community and hospice clients Open to everyone who has experienced a loss Caring and concerned staff Mailings to all our families at significant times in their grief process Client, family and community centered Experienced counselors Compassionate, professional staff Have trained and licensed counselors providing bereavement Training of staff – all Masters level or above Ability to listen and unconditional acceptance	Ability to see community clients not connected with hospice Timely follow up Compassionate care Determined to deliver quality programs Staff open to learning Provision of excellent and competent care Free bereavement services to both hospice and community bereaved Well trained volunteers Offer different modalities of support, group, individual, workshops, memorials Team work within department Job knowledge and skill	Bereavement mailings Support from administration Flexibility in schedules

Open-Ended Responses for Survey Question 3, Section 5: *In your opinion, what are the top 3 strengths of your Bereavement department when offering services to Hispanics. Please list them in order of importance with #1=Extremely Important Strength, #2=Important Strength, #3=Less Important.*

Extremely Important Strength	Important Strength	Less Important Strength
Provision of comfort in a supportive environment with the understanding of participant's background Individual counseling in person or over the phone Free of charge Bilingual people answering phones for the agency Bilingual/trained staff If they speak English, all of the above Desire to serve all clients Bilingual bereavement counselor on staff Services are offered without regard to ethnicity or religious preference One-on-one counseling in Spanish Find resources to assist the counselors in working with families with limited English We now have a bilingual Latino Counselor Bilingual bicultural staff Printed material 15 months of follow up Spanish speaking BV Coordinator Quality Staff Free bereavement services The one dedicated tri-lingual staff member Caring and concerned staff	Empathy and validation of their feelings Services for adults and children Bilingual degreed workers Bilingual staff in bereavement dept Services are available to any Hispanic individual in the community Our resources translated into Spanish Commitment to working with all clients who present, regardless of background Individual counseling and support groups offered to Hispanic clients Much of the grief information mailed is written in Spanish Small groups in Spanish Provide literature on grief and grieving to the families in Spanish We now have forms written in the Spanish language Spanish speaking personnel Translators available Timely follow-up Spanish speaking field visits offered in north and east metro Orlando All staff interested in providing good care to all cultures	More empathy and validation of spiritual and cultural background In home services available Culturally competent Offering of Bilingual groups Staff collaborate with one another to provide services to Hispanic families Knowledge of additional community resources & referrals N/A Children's play and Sand Tray Therapy program in Spanish We are now able to write programs for the Latino Community and begin the education process Spanish lit. on bereavement Bilingual written resources A full range of support services/programs Spanish speaking Osceola County ongoing support group (1x/month) Culturally competent staff Providing community outreach through our marketing department Satellite office in the Hispanic community Crafts Group Knowledge of Hispanic culture

Open-Ended Responses for Survey Question 3, Section 5, Continued: <i>In your opinion, what are the top 3 strengths of your Bereavement department when offering services to Hispanics. Please list them in order of importance with #1=Extremely Important Strength, #2=Important Strength, #3=Less Important</i>	
Extremely Important Strength	Important Strength
Bilingual social worker, bereavement counselor Knowledge of community resources Children's Grief Program Desire to serve Having Hispanic speaking staff to work with that population	Good relationship with the staff members in other departments who speak Spanish Having Hispanic literature available Support groups available in the Hispanic community