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End of Life Issues Among Hispanics/Latinos: Studying the Utilization of Hospice
Services by the Hispanic/Latino Community

by

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A dissertation submitted in partial fulfillment
of the requirements for the degree of
Doctor of Philosophy

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Dedication

I dedicate this dissertation to my parents, Ramiro Ayala Vazquez and Ana Generosa LaSalle Vazquez, for their legacy of determination, compassion and commitment to improving the quality of life of everyone in my community and beyond.

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End of life issues among Hispanics/Latinos: Studying the utilization of hospice services by the Hispanic/Latino community

Iraida V. Carrión

ABSTRACT

This study focuses on how terminal diagnoses impact individuals and families within the Hispanic/Latino community. Hispanic/Latino hospice caregivers, Hispanic/Latino non-hospice caregivers and physicians participated in the study, which explores the utilization of hospice by Hispanic/Latino terminally ill individuals. The data collected from 30 semi-structured interviews, ethnographic participant observations, and archival data were analyzed using structured and statistical analysis. Verbatim transcripts were examined through a combination of ethnographic and content analysis. Barriers related to language and culture, as well as immigration, are critical themes that impact access to healthcare. The physicians' discourses relate patients' responses to terminal diagnoses, including the Hispanic/Latino patients' perceptions of hospice services.

My research also ascertains how caregivers of Hispanic/Latino hospice patients cope with their loved ones' terminal diagnoses, structural organizational barriers to hospice utilization as well as cultural factors that contribute to the under-utilization of hospice services by this population. The findings indicate that higher incomes, higher education, and fewer years in the United States mainland directly affect healthcare decisions and treatment choices at end of life. Female gender and identity also directly impact access to health care, especially hospice services, at the end of life.

Chapter 1

Introduction

Statement of the Problem

As applied anthropologists, it is important to understand how migration, immigration, and documentation impact the Hispanic/Latino community's coping abilities and access to health care when confronted with a terminal illness diagnosis. The Hispanic/Latino community is a diverse population with an array of health care needs. For some families, their immigration status, length of time in the US and movement within the country (Kearney 1995) will influence their knowledge concerning services, and consequently, will affect access to these service and their utilization. For others, health care inequities and limited knowledge and cultural beliefs limit access to health care when coping with a terminal illness. Throughout this dissertation I will discuss the structural organizational barriers to hospice utilization by Hispanic families and individuals.

A person's immigration status and ethnicity directly impact access to health care, housing, employment, and overall health and mental health services. Byrd and Clayton (2002) have argued that access to healthcare, preventative medicine, and early intervention will decrease onset of chronic and terminal diagnoses, while Hayward and Heron (1999) note that health care inequities impact the number of years of an adult life. It is also crucial to differentiate political and economic factors that influence allocation of health care for immigrants (Leclere et al. 1994) and non-immigrants alike. Immigration and migration have played a long-term role in the structure of the American economy. However, in spite of the sizeable contributions made by immigrants, they have suffered

negative health consequences due to inadequate health care particularly at end of life. I will discuss the cultural factors that contribute to the known under-utilization of hospice services by this population.

Regardless of the terminology used, an individual who immigrates to the United States with the intention of becoming a permanent resident, but lacking the documentation deemed necessary by the INS, is in jeopardy of not being able to access health care. Education and literacy are directly related to knowledge and the use of available health care services. For example, “most refugees are not counted as immigrants when they arrive in the United States, but only after a lag of two years when they ‘adjust status’ from refugee to resident alien” (Massey and Schnabel 1983:213). Despite this inadequate process of attaining census of undocumented individuals, the INS often inflates the statistics, which leads to negative propaganda concerning this group.

The immigrant’s mode of entry contributes significantly to the differences in family structure, as well as their social cultural adaptation. The research of Glick et al., on the changing patterns of extended family household structure in the United States from 1970 to 1990, indicates, “immigrants who migrated earlier and who chose to remain in the U.S. are less likely than new arrivals to live in a horizontally extended household” (Glick et al. 1997:187). Resultantly, an immigrant’s financial stability in the labor market, socioeconomic status, and access to a supportive network will directly determine living arrangements.

Due to the broad scope of this issue, at this time, I will focus on the need to devise strategies that would enable members of the Hispanic/Latino community to access hospice services. Why is it that some Hispanic/Latino families utilize hospice services

while others do not? The health care issues of Hispanic/Latino individuals are not confined to end-of-life care. On the contrary, the disease process of the Hispanic/Latino person often has progressed due to healthcare inequities and lack of healthcare. I will explain the cultural differences between hospice caregivers and non-hospice caregivers.

This issue is broad and is imbedded in political, economic, and historical power relations. Therefore I will present the roles physicians play in the utilization of hospice services by Hispanics/Latinos.

The political economy of medicine impedes access to on-going preventative health care for the poor, the undocumented, and the uninsured throughout their life span. These are categories that immigrants disproportionately occupy; therefore, there is a high propensity of chronic, untreated health conditions that cause severe complications, and in many cases, hasten a terminal diagnosis. Ironically, although preventative services are not available, end of life services can be had. Fortunately, a condition of participation (Medicare) requirement mandates that non-profit hospices as well as for-profit hospices provide services to everyone regardless of their ability to pay, including the uninsured and undocumented individuals.

Rationale

Many emotional, psychological, financial, and cultural factors surface when persons are confronted with a terminal illness (Braun and Blanchette 2000). Applied anthropology can offer ways to explore how cultural, historical, political and economic factors contribute to end-of-life decisions in diverse ethnic groups (Wolf 1988). The proportion of Hispanic/Latino elderly is increasing in the United States, and many problems associated with aging in this population are related to caregiving issues (Talamantes et al. 1995). These issues raise questions such as: Do terminally ill

Hispanics/Latinos prefer to rely on family members? Do they expect family members to be the sole caregivers? How feasible is caregiving for family members, particularly if they are residing in another country? Factors such as caregiving, access to health care, and utilization of services need to be explored within the larger societal context (Cohen 1994). The utilization of hospice services among Hispanic/Latinos is significantly less than among non--Hispanic/Latinos, and "Nationally, only 4% of Hospice patients are Latino or Hispanic/Latino" (Gelfard et al. 2004).

I researched how terminal diagnoses impact individuals and families in the Latino community, the extent to which such persons are involved with institutionalized assistance from hospice, and the barriers that exist due to language and culture. Applied anthropology provided the vehicle by which I researched how factors such as values, family, gender, and identity impact the utilization of health care, especially hospice services, at the end of life.

Chapter 2

Literature review

The purpose of this chapter is to examine literature about health care of contemporary Hispanic/Latinos, including those with immigrant status, particularly when confronted with life-threatening illnesses. Factors related to language barriers and to the intimidating nature of the health care system for Hispanic/Latino immigrants, migrants and those born in the United States will be explored. The current politics of anti-Hispanic/Latino immigration will also be examined, especially relating to Hispanic/Latino health care access.

Barriers to health care, caregiving, end-of-life issues, and the social and cultural factors that impact the Hispanic/Latino population in the United States will be evaluated. I will review the politics of access to health care in the United States, particularly for poor and older Hispanic/Latino individuals and especially regarding use of hospice care. Political economy influences the utilization of hospice care by Hispanic/Latinos. The history of hospice will be reviewed as well as the nature of palliative care. I will discuss how the hospice referral process is intertwined with the medical system and how this process impacts the delivery of service.

The research illustrates how political economy directly influences the utilization of hospice care. Hospice services and the nature of palliative care are examined in relation to Hispanic/Latinos. A discussion of the hospice referral process and how it is intertwined with the medical system, as well as how this process impacts the delivery of service is also reviewed.

The Hispanic/Latino Population in the United States

“The label ‘Hispanic’ may be seen as a denationalized identity, one that bears no relationship to origin or cultural background, and which more accurately, summarizes one’s experience in America” (Phinney 2003:64).

The term “Hispanic” was defined and formally created by the U.S. Government Office of Management and Budget (OMB) in 1978 (US Census 2000). According to the OMB, their goal was to “enhance the accuracy of demographic information about the nation’s population” (Amaro & Zambrana 2000:1724). Unfortunately, this data-gathering system is flawed due to Hispanic/Latinos’ multiracial self-identification.

The term *Hispanic* evokes an erroneous collective consciousness in mainstream American minds concerning a wide variety of people, both migrant/Hispanic/Latino immigrants and US born. The term *Hispanic* “racializes national origin and triggers the perception of stereotyped *Hispanic*, thus subverting historical” (Giménez 1989:569) identity, as a result lumps everyone into one socially and politically constructed identity. Meanwhile, “Hispanic/Latinos” themselves tend not to self identify as “Hispanics.” Instead, they self-identify by their country of origin or often use hyphenation. For example, they self identify as Cubano/Cuban-American, Columbiano or Mexicano/Mexican-American, etc. I will use the term *Hispanic/Latino* in order to utilize existing research and literature titled in this manner. For purposes of this study, the category will include immigrants Hereafter, when Hispanic/Latinos are mentioned, this category will include immigrants, migrants and non-immigrants unless otherwise noted.

Hispanics/Latinos are the fastest growing segment of the population of the United States; therefore, accurate data are vital in order to address the array of needs of

individuals who comprise this diversified category. “Latinos accounted for 30.8 percent of the country’s growth in 2000” (Chavez 2004:178).

The largest group within the Hispanic/Latino category is of Mexican origin comprising a little more than 61 percent residing primarily in the Southwestern states. The second largest group are Puerto Ricans, which account for 12.1 percent of the Hispanic/Latino population, residing most likely in eastern seaboard cities, in the New York-New Jersey metropolitan area followed by Cuban consisting of more than 1 million. The population of Central and South Americans are rapidly growing. Central Americans currently comprise 6 percent of the Hispanic/Latino population with the leading country of origin being El Salvador followed by Nicaragua, Honduras, Panama and Costa Rica. (More than 1 million persons from the diverse countries of South America live in the United States.) The ‘largest groups come from Colombia, Ecuador and Peru. Other groups that indicate Hispanic origin include those from Spain and the Caribbean. [The] largest and numerically most important are 520,000 individuals from the Dominican Republic, largely concentrated in New York City and with smaller numbers in Florida.’ [Sullivan 2000:5-9]

The rapid growth among the Hispanic/Latino community highlights the urgency to address present healthcare policies and future planning. A Hispanic/Latino is "a person of Mexican, Puerto Rican, Cuban, Central or South American or other Spanish culture or origin, regardless of race" (Castex 1994:288). Individuals from Spanish-speaking countries were placed by the U.S. Government Office of Management and Budget (OMB) in 1978 (US Census 2000) into one categorical group despite the vast differences between them and for a compilation of political reasons. “Differences exist among Hispanic subgroups, and these are related to their country of origin and their histories or immigration/migration or experience with colonization” (Talamantes et al. 2000:84).

According to the literature on aging and health, “It is widely recognized that Mexican Americans, Cuban Americans, and Puerto Ricans differ greatly in levels of

cultural assimilation, socioeconomic status, and economic mobility as well as their migration experience” (Angel and Angel 1992:481). Mexicans, Puerto Ricans, Cubans, and Central and South Americans all migrate or immigrate to the United States due to an array of political and/or economic factors in their country of origin. Interestingly “the proximity of Latinos’ homelands to the United States shapes their immigration patterns” (Alicia 1994:35). For example, “Mexico shares a 2,000 mile long border with the United States, which makes it a relatively easy entry point for Mexican and other Hispanic Hispanic/Latino immigrants” (Engstrom 2000:35). Likewise, 90 miles of ocean separate Cuba from the United States, which provides Cubans relatively easy access to southern Florida.

Although groups within the Hispanic/Latino population also have some similarities due to colonialism, economic, and political oppression, the United States government conveniently classifies them distinctly due to its own economic and political interests. Their experiences are related to issues of conquest and occupation, economic exploitation, and immigration. Lumping Latinos into one broad category disregards the “particular historical and economic conjuncture during which each group entered the United States-whether conquest, colonization, or immigration” (Oboler 1995:7).

Contemporary socioeconomic conditions for Hispanic/Latino subgroups can be traced back to their different histories. Many Hispanic/Latinos have fled dictatorships in Central America and the “United States’ involvement in suppressing insurgency movements played a central role in creating large-scale exodus” (Engstrom 2004:42). These emigrants were also escaping military forms of government and extreme poverty as a result of repressive national and international policies. Ironically, individuals who

have emigrated from countries that the United States opposed, such as Cuba and Nicaragua, have been given political asylum, while those who have fled nations whose governments were supported by the United States seldom have been granted favor. In “1987, 86 percent of asylum cases from Nicaragua were awarded asylum status while only 5 percent of cases from Salvador and 4 percent of cases from Guatemala were granted asylum status” (Zucker & Flink 1987:15) despite similar oppressive political and economic circumstances.

In contrast, Puerto Ricans possess citizenship status since Puerto Rico is a territory of the United States. Therefore “the colonial status of the island and the political history of Puerto Rican community in the United States differentiated” (Oboler 1995:47) Puerto Ricans as it relates to mandated military drafts. As a result of this *costly privilege* Puerto Ricans in Puerto Rico have been drafted into the U.S. military during WWI, WWII, the Korean War, and the Viet Nam conflict while residing in their own country. As United States citizens, Puerto Ricans “see no contradiction between asserting their Puerto Rican nationality at the same time that they defend their U.S. citizenship” (Duany 2000:6). In addition, the Puerto Ricans’ “bilateral flow between the island and the US also creates a new construction of cultural identities” (Duany 2000:5).

Although closer geographically, and despite the fact that Mexicans comprise the largest Hispanic/Latino group in the U.S., they have historically experienced continuous exploitation and have been disadvantaged as a result of contradictory immigration laws, which change depending on fluctuating labor needs. United States policies have encouraged “Hispanic immigration, in order to meet labor shortages and serve foreign policy objectives” (Engstrom 2004:33. For example, migrant laborers (men) from

Mexico were contracted to work in the U.S. Bracero program from 1942 until 1964. This began during World War II when America was in need of migrant laborers and negotiated a labor agreement with the neighbor country. This institutionalized program provided highly skilled workers but impoverished Mexican peasant men. The Mexican laborers endured financial inequities and unfair treatment in the United States. Their wages shifted haphazardly to benefit the growers. They were also forced to pay despicable portions of their income for housing and food even though they purchased their own food and housing consisted of sleeping in tents. The jobs available in the agricultural field were emotionally and physically demanding and involved invasive “medical examinations, processing centers, consistent short-changing of workers’ wages, deplorable housing conditions, inedible food and poor treatment ” (Mize 2004:143). The Mexican laborer was rendered powerless because the individuals who were designated to represent them were the growers’ association who were responsible to select the laborers and who also had the power to determine the type of work they would perform. Due to economic factors the Braceros continued to participate in this type of employment despite the humiliation and shame they endured. Along with the harsh working conditions and inequitable treatment they did not have any legal recourse because they signed contracts in English without understanding their full rights and the conditions of employment. When the contracts expired, the Braceros were required to turn in their work permits and return to México. The United States government disregarded the Mexicans’ ability to “establish the social networks that served as the basis for undocumented migration when the program ended in 1964” [nor] “did the government plan for migrants who arrived

with valid visas, but then decided to stay in the United States past their legal deadlines” (Rumbaut et al. 1988:146).

Historical factors directly impact the current political status of the various Hispanic/Latino communities and highlight the heterogeneous nature of this population. When persons are unable to read and understand the laws of a new country, they become victims of abuse and fraud. Mexicans, Puerto Ricans and Central Americans are currently the most educationally disadvantaged group in America” (Roderick 2000:123). Much data has been produced to indicate that this population is marginalized economically and socially, and this low socioeconomic status would be expected to produce poor health outcomes. The Hispanic population in the U.S. has higher rates of poverty and lower educational status than the dominant culture. Mexicans are the least educated; “less than half are high school graduates, between 60 to 65 percent of Puerto Ricans, Cuban-American and South and Central Americans are high school graduates” (<http://www/censusgov/pop/www/cen2000/phc-tl.html>).

Diversity among Hispanic/Latinos

Although Hispanic/Latino are often viewed as comprising a single group, Hispanic/Latino individuals actually “view multicultural identification and ethnic identification as a dynamic process that reflects societal trends and political identification as well as stigmatization” (Amaro and Zambrana 2000:1725). As noted above, the “Hispanic community” is a problematic construction and the notion of “Hispanic” is even more so. The term, *Hispanic/Latino*, is rooted in the use of a language rather than in racial/ethnic origin; thus, while Hispanics share a common language (Spanish), they do not share a common skin color. This diversity is particularly apparent when “some

Hispanics consider themselves White, and they have blue eyes and blonde or red hair while other Hispanics are descended from ancestors who were brought from Africa as slaves; they are dark skinned and may identify their race as Black” (Sullivan 2000:2).

In Greenbaum’s book *More Than Black*, the struggle of Afro-Cubans in Tampa is thoroughly analyzed. Greenbaum argues that the “Cuban racial nomenclature elaborates rather than diminishes the phenotypic traits of African ancestry, is intricately pejorative rather than generously inclusive” (Greenbaum 2002:38). Afro-Cubans “entered disadvantageous labor market carrying added burdens of little education and limited English” (Greenbaum 2002:222) due to their phenotype. The variability in self-identification is indicative of the various groups’ unique history of colonization, oppression, and distinct political and economic struggles.

The fact that many Hispanic/Latinos choose to maintain and celebrate their cultural heritage has raised concern as it relates to their ability to develop and maintain loyalty and allegiance to the United States. In the “2000 General Social Survey, 73% of the respondents felt that more Hispanic/Latinos coming to this country would make it ‘harder to keep the country united’” (Monsivais 2004:14). This may also be due to the claim by some researchers that “US Latino populations challenge the Hispanic/Latino immigrants’ language loss paradigm and exhibit the greatest language loyalty among ‘new Hispanic/Latino immigrants groups’” (Mendoza-Denton 1999:381). These sentiments compounded by the 1996 Immigration Act, the current immigration policies, and English-only legislation create a tenuous environment for Hispanic/Latino individuals regardless of whether they were born in the United States or immigrated.

Mason's (2004), research compared annual income, hourly wages, and identity among Mexican-Americans and other Latinos and concluded: "Neither the abandonment of Spanish nor the abandonment of a specifically Hispanic racial self-identity is sufficient to overcome the penalties associated with having a dark complexion and non-European phenotype" (Mason 2004:817). In essence, an individual's phenotype has a direct impact upon his/her income. The data used by Mason consisted of a merger of the 1998-1990 Latino National Political Survey and the 1990 Latino Political Survey/Panel Study on Income. The findings indicated that persons of "Mexican descent with dark complexions and Indian features earn \$921 less annual income than those with light and medium complexions with European features" (Mason 2004:824). Similarly, "dark-skinned Cuban-Americans receive lower earnings and hourly wages than their medium-color counterparts, especially among Hispanic/Latino" (Mason 2004:830).

Espino and Franz (2002) had conclusions similar to Mason's. Their findings indicated, "darker skinned Latinos face the burden of labor market discrimination, especially Hispanics with distinct accents" (Espino and Franz 2002:621). Likewise, "Afro-Puerto Ricans continue to be represented as marginal and subaltern, as somehow less Puerto Rican than white people" (Duany 2000:14). Factors of discrimination compounded with "the United States' position as a center of international capitalism, as well as its dominant relationship with less powerful or subordinate countries, has attracted labor migrants and displaced persons to its shores" (Chavez et al 1992:8) to earn meager wages in ethnic enclaves without healthcare benefits.

The common denominator among the diverse Hispanic/Latino communities is the Spanish language. It is known that "Hispanic/Latino immigrants vary on many

dimensions: in their origins (what regions they come from as well as what nation-states), their length of residence in the United States, the nature of the community in which they now live (for instance, one in which they have contact with other co-ethnics), the degree of contact they have with their home country, and their present and past social class position, among other factors” (Orellana 2003:28) along with their experience with colonization.

In spite of the differences, Hispanic/Latino groups do have common inequities and disenfranchisement when it comes to health care. According to the US Census, the rate of poverty for Hispanics in “2003 was 22.5 percent while the national rate of poverty for the overall population was 12.5 percent” (www.census.gov/hhes/www/income/html). In this same dataset, 33.7 percent of Hispanics did not have any health insurance versus 15.6 percent of uninsured nationally. Hispanic/Latinos’ economic station, educational status, and level of English language proficiency dictate their employment opportunities. As a result, those who are poor, less educated, and non-English speakers have limited employment and housing options and do not assimilate as easily. Therefore, the issue of “class is important because it focuses our attention on economic, political and social resources available to specific groups” (Chavez et al 1992:7).

Education Issues

The lack of educational achievement is indeed a crisis in the Hispanic/Latino community. This is due to the fact that in “1993, approximately half (47 percent) of Mexican-origin young adults aged 25 to 34 had not graduated from high school or obtained a high school equivalency degree, compared to 26 percent of Puerto Ricans

residing on the U.S. mainland, 16 percent of young adults of Cuban descent, and 32 percent of young adults of Central and South American origin” (U.S. Census). The United States Department of Education reported that for individuals 25-29 years of age, there was an increase in high school graduates (or the equivalent) and a rise in those receiving four years or more of college education for the time period of 1971 to 1996. However, for Hispanics, the increase of high school graduation was 48 percent to 61 percent, while for White non-Hispanics, the graduation rate increased from 81 percent to 92 percent. Additionally, although high school rates for Hispanic/Latinos increased by 12 percent, the rate of Hispanic/Latinos attaining four years of college improved only by 5.9 percent. The data are important particularly because the Hispanic/Latino population “tends to be younger with a median age of 25 compared to 35 for non-Hispanic Whites” (Suarez 2000:1996).

Economic Factors

Due to their educational lag, Hispanic/Latinos tend to be employed in lower skilled and semi-skilled jobs as maids, janitors, gardeners and factory workers, often referred to as the “cornerstone of our nation’s low-wage workforce” (<http://www.nclr.org/content/policy/detail/1785/>). Thus, regrettably, Hispanic/Latinos are not represented in the fast growing, information-sector occupations due to limited education. As a result of this unfortunate phenomenon, Hispanic/Latinos are “becoming concentrated in low-wage, low benefit work that often leaves them without health insurance and without money to buy it independently” (Suarez 2000:197), and “among low-wage workers 63.2% are non-citizens of Hispanic origin and 36.3% of citizens of Hispanic descent are uninsured” (<http://www.nclr.org/content/policy/detail/17/1785/>).

According to the Kaiser Family Foundation's most recent analysis of the 2000 Census, "34% of Hispanics are uninsured, compared with 22% of African Americans, 20% of Asian/Pacific Islanders, and 12% of whites (<http://www.nclr.org/content/policy/detail/17/>). In fact, "foreign-born Hispanics (49%) are nearly twice as likely as their U.S-born (24%) counterparts to be uninsured and are more likely to be uninsured for longer periods of time when compared to U.S-born Hispanics" (U.S. Census Bureau). According to a study by the National Council of La Raza (NCLR), 63 percent (208,153) of the 328,064 families sampled were uninsured even though they had at least one full-time, full-year worker (<http://www.nclr.org/content/policy/detail/17/>).

The impact of low economic mobility on health among the Hispanic/Latinos is a serious concern (O'Connor 1998). Unfortunately for Hispanic/Latino, the 1990 Welfare Reform Act has created many barriers blocking their receipt of health care through various public aid programs. Even Hispanic/Latino immigrants who meet the requirements for such public aid programs are afraid to apply because they fear such actions might jeopardize their naturalization and citizenship status. This policy encourages individuals to delay in seeking care and treatment. Once again, the "historical and economic conjuncture during which each group entered the United States-whether by conquest, colonization, or immigration" (Oboler 1995:7) impacts the various Hispanic/Latino groups and the heterogeneity is magnified, particularly as it pertains to access to services and health care.

Social and Political Considerations

The bio-psychosocial theory and viewpoint suggests that there may be social, emotional, psychological, spiritual, or cultural factors that relate to the under-utilization (or reluctance in utilization) of this health care service. George Engel's most important contribution was the recognition that perturbations occurring at any level in the hierarchical biopsychosocial system exert effects on other levels (Yamada 2001:703). According to Engel's systems, "the upper reaches of the hierarchy consist of culture, the nation state, and the biosphere which in turn are part of the of an [individuals] environment" (Engel 1980:537). The "biopsychosocial approach is ideally suited to cope with the increasing complexities of the clinical sciences, because its focus is on interactions in various domains" (<http://www.critpsynet.freeuk.com/Gilbert.htm>). Interestingly, Yamada states that, the biopsychosocial schema can thus account for the social production of disease, particularly as it relates to social and cultural factors related to access to health and utilization of services at end of life.

It is apparent that "structural violence is visible in the steep gradients of social inequality that, by producing indecent poverty in an era of increasing wealth, expose the poor to fatal diseases. The health impacts of structural violence are compounded by lack of access to effective care for the powerless" (Nguyen and Peschard 2003:457).

A political anthropology of health offers a compelling theoretical framework for addressing the relationship between inequality and disease because it fulfils the requirement that social change and the forces that drive it be taken into account in consideration of how social inequalities are embodied. This theoretically driven approach has the additional merit of allowing a broad range of ethnographic evidence to be used to shed light on this important question and to trace the contours of social, cultural, and political

formations that are too large to be captured within individual ethnographic studies. [Nguyen and Peschard 2003:462]

According to Farmer, the “health impacts of structural violence are compounded by lack of access to effective care for the powerless” (Farmer 1999:457). He also argues that “health care is a human right [and that we need to] erase the double standard for rich and poor” (Farmer 2003b:201). He advocates that health care inequalities should be the agenda of us all. “Without a social justice component, medical ethics risks becoming yet another strategy for managing inequality” (Farmer 2003b:201). The “wealthier are able to maintain access to health capital—clean water, good food, medical care, and salubrious living conditions—while the vulnerability of the poor increases” [therefore] “as the poorer get sicker and poorer, the cost of mitigating the social consequences rises, triggering a defensive reaction on the part of the rich, who do not want to shoulder the medical cost of inequality” (Nguyen and Peschard 2003:464). Despite evidence of the growing impact of “violent conflict on world health, the effect of politics on population health has been most widely understood in terms of how particular policies, such as taxation, health insurance, and access to schooling, inflect disease rates” (Nguyen and Peschard 2003:459). According to Farmer, when “structural violence is structured and structuring, it constricts the agency of its victims” (Farmer 2004:374). Similarly to Singer, Farmer advocates that we cannot study structural violence without understanding history.

If an individual does not have the “social capital ‘connections’ or cultural capital” (Bourdieu 1990:243) to aid them in accessing and in negotiating the complicated medical systems, they will be deprived of services that could improve their quality of life.

According to Bourdieu's concept of *habitus*, "socialized subjectivity" is critical in how one views society as healthy and trustworthy. The plea for local context "questions the idea of social capital as a historical and cultural essence, arguing instead for understanding how social ties are produced in historically and culturally conditioned networks of reciprocity and exchange, result from asymmetrical relations of power that are highly hierarchized" (Nguyen and Peschard 2003:453). The authors mentioned above reference Farmer, who states that a need for "an engaged anthropological critique of social suffering has joined forces with critics of medicalization to denounce the depoliticization of health and to mount a powerful critique of the social forces that shorten the lives of the poor" (Nguyen and Peschard 2003:454).

According to Eric Wolf's theory of power, happenings on local levels should be understood in terms of reactions of the local people and the economic and political forces from the larger societies. He has been against functionalism, viewing society as a bounded system of ordered relations and structured entities. Wolf views society as "heterogeneous, interacting across boundaries, more interpenetrating, more interdigitating, and more complex and interconnecting" (Wolf 1988:753.). To explain a society, Wolf argues, "it is important to see it in a historical context as well as within a larger community and the history itself is like organized flow-processes of fusion and fission" (Wolf 1988:757).

Wolf shows the relationship between society, culture, ideology, and modes of production by stating: "Cultures are not integral wholes carried by social isolates. We must distinguish between reality culture and ideology making, and recognize that the creation or dismantling of cultures always goes on within extensive social fields,

structured by the dominant modes of production. It is suggested that ideology-making derives from the prevalent mode of production and is entailed in its operations” (Wolf 1984:393).

Wolf brought up "structural power," which structures the political economy. It is related to the notion of "the social relations of production" and it emphasizes power to deploy and allocate social labor. These concepts of " structural power" and "organizational power," Wolf argues, help explain the world, since they are related to the mode of production. Donahue and McGuire discuss Wolf’s theory of “structural power” and how it varies according to political economy of health. They state, “The differences in structural power profoundly influence each society’s allocation of responsibility for health and illness” (Donahue and McGuire 1995:47). They address how health care policies are formulated by the following “three broad strategies, linking their larger political economy and modes of exercising power” (Donahue and McGuire 1995:48). Responding to anthropology's long reliance on a concept of culture that takes little account of power, Wolf argues that power is crucial in shaping the circumstances of cultural production. He demonstrates how power and ideas connect through the medium of culture. In this way, I am compelled to emphasize the connections between social justice, racism, poverty, and healthcare particularly as related to end of life issues for Hispanic/Latinos. As social scientists, we are obligated to conceptualize the parallel relationships between class/healthcare and power/policy. And as applied anthropologists, it is essential to include not only historical perspectives on social justice research, but also a focus on current critical issues facing the U.S. health care system. To this end, tools from a variety of disciplines provide greater flexibility and data.

Thus, issues related to the aging Hispanic/Latino population are relevant and applicable to the research. Particularly, “given a high degree of individuality and physiological diversity, it is not surprising that parameters used to describe normal aging and to predict longevity vary across most classifications of humanity: ethnicity, nationality, race, population, socioeconomic status, sex, and culture; or that definitions of normal aging are sample- or population-specific, rather than being universal” (Crews 1993:399). This tells us that the biological anthropologists’ definitions of aging are congruent with the political economy theoretical perspective. This is particularly applicable when addressing factors of health care inequities, as they pertain to factors of ethnicity and socioeconomic status.

When taking these theoretical ideas into consideration, we begin to change the way that we think about designing “effective services.” Each presumed, assumed or named barrier comes with a range of experiences attached to it. Therefore, “culturally appropriate services... must reflect the relevant significance of a cultural value in the target population” (Marin and Gamba 2003:91).

End of Life Beliefs and Religion

Coping with end of life issues is challenging for most individuals. These issues are compounded for Hispanic/Latino individuals who have immigrated to the United States, fleeing countries experiencing war. Immigrants escaping war may cope differently with issues of dying than those who are emigrating due to political, economic or religious oppression. Immigrants who have been exposed to multiple traumatic, violent and sudden deaths as a result of wars in their home countries may have additional

complications when coping with end of life issues in the United States, particularly if their immigration status does not allow them to return to their country of origin.

The religious and spiritual beliefs of the Hispanic/Latino community vary and are diverse yet assist individuals to cope with end of life issues. The view of death may be totally different for a Mexican who is Jehovah's Witness, a Peruvian who is Catholic, and a Dominican who is a Seventh Day Adventist. Each distinct religion and affiliation may have unique end-of-life beliefs. These beliefs may also have direct implications on how health care services should be offered and provided to terminally ill individuals.

Historically, due to Spain's colonizing enterprises and the Catholic Church's close ties to Spanish colonialism, Hispanic/Latinos became largely Catholic. Therefore, "among the people who were to become Latinos, the roots of religion were often deeper than their loyalty to Spain" (Stevens-Arroyo and Diaz-Stevens 1994:259). Researchers report, "among Latinos today, particularly those of rural background, the Catholic religion and the Spanish language are so intertwined in a cultural complex that preserving the one is equivalent to preserving the other" (Stevens-Arroyo and Diaz-Stevens 1994:259). Similar to other religions, "traditions are so rooted in a communal identity and ethnic origins that at times they operate more as culture than as faith commitment (Stevens-Arroyo and Diaz-Stevens 1994:265). This often includes godparents (*compadres*) for baptism, sacraments such as the First Holy Communion, processions, altars, annual feasts tied to agricultural and pastoral cycles, Easter/springtime feasts, summertime feasts of relevance to maritime settlements, the harvest season matched with particular harvest or agricultural practices, the feast of All Saints, which included rites of communicating with the dead (particularly in Mexican-influenced areas), and Christmas,

beginning with the Feast of the Guadalupe in the Mexican culture and “*aguinaldo*” (nine days before Christmas with masses celebrated using native musical instruments) and the Feast of the Epiphany (“Three Kings Day”).

Along with celebratory traditions, there are traditions related to death. One such tradition is “*velorio*” (to “watch” or to view the deceased in his or her own home), which customarily occurred overnight, on the night immediately following a person’s death. At this time, people came to pay their respects, say prayers, eat, and drink. After the burial, the “*dolientes*” (bereaved) would return home to provide comfort to one another, share a meal, and come together for eight additional days to pray for the repose of the departed soul. Traditions also dictated “every year this day would be commemorated by an anniversary *velorio*, where a *rezador* [person who says prayers] and the friends and family would be invited back” (Stevens-Arroyo and Diaz-Stevens 1994:269).

Despite these religious/cultural factors, which have been embedded in the lives of many Hispanic/Latino Roman Catholics, many are converting to Protestantism. Some scholars attribute this phenomenon to Americanization. Stevens-Arroyo and Diaz-Stevens note that Americanization and Protestantization

“describe a process of change in values and in patterns of social behavior. The shift from dependency upon tradition for discernment of the divine, exclusion from worship of devotions to Mary and the saints as well as a paucity of religious symbols, candles and medals are exchanged for an egalitarian/democratic choice of leader. As a result of Protestant missionary work, many Catholics have converted to Protestantism and among Latinos in the United States and in several Latin American countries “Pentecostalism and evangelical denominations are the fastest growing religious groups” (Maldonado 2000:102).

According to a Newsweek article on September 5, 2005, entitled “Spirituality in America” in 2002, “experts at the City University of New York asked 50,000 U.S. adults

about religion” (Newsweek, September 2005: 54). The findings indicated that among the Hispanics interviewed 19 percent identified as Catholic, 3 percent as Baptist, 11 percent no religion, 5 percent Jewish, 10 percent Muslim, and 2 percent Buddhist. While these findings may be unique to New York City, they are, however, indicative of the religious changes among the Hispanic/Latino population at large.

The shift among Hispanics/Latinos from Catholicism to Protestantism may cause them to be less dependent on traditional beliefs such as religious symbols, rites and sacraments for hope and healing when coping with end of life issues. There are various set traditions performed before and after a death in Catholicism by Hispanics/Latinos that are absent in Protestantism. Protestantism beliefs tend to be more individualistic and less dependent on group rituals. In Protestantism there is a belief that immediate transformation occurs for believers after death. For non-believers of the Protestant orthodoxy, there can be an underlying hopelessness concerning the final destination of the soul after death. The ultimate hope for Protestants is based on the immediate arrival to a “paradise state” as opposed to the Catholicism’s purgatory that enables families to participate in facilitating the “final resting place of a soul” through prayer and traditional rites. The involvement by Catholics in the destiny of the deceased assists the process of coping with end of life issues and the death of a loved one more easily. These minor differences however, have implications for the way in which Hispanics/Latinos contend with end-of-life and issues related to death.

Healthcare, Immigration and Hispanic/Latinos

It can be argued that the philosophical, historical, and cultural belief systems of the Hispanic/Latino towards health and disease are different from those of the dominant

culture. Among health care providers these differences are often ignored or are viewed as hindrances to the provision of services. An individual's place of birth and years of residence in the U.S. are significant factors in determining cultural behaviors. Some Hispanic/Latino groups rely solely on indigenous healers and homeopathic medicinal treatments for ailments, while others prefer to receive treatment by traditional licensed medical doctors and expect them to make medical decisions on their behalf. The Hispanic/Latinos' perception of illness is as important as their help-seeking behaviors. A Hispanic/Latino individual may view the etiology of illness as a result of evil spirits, spells, and culturally bound syndromes, which will cause them to be reluctant to seek formal traditional healing (Baer et al. 2003) such as hospice services. And although Cubans are traditionally Catholic, many younger recent refugees and Hispanic/Latinos have had little exposure to religion of any sort. Within the Cuban culture there is the belief that the mind, body and spirit are interrelated. Being healthy includes feeling and being well along with being full-bodied. Traditionally, many Cubans believe that moderate obesity indicates good health and thinness indicates poor health.

The degree of acculturation to mainstream U.S. culture and values determines the preferred method of communicating related to a serious or terminal illness to patients and families. Highly acculturated individuals may prefer to be informed of their terminal illness while less acculturated ones might not. Often Cuban cultural norms indicate that the spouse, eldest child or person directing care will be informed first of a serious or terminal illness, followed then by other immediate family members when appropriate. Physicians who are culturally competent follow these cultural norms and allow family members to inform the patient of their diagnosis and prognosis. Family members may

often choose not to disclose this information, believing that this knowledge would affect the patient's will to live and thus minimize fight for life.

Latin American Folk Belief about Sickness and Death

Santería is a combination of Roman Catholicism and indigenous African religions. In this form of syncretic religiosity, the supernatural is responsible for both illness and its cures. Therefore, diagnoses and treatments by a physician, therapist or other health care professionals are seen as supplementary rather than complementary.

Janice M. Heller (2001) interviewed two Cuban women in an article entitled “Death and Grief Cuban Style-Or is that American Style? A Mother and Daughter’s Perspective” written for *Grief in a Family Context*. They discussed issues of death, grief, and loss. Several factors about Cuban traditions at the time of death emerged; for example, the viewing of the deceased took place in their living room, unlike most American funerals. The viewing was set up to last for several days due to the volume of visitors coming from different places; the body was not to be left alone; and prayer rituals as well as loud conversations occurred during the viewing. Heller’s interview illustrates that culture is a fluid process and many variations of tradition exist including disparate beliefs regarding life after death, belief in spirits, and prayer rituals after the burial.

In working with the diverse Hispanic/Latino community, it is necessary to be mindful of distinctions between the subgroups. We must not assume that there is one set of predictable behaviors associated with sickness, death, and bereavement that are common to all those who fall under the category of Hispanic/Latino. Some of the variations are due to income, country of origin, acculturation, and age. For example, “susto,” “mal de ojo,” “nervios” and many other culturally bound syndromes are

manifested differently among the so-called “Hispanic/Latino” community. “Susto is thought to be caused by a frightening event involving another person, an animal, or a situation” (Weller et al. 2002:449). In addition, “susto” has been researched among the Mexican, Guatemalan, and Latino population in south Texas. “Susto” and “mal de ojo” was researched among south Florida farmworkers (Baer and Bustillo 1993:90) and “nervios [is] associated with anxiety and anger in Northeast Brazil” (Rumbaut 1993:131) and is a term commonly used by Puerto Ricans to refer to emotional stress.

It is generally believed that “Mal de ojo” is caused by glances of power by a stranger acting on a weaker person. In the southern Peruvian Andes “manchariske is associated with fright or lost soul, machu wayra is associated with old wind and machu hapiska is associated with being seized by the earth” (Carey 1993:281). Similar to other Hispanic/Latino subgroups, the Puerto Rican community also varies in their use of folk healing support systems and natural support systems. Among the Puerto Ricans “one can find up to four major healers: medium, santero, herbalist and curandero” (Delgado 1982:242) along with the influence of Catholicism and other religious groups. Each cultural group has specific symptoms to describe the manifestation and cure for the culture-bound illness that ails them. Each condition is known to affect one’s gender and age differently.

Chavez notes “A belief in folk illness and folk practitioners did not significantly deter Mexican Hispanic/Latino immigrants in San Diego from seeking conventional medical care” (Chavez 1984:36). The largest barriers were “economic and fear of deportation” (Chavez 1984:36). “A study in Los Angeles by Blackwell et. al in 1995... found that Mexican Americans...were less likely to believe that patients should be told

about a metastasis cancer diagnosis, a terminal diagnosis or make decisions about using life support” (Talamantes 2000:88). However, in 1996, Talamantes and Gomez conducted a random convenience sample of 50 Mexican elders in the San Antonio area of Texas and “84% stated that it did not bother them to talk to their children about their illness” (Talamantes 2000:88).

Health Status and Problems

As a whole, the Hispanic/Latino community under utilizes medical services due to the high cost of health care, lack of health insurance, and limited access to transportation. The late diagnosis of illness and disease cause them to have a higher rate of chronic conditions. “Hispanic ethnicity reduces the average length of adult life at age 20 by almost 5.5 years” (Hayward and Heron 1999:85). Rates of “diabetes, respiratory disease and infectious diseases” (Hayward and Heron 1999:79) are higher within the Hispanic/Latino community.

There is also an increase of occupational hazards due to the high-risk job positions that Hispanic/Latinos occupy. For example, the use of pesticides in agricultural settings induces lung cancer and chemically induced schizophrenia. The overall health of the American population has improved over the past few decades, but all Americans have not shared equally in these improvements. “Among non-elderly adults, for example, 17% of Hispanic, and 16% of black Americans report that they are in only fair or poor health, compared to 10% of white Americans” (<http://www.ahrq.gov/research/disparit.htm>).

Diabetes is one of the leading underlying causes of death among women aged 65 years and older. The death rate for diabetes increases with age. “Diabetes is a leading cause of death among middle-aged American women; rates in 1996 follow: fifth among

White women, fourth among Black and American Indian women, and third among Hispanic women aged 45-64 years. Elderly Black women have twice the rate of death from diabetes as elderly White women, and elderly Mexican American women have almost four times the rate among women aged 60-74 years, 33 percent of Black or Mexican American women have type 2 diabetes compared with 16 percent of White women” (<http://www.cdc.gov/diabetes/pubs/women/index.htm>).

HIV/AIDS is disproportionately spread within the Hispanic/Latino community. Hispanics accounted for more than 8,000, or 20%, of the more than 42,000 new AIDS diagnoses in the United States. In 2001 the reported AIDS cases indicated that Hispanic/Latino women accounted for 20% of all women with AIDS and Hispanic/Latino children accounted for 23% of all children. In 2002 it was estimated that there were 59,343 Hispanic men or adolescents living with AIDS and 15,867 Hispanic female adults or adolescents living with AIDS. (CDC HIV Surveillance Report 2002). These statistics are disconcerting particularly since the Hispanics/Latino population is 10 years younger than non-Hispanic whites.

Many factors contribute to the devastating statistics of HIV/AIDS among the Hispanic/Latino community. The philosophical, historical, and cultural belief systems of Hispanic/Latinos towards health and disease are distinct from those of the dominant culture. Many Hispanic/Latinos are disadvantaged prior to HIV due to economic disparities. Lack of proficiency of the English language, undocumented immigration status, and poverty are factors that contribute significantly to the spread of the AIDS epidemic in the Hispanic/Latino communities. The HIV/AIDS epidemic needs to be analyzed within the context of “health and social issues facing the urban poor [as well as]

in terms of class, ethnic and gender relations that define American society” (Singer 1994). The inner cities’ devastating housing crisis and shrinking education budgets for the poor directly impact the increase of HIV/AIDS within the Hispanic/Latino community. These individuals are abandoned by our society, stripped of resources and opportunities due to inadequate health care policies, racism, and classism.

The Hispanic/Latino elderly population is projected to increase in the United States; currently the “median age for the whole population is 34.3 years” (Sullivan 2004:12). The life expectancy of Cubans was the highest for the period of 1990-1995, and was estimated at 76.1 years, compared with 75.4 years for the overall U.S. population (<http://www.geocities.com/cubawebsite/HealthCare.html>). Along with this increase exists “the problems associated with aging in the Hispanic elderly including their experience of caregiving” (Rivera and Marlo 1999:63).

It is critical to acknowledge that most individuals who immigrate to the United States tend to be employed even if they are older adults, and the available employment opportunity often require arduous hours and long commutes from their residence. In numerous “coastal and metropolitan areas of the United States Hispanic/Latino immigrants women have become ubiquitous as nannies and housekeepers, and not only among the rich” (Maher 2001: 173). These women are often responsible for sending financial resources to their country of origin to support children and family members who have remained. Therefore, when issues pertaining to caregiving arise there is an enormous amount of strain and pressure for them. The issue of who assumes caregiving responsibilities for family members living nearby as well as that of those afar are rather complex, especially if women are expected or perceive their role to be that of a caregiver.

Caring for an elder or ill family member is multifaceted. Caregiving often involves financial and emotional stressors for all families as it does for Hispanic/Latino families. It can be financially and emotionally overwhelming for the Hispanic/Latino community as well.

Immigrant Health Risk Factors

When examining various barriers experienced by Hispanic/Latinos, it is important to consider the multiple determinants of risk and the ways in which cultural identity shapes these risk factors. This involves an understanding and recognition that acculturation does not proceed in a straight line, nor does it follow a timeline, even a generational one. Most of the acculturation research “ignores macrolevel influences and that transnational identities are overlooked” (Chun and Akutsu 2003:90). When public health officials speak of ‘social and cultural factors’ related to health, they conceive of cultural identities and cultural barriers as insular, population-wide, and static. There is little room for or understanding of “the dynamic processes that is the constant tension between the two dimensions of ethnic or cultural identity: the old and the new” (Phinney 2003:66). Interestingly, Meyers and Rodriguez argued for “a new perspective when looking at health outcomes—one which looks at the role of individual components of acculturation (changes in constructs of ethnic identity within the cognitive, affective, evaluative and behavioral components) mediating changes in relative risk factors rather than using place of birth or some proxy for acculturation like language use when accounting for differences in disease rates” (Meyers and Rodriguez 2003:170). When taking these theoretical ideas into consideration, we begin to change the way that we

think about designing effective services. Each presumed, assumed or named barrier comes with a range of experiences attached to it:

Understanding core values and how they change or remain stable as a result of the acculturation process has various implications in service delivery and in basic and applied research. Culturally appropriate services... must reflect the relevant significance of a cultural value in the target population....[Marin and Gamba 2003:91]

The face of immigration has changed significantly in the United States. Unlike the immigrants of the 1880s, contemporary immigrants are people of color whose reception has been even more tentative and suspicious than previous generations. Although many facilitate their travel by accessing airplanes and jetliners to arrive at their destination in a matter of hours, there continue to be many Hispanic/Latino immigrants (particularly individuals from Mexico and Central America) who suffer long, arduous journeys utilizing “coyotes” (transporters of Hispanic/Latino immigrants) who financially exploit them while navigating to the US/Mexico border. Interestingly, the “INS is engaged in probably the world’s largest effort to control human movement by arresting over 1 million persons a year, yet paradoxically it facilitates the entry of undocumented immigrants laborers in the U.S. economy” (Heyman 1995:261).

According to the U.S. Census Bureau Current Populations Survey, for the year 2000, the size of the foreign-born population was estimated to be 28.3 million. This was an increase from 9.6 million in 1970 (U.S. Census). Therefore, “approximately 1 in 10 people currently living in the United States was born abroad” (Goel et al. 2003:1028). In contrast to the European migration of the late 19th and early 20th centuries, the majority of the Hispanic/Latino foreign-born population in the United States in the 21st century came from “Mexico (28 percent), Central America El Salvador 3 percent, Nicaragua 1 percent,

Cuba 3 percent, and Dominican Republic 2 percent (U.S. Census Bureau). Hispanics are the fastest growing segment of the population of the United States; therefore, accurate data are vital in order to address the array of needs of individuals who comprise this diversified category. According to the 2000 Census, the Hispanic population totaled 35.3 million or about 13 percent of the population (U.S. Census Bureau 2000). The Hispanic population continues to increase rapidly, and grew by “53 percent during the 1980’s and then by another 27 percent between 1990 and 1996” (Sullivan 2000).

Undocumented Hispanic/Latino immigrants and those who overextend travel visas confront enormous financial, physical, and emotional adversities. Documentation and national origin determine the availability of federal, state, and local services, which includes healthcare. For example, “Cuban political refugee status and US sanctions against Cuba facilitate the numerous waves of Cubans seeking legal entry into the US” (Vega and Amaro 1993). Similarly, immigrants from the USSR, Poland, and Vietnam have also been granted political refugee status, which means that all those eligible would qualify for federal aid, “medical services, supplemental income and emergency assistance benefits” (Alicea 1994:54). In comparison, the US citizen-status of Puerto Ricans (Rodriguez-Morazzani 1998) permits them to access considerable resources, which undocumented individuals are unable to access.

Ironically, the fate of individuals seeking documented status is solely contingent on whether an individual is considered a political immigrant or an economic immigrant. This causes dissention and serious controversy among Hispanic/Latino immigrants. For example, “Mexicans are ‘economic’ immigrants, ‘pulled’ in, often able to return to a homeland just across the border; the Indochinese are ‘political’ emigrants, ‘pushed’ out,

unable to return to a homeland that is an ocean and a civilization away... Mexicans seek work; the Indochinese seek refuge” (Rumbaut et al. 1988:145). Portes and Rumbaut have developed a “typology of manual labor immigrants, professional immigrants, immigrants entrepreneurs and political refugees as a framework for the description of contemporary U.S. bound immigration” (Portes 1997:806).

The new Hispanic/Latino immigrants have arrived from Central America, South America and Mexico. Hispanic/Latino immigrants are a heterogeneous population with different levels of readiness to acculturate and assimilate. They have settled in urban areas throughout the country including the South. According to Greenbaum, “immigrant communities from Asia, Latin America, the Caribbean, eastern Europe and Africa have become increasingly prominent features of southern urban life” (Greenbaum 1998:144).

Just as their countries of origin vary, so do the educational level and economic status of Hispanic/Latino immigrants. “One striking contrast has to do with the sizable numbers of newcomers from the middle and upper-classes in their home countries” (Foner 2000:89). Unlike the immigrants of the late 1800s, current immigrants are considerably diverse although the ethnic niche remains rampant. “As before, distinct ethnic occupations specialization develops as the newest arrivals steer their kin and compatriots in berths in the economy and as employers rely on ethnic recruitment to fill job openings” (Foner 2000:91). Many immigrants speak English fluently as well as several native languages. However, “lack of English, U.S. job experience, and network ties that connect them to the mainstream economy often prevent immigrants who held professional or highly regarded jobs in their home countries from getting work of comparable status” (Foner 2000:93).

Hispanic/Latinos are directly impacted by the tenuous opportunities for health care and overall access to health care. Becker (2003) illustrated how Hispanic/Latinos' annual income, hourly wages, and housing opportunities are unpredictable. She noted "older adults who live in deteriorated neighborhoods report more physical health problems than elderly people who reside in better physical environments" (Becker 2003:132). Poor living conditions increase the risk of "inadequate sanitation, falls, accidents, and environmental toxins, overcrowding and heightened psychological distress" (Becker 2003:132).

Issues related to adequate housing are complicated and worsen when a Hispanic/Latino individual has an undocumented status, low income, and a limitation or an inability to communicate in English.

Utilization of Health Care by Hispanic/Latinos

The Hispanic/Latino community underutilizes medical services due to the high cost of health care, lack of health insurance, and limited access to transportation. "Nationally, 56% of Hispanic/Latinos today are native born" (U.S. Census Bureau 2000). Their "median income in 1997 was \$26,628 and more than 1/3 of Hispanic/Latino children live in a family making less than \$16,700 per year (below poverty level)" (Kirschten 1999:2353). Many undocumented Hispanic/Latino migrants "work in the informal sector and rarely receive medical insurance as a benefit of their employment" (Chavez 1992:8).

Recent Hispanic/Latino arrivals also confront barriers due to language, immigration status, and their limited knowledge of the medical system. If a person's preferred language is Spanish, that person could be said to be operating from a Latino

cultural influence. However, when a person's only language of proficiency is Spanish, their access to health care is compromised significantly. Although Hispanic/Latinos may unanimously acknowledge that it is essential to learn English in order to progress in the United States, they are confronted with the urgency to seek employment in order to meet basic needs such as food, shelter, and clothing. Meeting these immediate essential needs overrides their long-term goal to learn the English language. And although many Hispanic/Latino individuals may indeed speak English fluently and are bilingual, they often prefer to speak Spanish in times of stress or health crises.

An independent study commissioned by the National Council of La Raza (NCLR), the largest national Latino civil rights organization in the U.S., "found that language barriers and related discriminatory practices at the District of Columbia's Department of Human Services (DHS) have drastically limited access to medical services, such as Medicaid, for the District's large Spanish-speaking community." According to the report issued on January 31, 2005, "80% of Spanish-speaking Latinos who participated in on-site visits and telephone testing faced at least one serious hurdle in obtaining vital medical benefits at DHS" (<http://www.nclr.org/content/policy/detail/1771/>). Despite the fact that individuals are most vulnerable when seeking medical help for themselves and their families, they are additionally confronted with enormous disparity in the medical services and personal treatment by the very system that is established to assist them.

The lack of utilization of health care is particularly evident among recent Hispanic/Latino immigrants to the United States and there is a strong relationship between duration of residence and health care utilization. Factors related to adaptation,

economic and social network, directly impact utilization of health care. According to Leclere et al. “socioeconomic characteristics, access to health insurance, and differences in morbidity, [directly impact] recent immigrants [and therefore they] are much less likely than both the native-born and those immigrants of longer duration, to receive timely health care as well as fewer total contacts with physicians” (Leclere 1997:381).

Along a similar line, Byrd and Clayton (2002) have argued that access to healthcare, preventative medicine, and early intervention will decrease onset of chronic and terminal diagnoses, while Hayward and Heron (1999) note that health care inequities impact the number of years of an adult life. The Institute of Medicine’s (IOM) examination finds that disparities in health care are substantial, even after accounting for characteristics typically associated with disparities, such as health insurance coverage and income. Immigrant groups encounter obstacles related to health care primarily due to their “legal status, their economic resources, their degree of cultural understanding of United States medical care and the political climate in Washington” (Rumbaut et al. 1988:196).

Rather than solving problems, research indicates that health care providers’ biases, stereotypes, discrimination, and racism are major contributors to health care disparities among immigrants. Jones (2000), argues there are two types of racism, “institutional racism which would cause persons to have little exposure to health education materials, instruction, or preventive medical advice and access racism in which a person would have difficulty obtaining urgent medical assistance due to the overload of patients in low-socioeconomic status geographic areas with meager urgent care emergency care equipment” (Jones 2000:1212).

It is salient to note that “within the framework of race as a social-political construct, race is used to understand the health consequences of variations in factors such as health care quality and utilization, adequate housing, education and nutrition” (Ford and Kelly 2005:1659-60); and health “disparities in care are associated with higher mortality among minorities” (Bach et al. 2002:2113). A study conducted by Bach et al. revealed that within actual clinical settings, doctors are more likely to ascribe negative racial stereotypes to their minority patients. This was done even when differences in minority and non-minority patients’ education, income, and personality characteristics were considered. Similarly, Saha and others determined that “racial differences in patient–physician relationships contribute to disparities in the quality of health care and that both satisfaction with and use of health services were lower for Hispanics and Asians than for Blacks and Whites” (Saha et al.2006:1715). In Barr’s 2004 research study, he indicated that “physicians may treat non white patients differently than white patients in ways that adversely impact patient satisfaction and these differences may reflect the stereotypes and unconscious attitudes which physicians may bring to the racially discordant patient encounter” (Barr 2004:941). Thus, the various studies indicate that a barrier in the patient–physician relationship contributes to health disparities, and negative personal experiences with health care providers is likely to directly impact utilization of health services, especially for Hispanic/Latino immigrants. According to Siegel et al., 2004 the disparities in health manifested are cardiovascular disease, diabetes, and cancer.

According to the Department of Health, the “United States adopted a national priority of reducing or eliminating disparities in health and health care by 2010” (Shi et al. 2005:148). However, this lofty goal is not likely to be fulfilled in a timely manner,

especially for the most vulnerable populations. Throughout the literature, the term *health care disparities* is synonymous with vulnerable populations. Vulnerable populations “defined as those at greater risk for poor health status and health care access generally include racial and ethnic minorities, low SES populations and those without adequate potential access to care e.g., the uninsured or those without a regular source of care” (Shi et al. 2005:148). Typically, individuals who are uninsured are much more likely to delay medical care and treatment.

Research findings on such disparities have uncovered an array of factors that augment barriers to health care; most notably that health care providers significantly contribute to health care disparities. Burgess et al. discussed social cognition research to explain how providers contribute to racial/ethnic disparities in health care. A provider’s bias, discrimination, and stereotypical views directly impact the overall provision of care to others. Unfortunately, “in health care, race/ethnicity, gender, age, sexual orientation, and socioeconomic status influence provider beliefs and expectations of patients [and] the research findings on provider-patient communication supports the idea that white providers are less comfortable interacting with members of racial and ethnic groups” (Burgess et al. 2004:1155-6).

Consequently, “mammography within the last year and Pap test in the past three years was lower among women who immigrated to the United States in the past 10 years and who lacked insurance coverage” (Ward et al. 2004:85). The National Health Interview Survey, 2000 (NHIS), conducted by the National Center for Health Statistics (NCHS) reports that Hispanics/Latinos have the highest incidence of cancer of the cervix [and have] higher rates of liver cancer (Ward et al. 2004:81-85). Similarly, Goel et al.

used the 1998 data from the National Health Interview Survey and reported that “foreign-born persons are more likely to encounter barriers related to health access, such as lack of insurance, language and cultural barriers which have been shown to affect communication with providers” (Goel et al. 2003:1026).

These researchers also determined that lack of access to health care was particularly significant among this population. Their overall analysis concluded that by “examining the influence of birthplace [they] confirm prior studies which show that racial/ethnic subgroups comprised largely of immigrants have lower screening rates for cervical, breast, and colorectal cancer [as a result of], barriers such as lower income, less education and lack of access to care”(Goel et al. 2003:1033).

Additional barriers to screening and utilization of health care include health behaviors, access to and availability of prevention and treatment services, environmental and occupational risks, community support and cohesion, difference in insurance coverage, and underlying biological risk factors. Other factors such as limited English proficiency, religious or cultural values, belief systems, life experiences, and a group identity shape powerful filters through which information is received.

The CDC reports that there has been an increase of HIV/AIDS within Hispanic/Latino immigrant communities. According to Singer, “AIDS is socially constructed, in the sense that its impact as an arena of focused human experience is shaped by definitions, social values and social relationships (Singer 1994: 941). He analyzes “AIDS within the context of health and social issues facing the urban poor and attempts to locate this crisis in terms of the class, ethnic, and gender relations that define American society” (Singer 1994: 931). Although this perspective is criticized for

disregarding human agency, it is extremely relevant when analyzing multi-faceted health-related issues.

The passage of the Personal Responsibility and Work Opportunity Reconciliation Act of 1996 and the Illegal Immigration Reform and Responsibility Act of 1996 has had a devastating impact on the undocumented population in the United States. As a result, only those with refugee or asylum status remain eligible for publicly funded programs. All others, regardless of employment history, are excluded.

Immigration status is directly connected to access to healthcare services and the healthcare system in the United States. Familiarity with the healthcare system, cultural competence of the health care providers, and expectations of the medical system also influence the utilization of health services. In 1996, the U.S. welfare system was overhauled by the “Welfare Reform” bill, and changed into the Temporary Assistance to Needy Families (TANF) program. The new TANF program restricted legal immigrant access to federal work support programs, including Medicaid and Food Stamps, despite the fact that immigrants pay taxes supporting the very programs from which they are banned. Under the new TANF program, most legal immigrants who entered after August 22, 1996, were banned from receiving federal public benefits for the first five years they lived in the United States. The restrictions to the Supplemental Security Income (SSI) Program were even greater. These barriers to regular health care and other programs have forced low-income documented Hispanic/Latino immigrants either to avoid using health care services or to use costly emergency rooms as their main source of medical care.

This would seem to contradict the popular misconception amongst the non-Hispanic US population that illegal Hispanic/Latino immigrants abuse and gain from our welfare and medical assistance programs. Recently the media and scholars alike are highly critical of undocumented individuals and accuse them of “stealthy assaults on medicine” (Cosman 2005:6). Cosman also attributes the closing and deterioration of hospitals throughout the country to over usage brought on by undocumented immigrants. Further, she blames them for the overall decay in the medical system. Closing American borders, rescinding the citizenship of anchor babies, punishing those who aid and abet illegal aliens, and granting no new amnesties are Cosman’s proposed solutions (Cosman 2005:7). Many conservative groups and legislators are proposing anti-immigration policies. The guise of these policies is to secure and protect our borders in order to keep our terrorists who seek entry into the United States. This discourse is erroneously creating parallels between undocumented individuals and U.S. security and terrorism.

However, this argument is not sustainable in the face of accurate reports of under usage of medical providers by illegal Hispanic/Latino immigrants who fear expulsion. Contrary to being a financial burden, the evidence is suggestive that such persons shy from authorities and do not participate in government-sponsored programs.

Although undocumented Hispanic/Latino immigrants share some similarities, their motivations for migration differ, as well as their history of migration to the United States. These differences must be taken into account when examining health-seeking behaviors. Furthermore, despite the fact that many undocumented Hispanic/Latino immigrants live, work, and pay taxes in this country, they cannot access public safety net programs, with the exception of emergency Medicaid services “not related to transplant

procedures, short-term non cash in-kind emergency disaster relief and public health assistance for immunization for immunizable diseases and for the testing and treatment of symptoms of communicable diseases” (Loue et al 2000:23).

In recent months, there have been a number of legislative proposals directed at immigrants’ communities, which would further create barriers and negatively impact their access to health care. Many of these proposals, which require hospitals to document their treatment of undocumented immigrants, would create a “chill factor” within these communities. The majority of undocumented Hispanic/Latino immigrants live in mixed-status families, or households where one or more family member may be of lawful status. Therefore, other family members, often citizen-children, might avoid treatment due to the uncertain risks of going to a medical provider.

These current policies are cause for concern since there are significant negative consequences related to questions of legal status. This type of questioning could possibly lead to racial profiling and civil rights violations targeting racial and ethnic populations with higher percentages of Hispanic/Latino immigrants. Since fear of deportation is rampant among the undocumented community, there is a risk that confusion and lack of appropriate information can actually cause Hispanic/Latino immigrants and their families (some of whom are U.S. citizens) to disregard seeking health services. This is dangerous and can cause the public health to suffer. Supportive services, such as “medical translation and health education is essential to enable refugees and immigrants to have equal access to adequate health care” in the United States (Rumbaut et al. 1988:196).

Fortunately, there are some provisions that protect individuals who are residing in the United States without appropriate INS documentation. For example, “Medicaid

emergency medical care is exempt from the verifications requirements, because emergency access to such care is considered a public health imperative” [and] “ nonprofit charitable organizations that provide both social and hospital services are entirely exempt for screening or verifying eligibility” (Suarez 2000:209). Due to Hispanic/Latino immigrants’ lack of knowledge of services, language barriers, fear of deportation, and distrust of the health care system, they underutilize the available health services. The underutilization of health services by Hispanic/Latino immigrant minimizes the opportunities of preventative treatment, causes late diagnoses of diseases, and limits treatment options.

As a result of cumulative years of untreated health conditions, the Hispanic/Latino immigrant population is at high risk for many diseases. They are likely to be diagnosed late in their disease process due to health care inequities, including lack of culturally appropriate preventative health care. Consequently, when finally diagnosed, their medical conditions have progressed and may be untreatable or at a terminal stage.

End of Life and Hispanic/Latinos

When Hispanic/Latino immigrants are diagnosed with a terminal illness in a foreign country, they face many challenges. They must learn to negotiate a complicated medical health care system while making legal as well as medical decisions that determine their course of medical treatment. When Hispanic/Latino immigrants are terminally ill, their families are forced to grapple with end of life issues within a limited and fragmented family support system due to geographic distances and immigration laws. Along with coping with the physical, emotional, spiritual, and financial aspects at end of life, they must also deal with decisions such as place of death and burial/cremation.

Terminally ill individuals and their families face anticipatory grief, which is further complicated when family members residing in other countries are unable to visit in a timely manner due to immigration restrictions.

The healthcare needs of older Hispanic/Latinos are intensified and problematical due to language barriers, limited support systems and financial resources, as well as incomplete knowledge of new medical systems. It is also noted “both foreign-born and U.S. born Mexican Americans indicate a preference to live with their children if they were to experience declines in health” (Angel et al. 1996:465). The “increasing size of the Hispanic/Latino population over 65 suggests that healthcare issues associated with later life” need critical attention (Vega and Amaro 1994:42).

Older rural Hispanic/Latinos encounter additional barriers to accessing much-needed health care due to isolation, transportation, and issues of geographical access. Much of the contemporary literature in medical anthropology addresses the relationship between health, biomedicine, and social change (Nguyen and Peschard 2003:462). Anthropologists observed the development of anthropological gerontology and how it has begun “shaping itself into a distinct specialty” (Shenk and Soklovsky 1999:82). Definitions of aging used by biological anthropologists are congruent with the theoretical perspective of political economy. This is particularly applicable when addressing factors of health care inequities pertains to ethnicity, socioeconomic, and immigration status.

A Hispanic/Latino’s ability to gain employment that offers health insurance or the feasibility of privately purchasing insurance, directly impacts their access to healthcare. As a result of cumulative years of untreated health conditions, the uninsured Hispanic/Latino population is at high risk for many diseases. The uninsured,

undocumented Hispanic/Latino immigrants “may forgo care for serious illness as well as preventative care” (Chavez et al. 1992). For example, a study conducted by Jezewski in 1989 indicates how “migrant farm workers wait to seek care until illness prevents them from working...a Mexican farm worker sustained a gash on his lower leg but did not seek care for 2 weeks” (Albrecht et al. 2000:198). Such laborers also tend to return to work sooner than the medically suggested time. Unfortunately, “lack of health insurance including Medicaid, is a major barrier to access and use of health services” (Slesinger and Ofstead 1993:140).

Lack of health insurance is a major problem for all uninsured individuals in the United States and doubly compounded for the undocumented, uninsured Hispanic/Latino. Many researchers correlate “higher incomes with increased survival chances by providing a life characterized by adequate access to health care, proper diet, quality housing, consistent employment and healthful lifestyle...conversely, poverty may directly hasten poor health and mortality because of its association with poor housing, inadequate diet, and limited health care” (LeClere et al. 1997:170). This population is likely to be diagnosed late in their disease process due to health care inequalities, which include lack of culturally appropriate preventative health care. Thus, when finally diagnosed, their medical conditions are often at a terminal stage. Therefore, when Hispanic/Latino are diagnosed with a terminal illness in a foreign country, they confront numerous and significant challenges not necessarily shared by the native citizen population.

The philosophical, historical, and cultural belief systems of the Hispanic/Latino towards health and disease are different from those of the dominant culture. These differences are often ignored and are viewed as hindrances to the provision of hospice

services. Therefore it is “critical to map the social, cultural, and radicalized pathways that disconnect poor communities from mainstream-dominant institutions and outside social groups” (Lopez and Stack 2001:3).

The utilization of hospice services among Hispanic/Latinos is significantly less than among non-Hispanic/Latinos, and "Nationally, only 4% of Hospice patients are Latino or Hispanic/Latino" (Gelfard et al. 2004). The objective is to explore not only the structural organizational barriers to hospice utilization (Greiner et al. 2001) by Hispanic/Latinos but also cultural factors that contribute to the under-utilization of hospice services by this population. In contrast with aggressive forms of treatment, palliative care treatment improves the burden of terminal illness and the health symptoms of the patients (Egan and Labyak 2002:16)

In many cultures, issues of death and dying are often considered taboo subjects. Likewise, this topic is also seldom addressed among the Hispanic/Latinos. However, when an individual is diagnosed with a terminal illness, the discussion of death must occur. Universally, when an individual is diagnosed with a terminal illness it impacts the entire family system. The family members of a terminally ill person are often emotionally overwhelmed, coping with anticipatory grief issues, managing financial losses, and striving to comprehend their loved one’s disease process. For Hispanic/Latinos, the family support network is often limited due to geographic distances and the complexities of obtaining visas from INS.

Among the non-Hispanic/Latino community, there is often the erroneous assumption that all Hispanic/Latinos reside with extended family members and that these family members will be available to care for the terminally ill relative. For example,

"physicians may play a large role in brokering services to elderly and their families and may not refer Hispanic patients to a hospice because they observe families providing in-home support and assume that such assistance is provided for cultural reasons" (Wallace and Lew-Ting 1992:338). And while some researchers state that the extended family is no longer a reality, yet other researchers advocate that "medicine tends to focus on individuals, care near the end of life is increasingly recognized as a family matter" (Haley et al 2002:284).

Changes noted particularly in the Mexican American family may reflect the challenges of immigration and migration. The study by Talamantes et al. in 1996 entitled "SES and ethnic differences in perceived caregiving availability among young-old Mexican-American and non-Hispanic Whites" indicated "30 percent of Mexican American respondents reported that they would no longer have an available caregiver if they became ill and needed help" (Talamantes et al. 2004:38). Due to these changes, the Hispanic/Latino community needs to be knowledgeable of hospice services, which are funded by their taxes and these services are usually a benefit of their health insurance, when they have it.

The federal government mandates non-for-profit hospice and for profit hospice organizations to serve everyone, regardless of ability to pay. The only requirement is that the individual have a terminal diagnosis of six-months or less. Terminal illnesses include: end stage cancer, heart disease, pulmonary disease, Alzheimer's/dementia, HIV/AIDS, and cerebrovascular disease. Heart disease is the leading cause of death for all Hispanics, and is responsible for 24 percent of all Hispanic deaths. Cancer deaths contribute to 20% of all Hispanic deaths in the U.S. The incidence of breast cancer is

increasing faster among Hispanic women than any other group. Cerebrovascular disease accounts for “nearly 6 percent of all deaths among Hispanic/Latinos while diabetes accounts for 5 percent” (<http://www.cdc.gov/nchs/fastats/pdf/nvsr5016tb2.pdf>).

Hispanics are more likely to suffer from chronic health conditions such as cardiovascular disease and diabetes when compared to non-Hispanic Whites, but they are less likely to receive regular, continuous care to combat their serious health conditions. Unfortunately, many Hispanic/Latino families do not have access to a regular doctor to help treat or maintain their medical conditions. Many Hispanics are forced to rely heavily on emergency hospital care or public clinics as their primary source of care.

As a result of lack of continual care and issues related to being uninsured, many Hispanics/Latinos are not given the opportunity to practice preventative care. In the end, many Hispanics/Latinos will suffer from major complications due to their chronic disease. In addition, Hispanics/Latinos are unlikely to participate in or receive the benefits of preventive programs such as cancer screenings and smoking cessation.

Along with coping with the physical, emotional, spiritual, and financial aspects at end of life, they must also deal with decisions such as place of death and burial/cremation. Terminally ill individuals and their families face anticipatory grief, which is further complicated when family members residing in other countries are unable to visit in a timely manner due to immigration laws. When a Hispanic/Latino individual is diagnosed with a terminal illness, it is not only physically, psychologically, and emotionally devastating for a family but financially crippling as well. Especially, as it relates to extended family members. "Practitioners...need to recognize that the definition of family goes beyond the family of origin so that it encompasses not only those related

by blood and marriage but includes those who are tied to it as well through custom" (Delgado 1982:242). Similarly, their national, generational, and spiritual belief differences will directly affect death/funeral rites and how they manage end of life transitions

"Hispanic/Latino patients may be reluctant to use Hospice services because of the reluctance to admit that family members cannot perform caregiving" (Gelfard et al. 2001:392). Traditionally, Hospices are designed and equipped to care for a terminally ill person within the context of their family. Being aware of and sensitive to Hispanic/Latinos' cultural needs surrounding their end-of-life care will be essential in order for Hospice to create a successful program to meet those needs. Although it is challenging to know the culture of each group within the Hispanic/Latino category, it is, however, essential to acknowledge that unique needs exist.

Health care providers are obligated to comprehend cultural factors and their impact on end-of-life decisions. It is crucial for practitioners to utilize "the concept of cultural relativism which means that a client's beliefs and behaviors are considered within his or her own culture's context rather than within the context of the dominant culture or, if different, the provider's culture" (Braun and Blanchette et al 2000:7). This includes crucial factors such as the use of traditional or herbal medicines and certain cultural beliefs such as not informing patients of the full extent of their disease, which is referred to as truth telling.

Hispanic/Latino healthcare challenges include "a struggle with a lack of access to health information in Latino communities, illiteracy and inability to speak English, illegal immigrants status that hinders economic opportunities, discrimination, apathy, denial of

certain illnesses, and cultural stigma associated with many physical and mental illnesses" (Campo 1999:21). This research will explore how families of Hispanic/Latino hospice patients cope with their loved ones' terminal diagnosis and the role that hospice plays in these scenarios.

Chapter 3

Perceptions and politics of hospice care

Perceptions about hospice care

When the word hospice is uttered, many individuals immediately envision an institution to which one goes to die under massive doses of morphine. However, the concept of hospice encompasses much more. Since the inception of the concept of hospice services in London in 1967, the goal of hospice has been to provide a holistic approach: caring for a patient's physical, spiritual, and psychological wellbeing at the end of life (Haber 1999). In contrast with aggressive forms of treatment, palliative care treatment improves the health symptoms of the patients, and lessens the burden of terminal illness upon the patients and their families. Thus, the introduction of hospice services marked a new beginning, not only for the care of the dying, but also for the practice of medicine as a whole.

Hospices provide palliative care in an array of settings to persons who have a terminal diagnosis with a prognosis of six months or less to live and specialize in pain management while ensuring quality of life for the individuals it serves. Currently, hospice services are provided in an individual's home, nursing homes, assisted living facilities, hospice houses, in jails and in palliative units in hospitals throughout the United States and the world. Some hospice organizations require a patient to have a primary caregiver residing with them while other hospices only expect patients to have an anticipated plan of caregiving when they are no longer able to care for themselves.

It is important to note that hospice services decreased the number of hospital deaths, which ties into the previous discussion of competition among healthcare providers

and services rendered. Physicians tend to refer patients to Hospice, yet patients can also refer themselves or loved ones for services and then attain the necessary documentation indicating their terminal diagnosis from a physician. However, due to an array of factors, not all terminally ill individuals avail themselves of such service programs.

The Influence of Organizational Culture Upon Decision Making

Hospice offers supportive care to the dying patient and to family caregivers, with the goal of improving their quality of life. It offers support to the patient through the end-stages of disease management as well as addressing the emotional, social, and spiritual aspects of the end-of-life experience for both patients and families. Hospice care enhances quality of life at the end of life by reducing the pain and suffering resulting from the disease, addressing symptom management, promoting patient choice and informed treatment decisions, along with enhancing dignity and respect for patients and families. Hospice care thus improves both the burden of terminal illness and the health symptoms (Egan & Laybyak 2002:). The hospice team consists of a physician, nurse, social worker, chaplain, home health aide, and trained volunteer. The team members visit the hospice patients in their home or wherever the patients reside.

Unfortunately, many cultural groups are deprived of hospice services. As a result, terminal patients needlessly suffer pain without assistance, chiefly due to hospice's inaccessibility to them at a time when such services are most urgently needed. The literature states "much of the data on disparities in palliative care concerns the adequacy of pain management and usage of hospice care" (Ward et al. 2004:89).

Payne et al. (2003) "studied other elements of the health care system, finding racial and ethnic disparities in the palliative care setting in treatment patterns, pain

management and utilization of hospice care” (Payne et al. 2003: 312). There are disparities not only in preventative health care treatment approaches, but also “racial and ethnic minorities tend to be under treated for pain when compared with non Hispanic Whites” (Green et al. 2003:277).

The research by Green et al. (2003) reported that “while only 16% of non-Hispanic Whites received no analgesics in emergency departments, 55% of Hispanics went without pain medication and among 281 racial and ethnic minority outpatients with recurrent or metastatic cancer, 74% of Hispanic and 59% of African American patients did not receive the WHO-recommended analgesic for their pain” (Green et al. 2003:280). Along with suffering disproportionately while in medical institutions due to lack of adequate pain management, when sent home with prescriptions for pain medications “Hispanic and African American neighborhoods were significantly less likely to stock opioid analgesics than those in non-Hispanic White neighborhoods” (Morrison et al. 2000:1125), and when they do stock such substances, it is in minimal quantity. This is another blatant example of victimization due to the current political economy of health care.

Studies by Crawley et al., Ngo-Metzger et al., and Ward et al. “showed lower use of hospice care among minority persons, including African Americans, Asian Americans and Hispanics/Latinos” (Ward et al. 2004:99.) In 2000, the National Hospice and Palliative Care Organization’s study reported: “82 percent of hospice patients were non-Hispanic white, 8.2 percent were Black or African American and 3.4 percent were Hispanic or Latino” (Lackan et al. 2004:978). To address the observable fact of access to hospice care by “minorities”, in 1987 the National Hospice Organization established the National Task Force on Access to Hospice Care by Minority Groups. This task force was responsible for examining hospices’ organizational programs of cultural sensitivity, describing issues that arise when working with people of diverse cultures, and for reviewing the existence of obstacles that prevent people of color from accessing hospice

services. In the late 1980s, the National Task Force on Access to Hospice Care by Minority Groups conducted a literature review and found no significant national studies at that time pertaining to access to hospice care by people of color.

In 1996 Gordon surveyed 1,362 hospice programs in the United States. Of the hospices surveyed, “61 percent responded indicating that respondents rated referral, primary care givers requirements and lack of relationship with a physician as the most important factors affecting service to minorities” (Gordon 1996:68). Gordon suggested that further research is necessary concerning access and hospice utilization by minorities, especially since not all researchers agree on the source of the problem.

Topoleski developed a contrasting interpretation when studying underutilization of services by elderly Mexican American women in Lansing, Michigan. Her analysis concluded that there is no barrier impeding Latinos from using hospice services, and “the fact that Latinos disproportionately underutilize these services does not necessarily mean they do not have equal access...but that Mexican Americans don’t feel a need for this kind of help” (Topoleski 1997:16). However, this perspective is disputed in the existing but limited research literature, and once the literature review was completed “the task force concluded that there was inadequate data about the access to hospice care by People of Color”(Harper 1995:3) Thus, the reason for under utilization of hospice services among the Hispanic/Latino community is uncertain and unclear.

Historically, these groups have contributed financially to the Medicare, Medicaid, and healthcare systems. This includes “some Black and Asian patients and their relatives/caregivers who are very disadvantaged as they do not know what they are entitled to and hence what to ask for by way of services and benefits” (Smaje and Field

1997:156). The individual's "decision making may be affected by distrust of conventional medical care, inability to navigate the medical systems, fatalism and the lack of a trusted provider" (Ward et al. 2004:89).

For instance, there are many reasons "for low service utilization by Hispanics: this may be related to provider referral" (Talamantes and Espino 1995:40). The literature indicates "physicians may play a large role in brokering services to the elderly and their families and may not refer Hispanic patients to a hospice because they observe families providing in-home support and assume that such assistance is provided for cultural reasons" (Wallace and Lew-Ting 1992:338). Also, "physicians may make different clinical recommendations for patients of different race, ethnicity, or socioeconomic status, even when stage of disease, other prognostic indicators and comorbidities are the same" (Ward et al. 2004:89).

Throughout my readings, I have noted that research is limited as it relates to factors concerning lower use of hospice care by specific racial and ethnic groups. There appears to be a direct correlation between disparities in health care treatment, health insurance, and economic and educational status. It is critical for everyone to have access to hospice services since at some point, everyone will face end of life decisions. And while the under utilization of such services by *all* cultural groups is of concern to me, for the scope of my dissertation research at this time, I focused on the Hispanic/Latino community.

To reiterate, the utilization of hospice services among Hispanic/Latinos is significantly less than among other groups. "Nationally, only 4% of Hospice patients are Latino or Hispanic/Latino" (Gelfan et al. 2001:393). The National Hospice Organization reported

that “81.2% of hospice patients were White or Caucasian (does not include Hispanic or Latino whites), 9% of hospice patients were Black or African American, 4.3% of hospice patients were Hispanic or Latino, 0.9% of hospice patients were Asian or Hawaiian/Pacific Islander and 4.6% of hospice patients were classified as multiracial or “another race”(http://www.nhpco.org/templates/1/homepage.cfm).

In a study of hospice users for St. Luke’s/Roosevelt Palliative care service, an inner city program in New York City, 14 percent of recipients of care were Hispanic compared to 58 percent Black and 28 percent White (Talamantes 1995:39). According to the "New York State Hospice Association, 2 percent were Hispanic, 6 percent were black and 92 percent were non-Hispanic White” (Pawling-Kaplan and O’Connor 1989:40). "There is an ethnic/racial difference in utilization of services at the St. Luke’s program and in the New York State Hospice Association" (Talamantes 1995:39).

Under utilization of hospice services also exists in the State of Florida. The hospice organization in my research serves four counties. Among these counties there was a total of 1069 Hispanic/Latino deaths, not including accidents or suicides (U.S. Census Data 2001). In 2001, the entity sanctioned to provide service to these counties served 239 patients, which is only 22 percent of the total deaths. Recruitment of bicultural and bilingual health care providers, social workers, and chaplains was also needed. Educational and cultural diversity training are also necessary. Culturally appropriate active outreach interventions by hospice organizations may increase the community awareness of hospice providers and increase the numbers of linkages in the Hispanic community to people who could then refer individuals to hospice.

Hospice organizations must become aware that the Hispanic/Latino population has unique needs and beliefs about health, disease, and terminal illness; however, these beliefs do not eliminate or nullify their need for health care or hospice services. Instead of limiting the Hispanic/Latino population's access to care, health care providers and hospice organizations alike should seek to eliminate existing barriers that inhibit Hispanic/Latino individuals from utilizing their services. As a result, the knowledge and increased awareness of hospice services as a resource to terminally patients will not only assist them, but also their families during a most trying and difficult phase of life.

Persons who are sick tend to take on a passive and dependent role. The physician is highly respected and expected to be more directive than in a partnership role. Decision-making usually includes older or more respected family members. Women are expected to provide and be in charge of sick care within the family, including when the patient is hospitalized (Varela 1996).

Some individuals expect bad news (e.g. poor prognosis) to be shared with the family or the oldest immediate family member before the patient is told. However, HIV/AIDS diagnosis should be shared only with the patient and only with staff translators (vs. family or community). The desire for family to be notified about a terminal illness or poor prognosis, before the patient has been informed, contains the potential to lead to conflict. To avoid such conflict, it is best to clarify in early contacts with the patient and family that such information is to be given only to the patient unless otherwise expressly requested.

It is also difficult for patients and families to agree to DNR orders since such orders and acceptance of terminal status may represent giving up and abandonment of the

patient. Major health care decisions are often based on the patient's health insurance, income, and ability to pay. In this revenue-driven circumstance patients are often distrustful of physicians and medical institutions, since due to the political economy of health, medical institutions are profit-driven.

Accordingly, health care decisions are often determined and driven by fiscally minded administrators who are commended when they generate profits and prevent financial losses. Thus, they are encouraged to provide only outpatient treatment care to those without health insurance, while hospitalizing and providing aggressive treatment and interventions to those with the same condition but in possession of health insurance. The difference in care is in the money.

Individuals from under representative populations tend to be suspicious of the medical profession as a result of historically unethical and unjust treatment. The research of Cavalis et al. (1993) supports the "theory that racial and cultural biases must be better understood to facilitate communication between physicians and their patients concerning decisions about advance directives and life-prolonging treatment"(Cavalis et al. 1993:161).

Likewise, within the Hispanic/Latino community, the issue of death and dying is not readily discussed or addressed. For that reason, it will be rather challenging to engage individuals in this discussion, for there is a tendency among many Hispanic/Latino groups to believe that if one discusses the issue of death, one then brings it on. Taboos of this type tend to create reluctance among Hispanic/Latino individuals to discuss the topic of death. Various religious beliefs may also inhibit dialogues about issues of death or may create conflicts.

In order to facilitate end of life care, “an individual should have some choice with regard to where and how they choose to spend their final days...as long as the ability [remains] to choose to continue active treatment, choose palliative treatment, choose to be at home with or without a support program, or choose to be in a hospital” (Vachon 1993:588) or at home receiving hospice services. Since hospice services have been shown to improve quality of life and to decrease the burden for terminally ill patients and their families, it is essential for the Hispanic/Latino community to be aware of hospice services, which are beneficial to *all* individuals diagnosed with a terminal illness. The terminal illnesses include: end stage cancer, heart disease, pulmonary disease, Alzheimer’s/dementia, HIV/AIDS, and cerebrovascular disease.

In my clinical experience, I have served children, adolescents, young adults, middle aged, and older patients. It is estimated that hospice programs served “950,000 patients in 2003. The National Hospice Organization reports 54% of hospice patients were female, 46% of hospice patients were male and 63% were 75 years of age or older” (http://www.nhpc.org/files/public/Hospice_Facts_110104.pdf). Since, unfortunately, individuals of all ages are diagnosed with terminal illnesses, the knowledge and increased awareness of hospice services as a resource to the terminally ill will not only assist patients but their families as well, at any phase of life.

In the State of Florida, hospice organizations have an additional vested interest in serving as many terminally ill patients as possible within their jurisdiction. In this State, a hospice organization is not able to function unless they have attained a “Certificate of Need” (CON) from the Agency for Health Care Administration (AHCA). The “Certificate of Need” is a state regulatory process of health care organizations overseen

by the AHCA. The 2002, “Florida Statutes of Certificate of Need Program Sections 408.031 through 408.0455, F.S. states: ‘CON’ means a written statement issued by the agency evidencing community need for a new, converted, expanded or otherwise significantly modified health care facility, health service, or hospice” (http://www.fdhc.state.fl.us/MCHQ/CON_FA/Rules/statutes.shtml).

The “CON” calculates the need for hospice providers in the area a hospice serves. Every six months, the AHCA performs an analysis that examines the number of deaths in each district and establishes a projection based on need. This projection determines the estimated number of people who should be cared for by the hospice programs serving that area. If the hospice program fails to care for the projected number of patients and families, a “CON” is issued and another hospice program can apply to serve that district, thereby establishing competition based on the original projected assessment of need.

The “CON” program does not grant any hospice organization a monopoly over an area. It is designed to create accountability and responsibility in order to ensure that hospice organizations meet the needs of the whole communities they are intended to serve. Hospices that function under the criteria of “CON,” like any other business organization, dread the notion of a competitor in the same area. This is confirmed by the following quote from the executive director of one such enterprise: [The creation of] “‘a new hospice would dilute the limited nursing, volunteer and charitable resources in the community’ wrote Susan Ponder-Stansel, Community Hospice's executive director” (<http://www.bizjournals.com/Jacksonville/stories/2003/09/01/daily2.html>).

In the State of Florida, the position of the “CON” is tenuous because there are many legislators, lobbyists, and interested parties who oppose it and are striving to have it dismantled.

Hospices are constantly challenged and threatened by other entities interested in gaining access to their existing market. Therefore, it is mutually beneficial for hospices in Florida to provide services to as many terminally ill individuals as possible in order to prevent another organization from receiving a “CON.”

Also, “physicians may make different clinical recommendations for patients of different race, ethnicity, or socioeconomic status, even when stage of disease, other prognostic indicators and comorbidities are the same” (Ward et al. 2004:89). The research also indicates “patients participated more actively in treatment decisions when their physicians were of the same ethnic background” (Green et al. 1999:285).

Physicians also have professional ethics that tend to encourage them to provide aggressive medical treatment, which is in conflict with palliative care. And, on a business level, there also exists the monetary enticement to perform exploratory surgeries, provide extensive and possibly excessive treatments, and recommend invasive technological life-prolonging measures for the provider’s economic gain.

The complexities of death, quality of life, and the topic of ‘death with dignity’ are thoroughly explored from an anthropological perspective by Kaufman 2005. She captures the essence of physicians’ dilemmas and conflicts in their language constructs and discourse. For example, in one instance, a physician stated, “doctors use the terms ‘quality of life’ and ‘death with dignity’ especially, as shorthand for complex feelings that doctors find difficult to consider or express.

The phrases “quality of life,” “death with dignity,” and “sanctity of life” are multifaceted. Each distinct phrase has broad ramifications depending on how a physician chooses to use the term. One physician may consider maintaining someone on life support as preserving the “sanctity of life” while another physician may rationalize discontinuing life support as sustaining the same “sanctity of life.” The situation is similar with regard to the phrases “quality of life” and “death with dignity.” Thus, in lieu of utilizing artificial measures to prolong life, when physicians refer patients to hospice, they may be opting for clients to have “quality of life” or a “death with dignity.”

Nonetheless, it is difficult to get physicians to agree on what palliative care actually entails since the concept of palliative care is rather elusive and ambiguous. Some palliative care treatment includes chemotherapy and radiation for pain management while other forms do not. The Institute of Medicine defines palliative care as the “active total care of patients whose disease is not responsive to curative treatment” (Institute of Medicine 2001). According to the National Hospice and Palliative Care Organization (NHPCO):

The standards of practice for hospice programs describe palliative care as: treatment that enhances comfort and improves the quality of an individual’s life during the last phase of life. No specific therapy is excluded from consideration. The test of palliative care lies in the agreement between the individual, physician(s), primary caregiver, and the hospice team that the expected outcome is relief from distressing symptoms, the easing of pain, and/or enhancing the quality of life. The decision to intervene with active palliative care is based on an ability to meet stated goals rather than affect the underlying disease. An individual’s needs must continue to be assessed and all treatment options explored and evaluated in the context of the individual’s values and symptoms. The individual’s choices and decisions regarding care are paramount and

must be followed.

[<http://www.caringinfo.org/i4a/pages/index.cfm.pageid=3469>]

All hospices are required by federal mandate to provide bereavement services to the family members of the deceased whether or not the hospice is profit-motivated. They all tend to voluntarily be members of the National Hospice and Palliative Care Organization (formerly National Hospice Organization), which maintain standards of practice for hospice organizations. Bereavement services are provided for everyone identified by the caregiver regardless of place of residence, including “out of state” locations. For example, if an individual dies while a patient with the local hospice, family members in other states can receive free bereavement services from the hospice in the area where they live. This is extremely helpful for caregivers who have chosen to relocate in order to reside near other relatives following the death of their loved one.

Cultural, social, economic and political barriers

Prior to death, however, physicians and medical institutions philosophically (and perhaps financially) prefer to treat illnesses aggressively, despite the patient’s terminal prognosis. Family members are often persuaded and influenced to follow the directives of physicians and the medical community, which advertises its ability to prolong life mechanically while attempting to prevent the inevitable. Such practitioners sometimes encourage patients to seek out medical interventions such as invasive chemotherapy, aggressive radiation, and surgeries despite the patient’s terminal status. The medical options and treatment offered to patients are often dictated by the individuals’ healthcare benefits and insurance coverage.

The physician's ability to prolong life without quality, as well as the medical professional's definition of quality, is a central theme in this research. The role of standard practice of care and its evolution since the use of technology adds controversy issues of end of life decisions. The issue of 'technological development and cultural production' as it relates to the complex matter of permanent or persistent comatose condition and the institutions and practices that enable this life form to exist, has impacted hospice care directly. Kaufman's research questions examine how a person in a vegetative state or comatose state is approached and known, how agency is enabled and contested, and how power is diffused and located.

This topic compels individuals, family members, long-term care facilities, ICU wards, ethicists, and the medical community at large to explore the quandaries of the persistent vegetative state. Many ethical dilemmas emerge for both health care practitioners and family members. Overall, the perspective on how to medically treat individuals with a terminal illness is a rather complex one due to financial and political factors, but it directly affects the timeliness in which physicians refer individuals to hospice.

The political economy of medicine impedes access to on-going preventative health care for the poor, the undocumented, and the uninsured throughout their life span. These are categories that immigrants disproportionately occupy, therefore there is a high propensity of chronic, untreated health conditions that cause severe complications, and in many cases, hasten a terminal diagnosis. Ironically, although preventative services are not available, end of life services can be had. This is because non-profit and for-profit

hospices are mandated to provide service to everyone, including the uninsured and undocumented, regardless of their ability to pay.

Nonetheless, hospice care remains a viable option for individuals who choose to die at home with respect and dignity while receiving palliative care (Kubler-Ross 1981). At first glance, this form of intervention would seem to be culturally compatible with family-based care giving and thus less intimidating to immigrants than a hospital might be. However, research has indicated that some cultural groups under-use this service. This may be due to language barriers, factors related to distrust and suspicion of formal medical treatment, lack of knowledge of available services, religious beliefs about end of life issues, and uncertainties concerning aggressive versus palliative care at the end of life.

As a former hospice employee and an emerging anthropologist, I acknowledge my responsibility to use my skills to advocate for the underserved. However, it is necessary to have the commitment of all the stakeholders, including the board of directors, management, and employees to engage in promoting change. Politically and economically, it benefits the organizations to embrace this goal on various levels. For example, if hospice were to provide services to more Hispanic/Latino patients, the organization would in turn increase its overall income and strengthen its base. However, in order for this to occur it would necessitate that the organization make internal changes as well as have a financial commitment to provide services to populations currently not being served. This would result in a mutually advantageous situation for all concerned parties, since providers would augment their earnings and recipients would expand their choices of options for care.

Chapter 4

Methodology

Need for Research

The research questions are related to two key concerns:

- 1. Are there structural organizational barriers to hospice utilization by Hispanic families and individuals, and if so, what are those barriers?**
- 2. Are there cultural factors that contribute to the known under-utilization of hospice services by this population?**

These issues were operationalized in the following specific questions:

- 1. How does a terminal diagnosis impact Hispanic/Latino individuals and their families?**
- 2. Why is it that some Hispanic/Latino families utilize hospice services while others do not?**
- 3. What cultural differences are there between hospice caregivers and non-hospice caregivers?**
- 4. What roles do physicians play in the utilization of hospice services by Hispanics/Latinos?**

Study Design

The research design involves in-depth, semi-structured, open-ended interviews, coupled with a statistical analysis about existing archival data of utilization of hospice by Hispanic/Latino patients from August 2002 to June 2006. Ervin argues that this type of combination of “methods mutually reinforce each other and their benefits are greater than their individual strengths, [therefore] the use of quantitative methods in applied

anthropology, combined with our traditional strengths in qualitative research” will provide meaningful insights to this study (2000:171).

The research project also includes aspects of an exploratory ethnographic study of a hospice organization and services rendered. Denzin (1989) refers the participant observer who “makes her presence as an investigator known and attempts to form a series of relationships with the subjects such that they serve as both respondents and informants” (Denzin 1989:163). The qualitative design and data collection method facilitates my understanding of the people and the social and cultural contexts within which they live.

The qualitative component of the study describes and analyzes the health care utilization perspectives of Cubans, Mexicans, Puerto Ricans, South Americans, and other people of Hispanic/Latino origin by specifying reasons for use or non-use of hospice services. In spite of the differences among these groups, they have common inequities and disenfranchisement when it comes to health care access and utilization. The rate of poverty among Hispanics in 2003 was 22.5 percent, with the national rate at 12.5 percent, and 33.7 percent of Hispanics did not have any health insurance versus 15.6 percent nationally (<http://www.census.gov/hhes/www/income/html>).

Essence of Hospice

The exploratory ethnographic components of the research include the hospice organization and the services it renders. In order to assume the role of a participant observer and to become involved in the daily functions of the hospice organization I was required to undergo a rather extensive approval process. I telephoned the research director of the hospice organization. At this time, I discussed the proposed research and

requested a meeting date. At the scheduled meeting, the proposal and research goals were explained in detail. According to the director, the research goals presented would best be accomplished with me functioning in the capacity of a research intern. The director then requested that I commit to at least 6-8 hours a week as a research intern within the organization. It was agreed that the internship would begin March 2006 and end in August 2006 and could be extended as needed. Upon agreement by both parties, the director then made the official request to the Human Resource Department (HR) of the hospice organization. The HR staff person explained the process and provided all the information necessary to assure the research intern status. This included completing an application similar to the employment application, attending a mandatory orientation, and attaining medical and legal clearance. Proof of car insurance was required, and I also was required to be submitted to a criminal background check. Once the application was approved, I was contacted and the availability of orientation dates was discussed. Prior to attending the orientation, documentation of a complete physical examination, a tuberculosis test and hepatitis shots were to be submitted to the Human Resource Department. Once this process was completed I received an identification card, e-mail, voicemail, and a key to the main office. Becoming “official” in the organization enabled me to freely interact with hospice staff, observe hospice interdisciplinary team meetings, accompany hospice social workers, nurses, physicians, chaplains, nurses aides, and visit existing hospice caregivers and patients in their places of residence.

I attempted to understand the depth and breadth of the hospice organization, the daily functions of the hospice teams, and the overall mission of the organization in my role as a research intern. This identification allowed me to assume the role of participant

observer. Participant observation “represents the starting point in ethnographic research, it is central to identifying and building relationships, gives the researcher intellectual grasp of the way things are organized and how people relate to one another and the ways in which social and physical boundaries are defined” (Schensul et al. 1999:91).

Shadowing clinical field staff and observing their day-to-day interaction with the patients, caregivers, and family members enabled me to assess their tasks, responsibilities, and the performance of their duties. I interacted with office clinical staff, office clinical team supervisors, clerical staff, and office personnel. This included reviewing hospice newsletters, brochures, announcements and websites, as well as informal conversations with hospice personnel. I was also able to observe the general essence of hospice care on a daily basis. I focused on the “meanings of behavior, language, and interactions of the culture-sharing group (Cresswell 1998:58). An analysis by themes or perspectives and some interpretation for meanings of social interaction and generalizations about human social life will emerge through this process.

Along with the daily visits, I observed the admissions process in the Admissions department at the hospice organization. I accompanied hospice nurses to admissions conducted in patients’ homes, a hospital, and a nursing home. Examining how the various team members deliver services facilitated my understanding about the hospice program. Insights about the unique role of each team member as well as how the boundaries were sometimes blurred were explored. The patient/caregiver and staff interaction was also observed.

Each team member represented a critical aspect of the organization as they provided a specific service. Participant observation permitted me to frame the experience

of hospice, to describe what daily occurrences and processes are like, and to explore the normal happenings of the system in a descriptive manner. This approach utilizes the ideational theory wherein “researcher view the human world from the perspective of its mental origin-ideas, cognitive maps, beliefs and knowledge” (Fetterman 1998:6).

I attended interdisciplinary team meetings and observed the functioning of the three Hospice Houses. In the various interdisciplinary team meetings, which I attended, the opportunity was provided for me to explain my role and research topic. At these meetings I asked the team members if they would assist me by identifying Hispanic/Latino caregivers who would be interested in participating in my research. Several of the nurses, social workers and nurses aides willingly shared with me the names of the Hispanic/Latino patients and families they were providing services to and encouraged me to visit the patients’ homes with them. Once the team members learned that I spoke Spanish, the non-Spanish speaking nurses and social workers asked if I was willing to translate for them on future visits. My willingness to assist them facilitated me scheduling home visits with them. I was pleased with their response and immediately scheduled dates and times to shadow them. It was emotionally challenging to remain in my role as a translator while visiting Hispanic/Latino individuals with declining and unpredictable health conditions and to observe overwhelmed and fearful caregivers.

During this process I learned about the patients’ health concerns, their fears and their strategies in coping with their own impending death. I also gained insights about the caregivers’ support systems, stress and anticipated grief process. Both the patients and caregivers appeared to be relieved when they were able to articulate their most intimate thoughts and feelings in their native language. Although the role of the researcher was

blurred with that of a translator, the team members and I gained enormous insights and knowledge about the patients' and families' life lives. The team members learned new information about the patients and families, which enabled them to more effectively, provide health and mental health care.

Scheduling the dates to visit the patients and families seemed effortless but to actually conduct the visit was much more challenging and complex. The hospice patients I was scheduled to visit would suddenly be admitted into the hospital due to unexpected medical crisis, transferred to a nursing home due to the caregivers' increased stress or illness or the patient would die prior to my visit. I received numerous cancellation calls from the team member when I was already on route to the patient's home.

While visiting patients and families in their homes with hospice nurses, social workers, chaplains and nurses aides, I had an opportunity to introduce myself and explain my role those individuals I visited. Depending on the patient's health status and the families' reception and interest, I would then discuss my research topic. At this time, I inquired if the caregiver would be interested in partaking in the study by responding to twelve questions in a semi-structured interview at a later date. When they agreed to participate, I followed up with them shortly after my visit by telephoning the caregivers and arranging a convenient date and time to interview them that was most convenient for them. All of the caregivers preferred to have the interview conducted in their homes. Therefore the homes became the sites of qualitative data collection. Friendly, non-threatening settings are intended to minimize social desirability response set (Locke, Spirduso, and Silverman 2000) and should also maximize the respondents' comfort level and sense of safety and security. The research department at the local hospice provided

me with a list of Hispanic/Latino caregivers who have indicated interest in participating in research upon admission. I telephoned them and requested their participation.

In consultation with the hospice organization, I selected caregivers of patients who have self-identified as Hispanic/Latino upon admissions. The participants were individuals who have provided the local hospice consent to participate in research opportunities. The interview enabled me to compile demographic data from caregivers regardless of their immigration status. All participants were at least 18 years of age.

Caregivers

I interviewed a primary sample of a total of 20 residents in Central Florida Area who are the professional caregivers of terminal patients and/or are family members who are providing care. Ten of those interviewed are caregivers of hospice patients and ten are non-hospice caregivers. The hospice caregivers were recruited from a local hospice organization and the ten non- hospice caregivers were recruiting by utilizing a “snowball” technique. I obtained a list of Hispanic/Latino caregivers from the hospice organization. These caregivers self- identified as Hispanic/Latino and indicated interest in participating in research upon admission. Nineteen of the caregivers’ interviews were tape-recorded; one non- hospice caregiver refused to be recorded. All of the interviews were conducted in the caregivers’ homes. The length of the interviews varied between thirty minutes to two hours. None of the caregivers that I requested to interview refused to participate. However, six patients died and two were hospitalized prior to the scheduled interviews with the caregivers.

The questions that were used in the semi-structured interview asked about hospice use, non-use, perceptions about hospice care, and recommendations. The questions also

explored factors related to the patient's immigration and migration history. Their employment history, prior experiences with physicians and beliefs about sickness were also ascertained. I explored families' decisions about accessing hospice services and their support systems. This entailed inquiring about their decision-making processes, time frames, and significant others who contributed to their healthcare choices.

Demographic data attained from the caregivers about the patient and about the caregiver included: age, gender, place of birth, length of time in the United States mainland (e.g. generation), income, religion, marital status, level of education, language preference, number of caregivers at home with patient, health insurance source, community services used and presence of advance directives.

The comparative sample consists of caregivers of terminally ill Hispanic/Latino individuals who have not used or accessed hospice services. Comparing non-hospice users with hospice users of similar ethnicity, who chose different medical treatment options at the end of life, enabled me to examine reasons for their choice of care. Two essential criteria were necessary for the comparative group; the non-hospice caregiver indicated that the patient self identified as Hispanic/Latino and was terminally ill. Utilizing a "snowball" technique, I elicited the help of Hispanic/Latino social workers, nurses and nurses' aides in the community to identify and recruit non-hospice caregivers. The initial contact with the non-hospice caregivers was by the individual who identified them rather than by me. When they expressed willingness to be contacted, I telephoned them. The research was explained in detail over the telephone, and once they agreed to participate, a visit was scheduled to conduct the interview at the interviewee's place of preference.

Comparing hospice caregivers with non-hospice caregivers enabled me to attain insights and knowledge about their family support systems, financial status, religious/spiritual beliefs, and thoughts related to illness and end of life. Factors related to age, gender, place of birth, length of time in the United States mainland (e.g. generation), marital status, level of education, language preference, health insurance source, community services were used and the presence of advance directives were also explored. All of the information attained in the interviews is critical to understanding the underutilization of hospice services and how non-hospice users differ from hospice users.

I telephoned the caregivers introduced myself and explained the nature of the research. When the caregiver agreed to participate, I scheduled an appointment with the caregiver and the interview took place. In the event that there was more than one caregiver, the investigator allowed the caregivers to select the primary caregiver. Prior to the interview I provided the each interviewee with a copy of the verbal consent form and all questions were addressed. Verbal informed consent was sought from all those who agreed to participate in the study. Hispanic/Latino individuals are not dispersed equally throughout the county and because the sample is intentionally small, the sample is “representative” of the regional population, and is intended to be a qualitative design.

When interviewing hospice caregivers, factors related to their decisions about seeking hospice care for their family members were explored. The hospice and non-hospice interviews were done with the caregivers rather than with the terminally ill persons due to the patients’ fragile health status. The caregivers also become increasingly the decision-makers. The risks for caregivers were minimal since the study

focused solely on decisions related to utilization of hospice or non-hospice services.

During the interviews, I compiled non-identifiable demographic information.

The results of the study are presented in an aggregated and non-identifiable form. Since the research is recorded and presented using fictitious names, the participants will be completely anonymous. Fictitious names are also used when providing information related to the caregivers and physicians.

Physicians

Physicians are “gatekeepers” in the hospice referral process. Although anyone can contact hospice and inquire about their services, a physician’s referral verifying an individual’s terminal prognosis of six months or less is required in order to receive hospice services. One reason for low service utilization by Hispanics may be related to provider referral (Talamantes and Espino 1995:40). I explored the role of physicians’ professional ethics, as well as the pressure to promote aggressive medical treatment, which may, in fact, conflict with the palliative nature of hospice care. Ten physicians in Central Florida Area were also interviewed to explore their knowledge and utilization and referral process.

While shadowing the hospice representative to local medical offices, I met several physicians; at this time the research topic was introduced. I recruited additional physicians with the assistance of a local hospital social worker. Physicians who were my acquaintances were also recruited to participate in the study. The physicians who expressed interest in participating in the interview asked me to schedule a meeting time with their office manager. Others asked me to return on a designated weekday during their lunch break or at five in the afternoon. The medical offices I visited had waiting

rooms crowded with patients. The physicians were treating unexpected medical emergencies and they were often delayed in local hospitals treating patients who were hospitalized. Seven of the scheduled interviews were cancelled and rescheduled two and/or three times. Scheduling these interviews required persistence, patience and flexibility. Despite the time consuming nature of the process it was necessary to effectively interact with the physicians' gatekeepers.

The data were prepared by briefly describing each of the thirty participants and by using quotes from their interviews to summarize and typify overall responses. Open coding and thematic categorization of the interviews' responses were included in the qualitative content analysis and translated interviews were analyzed seeking substantiate salience of themes across the sample. An inter-rater reliability process assured consistency of categorization of the meaning of analyzed data. Respondent quotes (not individually identifiable) illustrated important points of consensus or disagreement.

Archival Data

The quantitative portion of the research is a statistical analysis of existing archival data of utilization of hospice services by Hispanic/Latinos. This archival data was obtained from the organization's database. The director of Technological Services provided the research intern with training on how to access, manage and run queries from the data base program that stores data on former patients and families served. I will perform a statistical analysis of existing archival data on Hispanic/Latino patients served by the hospice from August 2002 to June 2006. The existing archival data supplemented and established the representativeness of my interview population. Patterns in utilization of hospice services according to ethnicity, diagnosis, age, payer source, advance

directives, gender, level of education, religion, income, marital status, language preference, and the number of caregivers were analyzed. The analysis includes length of stay in hospice, referral source and primary caregiver. This analysis enabled me to acquire demographic information related to the previous utilization of hospice services among Hispanic/Latinos.

I conducted a statistical analysis of 3123 Hispanic/Latino former hospice patients using the Statistical Package for the Social Sciences 15.0. The analysis included descriptives, frequencies, and correlations sought out trends and patterns of utilization of hospice services by Hispanic/Latino individuals. Quantitative data was compared with the (SPSS) results.

Data Analysis

A mixed methodology allowed me to triangulate the data collected from interviews, ethnographic participant observations, and archival data. The method of “triangulation always improves the quality of data and the accuracy of ethnographic findings” (Fetterman 1998:95), and contributes to the significance of research findings. It also allowed for integration of the statistical analysis of the archival data.

This mixed methodology enabled me to intertwine the depth of rich content from the individual interviews and the findings based on structured analysis of the responses from hospice and non-hospice caregivers in the data analysis. Verbatim transcripts of twenty-nine audio taped semi-structured interviews were analyzed through a combination of ethnographic and content analysis. One semi-structured interview was analyzed by reviewing interview notes, since participant declined for the interview to be recorded. While these two methods are often described separately, their combination--the

utilization of both systematic tallying and close readings of direct quotations--is believed to enhance the strength of interpretation (Morgan 1990, Ely 1993).

The data from the interviews was analyzed, seeking themes and identifying trends related to the utilization of hospice services, support systems, and barriers to healthcare. According to Ely (1993), as such themes were identified, the transcripts were re-coded to examine other mention of these themes. Through this process, I was able to both explore for undefined domains and to expand and fill-in as matches were found for expected results within the observed results (Schensul et al. 1999).

The results are presented from an anthropological perspective providing a voice for the terminally ill Hispanic/Latino individuals. By “investigating the cultural underpinnings of belief and practices associated with various universal life stages it will provide important information that will help us understand both cultural variation and the reasons for the continuation of such cultural practices” (Whiteford and Bennett 2000:126). The findings of this study are designed to underscore and to identify critical areas for further inquiry. Particular focus is on comparing the data collected from hospice and non-hospice Hispanic/Latino caregivers of terminally ill individuals. Analysis and reporting included integration of data from both qualitative and quantitative approaches.

Ethical Considerations

As a former employee of four hospice organizations in Florida, I had some prior knowledge about the inner workings of hospice organizations; awareness of significant ethical issues is crucial. However the agency has tripled in size since my employment and has change drastically. It was critical for me to be aware of my previous and existing

partialities. For instance, my present role as a researcher was distinct from my former role with these organizations as clinical social worker, supervisor, and manager. Maintaining boundaries and objectivity was essential to the research especially when employees I had worked with acknowledged my presence and inquired about my role as a researcher. Some of the employees felt comfortable to express their thoughts and ideas about the organization while others felt my research would make them work harder in the future. In conducting this research, it was essential for me to also be cognizant of the fact of doing “native anthropology” according to Delmos J. Jones in “Doing Native Anthropology” (1970) and the potential conflicts for the researcher as well as for those participating in the research.

There were no known risks or difficulties with the target population as respondents. The risks were minimal since the study focused on decisions related to utilization of services with caregivers only. Interviews were conducted in the participants’ primary language to decrease the potential for researcher bias and to preserve original meaning. Each interview was conducted on a single occasion. No ethical or programmatic concerns occurred with regard to the target population or data collection methods.

Although the study aimed to assess the factors that enabled the Hispanic/Latino patients to access hospice services, the interviews were conducted with the patients’ caregivers and not with the patients due to their vulnerable status. As a result, interviewing the caregivers provided the caregivers’ perspectives and not necessarily those of the patient. A portion of the study is also limited to caregivers utilizing hospice

services with one local hospice, which is a non-profit organization in the Central Florida Area.

The database from which archival data was obtained on Hispanic/Latinos served by hospice was not a comprehensive representation since ethnicity is not always entered into the patient's data profile. The research is limited to a specific geographic area and therefore generalizing findings may have some difficulties. Non-hospice caregivers of terminally ill individuals were identified as a result of "snowball" sampling, and this process introduces bias because the technique itself reduces the likelihood that the sample will represent a good cross section from the population. The sample of non-hospice population was difficult to obtain due to the nature of the required sample. A component of the study included interviews with ten physicians randomly selected in order to assess the hospice referral process. The random sample may not be reflective of the physicians providing medical care to Hispanics/Latinos or actively referring to hospice. Finally, although there are other populations that underutilize hospice services, this study focuses and is limited to the Hispanic/Latino population.

Protecting Confidentiality

The Institutional Review Board at the University of South Florida and of the hospice organization approved this study. Data will be stored with fictitious names in locked, secure metal file cabinets in the researcher's residence within the purview of only the researcher. Electronic data will be protected on an external hard drive for the purpose of storing research material with its own password. A software firewall and a hardware firewall built into the network devices will be used for security. A program "Sure

Delete” ensures that after files are deleted they are permanently and completely deleted from the hard drive.

Chapter 5

Results

General description of data

I interviewed a primary sample of a total of 20 Hispanic/Latino caregivers in the Central Florida area. The caregivers were either family members or professional caregivers of terminally ill Hispanic/Latino individuals. Ten of those interviewed were caregivers of hospice patients and ten were non-hospice caregivers. The hospice caregivers were recruited from a local hospice organization. A convenience sample was used to recruit participants in the research study, due to the sensitivity of the research topic and specificity of the population. The ten non- hospice caregivers were recruited by utilizing a “snowball” sampling technique. Ten physicians in the Central Florida area were also interviewed in order to gain knowledge about their perspectives about concerning hospice services and their roles in the hospice referral process with Hispanic/Latino individuals.

The questions used in the semi-structured interviews were derived from the research questions and were developed by the researcher. They were designed to elicit information on beliefs and understanding of hospice concepts, services and its utilization from the perspective of hospice caregivers, non-hospice caregivers and physicians. This research attained information related to the respondents’ understanding, experiences, and diversity of perspectives regarding on the utilization of health care services. Since Hispanic/Latino individuals are not dispersed equally within the county in which the study was conducted, the sample is intentionally small, yet “representative” of the

regional population. This research also involved the review of hospice printed documents such as newsletters, forms, information packets and participant observation data in order to understand and explain social phenomena of hospice services.

Hispanic/Latino people in the Central Florida area also do not constitute a homogeneous population but rather are diverse and are made up of individuals who are of Cuban, Mexican, Puerto Rican, Central and South American background, as well as other individuals of pan-Hispanic origin. This diversity appeared to have a bearing upon hospice utilization and preference. These demographics are noted in discussions related to qualitative findings for comparative purposes with regard to hospice utilization and preference. The study was designed to help me understand the people and the social and cultural contexts within which they live. The aim of the semi-structured interviews was to understand the hospice phenomenon from the points of view of the participants and their particular social and cultural perspectives. All of the interviews were conducted in Spanish when the caregivers indicated that Spanish was their language of preference. Eight out of ten hospice caregivers' interviews were conducted in Spanish and all of the ten non-hospice interviews were conducted in Spanish. Three out of the ten physicians interviewed self-identified as Hispanic/Latino and those three interviews were conducted in Spanish.

The data from the three sets of interviews were analyzed by seeking identifying themes and patterns related to the utilization of hospice services, support systems and barriers to healthcare. All of the participants in the three sets of interviews agreed to allow the interview to be audio taped with the exception of one non-hospice caregiver. The interviews were transcribed for analysis. I compared the interview responses of

hospice and non-hospice users data between hospice and non-hospice users among Hispanic/Latino caregivers of terminally ill individuals. The physicians' interviews were examined to identify trends seeking trends in medical practice, knowledge of hospice, criteria used to prompt referrals to hospice and overall hospice utilization perspectives. An examination of patient and physician data allowed me to identify patterns, make comparisons and establish answers, which will facilitate responses to the research questions.

The quantitative portion of the research is a statistical analysis of existing archival data of the utilization of hospice services by Hispanic/Latino patients served by a hospice in the Central Florida area from August 2002 to June 2006. The archival data was obtained from the organization's database, which stores data on former patients and families served. The overall data set included all individual served by hospice services during this period. The results represent a mixed-method integration of data from both qualitative and quantitative research approaches.

Structural organizational barriers to hospice utilization

Conducting research in the capacity of a research intern included extensive participant observation. I shadowed hospice team members, which included a primary nurse, patient family counselor, chaplain, certified nurses' assistant and hospice physician to as they visited patients in their homes, in hospice house, in the hospital and in a nursing home. Visits with hospice hospital nurses, a hospice hospital social worker, admission nurses and a public relations representative greatly enhanced my knowledge and understanding of the broad range of services offered.

I attained valuable insights while accompanying the public relations representative for two days, a total of sixteen hours. The primary function of the hospice representative is marketing or outreach to assure that all potentially eligible patients receive the necessary care. I observed the representative's daily interactions with physicians, nurses and administrative staff in medical offices and in hospitals. During these visits the representative educated office staff, nurses and physician about hospice services and its benefits to their clients. The representative also reviewed patients' medical records including diagnoses and assisted the physicians in determining whether a patient met the criteria for hospice services. The exchanges between the representative and the physicians were often extensive and at times brief. When a referral was made by a physician it often entailed numerous telephone calls to the admissions office of the local hospice to explore eligibility criteria for the specific diagnosis. Often during our visits the exchanges consisted of a physician and their staff expressing frustrations with patients who declined hospice services despite having a terminal diagnosis. The discourse related to Hispanic/Latino patients and the referral process was insightful. During one of our visits to a medical office, a Cuban born office manager asked the representative "can you assure me that this 82 year old Cuban [born] man that the physician wants to refer to hospice gets a Spanish speaking nurse if we refer him to you? I'm trying to convince his 80 year old Cuban [born] wife to agree on hospice for her husband but she does not want anyone who she does not understand in her home". The representative nodded her head, and it was apparent that she had heard similar requests in the past. She gently stated, "We would do our best to meet the patient and families needs". The office manager was insistent and repeated "in this case a Spanish-speaking nurse is what they really need, the

wife brings the patient to this office every week. She drags him here and they sit here for hours and wait to be seen, neither of them could walk instead shuffle. The doctor can't see him weekly, sometimes the nurse talks to both of them, does the best she can and sends them home, but next week they're here again. You know the doctors are very busy, he tells me to handle them. I was waiting for you to come by, to see if you can help". The representative inquired about the patient's zip code and proceeded to determine if there was any Spanish speaking person on the team that served the patient's geographic area. She agreed to follow-up on the medical assistant's request and to assist the patient in need of hospice services. When we exited the office, the representative acknowledged that the office manager's request was a common one.

The incident with the office manager and the hospice representative motivated me to inquire about the number of Spanish-speaking field nurses employed to serve the county. I learned that there were two Spanish-speaking nurses employed to serve the county in which the patient resided. The hospice representative explained the dilemmas experienced when a request for a Spanish-speaking nurse is made. I observed that the office manager's question was not answered directly, yet assurances were made that the patient's need would be met. When the office manager (who is a referral source) firmly emphasized the request for a Spanish-speaking nurse, details were provided about Spanish-speaking team members and the translation services provided to assure that the patients' needs are met.

While shadowing hospice non-Spanish speaking social workers and chaplains, the need for Spanish-speaking social workers was also apparent. I was asked to translate for patients, family members and for the non Spanish-speaking team members. Throughout

my internship, and data collection phase and after even *after* my data collection phase, I received telephone calls from non Spanish-speaking social workers requesting that I visit Spanish-speaking patients with them in order to translate. They were aware of my interest in shadowing team members, my research and the interviews I was conducting for my research, but foremost they needed someone to assist them in communicating with non-English speaking patients and families regarding emotional and mental health issues. Essentially they needed someone to function as a translator. Due to the crisis nature of many of the visits and the emotional upheaval in the families' lives, I was often not able to conduct interviews for the research, yet assisted the patients and families by functioning as a translator for the staff member. The communication barrier between hospice care providers and patients and families occurred in home visits and continued to emerge throughout the hospital visits.

The need for translators was also apparent in the administrative offices throughout the county with the exception of the executive office. I spent several days in the various offices participating in team meetings and becoming acquainted with the staff. Whenever I was in the offices, I heard constant overhead pages stating " Spanish caller on the line, can a Spanish speaker please pick-up". One morning I decided to count and there were eight calls within an hour and half. The need for Spanish-speaking staff and assistance was evident.

Since the request for a Spanish-speaking nurse continued to linger in my mind I decided to telephone the two Spanish-speaking nurses on staff. I introduced myself and expressed my interest in shadowing them to the homes of Hispanic/Latino patients. Both of them informed me that they did not have any Spanish-speaking patients on their

caseload at that time. They encouraged me to contact the two Spanish speaking patient family counselors employed within the organization. I established contact with one of the patient family counselors and visited various Hispanic/Latino patients. The counselor I shadowed provided counseling to patients and families on five different teams including a hospice house throughout the county, unlike the non-Spanish-speaking patient family counselors who serve on one geographic team only.

One afternoon while observing the staff interaction in one of the administrative offices, one of the Spanish-speaking nurses greeted me and inquired about the details of my research. I was pleased about the expressed interest in my research and proceeded to eagerly provide a brief sketch of my project. The nurse immediately responded “your research is what caused me to stop visiting my patients today. I schedule my patients’ visits a week in advance, but today I had to stop and go do an admission for a Spanish-speaking patient”. The tone of the response shocked and puzzled me yet I remained calm and quiet. The nurse proceeded to express how it was not fair to cancel visits with existing patients as well as the stating the urgent need for more Spanish-speaking nurses, social workers and overall staff. The nurse added “I only get one thousand dollars a year extra for being bi-lingual, I’m going to go to human resources and ask them to take their money”. I apologetically informed the nurse that I was just beginning my research and that I sincerely doubted that my presence had such direct impact on the organization’s functioning and decision-making. I later learned that the other Spanish speaking nurse had indeed followed through and requested for Spanish-speaking \$1000.00 a year incentive be removed from their human resources deduct from their salary. Spanish-speaking office staff also receives the same amount of reimbursement for answering

Spanish-speaking calls, translating for staff on the phone and walk-ins. The Spanish-speaking office workers who are near a hospice house also leave their workstation to translate as needed. Several of them expressed frustrations due to the constant interruptions throughout the day and hours of lengthy translations related to patient and family issues. These observations and interaction highlighted the service gaps within the organization.

On another occasion when I visited a hospice hospital social worker, I was asked to assist by performing the function of a translator for a Puerto Rican patient who had recently been admitted into the hospice program while in the hospital. It was reported that neither the patient nor the family spoke English. The fifty six year old patient had been admitted to the hospital due to severe abdominal pain and after a week of extensive medical examinations the family was informed that the patient had stage-four stomach cancer. The patient's nuclear and extended family crowded the hospital hallway since only two visitors were allowed at the patient's bedside at a time. All precautionary measures were also in place for this patient. Everyone who visited the patient, staff and visitors alike, were required to wear gloves, a gown, a head cap, shoe covering and protective eyewear in order to protect both the patient and the visitors from an infectious disease. When I entered the patient's room after putting on all the required attire, I immediately heard the patient groaning and moaning in pain. Her hands were placed on her abdomen and in Spanish said "dolor" (*pain*) repeatedly. The hospice hospital social worker asked that I assess the patient's level of pain in Spanish by inquiring the patient's pain level 1 through 10 by asking the patient about her pain level using a scale of one through ten. When I indicated that the patient stated her pain level as ten (the highest) the

Social worker immediately contacted the nurse and pain medication was administered. We left the room in order to allow the patient's pain medication to take effect before we would attempt to talk to her again. We waited half an hour before we repeated our extensive precautionary measures of head cap, gloves, gown, protective eyewear and shoe covering and entered the patient's room again.

The hospice hospital social worker's goal was to determine whether the patient would agree to be discharged to the hospice house instead of her home in order to allow hospice nurses to manage her pain effectively prior to returning to her home. I learned this option is often recommended when the patient's pain is severe and not controlled at the time of the hospital discharge. Hospice house also functions as a place of transition from the hospital in order to allow individuals and family members to plan accordingly regarding caregiving issues.

I asked the patient in Spanish about her willingness to go to a nearby hospice house upon discharge. The patient responded by asking that we wait for her daughter to arrive. She stated, "Whatever my family decides will be fine with me". I continued in my role as a researcher/ translator during that morning when we also met with the patient's sister and daughter. During that time I learned that the patient was not aware of her diagnosis and that the family had agreed not to share it with her. Her daughter asked for the hospice hospital social worker to arrange a meeting with the physician in order to explore discharge plans.

It was obvious that the patient's daughter did not want to solely rely on the hospice hospital social worker regarding discharge planning. I translated for the hospice hospital social worker who gently reminded the patient's daughter that the patient was

admitted into the hospice program and that it was her role as the hospice hospital social worker to facilitate the discharge plan. The patient's daughter was not satisfied with her response and stated "I want to know what else the doctor can do for my mother before she leaves the hospital". The hospice hospital social worker elicited the assistance of the hospice hospital admission nurse to reiterate the role of hospice and why her physician had referred her mother to hospice. I was now in the midst of translating for both the nurse and the social worker.

Upon the patient's daughter insistence a discharge-planning meeting was arranged with the physician in which hospice services and function were further explained to the patient's family. The scenario that I observed illustrates multiple factors related to Hispanics/Latinos regarding hospice, end of life considerations, and a terminal diagnosis. I repeatedly observed the complexities regarding language barriers, limited understanding of the hospice referral process, lack of knowledge of hospice services and family members protecting patients regarding their diagnoses. I also observed lack of cultural sensitivity and understanding.

The results of the thirty interviews I attained will provide my research greater depth of understanding and will contextualize my observations in patients' home, hospital visits and in office setting. These data enabled me to identify patterns between the hospice caregivers, who were interviewed as well as the patients they cared for. The demographic data also illustrates patterns of the potential barriers to hospice utilization within the Hispanic/Latino community.

Demographic data on hospice caregivers and patients

The demographic data on hospice caregivers and patients in Table 1 includes the fictitious names of ten hospice caregivers and four secondary caregivers. The patients' demographic data indicated below is provided by the caregivers and at times by patients themselves. I used numbers to identify the hospice patients. The demographic data attained from the caregivers includes: age, gender, place of birth, length of time in the United States mainland (e.g. generation), income, religion, marital status, level of education, language preference and number of caregivers at home. The demographic data attained about the patient is the same as the data attained from the caregiver with the inclusion of their health insurance source, community services used and presence of advance directives.

Table 1. Demographic Data Information on Hospice-Caregivers/Patient

| Caregiver/ Patient/2 nd CG | Age | Gender | Place of birth | Length of time in the U.S. | Religion | Marita l status |
|--|----------------|-------------|-------------------------------------|----------------------------------|--------------------------------------|--------------------|
| 1 - Kayla 1- PT 1 | 47 82 | F M | Dominican Rep. Dominican Rep. | 20 yrs 20 yrs | Protestant Protestant | M W |
| 2 - Nina 2 - PT 2 2 nd CG Maria | 31 89 54 | F F F | US-PR Cuba Puerto Rico | 31yrs 45 yrs 54yrs | Protestant Catholic Protestant | S W D |
| 3 - Ana 3 - PT 3 2 nd CG Juan | 47 73 52 | F M M | Peru Peru Cuba | 7yrs 2 mos. 4 yrs | Catholic Catholic Catholic | M M M |
| 4 - Lola 4 - PT 4 | 20 53 | F F | US-Colombian Colombian | 20 yrs 20 yrs | Catholic Catholic | S S |
| 5 - Jenny 5 - PT 5 2 nd CG Lana | 43 64 56 | F F F | US-PR Puerto Rico Puerto Rico | 43yrs 49 yrs 56yrs | Catholic Catholic Catholic | M W M |
| 6 - Dominga 6 - PT 6 | 70 64 | F M | Puerto Rico Puerto Rico | 62 yrs 62 yrs | Protestant Protestant | M M |
| 7 - Lucy 7 - PT 7 | 49 78 | F F | Dominican Rep Dominican Rep | 40 yrs 50 yrs | Catholic Catholic | D D |
| 8 - Angela 8 - PT 8 | 47 98 | F F | US-Cuban US-Cuban | 47 yrs 98 yrs | Protestant Catholic | D W |
| 9 - Lisa 9 - PT 9 2 nd CG Liz | 63 87 68 | F F F | Cuba Cuba Cuba | 35 yrs 35 yrs 35 yrs | Catholic Catholic Catholic | D W M |
| 10 - Luz 10 - PT 10 | 75 87 | F M | Puerto Rico Puerto Rico | 32 yrs 32 yrs | Protestant Protestant | M M |

Table 2. Demographic Information on Hospice-Caregivers/Patient part 2

| CG/PT/ 2nd CG | Income | Level of Education | Language Pref. | Relationship To Pt. | Payer Source | Adv. Dir. |
|-------------------------------------|----------------------------|---|-------------------------------|--------------------------------|-------------------------|----------------------|
| CG 1 PT 1 | 30,000 10,000 | 16th 12th | Spanish Spanish | DGT | Medicare | None |
| CG 2 PT 2 2 nd CG | 25,000 30,000 25,000 | 12 12 th 5th | English Spanish Spanish | PD PD | Medicare | None |
| CG 3 PT 3 2 nd CG | 8,000 0 10,000 | 5 th 3 rd 8th | Spanish Spanish Spanish | DGT SIL | None | None |
| CG 4 PT 4 | 15,600 0 | 14th 4th | Spanish Spanish | DGT | None | DNRO /LW |
| CG 5 PT 5 2 nd CG | 21,000 10,000 13,200 | 11th 5th 8th | Spanish/Eng Spanish | DGT SIS | Medicare | DNRO |
| CG 6 PT 6 | 9,972 11,100 | 5th 8th | Spanish Spanish | Wife | Medicare | DNRO |
| CG 7 PT 7 | 8,000 10,000 | 12th 8th | Spanish/Eng Spanish | DGT | Medicare | LW |
| CG 8 PT 8 | 0 10,596 | 12th UKN | English Spanish | GD-DGT | Medicare | None |
| CG 9 PT 9 2 nd CG | 18,000 13,200 18,000 | 6 th 3 rd 6 th | Spanish Spanish Spanish | DGT DGT | Medicare | None |
| CG10 PT 10 | 11,000 11,000 | 12 th 12th | Spanish Spanish | Wife | Medicare | DNRO /LW |

The results in **Table 1** and in **Table 2, Demographic Information on Hospice-Caregivers**, illustrate patterns about Hispanic/Latino caregivers and the hospice patients they care for. The ages of the ten caregivers vary significantly. They range from 20 years of age to 75 years of age, making the median age to be 49.2 years. The youngest

hospice patient is 53 years of age and the oldest is 98 years of age, the median age is 76.7 years. All of the primary hospice caregivers were females and three out of four of the secondary caregivers were also female. One of the secondary hospice caregivers is male and is the patient's son-in-law. Four of the patients are male and six are females. Five of the primary hospice caregivers are the patients' daughters, one a granddaughter; two are wives and one is a paid caregiver. Three of the secondary hospice caregivers are the patients' daughters, one is a sister and another a paid caregiver.

There are four caregivers who self-identified as Puerto Rican; two were born in the United States mainland and two were born in Puerto Rico. Two primary caregivers were born in the Dominican Republic, one born in Peru and one in Cuba. Two were born in the USA and self identified as Cuban-American and one as Colombian-American. There were a total of four secondary caregivers; two were born in Puerto Rico and two in Cuba.

The length of time in the US varied widely among the hospice caregivers. Ana age 47 has lived in the US for seven years making her the primary caregiver with the least amount of years living in the US. Dominga age 70 has been residing in the US for 62 years, making her the caregiver with the most years of residence in the US. The median length of years in the US for the hospice caregivers is 35 years.

Five hospice caregivers identified their religion as Catholic and five as Protestant. Three secondary caregivers identified their religion as Catholic and one as Protestant. Seven of the hospice patients identified their religion as Catholic and three as Protestant. The marital status of the hospice caregivers is the following: five are married, three are

divorced and two are single. Five out of the ten hospice patients had been widowed; three married, one divorced and one was single.

The median annual income among the ten primary hospice caregivers is \$14,657, and \$10,586 for hospice patients. The highest income of one hospice caregiver and of one hospice patient is \$30,000. Two of the hospice patients and one hospice caregiver indicated having no income. According to the US Census Bureau, Poverty Guidelines, Research and Measurement page for 2007 the household the annual income for one person is \$10,210, for two-person household it is \$13,690 and for a three-person household it is \$17,170 (<http://aspe.hhs.gov/poverty/07fedreg.htm>). Four of the hospice caregivers and four hospice patients meet the guidelines for poverty.

The educational level of the caregivers and patients varies. One of the caregivers is a college graduate, one is in her second year of college, four graduated from high school, one reached 11th grade, one 6th grade and two completed 5th grade. Among the hospice secondary caregivers, two completed 8th grade, one 6th grade and one 5th grade. The hospice patients' educational level was as following follows: three high school graduates, two 8th grade, two 4th grade and two 3rd grade and one unknown. Spanish is the language of preference for eight out of ten primary hospice caregivers. Two caregivers reported fluency in English although they preferred to speak Spanish. English is the language of preference for two caregivers. The four hospice secondary caregivers reported Spanish as their language of preference.

Eight of ten of the hospice caregivers reported that Medicare was the primary health insurance for the individuals they cared for. Primary caregiver 3 from Peru did not have a legal documented status; however, her father PT3 did have legal resident

status. PT4 did not have a legal documented status. Both of these patients did not have health insurance. PT4 relied on non-profit community services for medical treatment. Four out of ten hospice patients have advance directives. Two patients have both a “do not resuscitate order” (DNRO) and a living will (LW). One patient has a DNRO and one has a living will.

Perspectives from hospice caregivers

Upon hearing a terminal diagnosis the reaction of Hispanic/Latino individuals and their families was one of shock and distress. Twelve questions were asked using a semi-structured interview with the ten hospice caregivers. During some of the interviews the hospice patient chose to be present during the interview. The following are the questions explored during the interview. The questions were derived from the literature as having probable significance to Hispanic/Latino individuals and families as a basis for the interviews.

**1. When did you first learn about the patient’s diagnosis?
Potential response: six months, one year or two years ago?**

Hospice provides services to individuals who have a terminal prognosis of six months or less. The services for an individual who has a diagnosis of six-months or less includes medical personnel, equipment, medications related to the terminal diagnosis and medical consultations for individuals who meet the criteria. Individuals who have a prognosis of one year or less are provided medical personnel only. Once their health declines and their physicians determine that they meet the criteria of six months or less, they immediately qualify for the full array of hospice services.

Three out of ten hospice patients learned about their diagnosis more than one year ago and three out of ten patients learned about their diagnosis one year ago. Two out of ten hospice patients learned about their diagnosis six months ago. One patient learned about her diagnosis two months ago and one patient eight months ago. All of the hospice patients were eligible to receive hospice services earlier than they did.

The following two responses from hospice caregivers illustrate these findings.

I learned that my father was very sick from my sister who lives in Peru, this all happened when he went to get his passport, they gave him a physical; this was just six months ago. He went to the hospital in the Capital and all sorts of exams were done on him. (Ana, 47 years old, born in Peru).

He became sick while we were on vacation, he been on dialysis for eight months, we went to the emergency room, in another county, he was hospitalized there for one week, a social worker told us about hospice there. He got a little better, came home and was hospitalized again another social worker here told us about hospice again (Dominga 70 years old, born in Puerto Rico).

2. Who informed you about the patient's diagnosis?

Potential response: Primary physician, oncologist or hospital physician

Their primary physicians informed three patients about their diagnosis, two were informed of their diagnosis by an oncologist and five by a hospital physician when the patients were hospitalized.

My mother collapsed one day when she was cleaning offices, that was her night job and they called 911, took her to the hospital, they did three surgeries they found that the cancer spread all over her back and everywhere. The doctor spoke to my mother but mostly with her cousin, she was out of it. She told the doctor to do whatever, later she told me that he said to her, 'I did my best and that hospice would help her when she got home'. I did not know anything that was happening in the hospital until my godmother told me in her house what was going on (Lola 20 years old, US born-Columbian).

Lisa age 63 and Liz age 68 Cuban born stated:

She was not feeling well so we called her doctor, she sent her to the hospital there. They said she had a stroke and something else wrong with her heart from there they called the hospice program. Before she got her the hospital bed, equipment and medicines were here. They behaved very good with us.

3. What treatment did he/she receive after his/her diagnosis?

Potential response: chemotherapy, radiation or none

Two patients received chemotherapy one of whom also had three surgeries after they learned about their diagnosis. One received radiation, one dialysis, two oxygen and medications, two blood pressure medication, one pain medications and one no treatment.

When interviewing the caregiver, the following two patients interjected and discussed the treatment they received in this manner.

A friend I had been also in treatment told me where to go, he said the doctor there can help you. I went and they did chemotherapy on me too (82 year old male patient born in the Dominican Republic).

When I was applying for a visa and underwent a complete physical. I had to render all the truth; they ordered that I get all the laboratory test including blood work and chest X-ray. The doctor told me that she saw a white spot on my lung and told me it was a tumor or could be cancer. After everything she said that it was cancer I did not receive chemotherapy (73, year old male patient born in Peru).

4. Who assisted the patient in his/her decision about treatment options?

Potential response: physician, caregiver or friend

Five caregivers reported that the hospital physician assisted the patient in deciding their treatment options. Two oncologists assisted two patients in determining their treatment options. One caregiver reported that a primary physician assisted the patient.

The treatment options presented included hospice services. One caregiver and one paid caregiver requested hospice services on behalf of the patient. Two caregivers describe the treatment option process in this way:

My mother's doctor talked to us about her diagnosis and gave her all the medications for her heart (Jenny, 43 years old, 1st generation US born Puerto Rican).

We did. As her full-time paid caregivers, we noticed her decline. She stopped doing things by herself. I had other patients on hospice, initially her son did not want hospice, but then he agreed. No family members are involved; her son may visit once a month (Nina 31 years old, 1st generation US born Puerto Rican and her mother Maria, 54 years old, born in Puerto Rico).

5. How did you learn about hospice services?

Potential response: physician, friend or health care professional

Four caregivers learned about hospice from physicians, two from friends, two from prior experience with hospice, one from one from a hospice hospital nurse and one from a hospital social worker. Although the hospice caregiver group is currently utilizing hospice services, three out of ten hospice primary caregivers who participated in the research had prior knowledge about the hospice organization and the services they provide. One out of four secondary caregivers had prior knowledge about the hospice organization and the services provided. Nina, a primary paid caregiver and Maria, a secondary paid caregiver indicated prior knowledge about hospice services because they are professional health care providers. Lucy's experience with hospice was as a result of having two non-Hispanic/Latino relatives who utilized hospice. Angela first learned about hospice from two of her non-Hispanic/Latino friends who utilized hospice services. Nina and Angela both indicated that English was their language preference and Lucy

reported comfort in communicating in English because her ex-husband was non-Hispanic/Latino.

Seven primary caregivers and three secondary caregivers in the research indicated that they learned about hospice from doctors, nurses and social workers when the patient was admitted to the hospital. The following accounts are from the two hospice caregivers who identified English as their language of preference.

I learned about hospice from my ex-father in law and my ex-father in law's mother. Not a lot of Latino people use hospice; like I said all my ex-in-laws are White who used it" (Lucy, 49 years old, born in the Dominican Republic)

Angela, 47 years old, born in US- 3rd generation Cuban stated:

I heard about hospice through other people like my boyfriend's sister-in-law who is a nurse; they told me about hospice and everything, and a friend of mine, his father died about 6 years ago and they had hospice too [both are non Hispanic/Latino]. So I'm like, 'ok I need help, send somebody here, I can't do this by myself and I can't afford it any other way, I need help'.

6. How long did it take you to begin receiving hospice services after the initial diagnosis?

Potential response: immediately, one day or one week

Seven caregivers reported that they received hospice service immediately once the patient decided to receive hospice services and three patients waited one day for services to begin.

7. Did you encounter any barriers to getting connected with hospice?

Potential response: yes, no or some

Five caregivers reported having difficulties and the patients present in the interview discussed the area in which the difficulties occurred. Five reported having no difficulties. The accounts highlight the barriers experienced by the caregivers.

I have problems understanding when they call in English, I just say yes when I hear the word hospice (82year old male patient born in the Dominican Republic, 20 years in US, high school graduate).

Ana, age 47 born in Peru, 7 years in US, 5th grade education said:

Yes, I speak only a little English; a lady in admissions helped a lot (Yes, with the nurse, but I have a Spanish speaking social worker even though I don't have papers (53 year old female patient born in Colombia, 20 years in US, 4th grade education)

A 64-year-old female patient born in Puerto Rico, 49 years in US, with maters degree noted:

Yes, you see, I speak limited English; I have a lot of barriers with the language. It is good that I have a lot of family around

This account details a series of events that occurred as a result of language barriers. Such barriers are reflected in the story told by Dominga born in Puerto Rico, 62 years in US, 5th grade education:

Yes, I had language barriers with nurses and social workers, one night at 12 o'clock [midnight] a white man knocks on my door and said he was a nurse that he was here to help me; I was scared. I told him to go away, but he did not. I waited a little bit, looked through the peephole and there he was. I said "Go away, go away", I did not want to talk too loud. The next thing I know the phone rings and they were saying something, a lot of things I did not understand then I heard the word hospice, I did not know what they were saying so I hung up. My husband woke up, I told him to go back to sleep. You see if he wakes up it is hard for him to fall back to sleep, then he is up all night and I'm all night with him. I called my daughter quietly and told her about the White man in my front door passing for a nurse and the telephone call with somebody saying the word hospice. She said "Mom don't worry I'll find out what this is about". I don't like to bother my daughters especially at night; they work all day and have their own families. But they tell me to call at anytime. My daughter said she was going to call the office. She told me to wait a little while and then to call her back. When I called her back, she [my daughter] said that my nurse, I mean my husband's nurse ordered a night nurse. I told her [my daughter] I did not order a night nurse. She said that

the day nurse ordered a night nurse. She [my daughter] told me to let the man in. I was so nervous, a man I don't know in my house with my husband being sick. My daughter remained on the phone with me, she said, "Mom, let him in, hospice sent him". He wanted to go into my bedroom and watch my husband sleep. I can't sleep with a stranger watching me. My daughter spoke to him and told him to sit in the living room. He sat down, I went to the room but I could not sleep knowing there was a stranger in the house. When it got light outside I sent him home. I felt bad, I don't want to take food out of his mouth but I was so tired I could not sleep with him sitting in the living room.

8. Who else helps? How many family members live in this area? What kinds of help do you get from family or friends?

Potential response: family, community services or friends

Four caregivers reported that they receive help from family and friends in caring for the patient. One out of the four caregivers also receives assistance from two community services. Three of the four caregivers have daughters who live in the area and one caregiver has a son. The three caregivers who have daughters also have nephews, nieces and cousins who assist them in shopping for groceries, taking the patient to medical appointments and caring for the patient. Two out of the four caregivers have friends from their church that assist them with yard work, running errands and providing visits. The other two caregivers have at least three friends who help by providing transportation, visits and emotional support. Three out of the ten caregivers rely solely on the secondary caregiver to assist with the patients' care. Three out of ten caregivers do not receive help from anyone, although one of them has a father and the other has an uncle and two brothers residing in the area.

These statements demonstrate the range of responses regarding family involvement.

No one, I'm the only granddaughter, my father is the only child but he is busy caring for his wife. She has two sisters in the area but they are also

very old. My boyfriend helps sometimes (Angela 47 years old, US- 3rd generation Cuban and caregiver for PT8)

Daughters, nephews, brothers and sisters in total eight, they take her to doctors visits, go to the pharmacy, keep an eye out for how she is doing, go grocery shopping, they do whatever she says she needs. She is never alone, or lacks of nothing (Jenny 43 year old, US 1st generation Puerto Rican and caregiver for PT5).

My husband and I alternate caring for my father. I work days and he works nights. We have no family members in this area that can help, we have some older sick family members here (Ana, 47 years old, born in Peru and caregiver for PT3).

Nobody, none of my children live nearby. I do all my housework I don't dare, if someone sees a woman come in the house, you know how people talk, my sister used to help me (PT1 82 years old, born in Dominican Republic).

9. Did anyone criticize you for seeking hospice help?

Potential response: yes, no or some

None of the caregivers were criticized for seeking hospice help. Nina and Maria (paid caregivers) reported, "Initially her son did not want hospice, but then he agreed".

Ana reported, "No, I thought it was difficult to access because I thought my father needed to be a citizen, he is only a resident."

Lucy stated that no one criticized her for utilizing hospice however explains how she feels when additional hospice services are offered to her.

Not a lot of Latino people use hospices; like I said all my relatives are White. Being Latin I'll be honest I never thought I would do this or be in this. But it has a lot to do that Latinos are always private or embarrassed to admit they need help. So they try to act like macho. I found my self at a point like that. The nurse is always offering help and I say I could do it, I could do it, but I may get to the point and ask for someone to sit here with her [the patient] because it is not easy.

10. How did receiving hospice services affect your relations within the family?

Potential response: none, some or a lot

All of the ten caregivers stated that receiving hospice service did not negatively impact their relationship with the family. Two caregivers reported that it actually helped their relationship. Dominga, age 70 reported “It helped because I no longer have to take him to the hospital” and Lola age 20 stated, “Everyone was in agreement.”

11. Would you recommend hospice services to a friend who needed them?

Potential response: yes, no or maybe

The ten caregivers reported that they would recommend hospice services to a friend and added that they would recommend it to a family member as well. It is reflected in the responses of why they would recommend hospice:

My father lives alone and I know he is getting checked on and the care he need (Kayla, 47 years old, caregiver for PT1, born in the Dominican Republic).

Lucy, 49 year old, born in the Dominican Republic stated:

The nurse when she comes she gives me more information on the medication and what hospice does, I don't get much from the doctors, me being ignorant of all this Medicare and what to do, it really helps me, it really does.

Both Angela 47 years old, US- 3rd generation Cuban and Dominga 70 years Puerto Rican caregiver described their responses by stating “surely, I'm more grateful to hospice than the hospital”. Consider the accounts related to areas of improvement of hospice services explained by six caregivers.

More Spanish nurses and more Spanish speaking people who can communicate with the Spanish-speaking people, there are many Spanish

elderly who do not speak English (Jenny, 43 years old, US-1st generation Puerto Rican caregiver for PT5)

Lucy, 49 years old, Dominican born caregiver stated:

A non Spanish speaking counselor came here for the first time when this all happened and she sort of started off talking about death and what were mom's expectations and asking what if she would die... I told her listen I did not let her know [mom] the extent of what is happening. When they first told her what they believed; she has a lot of issues. I did not want her to start freaking out it and commit suicide or something. She said... don't you think she needs to know and at what point, so that she could get ready and what point will you tell her, so she could get ready. I said no she is suffering from dementia, so all of this will not sink in anyway, but the counselor she kept prolonging the issue and about talking to her about it, I kept looking at her and I said respect what I'm saying in my house because I know what is best for her, you don't, It made me feel a little uncomfortable and I started getting a little weary about another counselor coming to my house, saying stuff I don't want her to say. You know but I handled it well. Mom did not understand what she was saying. I think us Spanish people need more information on what to expect and not to expect, that you are not going to cross a line you feel has to be there for whatever reason, that will help more. Like my father in law [White] they told him to expect to live a month but you can't do that to everyone. But my mother is different she may throw herself down the stairs you know.... A lot in the Spanish community don't know about hospice I didn't until my ex-father in law

For example Dominga, 70 years, old Puerto Rican noted:

The hospice white book, I do not understand it, it is in English. Two small booklets are in Spanish, one is about what happens when a person is near death and the other is the paper work on staying alive or not, I already have those papers.

12. What advice would you give to hospice providers in order to increase the number of Spanish speaking clients in the program?

Potential response: newspaper, radio or Spanish-speaking hospice workers

All of the caregivers provided three or more responses when asked what advice they would give hospice providers in order to increase the number of Spanish speaking

clients to the program. Newspaper and magazine advertisement was stated five times, radio advertisement eight times and television advertisement on Spanish television stations four times. The caregivers suggested that hospice providers communicate in Spanish with the Hispanic/Latino community about the benefits of hospice in churches, cancer support groups, aging services targeted to Hispanic/Latino older individuals, doctors' offices and health clinics. Flyers in the mailboxes of Hispanic/Latino individuals, inserts in free local Spanish newspapers and newsletters were also recommended. Jenny summarized the advice from the caregivers when she stated, "The word is out there in English but is not out there in Spanish"

Consider the recommendation described by Luz, a 75 years old Puerto Rican.

Go to the local medical clinics, provide patients and caregivers with information cards and when someone asks them [patients and caregivers] about the services they receive they can give them a hospice information card. We go to the clinics and every time somebody asks me about the care we receive, everyone can't go to the hospital for care. I would pass out cards if I had them, now I tell them to look up hospice in the yellow pages. I can't give anything from the book I have about hospice it is all in English.

Lisa, age 63 and Liz, age 68, sisters born in Cuba said:

We did not know anything about hospice until the doctor referred us. Word of mouth, existing patients and caregivers can share their positive experiences with others

Kayla, 47-year-old caregiver for PT1, emphasized the need and concern for Spanish-speaking staff in the context of a safety factor in this account:

I would recommend that hospice services be explained in Spanish and followed up with Spanish speaking nurses and counselors for those who need it, I worry that my father will let anyone in the house, that could hurt him, he lives alone. All my brothers and sisters are not around. PT1

interjects, “My children do not keep in touch. They think they are “big guy” and forgot about Papa”.

Table 3. Demographic Information of Non-Hospice Caregivers/Patient

| Caregiver/ Patient/2 nd CG | Age | Gender | Place of birth | Length of time in the U.S. | Religion | Marital status |
|--|-----|--------|----------------|----------------------------------|------------|-------------------|
| 1 - Tina | 62 | F | Puerto Rico | 18 years | Protestant | M |
| 1 - PT | 66 | M | Puerto Rico | 18 years | Protestant | M |
| 2 - Nick | 54 | M | Puerto Rico | 24 years | Protestant | M |
| 2 - PT | 44 | F | Puerto Rico | 41 years | Protestant | M |
| 2 nd CG | 43 | F | Puerto Rico | 25 years | Protestant | W |
| 3 - Rosa | 49 | F | Cuba | 10 years | Catholic | W |
| 3 - PT | 87 | M | Puerto Rico | 16 years | Catholic | W |
| 2 nd CG | 27 | F | Cuba | 10 years | Catholic | S |
| 4- Raquel | 47 | F | Cuba | 8 years | Catholic | W |
| 4 - PT | 85 | M | Puerto Rico | 70 years | Protestant | M |
| 2 nd CG | 28 | F | Cuba | 8 years | Catholic | S |
| 5 - Linda | 69 | F | Puerto Rico | 49 years | Protestant | W |
| 5 - PT | 87 | F | Puerto Rico | 5 years | Catholic | W |
| 6 -Haydee | 30 | F | Puerto Rico | 7 years | Catholic | M |
| 6-PT | 76 | M | US-PR | 76 years | Protestant | S |
| 2 nd CG | 28 | F | H/L diverse | Vary | Vary | |
| 7 - Liz | 32 | F | Puerto Rico | 6 years | Catholic | M |
| 7 - PT 7 | 84 | F | Cuba | 40 years | Protestant | M |
| 2 nd CG | 28 | F | H/L diverse | Vary | Vary | |
| 8 - Hazel | 28 | F | Puerto Rico | 9 years | Catholic | M |
| 8 - PT | 84 | M | US-Cuban | 40 years | Protestant | W |
| 2 nd CG | 28 | F | H/L diverse | Vary | Vary | |
| 9 - Fela | 75 | F | Puerto Rico | 5 years | Catholic | W |
| 9 - PT | 86 | M | Puerto Rico | 5 years | Catholic | W |
| 10 - Alice | 66 | F | Puerto Rico | 10 years | Protestant | M |
| 10 - PT | 49 | F | Puerto Rico | 10 years | Protestant | S |
| 2 nd CG | 69 | M | Puerto Rico | 10 years | Protestant | M |

Table 4. Demographic Information on Non –Hospice Caregivers/Patient part 2

| CG/PT/ 2 nd CG | Income | Level of Education | Language Pref. | Relationship To Pt. | Payer Source | Adv. Dir. |
|-------------------------------------|----------------------------|--|-----------------------------------|------------------------|-----------------|-----------------|
| CG 1 PT 1 | None 25,000 | 4 th 9 th | Spanish Spanish | Wife | Medicare | None |
| CG 2 PT 2 2 nd CG | 20,000 12,000 22,000 | 12 th 10 th 10 th | Spanish Spanish/Eng Spanish | Husband Paid | Medicare | None |
| CG 3 PT 3 2 nd CG | 50,000 8,400 6,000 | 13 th 12 th 12 | Spanish Spanish Spanish | Paid Paid | Medicare | DNR O /LW |
| CG 4 PT 4 2 nd CG | 50,000 10,200 6,000 | 14 th 12 th 12 th | Spanish Spanish Spanish | Paid Paid | Medicare | None |
| CG 5 PT 5 | 18,000 10,416 | 18 th 4 th | Spanish/Eng Spanish | DGT | Medicare | DNR O/LW |
| CG 6 PT 6 2 nd CG | 38,000 22,800 14,560 | 16 th UNK UNK | Spanish Spanish Spanish | Paid Paid | Medicare | DNR O |
| CG 7 PT 7 2 nd CG | 32,000 8,400 14,560 | 16 th UNK UNK | Spanish Spanish Spanish | Paid Paid | Medicare | None |
| CG 8 PT 8 2 nd CG | 30,000 22,800 14,560 | 16 th 12 th UNK | Spanish Spanish Spanish | Paid Paid | Medicare | DNR |
| CG 9 PT 9 | 30,000 22,000 | 6 th 8 th | Spanish Spanish | Paid | Medicare | None |
| CG10 PT 10 2 nd CG | 32,000 12,000 40,000 | 6 th 8 th 12 th | Spanish Spanish Spanish | Mother Father | Medicare | - |

The results in **Table 3** and in **Table 4**, Demographic Information on **Non-Hospice- Caregivers**, illustrate patterns about Hispanic/Latino non-hospice caregivers and the non-hospice patients they care for. Four non-hospice patients live in their home with family members. Three of the non-hospice patients live in small assisted living facilities and three live in the private homes of their caregivers. The ages of the ten caregivers also vary significantly. They range from 28 years of age to 75 years of age, making the median age to be 51.2 years. The youngest non-hospice patient is 44 years of age and the oldest is 87 years of age; the median age is 74.8 years.

Nine out of ten primary non-hospice caregivers are females and one is a male. The only male non-hospice caregiver has a part-time secondary caregiver. Six out of seven secondary non-caregivers are female. Six of the non-hospice patients are males and four are females. Six out of ten non-hospice primary caregivers are full-time, paid caregivers. The other four caregivers consist of a wife, husband, daughter and a mother. Unlike the hospice patient group where only one patient has a full-time caregiver, six of non-hospice patients have a full-time paid caregivers and one a part-time caregiver. The other four non-hospice patients have family members as their primary caregivers as well as family members as their secondary caregivers assisting them.

There are eight non-hospice caregivers who self identified as Puerto Ricans born in Puerto Rico. Two non-hospice caregivers were born in Cuba. Two non-hospice secondary caregivers were born in Cuba. The length of time in the US also varied widely among the non-hospices. Fela, age 75, has lived in the US for five years, making her the primary caregiver with the least amount of years living in the US. Linda, age 69, has

been residing in the US for 49 years making her the caregiver with the most years of residence in the US. The median length of years in the US for the non-hospice caregivers is 14.6 years.

Six out of ten non-hospice caregivers identified their religion as Catholic and four as Protestant. Two non-hospice secondary caregivers identified their religion as Catholic and two as Protestant. I was unable to attain the religious preference of the secondary caregivers in the small assisted living facilities.

The marital status of the non-hospice caregivers is as follows: six are married and three are widowed. Four out of the ten non-hospice patients had been widowed; four married, and two are single.

The median annual income for the ten primary non-hospice caregivers with an income is \$30,000. Two of the secondary non-hospice caregivers earn \$6,000 annually for assisting their mothers on a part-time basis and the secondary caregivers working in small assisted living facilities earn \$14,560. The median annual income for the non-hospice patient is \$15,401. The highest income is \$50,000 for two non-hospice caregivers who care for patients in their homes. The second highest income is Alice's at \$32,000. She is the mother of a 49-year-old non-hospice patient. This non-hospice patient also has her father as a secondary caregiver. His income is \$42,000 and the highest income among the secondary caregivers. According to the US Census Bureau poverty threshold 2000 guidelines, none of the non-hospice caregivers and one non-hospice patients is below the poverty level. The sole patient with the poverty level income receives housing assistance from the Veterans Administration.

The educational levels of the caregivers and patients varied. One of the non-hospice caregivers has a master's degree, three have a college degree, two attended some college, one graduated from high school, one completed 9th grade, two 6th grade. Four secondary caregivers graduated from high school and one completed 10th grade. The educational levels of the three secondary caregivers in the assisted living facility are unknown. The non-hospice patients' educational levels are the following: three high school graduates, one 10th, two 8th grade, two 4th and two unknown. Spanish is the language of preference for all ten non-hospice caregivers and for all 10 non-hospice patients. One caregiver reported fluency in English although she preferred to speak Spanish.

All ten non-hospice patients have Medicare as their primary health insurance. PT2 and PT10 are the youngest non-hospice patients, and in addition to Medicare, they also receive Social Security Disability benefits and six non-hospice patients receive benefits from the Veterans Administration. Six non-hospice patients receive added benefits from the Veterans Administration. Only four out of ten non-hospice patients have advance directives. Two of these patients have a "do not resuscitate order" (DNRO) in addition to a living will. The other two patients with advance directives only have a DNRO. The remaining six non-hospice patients do not have any advance directives.

Perspectives from non-hospice caregivers

It was especially challenging to access and schedule interviews with the non-hospice Hispanic/Latino caregivers. I utilized a snowballing technique to identify the caregivers and to attain the interviews. This included informing healthcare professionals,

churches and colleagues about my research. I explained my research to them and asked them to contact the Hispanic/Latino caregivers of non-hospice patients on my behalf and inquire if they were willing to participate in my research. Most of the individuals I contacted sincerely attempted to assist me and many were instrumental in helping me by establishing contact with caregivers to participate in my research. However, due to the severity and fragile nature of the non-hospice individuals' health statuses as well as the caregivers' demanding schedules, it was often problematic to arrange the interviews.

Many of the caregivers were difficult to reach via the telephone. Some did return my telephone calls, only to inform me that the non-hospice patients were hospitalized. Others just did not return my calls. Often, when the caregivers did return my calls, I would remain on the telephone with them for long periods of time, listening to their expressions of fear, sadness and confusion. The caregivers would proceed to share with me how physically tired they felt as well as their concerns and doubts about the non-hospice patients' recovery. They kindly declined meeting with me; however, they agreed to contact me once the non-hospice patient was discharged from the hospital. I would later learn from the individual who initiated the contact with the non-hospice caregiver that the non-hospice patient did not return home, but had died in the hospital. This occurred six times during the time I was conducting my research. In each case I contemplated whether or not to contact the non-hospice caregivers in order to express my condolences about their loss. I decided against contacting the caregivers after thoughtful consideration because of the uncertainty about the nature of my role. I did, however, ask the person who initially provided the contact information to express condolences on my behalf.

The semi-structured interview questions I used with the non-hospice caregivers are similar to the questions used with hospice caregivers. Comparing the responses from both groups will provide insights pertaining to the research question: Are there cultural factors that contribute to the known under-utilization of hospice services by this population? Essentially, why is it that some terminally ill Hispanics/Latinos utilize hospice while others do not? The following questions and responses are from non-hospice caregivers.

1. When did you first learn about the patient's diagnosis?

Potential response: six months, one year or two years

Three of the ten non-hospice caregivers learned about their diagnosis two years before our interview and five one year before our interview. One out of ten learned about their diagnosis five years ago and one six months ago. For example Linda, age 69, born in Puerto Rico, described her experiences about her mother's diagnosis in this way:

She first was diagnosed with Alzheimer and my father was taking care of her about 6 years. He was six years older than her. He had a lady from the neighborhood prepare meals for him and my mother. The lady knew my parents for many years. You see, my mother and father lived in the same house almost all their lives. They lady grew up in the same neighborhood. She also came by and cleaned for them. He would pay her. If she saw anything going on that was different with my mother or my father she would call me.

Five years ago she [my mother] had a massive stroke that was the beginning of everything. She became totally bed-ridden. She could not talk, move, eat or barely open her eyes. In the past two years she has been in the hospital a lot more. In Puerto Rico my father took care of her with the lady's help. My father died. I think it was all the worry, sadness and everything he was sick himself. She [the lady] could not keep taking care of my mother after my father died. After taking care of all the matters, I brought her [my mother] home with me. My mother couldn't stay in Puerto Rico; the lady could not care for her. She is our mother not hers, we could not leave the responsibility to her. It is a big change for me, I thought I would retire and travel little bit. I like to go out, after working all these years but we never know what the future holds. My husband died

and I had to keep working until I was 65 years old to get the highest amount of money from Social Security.

Rosa discussed a similar process describing the health decline of non-hospice PT3 and the non-hospice patient's increased dependency.

One year ago, when he moved here he could not longer take care of himself. He needs help to eat, bathe himself, well, everything has to be done for him but he has is mind. His wife also lives here; they got married 5 years ago. She walks and does a lot of things for herself but she has dementia. He has daughters in Pennsylvania who would take him but could not take his wife; they work and have families. In this country everybody has to work. I don't blame her; she [daughter] doesn't really know her [father's wife]. He does not want to leave her [his wife] they help keep each other company. They watch television together, sit together, talk. Her mind comes and goes she remembers and talks a lot about Cuba. [Rosa age 48, born in Cuba and 10 years in US]

Unlike the interviews conducted with hospice caregivers where all the hospice patients chose to remain present during the interview, PT 2 was the only patient in the non-hospice group to be present and voluntarily contribute information during the interview held with the caregiver. Perhaps the similarity of gender and age between PT2 and myself rather, facilitated her participation. PT2 may also have felt comfortable participating in the interview or may have just wanted to be involved out of curiosity. PT2 was also much more knowledgeable about her condition and much more responsive than her spouse. This was immediately apparent when I asked Nick, her spouse; the first question and his wife PT2 corrected him as noted:

Nick, age 54, born in Puerto Rico, said "She became sick five years ago, when we got married", whereupon the non-hospice patient [PT2, 44 years of age, born in Puerto Rico] interjected "It's been 3 years since I've been sick, we have been married 5 years that is probably why he got confused."

The non-hospice caregivers as a whole acknowledged that the patients they care for are indeed terminally ill, however they described them as being “very ill”. Therefore, during the interviews I also used *very ill* to describe the non-hospice patient’s health status and was hesitant to use the terminology *terminally ill*.

2. Who informed you about the patient’s diagnosis?

Potential response: Primary physician, oncologist or hospital physician

Six out ten non-hospice caregivers learned about the patient’s diagnosis from the primary physician, one from a visiting home nurse, one from the patient, one from the patient’s son and one from the patient’s medical record. This group contrasts the hospice patient group where six of the caregivers learned about the patients’ diagnosis from the hospital physicians after the patient was admitted. Six of the caregivers in this group are full-time paid caregivers and four family members. The four family caregivers are divided as following: one wife, one husband, one daughter and one both parents.

3. What treatment did he/she receive after his/her diagnosis?

Potential response: chemotherapy, radiation or none

Eight out of ten non-hospice caregivers reported that the only treatment the non-hospice patient receives is medication; one also has a feeding tube. The medications vary depending on the patient’s diagnosis. The medications prescribed for eight non-hospice patients by their physicians were either for a heart or lung condition. Rosa CG3 reported that the non-hospice patient received radiation and PT2 received chemotherapy, experimental surgeries, and prednisone as well as pain medications. All of the non-hospice caregivers described their relationship with the patient’s physicians as excellent to adequate. They all noted that the patients’ medical needs were taken care of. During the interviews I asked the non-hospice caregivers if any of the patients were seeking

additional treatment for their illness. Nick age 54 reported that PT2 age 44 is seeking experimental treatment, however the other nine responded by saying “the doctors have stated that there is nothing else they can do”. Alice, age 66 reported:

My daughter is only 49 years old and even though she was born slow, her life is important. We will do everything to keep her alive. We have struggled with her all our life and we are not going to give up now. The hospital told us we should let her go, but how can we do that. She has an older sister who is 52 who also is slow she will miss her. We will all miss her we are fighters. We brought her home from the hospital where they said she would die soon. She lays down on the sofa she cannot do anything for herself, she does not walk or eat for herself. She is like a big baby we have diapers on her, but we will keep trying. We have a physical therapist that comes to the house. She said there is not much she can do. But I think if she keeps trying something could happen. We trust in the one who is up there and sees everything. A nurse comes to the house too, she says there is not much she can do because her condition of seizures has made her loose everything. She takes a lot of medications we will see what happens. We cannot lose hope.

4. Who assisted the patient in his/her decision about treatment options?

Potential response: physician, caregiver or friend

Seven non-hospice caregivers reported that their physicians assisted them with treatment options; two indicated a caregiver and one the patient. Linda age 69, born in Puerto Rico, reflects on how she is now responsible for a healthcare decision made by her now deceased father that she disagreed with. This discourse illustrates the multi-faceted dimensions of decision-making at the end of life. The discourse addresses the generational and educational differences related to end of life. Linda is a 69-year-old female with a master’s degree while her father was 86 years old with elementary school education.

My father made the decision to put a feeding tube in her. I asked him, please don’t. Let God have his way, you know that she has a bad heart and Alzheimer’s but he made the decision when they both were living in

Puerto Rico. I used to go visit but my father was taking care of her with the help of a neighbor he paid to help him. I knew from experience that the feeding tube was not a good idea, but I could not do anything. My father was a stubborn man. He said she is not eating and she needs her nutrients. I went to Puerto Rico when I retired. While I was there visiting and helping out, my father had a stroke and died. Now, I who was against the treatment for my mother, have to live with his decisions. She could not stay in Puerto Rico because her three daughters are here; I mean two in NY and me here. They could not take her so I made plans to bring her with me. I had to bring her by air flight. They brought her to the door. Here we took her to the doctor but she can't continue to go, every time we take her we have to go in like an ambulance because she can't walk, stand or nothing she is bedridden. (Linda, 69 years, old born in Puerto Rico)

Consider the description of the process that PT2, age 44, underwent in order to determine treatment options for her diagnosis.

No one really helped, they just told me what was out there, and initially they just put me on something. They didn't officially know what it was that I had so they just put me on the chemo, because they know something was happening, so just they said we need to put you on this right away and then 7 months later I went to Cleveland and the doctor over there confirmed what the other four doctors said, so they started a treatment plan, the doctors here were checking, they were treating me for asthma in the beginning. When I had my surgery they sent my specimen to the Mayo clinic, something showed up that they sent it to the Mayo clinic and that's when they got the ball rolling. I looked it up on the internet, went to library, no body knew about it so it was kind of hard to decide you know because the disease is rare, I looked up, what they were treating patients at that time with and then I had to decide, I basically decided, I did not want steroids but I need them. I looked at the side affects, of all the different ones and what they did present, what was out there for me, which is very limited and then they told me that is what they want to do, put me on steroids and I agreed. It is not like have many choices. All the other medicines I take are the results of the treatment.

5. What do you know about hospice services?

Potential response: nothing, a little, a lot

Only Tina (CG1) age 62 born in Puerto Rico with a 4th grade education without employment history outside the home reported having no knowledge of hospice. Six

indicated having a lot of knowledge about hospice and three a little knowledge. PT2 discussed her knowledge of hospice in the following manner:

Hospice takes over only when you are already like at the end. I'm not at the end stage. I'm not in need of hospice. There are no other types benefits out there, because I was receiving chemo I went to the cancer society because I was losing my hair and somebody told me about them because they help, but because I'm not diagnosed with cancer they could not do anything for me. I found out that there is no type of support group. Until recently, I got a card in the mail and found out there is a foundation but they are far, they don't have a local branch here. The foundation helped me by letting me know when they were having a symposium, the one that I went to with all the doctors. That way I got to know what the disease does because I really did not know. They gave me all the terminology and everything. The doctors, the doctors here did not want to overwhelm me. They just want to take it one step at a time. The symposium was scary but it is good to know, it good to know because I was kind of worried, like what to expect. I was having too many things happening that I did not know were part of the disease.

Haydee age 30, Puerto Rico born, paid caregiver describes her knowledge of hospice in this way:

I have a standard license to care for people in an assisted living. I don't have a nurse or staff; the people who live here are independent. If they need total help or if they get worse we have to indicate to the family member that they have two alternatives. Put them [non-hospice patient] in a nursing home, which many of them do not want or refer them the hospice service so that the person can remain here.

The two accounts noted describe how what is known about hospice is articulated.

It is for people who are terminal and when there is nothing the doctors can do for them. [Fela, age 75, born in Puerto Rico paid caregiver]

Linda age 69, born in Puerto Rico stated, "I know a lot about hospice. I used to work for a hospice." There is also some confusion about hospice as described in this way by

Haydee a paid caregiver, age 30:

I know about hospice but I can't say I understand how it really works; they have some rules I don't like. Sometimes things get more confusing with them. The nurses come here and I don't know what they have done, they come in and out and don't talk to anybody. It is like they do their thing and we do ours.

Consider the account by Rosa a paid caregiver, age 49, Cuban born and 10 years in the US as it relates her knowledge about hospice in the context of her experiences.

I know a little. We consider it shameful. For example we Cubans when we have been here for a long time the fabric of who you are begins to change. We start becoming familiar with hospice but we do not have that culture, we say, hospice, what thing is that? Exclusively there are people in hospice who live one year it does not mean they are going to die tomorrow. But it is not part of our culture like the Americans they are prepared they say hospice? Yes. I know. We like to depend on family and want to care and be cared by our family. Here in this country it is different it is more difficult. The man here he has daughters but they are far, they work. He married her [patient's wife] a little while ago they [his daughters] must say to carry with both of them is too much. It would cause difficulties. She has dementia she forgets everything; you tell her something and she forgets, poor thing, you have to check on her to make sure she does not fall, even going to the bathroom, you have to check if she dirtied herself. She is not aware of it. It would be difficult. They [his daughters] wanted to separate them but he [non-hospice patient] did not want to. It is best for them to be together it is best for both of them. They spend all day together. The day they are separated they will both die because they are adapted to each other. The day they separate them she will go back. She has a son; he visits I'm sure could take care of her but he could not handle both of them. He has to work.

Raquel age 47, born in Cuba and in the US eight years noted:

There is no hospice in Cuba, us from Cuba don't know about it. It is not our culture. Here I learned a little about it. I can't say I know a lot. It is for those ready to die. They are almost at the end, dying when they use it. His [non-hospice patient] children live in Canada their visits are rare. In this country it is very difficult to care for someone who is sick. In this country it is very difficult. If this happens in Cuba it is different over there people are in their homes, the neighbors, the cousin, the grandmother who comes for a little while, here no, over there is community. Here everybody works not even the family can help. Here you have to pay for everything it is very different.

6. Have you considered receiving hospice services? Why or why not?

Potential response: no, yes or sometimes

This question was awkward to ask the non-hospice caregivers. I asked it rather cautiously, because I did not want them to think that I was recruiting individuals to hospice nor critical about their decision not to utilize hospice services. Also looming in the background was the fact that the non-hospice caregivers described the patients' condition as very ill rather than terminal. I preceded the interview with all of these issues in mind and carefully framed the question.

Since Tina had previously stated that she did not know about hospice, I omitted asking her the question. All nine non-hospice caregivers indicated not considering receiving hospice services. Consider the circumstances described by Raquel, age 47, born in Cuba and eight years in the US.

No, because I have four people I take care of. I took care of one that was on hospice and when he died it affected all of them. I asked hospice to come quickly when he died. He died around 5 am and I called, asked them to come soon. I wanted them to take the body before the others woke up but no, they came late at about 9am and all of them were awake. The nurse took a long time to come and was here a long time, filling out so many papers. I know they have a lot of paperwork to do. They [other residents] had to watch the funeral people come in with the cart with wheels. I closed the door but it kept getting opened. Then they all saw him go out. They all got very nervous; it took me all day to calm them down. I did not like that they had to see everything, the man roll out and everything. Since they live together they get close it becomes like a family. That kind of thing is very difficult for them to see. They start thinking and worrying. I won't have hospice again. I will have the person moved somewhere else like a nursing home. It was very bad thing for everybody.

The accounts exemplify the reasons for the non-hospice caregivers declining to consider hospice services:

No, it is too much trouble, when we request hospice it becomes a big problem. They send continuous care, more people coming in all the time. I

try not to but when the person gets worse and the physician gives orders for hospice and the family does not want to put them in a nursing home they stay here with hospice because of the license I have. [Haydee paid caregiver, age 30 and born in Puerto Rico]

Linda age 69, born in Puerto Rico noted:

No, because the doctor said my mother's condition was chronic; that doesn't mean that she is well she can go anytime.

Fela paid caregiver, age 75 born in Puerto Rico stated:

No, I don't like a lot of people in my house. I think the nurse he has is good. I don't like too many changes.

Few accounts had the simplicity and intensity as such reflections:

No, I want to keep trying to do whatever it takes. I have a three-year-old son, a sixteen-year-old nephew who only knows me as his mother and a husband who works hard. [PT2 age 44, born in Puerto Rico]

**7. What do you anticipate would be barriers in getting connected with hospice?
Potential response: physician, family or friends**

All of the non-hospice caregivers identified the barriers to getting connected with hospice services immediately when asked. The barriers varied and were related to an array of issues including language barriers. Among hospice caregivers five identified language as the only barrier.

The desire to seek aggressive and alternative treatment was discussed by PT2 age 44 in this manner:

My family, my husband, my son and I want to try everything. Choosing hospice will mean that there is nothing more to do. I will continue to go to Cleveland and do whatever they tell me to do, even more surgeries, I will die trying. I have a 3-year-old son who needs me.

The language barrier factor coupled with the concept of strangers intruding in the caregivers' personal space, loss of power and making changes was evident in the narratives by four non-hospice caregivers. One paid non-hospice caregiver did not want a patient to die in her home. For example, consider Fela, age 75 describes her concerns:

I don't like people in my house. They come in and want to tell you what to do in your own house, oh no. I already have a problem understanding English when they talk to me. Although I take care of two people in my house I like to keep it like my house. I have been taking care of NHPT10 for many years he is part of my family

Rosa a paid caregiver born in Cuba, age 49 noted:

Having people who do not understand my ways, speaking English only. You see this is my home.

Linda born in Puerto Rico age 69 described her resistant to change in this manner:

If the doctor says my mother needs hospice it will be fine. Right now I am pleased with the help I have. It will be a hassle to change all the equipment, nurses and CNA and to show new people what to do in my house. I'm all right with what I have.

Paid caregivers in small assisted living facilities discussed additional factors that cause barriers for them in accessing hospice services. These involve issues related to lack of communication with hospice staff, expectations of hospice staff and eligibility criteria. These non-hospice caregivers expressed their thoughts in an agitated and frustrated manner. I felt as though this group has been suppressing these feelings for some time now and now were eager to ventilate them to someone who would listen.

Haydee, paid caregiver, age 30 born in Puerto Rico stated:

Yes, continuous care for us it is an obstacle instead of being a help. Here I have my staff that normally does everything for the patients. A person who sits here, that's not even a CNA cannot give medication because they are not authorized to give medications, do not clean ulcers they do nothing, the only

thing they do is look at the patient. Sometimes they send a CNA sometimes a HHA. In reality they do nothing but sit and look at the patient and take vitals, that's it. They don't help at all; they don't send nurses, nope nope. They tell the girls, my workers, what they cannot do and tell them to do it. In reality they are in the way. Then they take time away from the girls that are working to tell them their twenty thousand problems. We know the patients care we know how they eat how they don't eat. You know it is easier for us to say you do this, you do that, and you give the food we divide the work. It is a lot better than having a person sitting down say, "I could feed the patient but I can't clean their wounds".

Liz paid caregiver; age 32 born in Puerto Rico described her experience in this manner:

Yes, there are some of the nurses that don't have good communication with the facility. They come and go and they don't communicate. They don't say what they did, what they didn't do whether they cleaned a wound, or when they will return. It is the personality of the person not hospice it is just that they represent hospice.

Hazel paid caregiver, age 28 born in Puerto Rico, reflected her uncertainties about eligibility:

We have the Diversion program for Medicare patients living in ALF it covers room and board but if the patient switches to hospice services so that they could receive help for their terminal diagnosis they are removed from the Diversion program and they will be responsible to pay for their room and board. It is not worth it even if hospice will provide counseling for the family and everything like that, so they have to go to a nursing home because of money.

8. Who else helps? How many family members live in this area? What kinds of help do you get from family or friends?

Potential response: family, community services or friends

All of the non-hospice caregivers reported receiving assistance.

Five identified family members as helping with an average of at least three family members in the area. Two non-hospice paid caregivers identified the Veterans

Administration as providing help, one non-hospice caregiver identified the church, one a

friend and one a local nursing agency. Some rely on combination of family and community services, friends and church or community services and church.

Tina age 62, born in Puerto Rico described her help from church and community services:

I do not have any family here. All my children are in Puerto Rico. My church helps me if I need them but I'm healthy and can do a lot for myself. He is receiving good care from his doctors in the VA you see he has health problems but also problem with his nerves they treat him for both things at the VA.

Two caregivers rely on their daughters for help. Consider Linda's narrative on how she relies of her daughter as well as community services. She also describes her disappointments about the lack of help and the caregiving demands:

My daughter helps me. She comes every morning and helps me turn my mother from her side to her back. In the night, my daughter comes again and helps me turn my mother to her side. My mother is too heavy for me to move by myself. A CNA comes twice a week for 4 hours. This is the time I take to go to the doctors, bank and shop for food. I never have enough time. Time goes by so fast. The nurse comes to see her once a week. My son lives in the area but he is very busy working. He checks on me during the week and helps me do whatever I ask. My son-in-law is very helpful. You see my lawn, backyard and trees he takes care of it all. He keeps everything looking so nice. Last year during the hurricanes all the trees went down. He has made this place look nice again. I don't know what I would do without them. My two sisters who are retired live in New York. One visits about twice a year and says that she can't handle seeing mom like this. I know it is hard for everyone; it is not easy for me either. My other sister, well, in the four years my mom has been with me she has visited twice. I tell them that mom was the mother to all of us but I do not want to have any family problems and want to keep family unity. I know I do my best I love my mother, I would not have it any other way. When anything happens to her I will know that I have no guilt. She is very comfortable here, she has the Spanish radio, the Spanish television station, she is clean and the doctor says that she is stable. She has had to go to the hospital a lot and has been hospitalized every time she goes; when she is there I ask the doctor is she ready for hospice. We call the nurse and she tells me to call 911. She gets pneumonia and infections in her feeding tube. I pray that God gives me the strength to continue to care for her. [age 69, born in Puerto Rico]

Fela, paid caregiver for two patients in her home notes her daughter and the VA help:

My daughter helps me when I want to take a break and go to the store. They keep me busy cooking and cleaning. I have them on a schedule. They eat, watch TV but not too much, and listen to music. I take him out to sit outside the sun is good for him. He has no family. He has been living with me for 23 years with the help of the VA in Puerto Rico and here. [age 72, born in Puerto Rico]

PT2 responded when the question pertaining to who helps was presented to he husband and caregiver Nick age 54 born in Puerto Rico.

I have somebody who helps me a few hours a week. I have a friend I talk to, and when I hear bad news I call her. My pastor and his wife don't know too much about it but they are there. It is hard to talk to people who do not know. Physically I look all right but internally ... People don't understand that. They [doctors] don't know how you get it. They are still in the research stage trying to find out because I have not been a miner where there is a lot of fumes. It seems like different people in different jobs get it. They are researching and trying to see if it is work related. It is not something you can catch from someone, it is not hereditary, I'm not a smoker; I'm not a drinker so they [doctors] don't know why it affected me. It started with my lung, eyes, throat my ears the end stage is the kidney, I'm thankful because they can still control mine. They take it step by step. It was in remission but now it has gotten worse. I had surgery two months ago and experimental exploratory surgery. I keep getting worse because of I have inflammation of the vessel and the oxygen supply does not go throw the necessary organs the major and minor organs. I have to begin chemo again and begin the steroids. It does not seem to be getting better.

Alice, 66 years old born in Puerto Rico reported:

My husband helps. I don't drive but he goes shopping in his golf cart and gets everything we need. I sometimes go out when my daughter's aide takes them out I go with them. Sometimes I like to stay and just get a rest. My life is my girls and what they need.

9. Did anyone criticize you for not seeking hospice help?

Potential response: yes, no or some

Nine of the non-hospice caregivers did not receive criticism for seeking hospice services nor did the non-hospice caregivers receive criticism for not seeking hospice help.

One received criticism for the hospital nursing staff. This illustrates that within the Hispanic/Latino community there is a significant amount of respect for one's choices.

Four of the non-hospice caregivers describe their situation in this way:

No, it [hospice] is not for me, not her condition and her age. [Nick age 54, born in Puerto Rico]

Linda age 69, born in Puerto Rico stated:

No, because I listen to the doctor if he said she [my mother] does not need hospice that is it. At this time there does not seem to be anything that hospice will do that the agency I'm using will do. If she [mother] had cancer or a condition that needed pain management maybe I would encourage.

Haydee paid caregiver, age 30 born in Puerto Rico noted:

No, we do not have many alternatives if the patients' family does not want to move from here then they have to choose hospice or take the patient to the nursing home.

Alice, age 66 stated:

No one knows what is to be a mother of a delayed child like I do. I'm the only one who really understands her. Even though she can't talk I understand her [daughter] by how she moves her eyes. You see I've been taking care of her all my life, here and in Puerto Rico. I will fight for her and her life. I don't care what they say. I will do everything for her. I know hospice is for people who are dying. In my eyes she is not dying. Yes, she is very sick but she has come out of bad times like this before. It is true that this is the worse she has gotten but with God's help she will get some strength back.

10. How did not receiving hospice services affect your relationships within the family? Potential response: none, some or a lot

Seven non-hospice caregivers unanimously reported that not receiving hospice services did not affect the relationship within the family. Three reported that due to their

assisted living status, not receiving hospice services would cause the patient to be relocated to a nursing home. They reported, “The decisions have not yet been made”.

The circumstances related to decision-making is reflected by Linda age 69 born in Puerto Rico:

My sisters let me make the decision. I talked it over with my mother’s doctor because I felt she needed hospice but he said no. He makes home visits and a nurse come from a nursing agency. I followed what the doctor said even though I knew she could be in hospice. I asked my mother’s doctor he is also Puerto Rican about hospice straight out and he said that his mother had the same condition as my mother. I think that is why he makes the home visits here and feels she does not need hospice. He said her condition is chronic but she could die soon.

These narratives indicate the internal barriers caregivers face when determining whether to utilize hospice services. In each of these families the non-hospice caregiver and patient will suffer a loss and a change in healthcare providers. Often the loss and or change of healthcare providers in itself are a deterrent in utilizing hospice services.

**11. Would you recommend hospice services to a friend who needed them?
Potential response: yes, no or maybe**

Six out of nine non-hospice caregivers who had prior knowledge about hospice indicated that they would recommend hospice services to a friend who needed it. None of the non-hospice caregivers said no and three, which are paid caregivers reported that they were uncertain and noted:

Maybe, It depends on the person because some of them [family] don’t acknowledge all our efforts we have made but some do, but some are much more grateful to hospice even though the patient was with us alone for much more time. [Liz, paid caregiver, age 32 born in Puerto Rico]

Maybe, it depends on where the person lives, if it is going to work for them. Sometimes new people and things can make the sick person more confused. [Raquel paid caregiver, age 47 born in Cuba]

Maybe, everybody is an individual and may need the help but others it may be more interruptions. [Hazel paid caregiver, age 32, born in Puerto Rico]

The reasons why they would recommend hospice services were stated briefly with obvious qualifiers such as:

Yes, they were helpful, I will tell other people about it. But not in my home because of the bad experience I had. [Rosa paid caregiver, age 49 born in Cuba]

Nick age 54, born in Puerto Rico stated, “Yes, hospice is good for those who are at the end.”

Linda noted:

Yes, hospice is very good for those individuals who have a clear six months or less diagnosis like people with cancer that need their pain to be controlled.

Fela, age 75, paid caregiver born in Puerto Rico stated:

Yes, they can help; my brother died of cancer and did not get any help. My husband died in the hospital, he never came home after he went in.

12. What advice would you give to hospice providers in order to increase the number of Spanish speaking clients in the program?

Potential response: newspaper, radio or Spanish-speaking hospice workers

The responses to this question by the non-hospice caregivers were similar to those of the hospice group. Both groups actively engaged in providing advice, insight and ideas on how hospice providers could increase the number of Spanish speaking clients in the program. One non-hospice caregiver did not know about hospice; however, the other

nine had prior knowledge about hospice. They indicated needing more information in Spanish including literature written in a simple and factual manner. The following narratives provide details about the circumstances they face:

More information in Spanish, you see my husband does not know all the information I know about my condition because he does not speak English. The doctors speak to me in English, the material from hospice are in English. I'm sure it is the same for other people who do not speak English. [PT2 age 44 born in Puerto Rico]

Rosa paid caregiver, age 49 born in Cuba states:

Explain what it is. What they do of course in Spanish. In this country things are different. You have to pay for everything. In Cuba no, maybe people think they have to pay. Explain how it works give information in Spanish. We do not have this in our country so people need education about it.

Linda age 69, born in Puerto Rico noted:

More bilingual and Latino staff, more literature in Spanish, do more public relations in Spanish newspapers, local papers, local TV stations, in hospitals to doctors and train workers about the culture of Hispanic/Latino families.

Haydee, paid caregiver, born in Puerto Rico echoed the advice of the non-hospice caregivers when she stated:

Give people a pamphlet in Spanish explaining what hospice does and does not do. Simple and factual not too complicated. Sometimes there is too much information in the things you read, too complicated and people do not understand nothing at all.

Fela paid caregiver, age 75, born in Puerto Rico summarized the advice in this manner:

I think people need to know what the word means. It is difficult to pronounce it in English and it has a different meaning in Spanish. Make it clear what the word means, sometimes a person would think it is a place where they take care of older people. Focus on the Latino community.

There is a lot of fear about it, people do not know about it. Talk about it on TV, in the Spanish stores, churches, beauty parlors, barbershop where people talk about things like this sometimes.

Explain there is no risk, no financial responsibility if you have insurances to cover the cost and that it does not matter about your legal status.

While conducting my ethnographic observations of the hospice organization and during home visits, I attained knowledge about the factors that contribute to the known lack of utilization of hospice services by the Hispanic/Latino community. The interviews I conducted with hospice caregivers and non-hospice caregivers enabled me to identify cultural differences between both groups as it relates to their choice of support. The non-hospice caregivers group cared for non-hospice patients who are sixty percent male with a median age being 69. All of the males have a full-time paid caregiver. Forty percent are females, which consisted of the two youngest in the non-hospice caregiver group ages 44 and 49. The other two were ages 84 and 87. Ten percent of the females had a part-time caregiver. The non-hospice caregivers and non-hospice patients have a higher income and educational level. The median level of education for education for the eight non-hospice patient who reported their level of education is 9.3 years and 12.7 years for ten of the non-hospice caregiver. This group receives assistance from community services, 100% of the patients have Medicare health insurance, 65% of the patients have a paid caregivers the other 35% have family support. The patients in this group are United States citizens by birth.

The hospice caregiver and hospice patients have a lower income. The median level of education for the nine hospice patients is years 7.3 years and 10.5 years for ten of the hospice caregivers. This hospice group receives hospice services, however have additional barriers and limitations. 80% of the patients have Medicare health insurance,

40% receive family support, 20% receive support from friends, 30% no support and 10% have a paid caregiver. Sixty percent of hospice patients have advance directives while fifty percent of non-hospice patient have advance directives. There was only a 10% difference between non-hospice patients and hospice patients as it related to advance directives. There is a tendency to assume that hospice patients would more readily complete advance directives; however, in this study non-hospice patients have also prepared advance directives.

Since the non-hospice caregiver and non-hospice patients have higher incomes, access to community services, family support, more health insurance coverage and citizenship by birth, this group has more options about health care choices at end of life. The findings indicate that hospice services may not seem as appealing to non-hospice patients and non-hospice caregivers with support systems in place. Hospice services are generally perceived as an intrusion that causes caregivers and patient alike to lose control over their home. Also the lack of comprehensive information about hospice services in the caregivers' and patients' language of preference which is Spanish adds to the confusion about hospice services therefore hospice is disregarded and omitted as a healthcare option although perceived to be beneficial by non-hospice caregivers.

Demographic data of physicians

I also used a convenience sample to recruit the physicians in my study. Since Hispanic/Latino individuals seek treatment from physicians of diverse cultural backgrounds I endeavored to interview physicians that reflect this diversity. The demographic data pertaining to the ten physicians interviewed include their age, gender, place of birth, length of time in the United States mainland, religion, years of practice and

area of specialty. The median age of the physician is 46.3 years. Eight of the physicians interviewed are males and two are females. The youngest is Dr. Smith, a female physician age 33 years, and the three oldest are males, Dr. Cruz, Dr. Jones and Dr. Jones, both of whom are 52 years of age. The places of birth of the physicians varied. Four were born in the United States mainland, two in Cuba, one in Colombia, one in Germany, one in Jamaica and one in Puerto Rico. Four out of ten physicians in the study self identified as Hispanic/Latino. Within the Hispanic/Latino group one is a female born in Cuba and the three males were born in Colombia, Cuba and Puerto Rico. The median length of time as residents of the United States for the six physicians not born on the United States mainland is 22.3 years. The median years of practice in the United States is 17.7 years. The years of practice among the ten physicians range from 4 years to 25 years, with Dr. Ruiz from Puerto Rico practicing 25 years and Dr. Smith with 4 years of practice. Dr. Crum reported practicing medicine in Cuba for 11 years prior to leaving. Six of the physicians have a specialty in internal medicine, three in pediatric oncology and one in gerontology. Seven physicians identified as Catholic and three as Protestant.

Table 5. Demographic Information of Physicians

| MD | Age | Gender | Place of birth | Length of time in the U.S. | Religion | Years of Practice | Area of Specialty |
|-----------|------------|---------------|-----------------------|-----------------------------------|-----------------|--------------------------|--------------------------|
| Dr. Cruz | 52 | M | Colombia | 25 years | Catholic | 15 yrs | Internal Medicine |
| Dr. Zinn | 49 | M | US- NY | 49 years | Catholic | 18 yrs | Internal Medicine |
| Dr. Crum | 46 | F | Cuba | 12 years | Catholic | 21 yrs | Internal Medicine |
| Dr. James | 38 | M | Jamaica | 20 years | Protestant | 6 yrs | Internal Medicine |
| Dr. Estes | 45 | M | Cuba | 39 years | Catholic | 22 yrs | Internal Medicine |
| Dr. Gray | 48 | M | Germany | 21 years | Protestant | 21 yrs | Pediatric Oncology |
| Dr. Jones | 52 | M | US- PA | 52 years | Protestant | 22 yrs | Pediatric Oncology |
| Dr. John | 52 | M | US- NY | 52 years | Catholic | 23 yrs | Internal Medicine |
| Dr. Ruiz | 48 | M | Puerto Rico | 17 years | Catholic | 25 yrs | Gerontology |
| Dr. Smith | 33 | F | US-PA | 33 years | Catholic | 4 yrs | Pediatric Oncology |

The gatekeeping role of physicians

The physicians I interviewed actively engaged in the questions to assist in determining the physicians’ role in the utilization of hospice services by Hispanics/Latinos. The diversity among them was reflected in their ages, areas of specialty, years of practice and ethnicity. This also represents the range of physicians in the Central Florida area. The mixture provided an array of perspectives and insights. It also represents the range of physicians in the Central Florida area.

1. Do you refer all terminally ill Hispanic/Latino patients to hospice?

Many of the physicians initially had a guarded, or surprised when asked if they referred *all* Hispanic/Latino patients to hospice. Some asked if it was a trick question or a “loaded” question. After I clarified the question they all responded accordingly. The majority of the physicians indicated that they did refer Hispanic/Latino patients to hospice and proceeded to explain how they did so. Many stated that they focused on the missions of hospice when explaining what hospice is and assessed if the patient and family were indeed willing to seek palliative care.

The following four perspectives indicate the variation of responses among the Hispanic/Latino physicians.

Dr. Crum, a female, age 43 and Cuban born stated:

I refer them to hospice, unless the family refuses, but I always refer the terminal patients to hospice.

Dr. Estes, a male, age 45 and Cuban born noted:

No, not all, it depends on a lot of things, once we have exhausted all possible measures to help the patient and we have no other recourse, if they have the family support for hospice services, and they are willing to go through hospice end of life treatment. I always give them that option but most of them do not take it.

Dr. Cruz, a male age 52 born in Colombia reported:

No, it all depends how much care they need. We offer them the opportunity and it’s up to them, but generally we give them that option.

The question pertaining to whether physicians refer Hispanic/Latino terminally ill patients to hospice were also asked to non-Hispanic/Latino physicians. Dr. Smith, female, age 33, expressed her reflections in this manner:

We refer anybody to Hospice who is warranted and who wants it. We do have some patients who are resistant to the idea of hospice and don’t want that or some

patients who get so sick so quickly that there is no time to get hospice involved, but being Hispanic/Latino is not a barrier.

Dr. Zinn, White male age 52 and born in the United States expressed his thoughts about referring Hispanic/Latino individual to hospice by stating:

I would say no, but the reason I will said no is I offer all patients Hospice but if they refuse, then the answer will be no. I don't know if I made my referral based on ethnicity. I will refer the patient to Hospice that have terminal illness in which palliative care is going to be indicated when and where I believe some of the others services Hospice provide for support, for family members may be helpful. I guess once the decision is made, they will switch the palliative of care [and] regardless of race, ethnicity I will discuss the option with Hospice services.

2. What criteria do you use to refer Hispanic/Latino patients to hospice?

The physicians were extremely thoughtful in responding to this question.

Dr. James male age 38, Jamaican born, discussed the criteria in this fashion:

The criteria is pretty much uniform depending on the actual disease, stage of disease, it has to be end stage we have had to have exhausted all our resources in treating this individual. Also stepping back a little bit we have to really be attentive to the needs of patient, what he or she wants whenever these end stage diseases present themselves. Sometimes they [patients] may not want to go the entire way with treatment, they may want it stopped treatment sometimes treatment might mean more pain than actual pain free or comfortable situations.

Dr. James a female, age 43 and Cuban born noted:

The Hospice's criteria, the patients who we know have a terminal diagnosis and their life expectations are between six and one year, which is the fundamental criteria.

Dr. Smith, White female, age 33 and born in the Pennsylvania, is a pediatric oncologist. She provides us with insights about the complexities physicians confronts when working with terminally ill children.

I refer anyone who has a terminal condition that are in our line of work in oncology or hematology, I refer even if we are giving chemotherapy, or palliative chemotherapy. I refer if people need pain control, or when patients want to be able to be at home. Sometimes people feel more comfortable coming here because they've been coming here for so long. It's a little bit hard for them to get to that place where they are calling hospice for antibiotics, or because they're having difficulty breathing; we have patients who call us even though hospice is still involved. Some with more chronic conditions like sickle cell or different types of anemia we'll follow them from birth until they're 18, sometimes 21, and even older than that. Our oncology patients, if they don't have a good outcome we'll treat until they pass, or if they do have a good outcome we like to follow them for long-term side affects as well.

This discourse enables us to learn about the trust, confidence and emotional attachments terminally individuals have with the medical institutions and physicians who have been instrumental in providing them with treatment at the most fragile and frightening time of their lives.

3. Do you have any hesitations in referring Hispanic/Latino patients to hospice? If so, what are they?

Since a physician's referral indicating that an individual has a terminal diagnosis of six months or less is required in order for a patient to be admitted and to receive hospice services, it is critical to learn if physicians are hesitant to refer Hispanic/Latino individuals. If so, what are their hesitations in referring them to hospice? Dr. James a male, age 38 and Jamaican born describes the process in this manner:

I have no real hesitation when it comes to end of life issues; really, the patient is in the driver's seat and they really dictate what they want done. I try to provide as much as information as I know about the condition and what the options are and what I think they should do and what my opinion is. I try to put myself in their situations and I feel it makes it much more comfortable, especially with the family. I noticed with the Hispanics and African Americans there is a lot of family interplay here, giving them as much of information as I can and giving them my take of it. Let's say for

example “if they were my mom or my dad this is what I would want”. They appreciate that and they get a better sense as to where they are and where they want to be. It works well this way most of the time. Dr. John, 52-year-old, White male discussed his hesitations in this manner: The biggest thing is to make sure someone is bilingual in the hospice staff. I myself speak Italian and English so I can get by with Spanish but its better is we have someone that can speak Spanish fluently or can get an intermediary for them.

Dr. Ruiz male, age 48 born in Puerto Rico discusses how he pursues the referral process:

The culture is a little bit different. Normally, I explain to them that they are going to be helped at home, since they want to keep the patient at home, this is my first question and my first recommendation to the family. If they want to keep the patient at home, I recommend Hospice with all the Hospice benefits.

Dr. Crum a female, age 43 and Cuban born explains hospice service to family members indicating:

They offer them personalized services through Hospice where they will receive services not only for her physical well being, but also for their psychological welfare. Also they will have a social worker, and a psychologist; a complete team. This will help them to overcome the transition and will support the family. This way, we explain them the services.

4. How is hospice discussed with the patient and family?

The process of discussing hospice with the Hispanic/Latino patients or with family members present is often an issue of controversy among healthcare providers and addressed with uncertainty. I was particularly interested in attaining information regarding this matter. The findings indicate that physicians prefer for family members to be involved in discussions about hospice with Hispanic/Latino individuals and they strive to involve family members as much as possible. Physicians in the study discuss the terminal diagnosis with a family member and follow the family’s lead as it relates to discussing the diagnosis with the patient.

Dr. Crum a female, age 43 and Cuban born added:

The patients prefer the family to be in charge, the patient wants to know as less as possible. The family will request you to tell the patient as less as possible. The culture is different; here [in the USA] your commitment is with the patient, the family counts only if the patient agrees. That's why I try to tell them, "You are sick do you want me to talk to your children" and if he/she wants I continue....

Dr. Ruiz male, age 48 born in Puerto Rico stated:

I meet with the patient and the family in the room to discuss Hospice benefits. I like to involve the family and patient and let them know that it is important to learn about these benefits and to give them the opportunity to evaluate if the program will benefit the patient and the family. As soon as Hospice explains the program, there is small percent of patients that refuse the program. Sometimes I have the Hospice benefit information in the room, and I am blessed with a registered nurse, who is also the case manager who deals with difficult cases; she manages the patients with heart conditions and everything. When these difficult patients have less than six months to live, the nurse suggests that this patient is in the final phase and, rather than go to the hospital to receive unnecessary treatment, we refer them to Hospice, which works very well. In the beginning, it was difficult for me to understand the case manager role.

Dr. Jones, White male age 52 and born in the United States described the process in this manner:

Well, I just tell the people once I have had a discussion about that the disease process what ever it is or injuries happened, inevitable outcome of death and that we are not going to make our goals to prolong the of person life any more than necessary the child's life, rather to make them as comfortable as possible, then I would discuss with them and inquire for them, "in a perfect world where they would like to see the child die, could be at home, in the hospital", especially for these people that home is their desire, then that is a great opening to talk about Hospice. For the ones that do not want that and say no I want my child to stay in the hospital, hospice is not good. I tell them that what aren't going to be able to help much and that they can have hospice in the hospital. I try giving a better outline of what Hospice it is, and what it means and how it can be helpful to them and try to get a feedback for them.

5. How do the Hispanics/Latinos respond to a hospice referral? Do their responses differ from individuals of other cultural backgrounds? If so, how?

Responding to this question, the physicians described their experiences of how Hispanic/Latino individuals respond to a hospice referral. They also explained some of the differences between what they have observed. Dr. Ruiz's (male, age 48, born in Puerto Rico) responses related to Hispanic/Latino individuals "not wanting strangers in their home" are similar to several of non-hospice caregivers' reasons for not wanting to seek out hospice services.

Unfortunately, the biggest problem that I found is that the family does not want strangers in their home. But when they realize that they need help, then the situation is more understandable for them. In this neighborhood, where the people are humble, we also found this type of reactions: that the family is very close; the Latin families are very close. At least the families that I deal with are extremely tight. I have found very few cases where the family is not involved. There is always a family member living in the same place.

Dr. Crum, a female, age 43 and Cuban born illustrates some of the differences she has observed:

Most of the time it is more delicate than for American patients, because the Latin patients are more dependent to their origin. For example, if you say to a Cuban: You have cancer, he will say, "I am going to kill myself". This position has changed since they've lived here. I try for them (the patients) to know what they have, without being cruel. To give the patient the necessary information, and give the biggest picture to the family.

Dr. James, male age 38, Jamaican born discusses the lack of knowledge as well as the erroneous perception about hospice with this focus:

They respond I think the way most patients having to facing end of life. First of all they don't know what it is. The information that is out there is erroneous they think it's I'm going to be put in a room sterile room and be

put away to die, pretty much. Where hospice is much different. Having explained to them, that really is your participation and your family's participation in your care. That is a big part of hospice. The idea is to maximize the time that you have left, maximize the good days and to keep you comfortable. That is what I think hospice is all about. When you try to explain it in that way. When we explain it that way and say we are not going to change your environment, I can't change your disease but I'm going to try make your environment as familiar and as comfortable both physically and emotionally as possible. When you explain it that way and when they are put in that environment they are more appreciative.

Dr. Jones, White male age 52 and born in the United States.

I think is a little more resistance to the idea, there are multiple barriers to overcome. Partly, a person from any background that has to accept Hospice has had to really come to clear terms in their mind that this means that some one is going to die. That you are accepting that they are going to die and that is difficult. As you know, denial is more than a river in Egypt. So that is a problem and then I think that depending on upon the family background and support systems some people are more willing than others to accept it. I feel that perhaps that African American and Hispanic are less willing to accept Hospice services than Anglo type people. I don't know, I don't think that they are concerned about language or culture barriers but well maybe that is a perception that they have but I think hospice is big enough that they can overcome those barriers. I do think there is resistance I am not a hundred percent sure what all the reasons are, hopefully that is what you are figuring out. My perception may be wrong, but I think that denial of death and of terminal illness last longer and is more pervasive in both the African Americans and Latino population. There is not as much acceptance and the inevitability of dead but maybe I'm wrong.

Dr. Gray, 48-year-old male born in Germany identified a difference in how Mexicans respond to a terminal diagnosis.

Dr. John, 52-year-old, White male discussed his hesitations in this manner:

Patients respond to the referrals by listening to my insight. It is difficult when you deal with patients from Mexico when they are in this country they believe there are indeed a lot of opportunities.

6. Who facilitates the referral to hospice?

Many of the physicians discuss hospice services with the patient and/or family and the referral is then facilitated with the assistance of nurses and/or the hospice representative.

Dr. Zinn, a 49 year old male, born in USA reported: I call the hospice representative or my nurse calls hospice. This tends to be the procedure in which the physicians use to facilitate a hospice referral.

Dr. Crum a female, age 43 and Cuban born stated:

If the patient has been hospitalized, the referrals are made by the social worker for the floor, the nurses and I also make referrals.

7. Did you encounter any barriers to getting connected with hospice?

Similar to the hospice caregivers and patients the physicians did not encounter barriers in getting connected to hospice. They are pleased with the education they have attained about hospice services as well as with the on-going assistance they receive in the referral process. Hospice representatives are central in assisting physicians and families.

Dr. James, male, age 38 and Jamaican born expressed his thoughts in this manner:

No, hospice service over the last 5 and 6 years have been very good and very responsive to the questions that patients and families have as well as to physicians. They have offered a lot of teaching to doctors in training we have a fierce sense as to what we are getting into when we finish our training and we realize hospice will play an important role.

Dr. Ruiz, male, age 48 born in Puerto Rico added:

No, there is a Hospice worker [representative] who comes frequently to visit us. She is the one who we can discuss any problems or concerns. She told me about the hospice house and everything. I have never referred

anyone to the Sun City location, but I have referred many to the Temple Terrace. I have not been there, but people say that it is a beautiful place. You see, I told Mary [my patient] to call the doctor because her father had an injection fraction of 10%. He has a COPD and there is nothing that can be done. The doctor told her that he was sorry but he could not refer him to Hospice. I don't know if the doctor has a disagreement with Medicare, I do not have that information. I don't know why he couldn't refer the patient. I am sure I would refer the patient to Hospice. The patient died afterward.

Dr. Crum a female, age 43 and Cuban born stated:

Well, all the ones I have referred have being happy. I have had no problems in this aspect.

8. Do terminally ill Hispanics/Latinos prefer to rely on family members?

Dr. Ruiz, male, age 48 born in Puerto Rico answered this way:

I trust in the families, but unfortunately, I have been on both sides. It is difficult when you are part of the problem; sometimes we cannot see the situation clearly. I believe in family, because I have my own family. I also believe in Hospice services. If the family refuses the Hospice services, I respect their decision but I prefer to involve somebody out side of the family when a terminal patient is involved.

Dr. Estes, a male, age 45 and Cuban born noted: made this strong statement:

Yes, always, especially the wives, I think especially males want the wives to do everything for them; they rely on the wives more. One child usually gets stuck with the burden, they are either working or whatever, it's a good way to sort of help support the family in taking care of the patient. Yes, the wife or the husband, but usually the wife is the sole caregiver, I do have a hospice house, there are a few beds available, if they are very ill and need 24 hour day care help, sometimes they put them in the hospice house, once they are in a hospice house they are not there more than a few days, they died pretty quickly.

Dr. Cruz, a male age 52 born in Colombia responded concisely:

Yes, the majority of Latinos think differently; there is a sense of belonging.

So did Dr. James, male age 38, Jamaican born:

Yes, Much, much more so.

Dr. Gray, 48-year-old male born in Germany concluded:

I have surely seen how Hispanic/Latino family members rely a great deal on their families by living together and they tend to be traveling together visiting the physician that is treating the child.

9. Are family members likely to be the sole caregivers for Hispanics/Latinos?

The physicians unanimously agreed that Hispanic/Latino family members are likely to be sole caregivers. However they addressed the changes that occur when family members relocate from their country of origin and the shifts that take place as a result of family composition and availability. The issue of family support systems was also highlighted in the interviews with non-hospice caregivers and hospice caregivers.

Dr. Crum a female, age 43 and Cuban born highlights the cultural difference related to family support, which Rosa paid non-hospice caregiver also discussed:

Yes, sometimes this happens. The family doesn't want to take them to a nursing home, although they cannot do it. They try the last resource to keep the patient at home. I believe is a cultural problem; in Cuba, the family is not, only the spouse, children, mother and father. Cubans include the grandmother, the aunt, and the cousin; the concept is that they will take care of the patient until he closes his eyes. Mostly the female who is still single will be in charge of the patient.

Dr. Ruiz male, age 48 born in Puerto Rico had this to say:

Yes, that is right. It is not just with terminal patients, but also happens with chronic illness patients. I see old Hispanic patients attending Hospice, but only a small percent in comparison with the average American patient. When the family realized that they are not able to take care of the patient, then they decide to call Hospice. I have an 80-year-old female with pulmonary problems. One day I called her and she did not answer; I was afraid that she was dead and lying down on the floor. I called her son and he said he has not being able to go to her home and check on his mother because of the pressures of his job. I decided to refer her to Hospice and now she is happy. The patient also shared with me that her daughter came to live with her, but as soon as she knew that she should pay the electrical

bill she left. The patient is very happy at this moment living in her home with Hospice and I will still be her attendant physician until she dies.

Dr. Cruz, a male age 52 born in Colombia adds: The majority, yes.

Dr. James, a 38-year-old Jamaican born male said:

The family plays a big, big role in caregiving. We like to have hospice help us out as much as they can. It helps if we have a 70-year female living with a son and daughter who work. We try to get a hospice nurse to visit and follow-up.

Dr. John, a 52-year-old male expressed perspectives related to caregiving in this manner:

The biggest thing is the broaching the privacy in the family dynamics and they don't want to let people know anything that is going on in their family. After the first week they know that hospice is not there to spy on them so they accept it. In my experience Hispanics/Latinos want to do as much among the family as they can. I don't know if its cultural or due to other factors. They don't want someone in the house because they have an illegal alien there are other things that go on with this specific population. Even in other populations they could be Blacks or Caucasians they could give hospice a hard time if they don't want them there. I don't think its ethnic; I think it's more of a familial thing. If there is a couple they are more receptive to hospice. If it's a big family the spouse can have the kids or brothers of sisters to come in and give care but it only works for a month and then people start finding things to do. But at least they try doing the care for a month and 9 times out of 10; a month later they say we need the help.

Dr. Jones, male age 52 and born in the United States described the process in this manner:

Well I think family yes, but I think that the definition of family in that population is more extensive; it is not simply the mother and father but frequently the in law the grandmother, aunts the majority I think is the Latin families. There is large involvement of a constellation of people who are related by marriage or blood lines who are at least in this environment and they make every attempt to be very support, but I am not sure what happen to where they get outside if it drifts way or not. More than the Anglos, you see that Anglos its going to be very fragmented, more fragmented in families relationships, don't have such closed extended families and perhaps this is part of the reason they accepting more of the outside

help. I try to identify the primary care that is usually the mom and dad and then I asking for the people they want to be involved in the discussion, if they said yes that's fine if they said no that's not fine. I also when we discussing the inevitability of death that is coming I do try to have this conversation just with the father and mother along, because I want them to know that the decision is really their decision and it is not someone else or what they are expected to do. The job of everyone is to support them in whatever decision they make. I like one opportunity of separation from the big group so they say freely what they want without worry about someone else is hearing or thinking.

10. Did referring Hispanic/Latino patients to hospice services affect your relationships with them and their families? If so how?

All of the physicians reported that family members appreciated the referral to hospice. Some stated that the family members expressed they gratitude via correspondence.

Dr. James male age 38, Jamaican born states:

It has had a very positive affect. I have received many letters and cards from the family members. Even when the patient is still here thanking me for how we handled the situation, and being very caring and aware of any cultural sensitiveness and being very careful trying to learn they have been very appreciative.

Dr. Crum a female, age 43 and Cuban born smiled so happily and chirped:

No, the relationships are not affected, rather they in turn were happy after the referral.

Dr. Gray stated: No because I continue to be the patient's physician, most of hospice does not have any pediatric physician.

11. What follow-up is done after the referral has been made to hospice?

The physicians varied in their responses to the type of follow-up they provide after the referral to hospice in made. Some of the physicians continue to follow the patient and discussed how time consuming it is, however they do not want to abandon the

patient after the referral is made. Others immediately cease treating the patient and the hospice physician then provides the care. Some are available as consultants and function as mediator as needed for patients after they make the hospice referral.

These differences are articulated in this way by Dr. Cruz, a male age 52 born in Colombia:

Sometimes I remain the doctor but sometimes the hospice doctor takes over it depends of the patient's needs

Dr. James male age 38, Jamaican born stated:

Once a patient goes to hospice; in my practice they are assigned a hospice physician, which basically takes over the day-to-day care of the patient. At times there may be an issue where the patient or the family are not comfortable with the hospice physician making a decision. That is when I come in and either try to make the decision or facilitate the decision or explain to the family and patient that this needs to taken care by the hospice physician. Most of the time they are agreeable to that.

Dr. Crum a female, age 43 and Cuban born highlights how she manages the issue as follows:

Some of them yes, others do not. For example, if the patient cannot come to visit me, I am not allowed to go see them at home. I prefer the hospice's doctor to do his job. They call me and ask what's all right and what's not, what I would do, but that is all.

Dr. Zinn a male, age 49 born in USA explains:

It depends on the patients' status. If they are bed bound its not worth it to get an ambulance, we talk to the family and tells them since their close to the end and we can't get the patient in to the office we tell them we need to get a hospice physician take care over the care in that case. We are still in contact with the family and if the hospice doctor suggests something they call me up and ask if I agree with what the doctor wants to do. We are trying to save them from having to get the patient in here to see me.

Dr. Jones sheds light what could be a complicated situation:

I do not think so. This depend on the situation, this is more like a consulting source environment because patients come to see you, they have preexisting

relationships with other doctors either a primary care provider or could be a friend. When patients come here because they are very ill. Many depending on the diagnosis are very ill but they get better for a little while. But then they may have a severe illness related to a severe infection and chemotherapy or something and they come back in here. This tends to be the patient's primary family care provider. In that situation the answer will be no, but in few situations where the situation are very dramatic, well not a pre existing illness where you expect a short hospital stay and a discharge. The nurse will be in touch with the primary care provider but many of them are uncomfortable with that [hospice] scenario until the nurse make all the arrangements, but occasionally they will make some phone calls to hospice. We try to refer them to their usable doctors like well facilitating what's going to happen and then have them reconnect with their usable doctor.

12. What advice would you give to hospice providers in order to increase the number of Spanish speaking clients in the program?

Although some of the participating physicians had conflicting ideas as to the causes of underutilization, their advice to hospice providers concerning the strategy of increasing the number of Spanish speaking clients in the program is the same advice provided by hospice caregivers and non-hospice caregivers. The resounding suggestion is for hospice providers to increase Spanish-speaking workers, Spanish-speaking team members, and public education in Spanish.

Dr. James age 38, Jamaican born practicing for 6 years noted:

More public education in Spanish about hospice is needed. A lot of us do not have the right idea; we think that it is a lonely process where the patient will go through it by him or herself. Obviously we do not want to romanticize it, it is a serious issue but we should make families and patients aware of hospice. It is a viable option made to improve the quality of life that is finite, that is there and to minimize much of the discomfort that comes with end of life issues.

Meanwhile, Dr. Cruz age 52, Colombn born practicing for 15 years stated succinctly:

Increase the number of Spanish-speaking team members.

Dr. Ruiz, male, age 48 born in Puerto Rico reiterated:

I recommend having Spanish-speaking workers. I have a lot of patients that do not speak English. They are like my mother; they are never going to learn English. The only way that I could engage my mother in any part of this program is if they have people that speak her language and people whom she can identify with. This is the most important part. It is a compassionate type of care.

Dr. Crum a female, age 43 and Cuban born highlights the cultural difference as

see notes:

Hospice needs to have Spanish-speaking nurses and team members who visit. Because for example I have a Latin patient who is in hospice, and the personnel that visits her is American, therefore they don't understand each other and the daughter who has to act as a translator is at work. This person even though is at hospice, has to have someone else at home to take care of her. She is active right now and there are no nurses who speak Spanish and that affects the relationship, because it is not the personal nurse that takes care of me, but someone distant, a stranger. They should increase the number of Spanish speaking personnel

Dr. Gray, 48-year-old male born in Germany expressed this suggestion:

It would be helpful if hospice would give training on working with the Hispanic/Latino people. If I had a book or some information that I can look at about the different aspects of health care and experiences of what really is important to Hispanic/Latino patients and family members. If I had facts that I do not have now. I have different experiences; I need help not to fumble in the really difficult areas.

Dr. John, 52-year-old White male born in USA stated:

It really depends, as you well know there are many Hispanics who are Americanized. They're acculturated into sort of the mainstream; they have sort of a duality where they are just as comfortable in an English-speaking environment as they are in their traditional environment. Those people I think it doesn't really matter who they send out as the introductory person. But for the other ones whom are most comfortable speaking Spanish, interacting and behaving in a more traditional Latino culture then I think its helpful to those people, at least for the introductive phase for them to

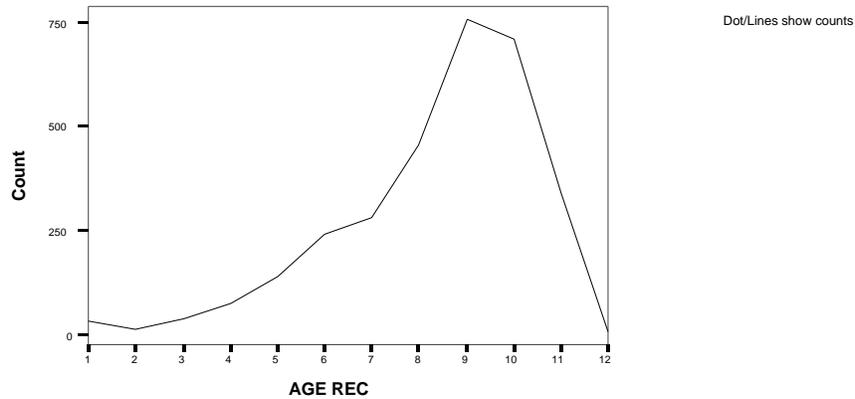
meet and see face to face another Latino person. If its going to be another Anglo person it should be someone who is extremely comfortable in that environment and can relate to them [Hispanics/Latinos] in a way they are accustomed to being related to. I think that would be helpful. The other thing, I think is that hospice needs to say that their goal is not replace their support system but to enhance it.

Archival data findings

After obtaining the archival demographic data on all patients in the hospice program from August 2002-August 2006, I extracted the patients who were identified as Hispanic/Latino and created a separate dataset. There were a total of 3,123 Hispanic/Latino patients served by hospice during this period. Using SPSS 15.0 descriptives, frequencies for age, gender, patient caregiver relationship, religion, referral source and correlations between age and length of stay were used to analyze patterns among Hispanic/Latino hospice users. I compared the demographic findings from the archival data with the demographics of the Hispanic/Latino patient and non-hospice patients who participated in my semi-structured interviews.

The gender of the Hispanic/Latino patients from the archival data is 52.3 percent female and 47.7 percent males. The median age for Hispanic/Latino patients in the archival data is 72.42 years. The distributions among the ages indicate that hospice serves a wide range of ages. I recoded the ages into the following groupings: (1 thru 18=1), (19 thru 26=2), (27 thru 34=3), (35 thru 42=4), (43 thru 50=5), (51 thru 58=6), (59 thru 66=7), (67 thru 74=8), (75 thru 82=9), (83 thru 90=10) and (91 thru 100=11) and (101 thru highest=12) to determine the cluster of age most served. The graph indicates that the largest Hispanic/Latino age group served by hospice is between ages 67-100.

Figure 1. Age Distribution of Archival Data



The primary caregiver relationship distribution table from the Hispanic/Latino archival data indicates that the hospice caregivers of the hospice patients were 32.3 percent daughters, 29.0 percent spouses and 11.7 percent sons. This finding is consistent with the findings of the hospice patients in my study. Four of the patients are males and six are females. Meanwhile 50% of the primary hospice caregivers are the patients' daughters, 20% a granddaughters, 20% are wives and 10% is a female paid caregiver. The primary caregiver relationship and table pie chart describes the distribution.

Figure 2. Primary Caregiver Relationship of Archival Data

| | Frequency | Percent | Valid Percent | Cumulative Percent |
|----------|-----------|---------|---------------|--------------------|
| Daughter | 1010 | 32.3 | 32.3 | 36.2 |
| Son | 366 | 11.7 | 11.7 | 70.5 |
| Spouse | 905 | 29.0 | 29.0 | 99.5 |
| Total | 3123 | 100.0 | 100.0 | |

The religious affiliations in the archival data are as follows: 56.7 identified as Catholic, 5.5 as Christian, 4.0 as Pentecostal and 3.9 as Baptist. The other religions were distributed evenly with 3.4 reporting no religious affiliation. The majority of hospice

patients in my research were also Catholic, 70% identified their religion as Catholic, 30% as Protestant and 50% of the hospice caregivers identified their religion as Catholic and five as Protestant.

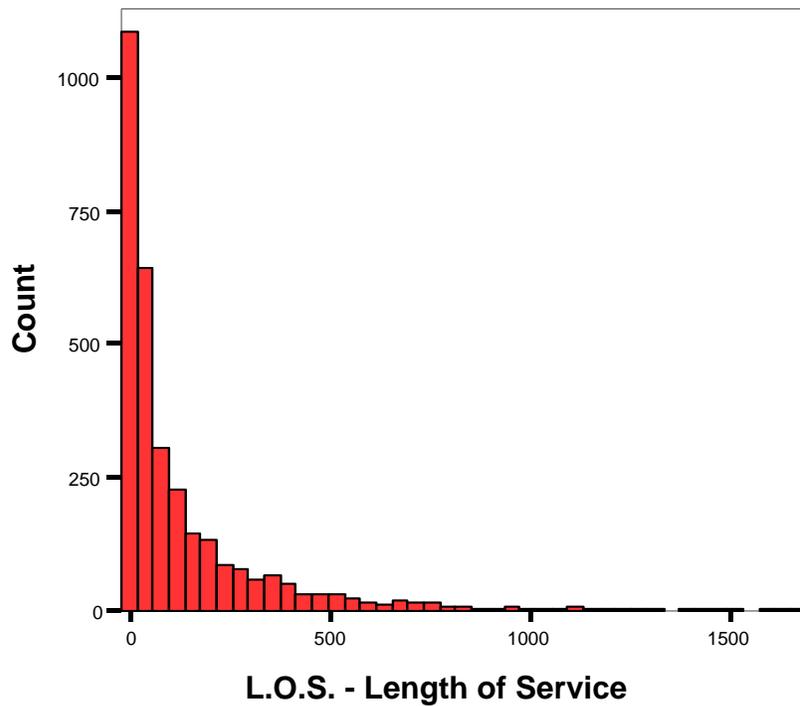
The referral source data proved to also confirm the findings in my semi-structured interviews. A high percentage of Hispanic/Latino hospice patients in the archival data set were referred to hospice while in the hospital. Due to confidentiality, I will not provide the names of the hospitals or physicians in my archival data. The total amount of Hispanic/Latino patient referrals made from hospitals is 1,426; the total amount of Hispanic/Latino patient referrals made from nursing homes is 303 and the total amount Hispanic/Latino patient referrals made from physicians' medical offices is 1,394. The combined total amount of referrals made by institutions is 1,729. This finding indicates that out of 3,123 overall Hispanic/Latino patients served by a hospice during the period of August 2002 thru June 2006, physicians made only 1,394 Hispanic/Latino referrals. The Pearson correlation between Length of Service and Age is positive but small and significant .105. This finding points out that there is a relationship between the two variables. The graph indicates that as the age of the Hispanic/Latino increases so does their length of stay in hospice.

Figure 3. Primary Caregiver Relationship Correlation

| | | L.O.S.Lengthof Service L.O.S. - Length of Service | Age |
|----------------------------|---------------------|---|----------|
| L.O.S.LengthofService | Pearson Correlation | 1 | .105(**) |
| L.O.S. - Length of Service | Sig. (2-tailed) | | .000 |
| | N | 3100 | 3090 |
| Age | Pearson Correlation | .105(**) | 1 |
| | Sig. (2-tailed) | .000 | |
| | N | 3090 | 3113 |

** Correlation is significant at the 0.01 level (2-tailed).

Figure 4. Length of Service Interactive Graph



In summary, my participant observations within a hospice organization and the semi-structured interviews that I conducted with the hospice caregivers and the non-

hospice caregivers answered my research questions and provided a wealth of information and insight about the utilization of hospice services by the Hispanic/Latino community. The results discussed the structural organizational barriers to hospice utilization by Hispanic/Latino families and individuals. The cultural factors that contribute to the known under-utilization of hospice services by this population were explored in depth. Both the hospice caregivers and the non-hospice caregivers expressed how the terminal diagnosis impacted the terminally ill individuals and their families. The research also offers important information on why some Hispanics/Latinos utilize hospice while others do not, as well as recommendations that are applicable to hospice organizations. My research presents the cultural differences between hospice caregivers and non-hospice caregivers pertaining to their choice of support system.

The roles that physicians play in the utilization of hospice services by Hispanics/Latinos were explored in depth through the semi-structured interviews I conducted. The responses and reflections from the physicians enabled me to link the relationships between the individuals' healthcare providers, end of life issues and the hospice referral process.

The findings provide vital information about gaps in training and education for physicians and caregivers along with critical information for hospice providers. The demographic archival data about Hispanic/Latino hospice patients added to the rich data I attained through the semi-structured interviews. The findings in the archival data reflected a likeness between the hospice patients in my study and the patients in the archival data. The type of caregiver relationship, age, religion and referring source

indicated in the archival data of Hispanics/Latinos was similar to the Hispanics/Latinos in my study.

Chapter 6

Analysis and discussion

Discussion of findings

This discussion section analyzes the findings related to hospice-caregivers', non-hospice caregivers' and the physicians' responses to the semi-structured interviews. The findings also explicate the research question pertaining to the cultural factors that contribute to the known under-utilization of hospice services by this population.

Both the hospice caregiver and non-hospice caregiver groups were asked to disclose the time when they first learned about the patient's diagnosis. Of the respondents in this study, 100 percent of the hospice patients currently receiving services were eligible to access hospice services sooner than they did, leading the researcher to conclude that earlier referrals could have benefited the patients and families as well as the hospice organization. The information obtained from the interviews was gathered approximately one month after the patients were admitted into the hospice program. Also critical to the research question is the finding that 100 percent of the non-hospice patients are currently eligible for hospice services. They all have a terminal diagnosis of six months or less which enables them to meet the criteria for hospice services. A second question of the study examined how the patient was informed about their terminal diagnosis. Central to the research question is the finding that 50 percent of the Hispanic/Latino caregivers reported that they learned about the patient's diagnosis from a hospital physician when the patient was hospitalized. In contrast, the non-hospice caregivers reported that 100 percent of the non-hospice patients learned about their terminal diagnosis from their primary physicians. Therefore, since the non-hospice patients were not diagnosed in a

hospital but by their primary physicians while living in their own residences with paid caregivers or with family members caring for them, perhaps their diagnosis was not perceived as severe since they anticipated that a hospital setting may provide hope of a cure. The fact that the non-hospice patients remained optimistic despite their terminal diagnosis may indicate that they perceived the hospital setting as the “next step to getting better” rather than the last treatment phase before their death. In comparison to the non-hospice patients in their own home settings, the hospice patients were diagnosed with a terminal diagnosis in a sterile hospital environment, coupled with the limited medical treatment alternatives provided. This persuaded the hospice patients to choose hospice services more readily in order to return to their homes for comfort and reprieve. Therefore, for the hospice patients, their hospitalization appeared to have the effect of serving to confront them with the severity of their health status.

Among the hospice caregivers 60% first learned about hospice service from a physician or a hospital health care professional, 20% learned about hospice from a friend and 20% as a result of a prior experience with hospice services from non-Hispanic/Latino relatives and friends. While in the hospital, 70% of the hospice patients chose not to pursue aggressive treatment after learning about their diagnosis. Only 30% of the hospice patients received treatment including chemotherapy, radiation, surgery and dialysis. The results indicate that 80% of the hospice-patient group reported receiving assistance from physicians in determining treatment options and 20% of the patients relied on caregivers to assist in decisions related to treatment. Once the decision to elect hospice services was made 70% of the hospice patients received hospice services immediately and 30% waited only one day. This statistic overwhelmingly reflects the

crucial nature of the physician/patient relationship as well as the physicians' trust and confidence in hospice when they refer. Hospice has established a positive relationship within the physicians' network in terms of their timeliness in the referral and admissions process. This is attributed to the readiness and promptness of the admissions department, the hospital admissions staff and the hospital team members to facilitate the admissions process. Both hospice caregivers and physicians reported the admissions process as occurring promptly and efficiently. They also appreciated the assistance they received in explaining the patient's condition, prognosis, need for hospice when they needed the admissions process to be facilitated. Hospice caregivers noted that their much-needed medical equipment arrived to their homes shortly before the patient was discharged from the hospital and immediately thereafter the patient's medications were then delivered to their home. The caregivers expressed gratitude for this tangible assistance at a time when they were experiencing a great deal of emotional upheaval and distress regarding the patient's terminal diagnosis.

Among this population of non-hospice caregivers, the median length of time of caregiving for the ill individual in the United States mainland was 14.6 years and 32 years for non-hospice patients. The median length of time for hospice caregivers is 33.7 and 41.1 for hospice patients. The length of time in the United States mainland was significantly shorter for non-hospice caregivers and non- hospice patients. This finding correlates with the non-hospice caregivers' limited knowledge and understanding about hospice's eligibility criteria and hospice's overall functioning. There is a direct correlation between the facts that the non-hospice caregivers have been in the US mainland an average of 19.1 years less than the hospice caregivers. The non-hospice

patients have been in the US 7.4 years less than the hospice patients. Therefore, according to the interviews conducted with the non-hospice caregivers/patients, they perceive hospice as intrusive and confusing, as well as taking away one's freedom of choice. Regardless of the variation of length of stay in the US between the hospice and non-hospice group, Spanish was reported as the language of preference for both groups.

Only five out of fifteen hospice and non-hospice caregivers (33%) reported proficiency with the English language. All twenty hospice and non-hospice patients identified Spanish as their language of preference and all depend on family members to assist them by translating. An important finding from the semi-structured interviews for both groups is the language barrier. The caregivers' and patients' inability to comprehend the English language was consistently reported as problematic. The need for Spanish-speaking staff was a central theme in the discussions related to the question "what advice would you give to hospice providers in order to increase the number of Spanish speaking clients in the program?" The patients and caregivers expressed the need to be able to communicate effectively in their language of preference with healthcare providers in their homes. It is critical to recognize that the caregivers report lack of proficiency in English, rather than just mere preference not to speak English. The physicians unanimously also identified the need for increased Spanish-speaking team members. This is primarily due to the complicated nature of medical terminology and their caregivers' eagerness to effectively follow instructions related to the patients' care.

Dominga's (CG6) inability to communicate with her husband's hospice nurse and with the continuous care nurse caused her and her daughter unnecessary stress, worry and fear. The caregivers' need for Spanish-speaking team members is consistent with an

individual's preference for their language of origin in times of crisis and vulnerability. Fela (NHG10) provided an extremely insightful fact when she stated "I think people need to know what the word 'hospice' means. It is difficult to pronounce it in English and it has a different meaning in Spanish". Dr. Crum, a female and Cuban born, highlighted the urgency for Spanish-speaking team members when she stated "I have a Latin patient who is in hospice, and the personnel that visits her is American [non-Spanish speaker], therefore they don't understand each other and the daughter who has to act as a translator is at work". Factors related to communication barriers were prevailing throughout my research among hospice caregivers and patients, non-hospice caregivers and patients along with physicians. The content of the caregivers' and physicians' discourses enabled me to identify gaps in services.

Among Hispanic/Latino older adults and individuals with limited years of residence in the USA, the concept of hospice is foreign; therefore detailed discussions need to occur about hospice services by the physician and mental health professionals. It is likely that when a physician first discusses hospice services with the patient/family, it is the first time the patient/family has heard of the hospice concept.

This factor is directly related to their level of knowledge about hospice; exposure to the hospice concept and confusion related to the eligibility criteria. Their beliefs, perceptions and attitudes are nestled within a context of viewing hospice services as an intrusion as well as foreign. Dr. James discussed how patients tend to view of hospice as sterile environment. This contributes to their decreased utilization of hospice services although it is a service that is needed. Dr. Jones' advice to hospice keenly highlights the

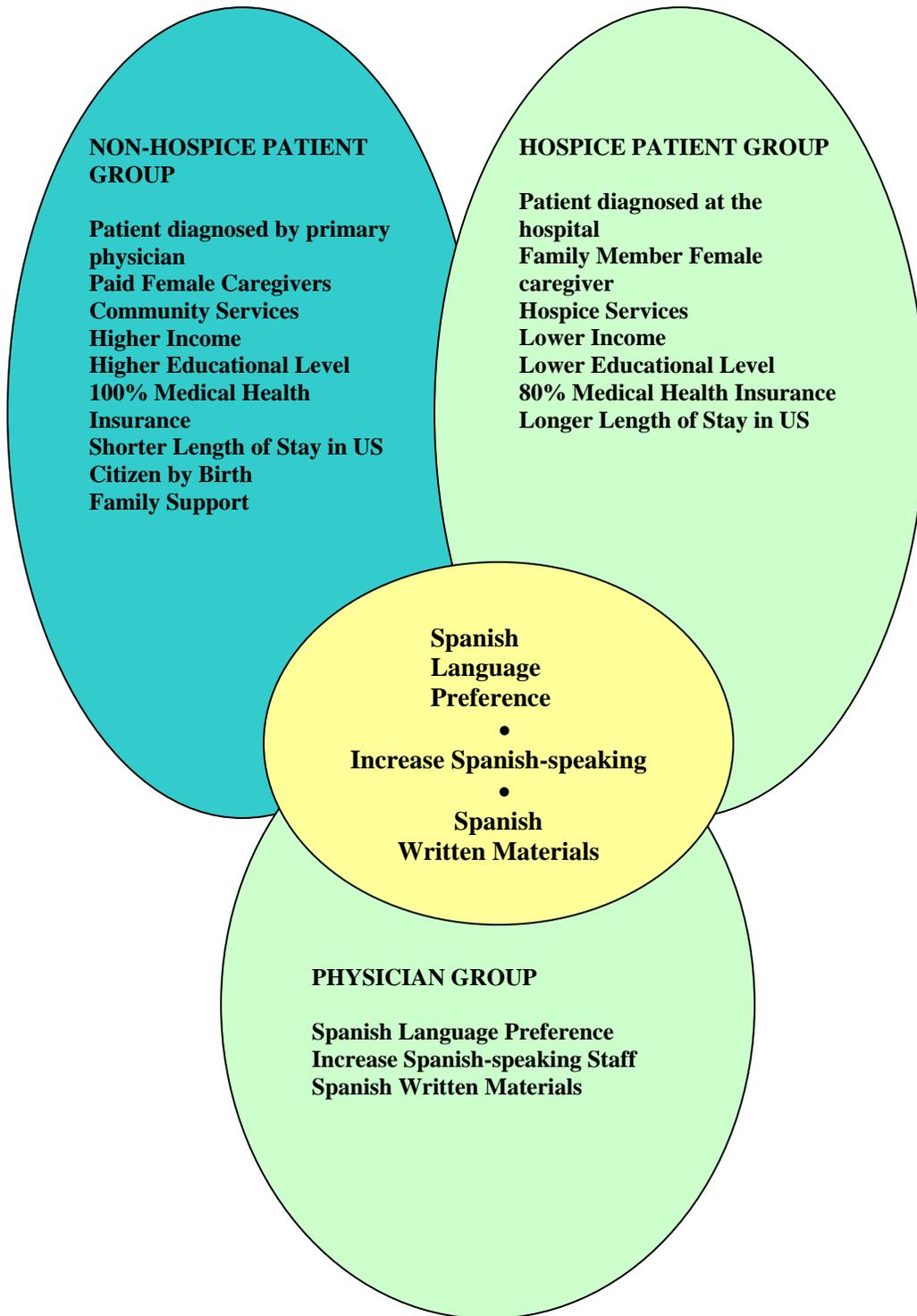
findings reported among the non-hospice caregivers. He stated, “hospice needs to say that their goal is not replace their [Hispanic/Latino] support system but to enhance it”.

Along with the ability to afford paid caregivers and the access to family support, the non-hospice patients also have more options and choices related to healthcare services. These options include routine health care and home based healthcare which provides them ongoing maintenance and monitoring of their health conditions. Factors of gender, income, length of time in the United States mainland, citizenship, educational level and choice of health care reflect that the non-hospice group may perceive hospice services as an inferior service. Gender roles were especially helpful considerations in determining aspects of preference for hospice care, deduced from my research. All ten of hospice caregivers were female and nine of the non-hospice caregivers were also female. The only male non-hospice caregiver had a part-time female paid caregiver.

The research also indicates that caregivers with one or more daughters living in the area have had larger support systems. Caregivers who belong to a church or have at least three friends also receive help. An interesting scenario in my findings is that of two hospice caregivers, Angela 47 and Lucy 49 did not receive help from family members. They both are both divorced and have a limited number of friends. Angela does not have any siblings and Lucy does not have any female siblings. Rapp notes “The family as an ideological construction is extremely important to poor people” (Rapp 1987:233). However, relocation from one’s homeland as well as from rural to urban dwellings often fragments families.

The diagram below summarize differences and commonalities among Non-Hospice patient group, Hospice patient group and physicians

Figure 4. Differences and commonalities among Non-Hospice patient group, Hospice patient group and physicians



Relevance of the findings

The non-hospice group has increased social and cultural capital, defined as resources and support, both social-emotional and financial, which enables them to have more alternatives. The wealthier are thus better able to shield themselves from unhealthy environments whereas the poor are increasingly vulnerable. Strikingly present across studies is the observation that social health inequalities worsen with existing inequities that in turn cause the poor to confront emergency situations that they are unable to overcome, causing what sometimes is referred to as “spiraling-down effect”.

In contrast, the hospice patient and the all female hospice caregiver group have lower incomes, lower educational levels, less family support and less health insurance coverage and INS status. The findings in my research are congruent with Nygugen and Peschard’s explanation of the ‘illness poverty trap’ as a social corollary (Nguyen and Peschard 2003). The outcomes of the my research clearly illustrate how the poverty status of an individual causes ill health and in turn their health status causes them to remain in poverty as a result of a late terminal diagnosis, lack of preventative care and unplanned hospitalizations. Also the research indicates that due to migration and immigration patterns and status, Hispanic/Latino terminally ill individuals who choose hospice are more isolated and separated from their social and cultural capital. An individual’s social and cultural capital is essential and vital throughout life but particularly crucial when one is terminally ill. According to Bourdieu “capital can present itself in three fundamental guises: as economic capital, cultural capital and social capital” (Bourdieu 1990:243).

Only two paid hospice caregivers, Nina and Maria, were knowledgeable of hospice services prior to the patient's admission into the program; the benefits and they requested hospice services. They initiated the discussion about hospice services with the patient's family and were able to persuade the patient's son to utilize hospice. But unlike the two paid hospice caregivers, the paid non-hospice caregivers expressed limited knowledge about hospice, confusion related to the eligibility criteria and were satisfied with their existing supportive services. Five of the non-hospice caregivers expressed discontent with the hospice service they had received in the past.

None of the hospice caregivers/patients were criticized for seeking hospice. They did not have any negative ramifications from family members by choosing to receive hospice services. On the contrary, the family members expressed gratitude to hospice for the services, which actually assisted the family. All of the hospice caregivers reported that they would recommend hospice services not only to friends but to family members as well. This is indicative of the benefits gained by hospice services.

Neither were the non-hospice caregivers/patients criticized for not seeking hospice services. The results indicate that seeking hospice services is acceptable and illustrates that within the Hispanic/Latino community there is a significant amount of respect for ones choices.

Ethical concerns

Prior to beginning my research I was knowledgeable about the structure and functioning of hospice organizations. I was a former employee of four hospice organizations in the Central Florida area as a master's prepared clinical social worker providing patient/family care. Along with working directly with patients and families, I also functioned in managerial positions. It was critical for me as researcher to be aware

of previous and existing partialities. My role as a researcher was distinct to my former function with the organization as clinical social worker therefore maintaining boundaries and objectivity was crucial to my research. In conducting this research it was essential for me to be cognizant of the fact of doing “native anthropology” according to Delmos J. Jones in “Doing Native Anthropology” and the potential conflicts for the researcher as well as for those participating in the research.

Study limitations

Although this study aims to assess the factors that enabled the Hispanic/Latino patients to access hospice services, the interviews were conducted with the patients’ caregivers and not with the patients due to their vulnerable status. Interviewing the caregivers rather than the actual patients provided the caregivers’ perspectives and not necessarily those of the patient, although these factors would certainly be advisable for the next phase of this study, which will yield comparisons between caregivers’ responses and those of patients. A portion of the study is also limited to caregivers utilizing hospice services in Central Florida area, which is a non-profit organization, as are many hospices. The archival data attained from the database on Hispanic/Latinos is not a comprehensive representation since ethnicity is not always entered into the patient’s data profile by the admissions staff. The research is limited to this geographic area although applications can adequately be made. The group of non-hospice caregivers of terminally ill individuals were to be identified as a result of snowball sampling, a process that introduces bias because the technique itself reduces the likelihood that the sample will represent a good cross section of the population. Although there are other populations

that underutilize hospice services, this study focuses solely on the Hispanic/Latino population.

Chapter 7

Recommendations

To service providers

The research findings conclusively indicate a need for an increase in Spanish-speaking field staff and office staff within hospice organizations in order to adequately serve the Hispanic/Latino community. Increasing the amount of Spanish speaking staff will also increase the amount of Hispanics/Latinos served by hospice; it will increase referrals and profit as well as secure the Certificate of Need for hospices in the state of Florida. The research indicates that existing financial incentives for Spanish-speaking employees are ineffective. Structural and organizational systems need to be devised in order to tackle the existing problems in retention and recruitment. It is imperative for hospice organizations to become knowledgeable and proactive in addressing the needs of the Hispanic/Latino community within the context of demographic increases and geographical shifts.

Since accessibility and timeliness is critical in the hospice referral process, establishing a Spanish-speaking telephone line is an imperative. A direct Spanish-speaking line or receptionist will enhance the quality of service for existing hospice patients. It will also facilitate communications between Spanish-speaking patients/families and their health care providers. The Spanish telephone component will enable the patients/families in crisis access to medical, psychosocial or spiritual care. This would reduce emergency calls to 911 as well as diminish sudden and unplanned hospitalizations. Prospective patients and families in the Hispanic/Latino community members will also inquire information about hospice services. Spanish-speaking

bachelor level social workers, licensed practical nurses, medical anthropologists and community health professionals are viable resources to employ in this capacity.

Professional translators are also required and should be included as part of the hospice teams and utilized as needed among the team members.

Hospice organizations are obliged to provide educational materials to hospice patients in Spanish. This necessitates the translation of the educational manual that is provided upon admission to all hospice patients and families into Spanish. The admission consent forms are available in Spanish; however, the detailed educational manual is not. Once translated, this educational material could be used to educate and provide training in assisted living facilities, in physicians' offices and throughout the Hispanic/Latino community at large. The educational material should not be limited to written material, but should be available also in video, DVD and audio disk formats. Hospices need to devise culturally and linguistically competent strategies to educate the Hispanic/Latino community about hospice benefits and services. Hospices should maximize the critical role played by physicians and mental health professionals in educating the Hispanic/Latino community by providing them with the skills and tools to do so more effectively.

Timeliness and support at the actual time of death is vital for Hispanic/Latino patients. Therefore, is necessary for hospice team members to respond promptly to family members when they call the hospice organization indicating that the hospice patient is actively dying or has died. Hospice organizations must be cognizant that existing communication barriers are magnified upon the death of a loved family member. When a hospice organization fails to meet the needs of a patient or family member when

they feel helpless, trust is breached and the likelihood that they will recommend hospice services to other Hispanic/Latino individuals within the community ceases. The informal “*word of mouth*” network strongly exists among the Hispanic/Latino community, especially among individuals with limited English proficiency and short length of stay in USA.

Hospice organizations can capitalize and utilize the existing informal networks within the Hispanic/Latino community to provide volunteer training in Spanish. This will enable former hospice caregivers to share their experiences with members of Hispanic/Latino community via the hospice public education format, health fairs, church events, and radio programs along with other arenas within the Hispanic/Latino community. If former caregivers are provided the opportunity to discuss the services they have received as well as the intricacies of the process, they will demystify hospice services and increase accessibility. All of the hospice caregivers in the research expressed gratitude toward hospice and appreciation for the services they have received. If these same Spanish speaking caregivers become hospice volunteers they can assist in the hospice offices with telephone calls and can also serve as translators for the field team members, hospice houses and the admissions staff.

To researchers

When conducting research in topics related to end of life, it is important to allocate a sufficient span of time to conduct interviews. Due to the population’s terminal diagnosis and health status, the caregivers are not readily accessible. The patient’s health status tends to be unpredictable and unstable, therefore the caregivers are not able to freely schedule time for interviews. The caregivers also tend to be protective and shield

the patient as well as their environment from unnecessary stressors, which at times includes researchers.

For some Hispanic/Latino families, conducting research on such private matters as a terminal diagnosis or caregiving is perceived as a violation of privacy and an intrusion. This is especially true if the families are recent arrivals to the USA and if there are pending immigration issues. These factors will force the researcher to wade through numerous contacts prior to conducting the actual interview with caregivers and to schedule multiple interviews due to cancellation. These circumstances increase the overall timeframe of a research project.

The researcher must also be conscious of the sanctity of life and of the privilege they are afforded to enter the lives of Hispanic/Latino patients and caregivers when they are most vulnerable. Respect for the families' homes, their decisions and their privacy is central to the research outcome. This includes flexibility in scheduling interviews and sensitivity to the caregivers' anticipatory loss. Awareness of the vitality in ones own life and the lassitude in the homes we visit is necessary when researching end of life issues. When conducting research with Hispanic/Latino individuals the researcher should assess their language preference and utilize translators as needed.

Hispanic/Latino older adults tend to rely on their physicians to determine treatment options. Are physicians prepared to be the primary educators of hospice services for Hispanic/Latino patients and families? Further research related to Hispanics'/Latinos' utilization of specific medical treatment recommendations at end of life is also needed.

To myself

I would follow-up on my research by devising a Spanish speaking volunteer training. I will target and recruit former Hispanic/Latino hospice caregivers who have attended hospice bereavement groups and/or have been bereaved for more than one year. Replicating my research in other counties in the state of Florida and in other states will enable me to compare the existing findings and strengthen their application. I would like to follow-up my research by exploring end of life issues in countries such as Colombia, Costa Rica, Cuba, Dominican Republic, Mexico and the commonwealth of Puerto Rico as perceived by caregivers and addressed by physicians.

Future considerations

A comparative study among African-Americans, Whites Caucasians, Asians and Hispanics/Latinos will identify utilization and referral patterns among these groups as well as health care needs and barriers. Conducting further research on Hispanic/Latino daughters as caregivers, will identify distinctive caregiver demands and services needed. Knowledge and beliefs about advance directives within the Hispanic/Latino community is also an area of future research.

Conclusion

Utilizing an applied anthropology perspective I examined the utilization of hospice services by Hispanic/Latino terminally ill individuals. Twenty Hispanic/Latino hospice caregivers and non-hospice caregivers as well as ten physicians participated in the study. The dissertation ascertained the structural organizational barriers to hospice utilization by Hispanics/Latinos along with cultural factors that contribute to the under-

utilization of hospice services by this population. Why is it that some Hispanic/Latino families utilize hospice while others do not?

The study explored how immigration, migration, and documentation impact the Hispanic/Latino community's access to health care, particularly related to end of life. The research findings were unexpected yet congruent with political economy theory indicating a direct correlation between poverty and economics. Factors such as educational level, economic status, English language proficiency, caregiver relationship, age, gender, religion and length of time in the USA, enabled me to explore hospice utilization patterns within the Hispanic/Latino community and the overall perception family members have about hospice.

There is a direct correlation between a Hispanic/Latino individual's educational level, income, length of stay in the United States mainland and their health care treatment choices. Individuals with higher levels of education, higher income and less amount of years living in the USA have more health choices and rely on other support services rather than hospice when diagnosed with a terminal diagnosis. They also have increased family support and are diagnosed with the terminal diagnosis by their primary physician. Hispanic/Latino individuals with lower levels of education, lower income and longer amount of years living in the USA have less family support and are diagnosed with a terminal diagnosis by a physician when hospitalized. Among Hispanic/Latino older adults and individuals with limited years of residence in the USA, the concept of hospice is foreign; therefore detailed discussions need to occur about hospice services by the physician and mental health professionals. Despite these identified categories, overall, the entire community under utilizes hospice services.

This dissertation highlights the key role physicians play in educating Hispanic/Latino individuals about treatment options and about hospice services, thereby underscoring their need of education, skills and tools in order to effectively work with this population. Are physicians prepared to be the primary educators regarding hospice services for Hispanic/Latino patients? Family members play a key role in a patient's health care treatment choices. It is critical for health and mental health professionals to educate the patients as well as the patients' families concerning hospice services. The research outcomes illustrate how limited English proficiency and lack of hospice literature in Spanish as well as limited access to Spanish speaking health care providers intensify the Hispanic/Latino terminally ill and caregivers' vulnerability when coping with end of life. The Hispanic/Latino community lacks knowledge and needs education about hospice services. Literature, audio and visual materials are needed in the Spanish language.

My aim has been to draw attention to essential components when referring a Hispanic/Latino individual to hospice; clinicians must consider the cultural, social and economic implications of a hospice referral, health care choices and treatment. Among Hispanic/Latino older adults and individuals with limited years of residence in the USA, the concept of hospice is foreign; therefore detailed discussions need to occur with reference to hospice services by the physicians and mental health professionals. Assessments of medical services at end of life for Hispanic/Latino individuals necessitate that health care providers consider the amount of family support a terminally individual has been given, immigration and migration factors and patterns of this population. Especially important is the family and individual's expectation of medical institutions in the United States in comparison to their country of origin. Hospice and medical

institutions need to devise culturally and linguistically competent strategies to educate the Hispanic/Latino community about health care treatment and services.

The pursuit of this research avails service providers and researchers with valuable insights, indicators and information related to end of life issues within the Hispanic/Latino community, particularly utilization of hospice and services regarding a terminal diagnosis. This dissertation provides a response to a formerly existing void pertaining to the Hispanic/Latino population's view of service utilization, medical treatment and physicians when coping with a terminal diagnosis.

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Appendices

Appendix A Instruments

Research Questions

1. **How does a terminal diagnosis impact Hispanic/Latino individuals and their families?**
2. **Why is it that some Hispanic/Latino families utilize hospice services while others do not?**
3. **What differences are there between hospice caregivers and non-hospice caregivers?**
4. **What roles do physicians play in the utilization of hospice services by Hispanic/Latinos?**

| Question | Method |
|---|--|
| 1. How does a terminal diagnosis impact Hispanic/Latino individuals and their families? | I conducted semi-structured open-ended interviews with caregivers to explore losses, limitations, adjustments, and coping. I compared the causes of deaths among Hispanic/Latinos. I reviewed relevant vital statistics on Hispanic/Latino deaths in Central Florida Area. An exploratory ethnographic study of Hospice services was conducted. |

| | |
|--|---|
| <p>2. Why is it that some Hispanic/Latino families utilize hospice services while others do not?</p> | <p>I reviewed archival data on Hispanic/Latinos' utilization of Hospice services from 2000-2005 and current.</p> <p>I conducted semi-structured open-ended interviews to ascertain knowledge of hospice services, myths, and beliefs.</p> |
| <p>3. What differences are there between hospice caregivers and non-hospice caregivers?</p> | <p>I compiled demographic information from both hospice caregivers and non-hospice caregivers.</p> <p>I conducted semi-structured open-ended interviews to ascertain knowledge of hospice services, myths, and beliefs.</p> |
| <p>4. What roles do physicians play in the utilization of hospice services by Hispanic/Latinos?</p> | <p>I conducted semi-structured open-ended interviews with physicians.</p> <p>I reviewed archival information on physician referral to hospice from 2000-2005 and current.</p> |

Information Sheet for a Participant

Social and Behavioral Sciences

University of South Florida

Information for People Who Take Part in Research Studies

Researchers at the University of South Florida (USF) study many topics. We want to learn about why some Hispanic/Latino utilize Hospice services and other do not. To do this, we need the help of people who agree to take part in a research study.

Title of research study: End of life issues among Hispanics/Latinos: Studying the utilization of hospice services by the Hispanic/Latino community

Person in charge of study: Iraida V. Carrion

Study staff who can act on behalf of the person in charge: None

Where the study will be done: Hospice and USF

Should you take part in this study?

This form tells participants about this research study. A participant can decide if they want to take part in it. A person does not have to take part. Reading this form can help participants decide.

Before you decide:

- Read this form.
- Talk about this study with the person in charge of the study or the person explaining the study. You can have someone with you when you talk about the study.
- Find out what the study is about.

You can ask questions:

- You may have questions this form does not answer. If you do, ask the person in charge of the study or study staff as you go along.
- You don't have to guess at things you don't understand. Ask the people doing the study to explain things in a way you can understand.

After you read this form, you can:

- Take your time to think about it.
- Have a friend or family member read it.
- Talk it over with someone you trust.

If a person chooses to be in the study, they can provide a verbal agreement. A person's lack of participation will not impact them adversely. The purpose of this study is to learn why some Hispanic/Latino utilize hospice services and why others do not. The study will focus on decisions related to utilization of services with caregivers and physicians.

Why are you being asked to take part?

We are asking participants to take part in this study because they are a Hispanic/Latino caregiver or a physician who refers patients to Hospice. I want to find out more about how hospice caregivers utilize hospice services and why non-hospice caregivers do not utilize hospice services.

How long will you be asked to stay in the study?

A person will be asked to participate in one semi-structured open-ended interview that will last a maximum of two hours. The interview will be conducted in the caregivers' home or at USF. The interviews with physicians will be conducted in their location of preference. Identifiable information will not be recorded. Fieldnotes, transcriptions, and other documents will be stored under lock and key in the principal investigator's office for a period of one year.

How many other people will take part?

A total of thirty individuals will take part in the study.

What happens if you decide not to take part in the study?

If a person decides not to take part in this study, it is okay. The caregivers' and physicians' participation is voluntary without pay. Lack of participation will not adversely impact a person.

How do you get started?

If a person decides to take part in this study, they will need to give me a verbal consent. A participant will be asked to participate in one semi-structured open-ended interview that will last the maximum of two hours. With the participants' permission, the interview session will be audio taped. During the interview a person will be asked twelve questions and non-identifiable demographic information such as age, gender, place of birth, length of time in the United States mainland income, religion, marital status, level of education, language preference, number of caregivers at home with patient, health insurance source, community services used and presence of advance directives.

These methods have been used and tested and are not likely to increase risks to participants. Those who feel uncomfortable answering certain questions can skip specific questions or stop the interview at any time without penalty. If a participant appears agitated or uncomfortable while being interviewed I will remind the participant of his or her right to stop the interview or skip certain questions. If the participant does not want to stop the interview I will continue. If the participant continues to appear agitated or uncomfortable the researchers will end the interview.

You can get the answers to your questions.

If you have any questions about this study, call **Iraida V. Carrion at 813-503-2922.**

If you have questions about your rights as a person who is taking part in a study, call USF Research Compliance at (813) 974-5638.

SPANISH VERSION

Hoja de información para el participante

Ciencias Sociales y del Comportamiento

University of South Florida

Información para las personas que participan en estudios de investigación

Los investigadores en la University of Florida (USF) estudian muchos temas. Deseamos saber por qué algunos Hispanos/Latinos utilizan los servicios de Hospice y otros no. Para hacer esto, necesitamos la ayuda de las personas que acepten participar en esta investigación.

Título de la investigación: Asuntos relacionados a pacientes terminales en la comunidad Hispana/Latina: Estudiando la utilización de los servicios del Hospice por la comunidad Hispana/Latina

Persona a cargo del estudio: Iraida V. Carrión

Personal del estudio que puede actuar a nombre de la persona encargada: Ninguno

Donde el estudio será realizado: Hospice y USF

¿Debe usted participar en este estudio?

Esta forma le explica al participante acerca de esta investigación. El participante puede decidir si desea ser parte de ella. La persona no tiene que participar. Leer esta forma puede ayudarle a decidir.

Antes que usted decida:

Lea esta forma.

Hable de esta investigación con la persona a cargo o con la persona que esta explicando el estudio. Puede tener alguien con usted cuando hable de este estudio.

Pregunte acerca de que se trata este estudio.

Usted puede hacer preguntas:

Usted puede tener algunas preguntas que esta forma no contesta. Si es así, preguntele a la persona a cargo o al personal del estudio en la medida que usted vaya avanzando.

Usted no tiene que adivinar las cosas que no entiende. Pídale al personal que esta haciendo el estudio que le explique en una forma que usted pueda entender.

Después que usted lea esta forma, usted puede:

Tomar tiempo para pensar. Pedirle a un amigo o a un miembro de su familia que lo lea. Hablar acerca del estudio con alguien en quien usted confíe.

Si una persona elige estar en el estudio, puede expresar su acuerdo verbalmente. La falta de participación no le afectara negativamente. El propósito de este estudio es aprender por qué algunos Hispanos/Latinos utilizan los servicios del Hospice y por qué otros no. El estudio se enfocará en las decisiones relacionadas con la utilización de los servicios por quienes cuidan a los pacientes y los medicos.

¿Por qué se le está pidiendo participar?

Estamos pidiéndole participar en este estudio porque usted es un Hispano/Latino que cuida a un paciente o es un médico que refiere pacientes a Hospice. Quiero saber más acerca de cómo quienes cuidan a sus pacientes en Hospice utilizan sus servicios y las razones de por qué algunos no tienen sus pacientes en Hospice.

¿Cuánto tiempo se le pedirá permanecer en el estudio?

Se le pedirá participar en una entrevista semiestructurada de preguntas abiertas y cerradas que demorará no más de dos horas. La entrevista será conducida en las casas de las personas que cuidan a los pacientes o en USF. Las entrevistas con los médicos serán conducidas en donde ellos lo prefieran. Datos de identificación personal no serán grabados. Las notas, transcripciones, y cualquier otra documentación serán guardados bajo llave en la oficina del investigador principal por el período de un año.

¿Cuántas personas más participarán?

Un total de treinta personas participarán en el estudio.

¿Qué otras opciones tiene si usted decide no participar?

Si una persona decide no participar en el estudio, está bien. La participación de quienes cuidan a los pacientes es voluntaria y sin pago.

¿Cómo usted puede iniciar su participación?

Si una persona decide participar en este estudio, necesitamos que nos de su consentimiento verbal. Le pediremos que participe en una entrevista semiestructurada de preguntas abiertas y cerradas que durará máximo dos horas. Con el permiso del participante, la entrevista será grabada. Durante la entrevista se le harán doce preguntas y se le pedirá información demográfica que no lo identifique, como edad, sexo, lugar de nacimiento, tiempo en los Estados Unidos, salario, estado civil, nivel de educación, idioma que prefiere, número de personas que cuidan al paciente en casa, fuente del seguro médico, servicios de la comunidad que utilizan y presencia de directivos. Estos métodos han sido usados y probados y no incrementan riesgos a los participantes. Aquellos que se sientan incómodos con ciertas preguntas pueden saltar estas preguntas específicas o detener la entrevista en cualquier momento sin ninguna sanción. Si el participante parece agitado o incómodo mientras es entrevistado le recordaremos al participante sus derechos de parar la entrevista o dejar pasar algunas preguntas. Si el participante no desea parar la entrevista yo continuaré. Si el participante continúa pareciendo agitado o incómodo los investigadores terminarán la entrevista.

Usted puede tener respuestas a sus preguntas.

Si usted tiene algunas preguntas acerca de este estudio, llame a **Iraida V. Carrión al 813-503-2922**.

Si usted tiene preguntas acerca de sus derechos como persona que quiere participar en un estudio, llame a USF Research Compliance al (813) 974-5638.

Semi-Structured Interview Questions

Hospice Patients

1. When did you first learn about the patient's diagnosis?
¿Cuándo supo usted por primera vez acerca del diagnóstico del paciente?
2. Who informed you about the patient's diagnosis?
¿Quién le informó a usted acerca del diagnóstico del paciente?
3. What treatment did he/she receive after his/her diagnosis?
¿Qué tratamiento él o ella recibió después de su diagnóstico ?
4. Who assisted the patient in his/her decision about treatment options?
¿Quién ayudó al paciente a decidir acerca del tipo de tratamiento?
5. How did you learn about hospice services?
¿Cómo supo usted acerca de los servicios de hospice?
6. How long did it take you to begin receiving hospice services after the initial diagnosis?
¿Cuánto tiempo le tomó recibir los servicios de hospice después de su primer diagnóstico ?
7. Did you encounter any barriers to getting connected with hospice?
¿Tuvo usted alguna dificultad para comunicarse con hospice?
8. Who else helps? How many family members live in this area? What kinds of help do you get from family or friends?
¿Quién más le ayuda? ¿Cuántos miembros de su familia viven en esta area? ¿Qué clase de ayuda recibe usted de sus amigos y familiares?
9. Did anyone criticize you for seeking hospice help?
¿Alguien le criticó por buscar ayuda en hospice?
10. How did receiving hospice services affect your relationships within the family?
¿Cómo le afectó sus relaciones familiares el recibir los servicios de hospice?
11. Would you recommend hospice services to a friend who needed them?
¿Le recomendaría los servicios de hospice a algún amigo que lo necesite?
12. What advice would you give to hospice providers in order to increase the number of Spanish speaking clients in the program?
¿Qué sugerencias le daría usted al personal de hospice con el proposito de aumentar el número de pacientes hispano-parlantes en este programa?

Non-Hospice Patients

1. When did you first learn about the patient's diagnosis?
¿Cuándo supo usted por primera vez acerca del diagnóstico del paciente?
2. Who informed you about the patient's diagnosis?
¿Quién le informó a usted acerca del diagnóstico del paciente?
3. What treatment did he/she receive after his/her diagnosis?
¿Qué tratamiento él o ella recibió después de su diagnóstico?
4. Who assisted the patient in his/her decision about treatment options?
¿Quién ayudó al paciente a decidir acerca del tipo de tratamiento?
5. What do you know about hospice services?
¿Qué sabe usted acerca de los servicios de hospice?
6. Have you considered receiving hospice services? Why or why not?
¿Ha considerado usted recibir servicios de hospice? ¿Por qué ó por qué no?
7. What do you anticipate would be barriers in getting connected with hospice?
¿Qué posibles inconvenientes encontraría usted para comunicarse con hospice?
8. Who else helps? How many family members live in this area? What kinds of help do you get from family or friends?
¿Quién más le ayuda? ¿Cuántos miembros de su familia viven en esta area? ¿Qué clase de ayuda recibe usted de sus amigos y familiares?
9. Did anyone criticize you for not seeking hospice help?
¿Alguien le ha criticado por no buscar la ayuda de hospice ?
10. How did not receiving hospice services affect your relationships within the family?
¿Cómo le afecta sus relaciones familiares el no recibir los servicios de hospice?
11. Would you recommend hospice services to a friend who needed them?
¿Le recomendaría los servicios de hospice a algún amigo que lo necesite?
12. What advice would you give to hospice providers in order to increase the number of Spanish speaking clients in the program?
¿Qué sugerencias le daría usted al personal de hospice con el proposito de aumentar el número de clientes hispano-parlantes en este programa?

Physicians

1. Do you refer all terminally ill Hispanic/Latino patients to hospice?
¿Remite usted todos los pacientes terminales hispanos/latinos a hospice?
2. What criteria do you use to refer Hispanic/Latino patients to hospice?
¿Qué criterio usa usted para referir los pacientes hispanos/latinos a hospice?
3. Do you have any hesitations in referring Hispanic/Latino patients to hospice? If so what?
¿Tiene usted algunas dudas en referir pacientes hispanos/latinos a hospice? Si es así, cuáles son?
4. How is hospice discussed with the patient and family?
¿Como discute usted con el paciente y familiares los servicios de hospice ?
5. How do the Hispanic/Latinos respond to a hospice referral? Do their responses differ from individuals of other cultural backgrounds? If so, how?
¿Cómo responden los hispanos/latinos al ser referidos a hospice? ¿Reaccionan diferente a personas de otras culturas? Si es así, cómo?
6. Who facilitates the referral to hospice?
¿Quién refiere los pacientes a hospice?
7. Did you encounter any barriers to getting connected with hospice?
¿Encontró usted alguna dificultad para comunicarse con hospice?
8. Do terminally ill Hispanics/Latinos prefer to rely on family members?
¿Prefieren los pacientes terminales hispanos/latinos confiar en los miembros de su familia?
9. Are family members likely to be the sole caregivers for Hispanic/Latinos?
Prefieren los familiares de pacientes hispanos/latinos ser ellos los únicos en cuidar de sus enfermos?
10. Did referring Hispanic/Latino patients to hospice services affect your relationships with them and their families? If so how?
¿Cuándo ha referido pacientes hispanos/latinos a hospice, le ha afectado su relación con ellos y sus familiares? Si es así, cómo?
11. What follow-up is done after the referral has been made to hospice?
¿Qué seguimiento se hace después de hacer un referido a hospice?
12. What advice would you give to hospice providers in order to increase the number of Spanish speaking clients in the program?
¿Qué sugerencias le daría usted al personal de hospice, con el propósito de aumentar el número de pacientes hispanos en este programa?

About the Author

Iraida V. Carrion is a first generation Puerto Rican, born on the U.S. mainland. She was raised in the Bronx, New York and is currently residing in the Tampa Bay Area in Florida.

She received her Bachelor of Science in Social Welfare and a Master of Social Work from Adelphi University in Long Island, New York. She joined the faculty of the School of Social Work at the University of South Florida in 2001.

Iraida has been a Clinical Social Worker since 1981 serving individuals, families and diverse communities. She is an experienced clinician, educator and trainer. Her research interests include issues related to death and dying, the Hispanic/Latino community and health care disparities.