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An Interpretive Analysis of Hospice Underutilization
By Mexican Americans in Lansing, Michigan:
En Sus Proprias Palabras (In Their Own Words)

presented by

Lisa M. Topoleski

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AN INTERPRETIVE ANALYSIS OF HOSPICE UNDERUTILIZATION BY
MEXICAN AMERICANS IN LANSING, MICHIGAN:

EN SUS PROPRIAS PALABRAS (IN THEIR OWN WORDS)

By

Lisa M. Topoleski

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ABSTRACT

AN INTERPRETIVE ANALYSIS OF HOSPICE UNDERUTILIZATION BY MEXICAN AMERICANS IN LANSING, MICHIGAN: *EN SUS PROPIAS PALABRAS* (IN THEIR OWN WORDS)

By

Lisa M. Topoleski

This study looks at the underutilization of hospice by elderly Mexican American women in Lansing, Michigan. The hospice literature refers to "barriers" as reasons why Mexican Americans do not use hospice and discusses three different categories: curanderos, familismo and fatalism. This study analyzes the claims made by the hospice literature and tests its validity by interacting and interviewing Mexican American elderly women at Lansing, Michigan's Cristo Rey Community Center.

The results showed that the claims about familismo and fatalism were still important elements which affected the women's beliefs on death and dying and the use of hospice; however, there was no reported use of curanderos. It was also shown that there is not a "need" for hospice, for an informal hospice already exists. Therefore, in order for hospice to understand the underutilization of its services, it is necessary to speak to the people of minority communities. In this way, they are able to tell, in their own words (*en sus propias palabras*), of their need for help in dealing with death and dying.

**In loving memory of my Grandmother Catherine Topoleski (1912-1997).
I would like to express my greatest admiration for her dedication to family, desire for
education, and her incredible faith.**

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INTRODUCTION

This thesis project looks at the lack of utilization of hospice services by Mexican Americans in Lansing, Michigan. More specifically, why Mexican American elderly women in Lansing, Michigan are not using hospice. Is it because of their cultural beliefs, as the hospice literature eludes, or is it simply a lack of need? This study will explore possible reasons why this phenomena exists. The goal of this study is to gain an understanding of the Mexican American traditions from within their own cultural context, while also testing the Mexican American cultural labels discussed in the hospice literature.

Looking more closely at previous studies on the underutilization of health care by Hispanics shows that Hispanics do not fully utilize health resources (Tajalli, 1984; Barrera, 1978; Garcia and Juarez, 1978; Torrey, 1972) and, if they do, it is at a much lower rate than their Anglo counterparts (Chambliss, 1990). Therefore, Mexican Americans as a subgroup of Hispanics, also underutilize hospice. The National Hospice Organization (NHO) reported that many of America's terminally ill have little or no access to hospice care and that African Americans, Pacific Island/Asian Americans, Hispanic Americans, American Indians Alaskan Natives and other people of diverse backgrounds are at special risk because of their non-mainstream status (NHO, 1994).

Also in a 1992 NHO study listing the ethnic percentage of hospice utilization, it was reported that the utilization of hospice by whites was 85% compared to 9% African Americans, 3% Hispanic and 3% what they call "other" (NHO, 1992). The hospice caregivers in Lansing, Michigan have also expressed concern over the underutilization of hospice by minority groups. When hospice manager Susan Penl was asked what she would most desire to research about the current hospice program, she said with a concerned expression, "I have always been interested in why the majority of our clientele are Anglo-Americans? If I were doing a research study, I would investigate the question of why more minorities are not using hospice and then suggest what we as hospice caregivers could do about this situation?."

Susan's concern soon became my concern and by and large the foundation of this thesis study. First, I researched local statistics in order to help confirm the concern stated by the NHO and the Lansing hospice manager. I found that there are four hospice organizations in the Lansing area. Three are affiliated with the three local hospitals: Sparrow Hospital, St. Lawrence Hospital, and Michigan Capital Medical Center. The fourth hospice organization, Hospice of Lansing, is an independent agency. I attempted to gather statistics from the area hospices on the ethnic utilization of hospice services, but found that there was no adequate record of this information. By word of mouth estimates, Sparrow Hospital hospice noted that last year 100% of their patients were Anglo American and Michigan Capital Medical Center's hospice reported that groups other than Anglo Americans that used hospice in the last year could be "counted on one hand". St. Lawrence and Hospice of Lansing were unable to give statistics because as one hospice resource noted. "They are unaware of the patient's ethnicity and, by policy are not able to

ask what ethnic group the patient belongs to.”

This identification procedure brought concerns about the exact nature of the NHO’s statistics on the ethnic utilization of hospice services. The NHO_[sd1] reported that the numbers were the product of a random sampling study which was sent out to local hospices. Therefore, the lack of knowledge by the local hospices in Lansing, Michigan lead me to believe that there is a significant issue worth researching. The local hospices were quick to report that they were caring for mostly Anglo American clientele; however, they did not have exact statistics to prove these statements. This fact leads me to believe that because ethnic groups using hospice are in the minority, the Lansing area hospice providers are not even aware of the need to research reasons why a more diverse clientele does not exist.

The word of mouth estimates and reported NHO statistics present a notion of the issue at hand. More specifically stated, why don’t minority groups use hospice services? I will attempt to look at this question targeting specifically the Mexican American population in Lansing, Michigan.

Unfortunately, the literature does not clearly reflect the reasons why Mexican Americans do not use the hospice option. Traditionally, studies explained Mexican American health behaviors by looking specifically at their cultural traits (Clark, 1959 Saunders 1954), such as familismo or “taking care of their own”, the use of folk healers, called curanderos, and strong religious beliefs or what is often referred to as fatalism. These traits have frequently been used to explain Mexican Americans lack of utilization of health services. Literature specific to Mexican American cultural beliefs about death and dying make similar conclusions. Reference is made to cultural concepts such as a

relatively strong concern with the family (familismo), the importance of positive interpersonal interactions (simpatica), and a belief there is little an individual can do to alter fate (fatalismo) (Crowley, 1993). The current literature generally cites such explanations as possible reasons why Mexican Americans do not use hospice.

I agree that these general cultural traits are important in order to orient oneself in relation to a different cultural belief system; however, it should only be used as an interpretation, not an explanation, of a group of people. Generalizations about a particular culture should not be used to explain something as complex as the group's utilization or lack of utilization of a health service. Giachello, (1985), notes that too often in the literature, ethnicity and cultural explanations are positioned as the reasons for low utilization of health care services when social class explanations are more persuasive. The former blames the victim, while the latter blames the system. (Giachello, 1985) Although I realize that other factors such as the social class struggles of the Mexican American population may have a great effect on the utilization of health services; however, because of the narrow scope of this study I am simply attempting to validate or refute the literature's claims of the cultural "barriers" to hospice.

A central point of this thesis is to recognize the need to understand Mexican American's cultural beliefs about death and dying from their own perspective. Therefore, allowing Mexican Americans to deal with death, not the way we or hospice organizations believe that they ought to, but in their own way. Moreover, standards can be applied in judging good and bad or right and wrong which are relative to the cultural background of the person making the judgment. Every culture has its own definition of what defines a "good" death and needs to be understood that way.

The individual Mexican American voice needs to be heard. Yet, the available data and interpretations look past narratives. This short-sided view may add to the reasons why caregivers are perplexed about the underutilization of hospice by minorities. Instead of assuming that the plight of the “other” exists because of conflicting cultures, I propose that as researchers we listen, interact, and converse with the people, who in a sense, may not be as different as they seem.

As Arthur Frank writes in his book, *The Wounded Storyteller*, we are living in “post-modern times” and the “post-modern times” in which we are researching have changed. For within these post-modern times is the demand to speak, rather than being spoken for, and to represent oneself, rather than being represented and being effaced entirely” (Frank, 1995). Frank is referring to the ill body and the need for the persons belonging to those bodies to be heard. In a sense, the Mexican American community is being treated like these ill bodies. They are not being given their true voice. Instead, assumptions are made about them. We are living in “post-modern times” where Mexican Americans face rapid change. We can no longer accept stereotypes for their behavior and beliefs. Mexican Americans are living in America and are experiencing society and culture as it changes. Each one of us, embodies different beliefs and traditions; however, often a priori assumptions are attached to a person because of his/her ethnicity. Stereotypes are given before the person even has a chance to speak for him/her self.

As an example, not all Mexican Americans hold the traditional beliefs so often associated with Mexican American culture. One of the most frequently referenced characteristic of the Mexican American culture is the cultural concept of “taking care of our own”. However, if taken as an a priori assumption this cultural assumption silences

the voice of the people that we are trying to understand.

Some hospice literature suggests that Mexican Americans do not use hospice because they are a close knit community who prefer to take care of their own (Gordon, 1995; Noggle, 1995; NHO, 1994, Crowley, 1993). However, in a group setting of seniors at Christo Rey Community Center-Lansing, Michigan, where I defined the hospice philosophy and told them how it could serve them, I asked if they would use hospice. The respondents unanimously answered they would use hospice. Their concern was that if they were to get sick tomorrow they would not know who would take care of them. Separation of family and the need for their children to have their own lives lead to this fear of care in old age. They would not want to burden their children.

Were these women simply responding to my questions by telling me what I wanted to hear? In doing qualitative research this is always a concern. However, by spending more time with the women and establishing a relationship, the problem of simply acknowledging questions can be minimized. I believe that in order to properly do qualitative research, a relationship is needed between the researcher and the respondents. As I report later, the view of these women changed from a unanimous yes, mentioned previously, to mixed views of animosity towards an idea like hospice, to be discussed later. Therefore, the idea of "taking care of our own" cannot be taken as absolute.

Acculturation into American society and the economic need for families to separate confirms the necessity for researchers and clinicians alike to listen to people of minority communities. "Acculturation is the dynamic process that occurs when two autonomous culture groups are in constant contact with each other leading to changes in one or both cultures ... this can occur on two levels; at the level of the group and at the

level of the individual" (Berry, 1980).

In order to gain an understanding of their needs, communication is essential. The diversity of culture must be realized. In a society which is always changing, the need for qualitative research is necessary. Therefore, when two groups, such as the Mexican Americans and the Anglo Americans, coexist they are mutually influential, although not necessarily the same (Negy and Woods, 1992). Consequently, one cannot use assumed cultural generalizations as a reason why Mexican Americans are not utilizing health services; in particular, hospice services. The Mexican American culture, as with most cultures, is always evolving. Dynamically, their culture changes and readjusts providing new meanings. They struggle to find their place within the Americans society in which they live. It is this concept of one culture living within another culture which strongly shows the need for narrative research. Because acculturation is a constant dynamic process which happens at varying degrees, the only way to understand a culture like the Mexican American culture is to use narratives and converse with them.

Basically, I want to show the importance of letting a culture speak for itself. Only then can one interpret and try to answer the question of why Mexican Americans are not using hospice.

Chapter Summary

In chapter one hospice is defined by discussing the history of hospice, its regulations for treatment, and its philosophy relating to death and dying. The chapter provides an overview of the service of hospice, as well as pointing out the philosophy of hospice as it stems from being affiliated with the western medical system.

Chapter two is the methods chapter. Here it is pointed out how the thesis question: Why Mexican American elderly women in Lansing Michigan do not use hospice?, is addressed. Within this chapter the interpretative approach including the use of narratives, thick description and cultural relativism is introduced and explained. The chapter also provides the methodology of how narratives were obtained. Questions relating to the three categories of fatalism, familismo, and curanderos are given as guidelines for interview questions in order that that thesis question will be properly addressed. Also, sections on field work hurdles and a brief descriptions of the five primary participants are included.

In chapter three, Research Findings, narratives are presented under the categories of fatalism, familismo, and curanderos in order to bring out the women's cultural beliefs of death and dying.

Chapter four discussed the importance of the narratives. Results showing that religion and family are still strongly felt traditions are reported. Curanderos, on the other hand, were shown to have no effect on the utilization of hospice. Within the discussion chapter the hospice literature's claim that there are "barriers" to hospice is argued with the help of cultural relativism.

Chapter six concludes the thesis by suggesting the need for an interface between hospice and the Mexican American community. Here, the narrative of a younger Mexican American woman who used hospice services is presented and analyzed. The narrative exemplifies the importance of change and acculturation.

Also discussed in the conclusion are suggestions for further research on this topic. In areas of further research it is discussed that there are other variables and topics that are

essential to the thesis question and also need to be addressed

My conclusion is that hospice may become a service utilized more frequently by the Mexican American people, but only when its philosophy and purpose is defined and has meaning within the Mexican American community.

Chapter One

What is Hospice?

In order to set a firm foundation for this study it is necessary to provide a definition of hospice and to discuss hospice organizations and their services. Hospice is defined as a special way of caring for a person whose disease cannot be cured. The focus is on care, not cure. Emphasis is on helping the person to make the most of each hour and each day of remaining life by providing comfort and relief from pain. Not only does hospice believe in helping the patient deal with dying, but they also provide support for the family members during the dying process. Hospice is a shoulder of support. The admissions coordinator of Lourdes Hospice talks about the benefits of hospice by saying, "I'd like people to understand that the whole purpose of the hospice program is to help. We judge our success on whether we've been able to help you. I hear people say to me over and over, 'We need some help.' I would hope that any hospice anywhere would be a resource and a help to you."

Hospice is normally run by an interdisciplinary care team of health professionals including nurses, physicians, social workers and spiritual counselors. Hospice also relies on its many volunteers to provide support for the patient and the family.

Those who are unfamiliar with hospice sometimes ask if hospice is a place? An answer to this commonly asked question is that hospice is not a place where patients go to die. It is a service that provides care wherever the patient lives.(Beresford, 1993) However, there are different models of hospice. The community-based model, which is what Hospice of Lansing would be considered, is a nonprofit corporation governed by a community board of directors in order to meet the needs of the dying in the community (Beresford, 1993). Community-based hospices have the financial disadvantage of not being affiliated with a larger organization. Michigan Capital Medical Center and Sparrow Hospital in Lansing, Michigan are considered home health agency based hospices. These organizations may offer home healthcare, but do not include all of the benefits of hospice care. Only the hospice alternative provides the benefits of the whole hospice philosophy of comfort care and spiritual help. St. Lawrence hospice is considered an example of a hospital-based hospice model. In this model, hospices are administratively part of a hospital corporation (Beresford, 1993).

Another frequent question asked is what are the eligibility requirements of hospice. In order to be considered for hospice care, the patient must have been given a diagnosis of a terminal illness, usually measured by a prognosis of six months or less left to live. The patient must be seeking comfort care, rather than treatment aimed at cure. The patient and the family must be informed about hospice and other options and give written consent for hospice care. Hospice also must be provided in a safe setting for care and, most importantly , the patient must elect the “Do-Not-Resuscitate Order”. Individual hospice may have other requirements, but these criteria provide the general requirements for most hospice organizations.

A question that could become an argument against the objective of this study is how does one pay for hospice. The concern is that some people including Mexican Americans do not use hospice because of cost. Although hospice is available as a benefit under Medicare Hospital Insurance (Part A) some would say that as a group Mexicans Americans are not well insured and are not receiving the Medicare benefit. This may seem to be interpreted as a barrier. However, according to information taken from Michigan Capital HealthCare Home-Based Services Visiting Nurse Services Hospice Brochure- *"Is Hospice an option for me?"*, "no one is refused for inability to pay."

This background information is intended to help understand the hospice philosophy, hospice organizations and the services provided for the patient. The hospice alternative is an option that should be widely disseminated to all ethnic groups. Communication and education are key factors in this goal. However, even if the ethnic group understands hospice and its philosophy, this does not necessarily mean that individuals within this group will choose it as an option. By educating the community and allowing them to define hospice from within its own cultural constructs enables individuals and families to make an informed choice about the use of hospice.

Historically, hospice programs started small and grew slowly to ensure that the care they provided was of high quality; even if that meant not being able to serve everyone who wanted it (Beresford, 1993). Therefore, hospice was a service which dealt generally with upper and middle class sectors of society. However, with the expanding success of hospice services it is realized that more than just the upper and middle class need high quality care in dealing with death and dying.

Today, hospice is an organization which believes that everyone has the right to receive their benefits. Therefore, they see the need to tackle the problem of underutilization. Hospice now understands the need to reach out to diverse minority groups and realizes that there are overwhelming statistics which point toward their service being utilized dominantly by a population that is disproportionally white, middle class and suburban (NHO; Beresford, 1993; Harper, 1991; Noggle, 1995). The literature refers to this underutilization phenomena as “barriers” to hospice care (Beresford, 1993; NHO; Noggle, 1995; McDonald, 1991).

I will explore, on a community level, if there really are cultural “barriers” as the literature suggests. If so, what they may be in relation to the Mexican American community in Lansing, Michigan. Fundamentally, I want to know why the people of the Mexican American community are not using hospice and not just automatically relate the reasons to cultural labels. However, all too often these cultural assumptions are used as explanations for the underutilization of health service and Mexican Americans as individuals are generalized belonging to a group. Although the hospice literature recognizes that there is a problem of underutilization of hospice by minorities, does it recognize the importance of the plurality of culture?

Most would agree that hospice is seen as a beneficial service which should be provided to everyone equally. However, one must remember that hospice is a service which fits into the Western concept of medicine and defined from within it. The hospice movement has been referred to as a “grass roots reform movement, a response to a rising consumer demand for more control over health services; a religious movement, an attempt to return spiritually to the dying process; and a professional movement, an effort by

nonphysician healthcare workers to rebel against authoritarian hospital systems” (Siebold, 1992). Therefore, it was established for a number of reasons and attracted participants by “virtue of one or all of these conditions” (Siebold, 1992). The social conditions which fostered the hospice movement dealt primarily with the people using its services.

Hospice has a goal of attaining a “good” death. Its philosophy puts forth the ideal of death with dignity in order to provide a humane way to die. However, the hospice idea of a “good” death was constructed from a social need for death with dignity and without pain and suffering in a society which seeks to improve the quality of life at all costs. “The twentieth-century consumer of medical care expects physicians to ameliorate pain and suffering. As a nation, we seem particularly vulnerable to the expertise of professionals. This is perhaps part of the belief that all things in life can be reduced to logical parameters” (Krant, 1974).

Hospice as a philosophy defines death from within the Westernized society. A “good death” for hospice would be one in which the patient dies a comfortable death, most often in the comfort of his/her own home, where pain is eased by the help of medicine and support is given to the patient as well as the family in order to mentally ease the fears of death. It fits nicely into our Western cultural ideas about death. For it represents a humane way of dying which includes the crutch of Modern Medicine; whereby, controlling the dying process with the use of pain medication. On the other hand, if one does not share the hospice definition of a humane “good” death or comprehend the need for hospice, then its philosophy may not fit within the person’s scheme of a humane death. In answering the question of why Mexican Americans are not using hospice, the differing definitions of a humane “good” death by both the hospice

philosophy and the Mexican American community will come into play.

Chapter Two

Methods

The Interpretive Approach

I propose an interpretive approach to the question of why Mexican Americans do not use hospice. The three methods included under the proposed interpretive approach are the use of narratives, thick description, and cultural relativism. Because of the qualitative nature of this study, the interpretive approach seems required. The people's voice needs to be heard, therefore absolving the use of generalizations which tend to depict static cultural traditions. Moreover, using narratives, the voice of the other, cultural diversity, and thick description will provide a cultural evaluation of generalized cultural knowledge.

Insight gained from narratives and interpretations of the narratives can also provide cultural relativistic definitions of a humane or "good" death. The interpretive approach allows the question of why Mexican American elderly women do not use hospice to be examined from a cultural relativistic point of view. Therefore, there is no way to make judgments across cultures. One can only approach the question by interpreting the narratives and thick description of the people who belong to the particular culture.

The interpretive approach according to Geertz, suggests that the analysis of man should “to be therefore not an experimental science in search of law but an interpretative one in search of meaning” (Geertz, 1973). By using the interpretive approach cross culturally one can hope to understand the point of view of the other by interpreting their actions, gestures, and words as meanings specific to their people. Therefore, one single dominant way of thinking will not dominate the other, the voice of the “other” will be heard. Experiences of dying and terminal illness are rarely the same, even if they belong to the same community. The use of the interpretive approach gives narratives meaning and allows the question of underutilization of hospice by Mexican Americans to be analyzed.

Thick Description

One characteristic of the interpretive cross-cultural approach includes thick description. Thick description, according to Geertz, defines a kind of “intellectual effort”. It is as an elaborate venture in, to borrow a notion from Gilbert Ryle, “thick description” (Geertz, 1973). Thick description is the “said” of social discourse which provides the ability to interpret narratives. It is a way in which meaning is taken from the narratives. Thick description is an abstract term which defined, calls for the importance of giving attention to detail.

By using thick description one gets a microscopic view of the particularities of a certain culture. In particular, I used thick description in my interviews with the Mexican American informants in order to interpret what they do, say and act in response to my questions about hospice and death and dying. A laugh, a smile, a blank look, strong words, a soft voice or a tear all helped me to interpret the narratives of the Mexican American women. A good interpretation, according to Geertz, “uses thick description to

construct a reading of what happens and must include from [sd2]what, in this time, or that place, specific people say, what they do, what is done to them, from the whole vast business of the world. To divorce from these thick descriptions is to render it vacant” (Geertz, 1973). Thick description addresses the concern of the underutilization of hospice by directly conversing with individuals within the culture. In this way, an intimate view of the cultural beliefs about death and dying, family, religion, and folk healers can be revealed.

Are the assumptions written in the hospice literature about reasons why Mexican Americans do not use hospice just generalizations? Is hospice care a service that Mexican Americans deem necessary? I have approached the question, thus far, by assuming that hospice is something the Mexican American elderly women would use if they had knowledge and availability. I will use the analysis of thick description to test this assumption.

In the course of my study, I specifically looked at three traditional cultural beliefs: familismo, fatalism, and curanderos which are components of the ethnography of the Mexican American culture. With the help of thick description, the validity of the aforementioned traditional beliefs were tested in order to discover if they have any bearing on the underutilization of hospice.

Narrative

The significance of the interpretive approach lies in the use of narratives or story telling. As was stated above, the main thrust of the study is to gain a greater cultural meaning. “Traditionally, when Mexican Americans have been studied, stereotypes and distortions prevail.” (Facio, 1996) Understanding people from their own personal

reflections illuminates experiences which are richly diverse.. Storytelling or narrative ethics is developing into an emerging field in bioethics, anthropology, sociology and also for use in clinical situations. The narrative approach to understanding cognition, personality development, culture, and community is one that is emerging from several disciplines as a way to understand human experience, memory and personal identity from the point of view of a person in social context.

In its simplest form, the narrative approach means understanding life to be experienced as a constructed story. The stories that people tell and are told as powerful forms of communication to both others and one's self (Rappaport, 1993). The narrative offers a way to take part in a conversation where the partners can be seen as equal agents able to claim individual truth. Narratives also offer a way of understanding individual lives within their community context. We are living in a decade of rapid and diverse change making narratives even more useful as a research tool. The stories that people tell highlights the nature and functions of the community, the power of its narrative, and how it changes. (Rappaport, 1993)

Many arguments have been made against the use of qualitative research such as narratives. In addition, its legitimacy has been questioned (Aunger, 1995). Opponents to the uses of narratives in research claim that it is not scientific or objective enough. "Qualitative studies need to be placed within a technical framework which will facilitate an effective combination of the two"(Aunger, 1995). I disagree. Narratives are very much needed in our "post-modern times" (Frank, 1995). For those who have been objects of others' reports are now telling their own stories. As they do so, they define the ethic of our times: an ethic of voice, affording each a right to speak her own truth, in her own

words”(Frank, 1995). No longer should people be invisible subjects that are just answering questionnaires or being wrongly assumed to be a silent people whose voices are not worth hearing.

For example, in a quantitative study by Kalish, (1976) assumptions are used to explain a group’s cultural beliefs on the basis of statistical percentages of answers to a questionnaire. His study assessed the cultural beliefs of different ethnic groups on the topic of death and dying. Statistical numbers gained from a questionnaire were provided as evidence for the cultural beliefs of death and dying held by that culture. Although Kalish’s study provides guiding models of beliefs to keep in mind when interacting with people in a particular culture, it is not a good tool for explaining why a group does or does not do something such as utilize hospice.

In my opinion, studies like Kalish’s really have no significance on assessing a particular group of people similar to the Mexican American community in Lansing, Michigan targeted in my study. First of all, Kalish’s numbers were not very different from the other ethnic groups interviewed and never were the numbers very different from the Caucasian American percentages. The numbers did not provide a very convincing argument for the relevance of his data. For example, Kalish reports that “Yet more than the other ethnic groups, the Mexican Americans consider very important reasons for not wanting to die to include no longer being able to care for dependents (Black American26%, Japanese American42%, Mexican American37%, Anglo American44%) and causing grief to relatives and friends (Black American19%, Japanese American14%, Mexican American38%, Anglo American29%).”(P. 167) The Mexican American statistics, M37% and M38%, are closely related to the Anglo American percentages,



A29% and A44%; therefore, I do not believe that one can truly say that this is a belief held strongly or as Kalish says a “very important reason”. Therefore, quantitative data is not as concrete, or scientifically objective as the critics claim. For, truth lies within the storyteller and can only be realized by conversing with them. If more technological statistical data is needed in order to “prove” the truth claims of a culture then why do we even converse with others? It is the voice of the people which is told by the self that will help us learn the real meaning of the Mexican Americans in Lansing, Michigan .

However, it is false to believe that using narratives can provide a complete cultural explanation of a particular community. For to explain a community like the Mexican American community in Lansing, Michigan would be the same as generalizing in our own way what we want the particular group of Mexican Americans to believe. One must “not bandy the term (narrative) about or attribute mysterious powers to it, more often referring to their work as cultural interpretation rather than cultural explanation.” (Wolcott, 1990) In the words of Geertz, “when doing ethnography, especially narrative ethnography, a sense of facing accepted assignments destined to remain elusively beyond reach must be realized. Cultural analysis is intrinsically incomplete, the more deeply it goes the less complete it is. It is a science whose most telling assertions are its most tremulously based, in which to get somewhere with the matter at hand is to intensify the suspicion, both your own and that of others, that you are not quite getting it right” (Geertz, 1973).

What is important in doing research with human subjects is not necessarily requesting exact data or scientific truth claims about particular cultures but realizing that human life is conducted in the form of narratives. The fundamental observable feature of human life is that it assumes narrative form and can be understood, by humans, only in that

fashion (MacIntyre, 1981). Consequently, what could be more natural than research using narratives. Arguments stem from the observation that the use of narratives in research is not thoroughly scientific (Aunger, 1985).

Yet, just because the use of narratives requires intimacy does not mean that it is not scientific. Even in the most objective quantitative study there is error or bias. Therefore, distance does not necessarily mean objectivity. Results from a quantitative study are analyzed by the researcher just as in the case of narrative data. Moreover, there will always be some sense of bias. For example, Kalish's quantitative study questions about cultural characteristics were asked to a particular group of Mexican Americans. Percentages were then calculated from the responses on the questionnaires. However, the percentages merely give a reflection of a specific group of Mexican Americans answers to a particular set of questions about certain cultural characteristics made up by the researcher. The statistics merely relate to one particular behavior, inattentive to the relevance of outside factors such as the person's history, personality, enthusiasm etc. Although an agenda of questions is used in obtaining narrative information, the informant has a chance to explain and elaborate on their answers; therefore, providing a much more rich explanation of a community's cultural beliefs.

Basically, a wider range of information can be obtained by using narratives. For in narratives, there are no set boundaries or questionnaire to be filled out. Without a face, a name, expressions, or a voice, the participants seem very unrealistic. Therefore, just because one science is distanced from the participants and one science is intimate does not automatically make intimacy less correct. Distance does not automatically mean objectivity. It would seem more reasonable to use narrative as a way of understanding a

community of humans. Subsequently, the intimate nature of narratives is what is most natural for humans to comprehend.

In times of change, narratives also provide a way of understanding people and hearing their voices. In a society such as ours where so many new innovations are changing our lifestyles by the minute, narratives seem to be the ultimate way of getting at the actual cultural context of a particular community at a particular time. Industrialization, economics, and social values are in a state of dynamic flux. Besides, the continuous progression of society the Mexican American community has to deal with other facets of living in America such as acculturation and migration (Sanchez, 1995). All of these things effect their culture and reestablish new traditions and cultural beliefs in context with the changing times. With all of this change, the best method to get accurate answers is to go to the source, the people. Because of this aforementioned cycle of change, narratives allow the people of a certain community a chance to be teachers educating those who are concerned enough to listen about the most current beliefs, cultural traditions, and ways of life of a particular ethnic community.

There exists an ethical obligation, if you will, for the caregivers and researches who seriously want to help the Mexican American community learn about and utilize hospice to reach out and get to know those in the community. The caregivers must not take assumed cultural characteristics of a culture to be true for everyone referred to under that cultural heading. Not every Mexican American has a close family unit or has a strong belief in God. By “playing dumb” the researcher is a blank slate who lacks the necessary knowledge of the individual in question. Like an eager child in a classroom excited to learn, the researcher awaits the teacher to teach him/her and fill in the blanks about there

culture. Therefore, without a priori assumptions clouding the mind the necessary conversation eliciting the patient's true feelings as an individual can be obtained. The caregiver may mouth the words that fit with his understanding of the case, but may fail to assess what these words mean to the patient and what image of reality is being created in her mind (Brody, 1987). Just as in the case of the patient and caregiver, the researcher and informant must also be aware of each others presence in the conversation.

My decision to use the narrative aspect of the interpretive approach as a methodological option in my study is grounded in both the literature and in the type of responses that will be elicited. The combination of thick description and narratives will be a powerful research tool to authenticate my study.

Population Identification

Before proceeding, it seems appropriate to talk about the population referred to as Mexican Americans. Generally, this subgroup is included under the "Hispanic" category. However, "Hispanic" is a rather encompassing term, referring to those individuals whose heritage is that of one of many countries of the world where Spanish is the native tongue (Chambliss, 1990). In the United States Chicanos, Latinos, Hispanics, Americans of Mexican decent, Mexicans, Spanish Americans, the Spanish surnamed, and the Spanish speaking are all referred to as Hispanics (Portillo, 1990).

One person, from the Mexican American community, discussed the confusion about identification and reiterated the point that one must use terminology carefully. For example, the use of Chicanos to the older generation of Mexican Americans connotes a derogatory meaning which is disrespectful to them. Chicano is used more frequently by the younger generation. The informant said that in order to be safe the most neutral

terminology to use would be “Mexican American”.

As the literature suggests, there is difficulty in using an adequate term of reference. This lack of terminological consensus reflects the varying historical, social, and political experience of this population as a whole, and as such, represents problems inherent in any generalized approach to Mexican Americans (Harwood, 1981). Therefore, since there is no definite solution to the problem of terminology for the purposes of this study and for my review of the literature, I have tried to focus as much as possible on the Mexican American population. However, as in the previous paragraphs above some statistics are given only in reference of Hispanics. I will use this data taking Hispanics as a whole group with Mexican Americans as a sub-group of the larger Hispanic population.

Christo Rey Community Center

Christo Rey Community Center located in Lansing, Michigan is a multicultural center which offers a variety of service programs to those in need. Although Christo Rey services are offered to everyone regardless of race or ethnicity, the majority of its visitors are Mexican American. A brochure published by Christo Rey lists the programs and services available to the community.

Some of the services that Christo Rey offers are a community kitchen and direct assistance for food, clothing, and appliances. Additionally, Christo Rey provides a community health clinic which offers treatment, intervention, educational information, and diagnostic services. Other service programs include substance abuse, youth programs, employment and training, diversion and community service, senior body and mind, counseling and guidance, group therapy sessions, and handicap programs.

The program which I worked most closely with was the senior citizens program. The senior citizens program offers senior citizens 60 years of age and older, with an emphasis on Spanish speaking persons, assistance with several helpful services. Services such as free meals, exercise, religious services, special events, information and referral, immigration assistance and minor home repair. Every Tuesday and Thursday, free lunch and dinner are offered for the seniors. It was during this activity that I spent time getting to know the Mexican American women.

A mixture of men and women attended the breakfast gatherings; however, for the purpose of my study I concentrated on conversing with the women. After spending numerous days at Christo Rey, I noticed that the same women attended each day I visited. Each of them had their own exclusive “group” of friends and tended to sit at the same table. I spoke with two different “groups” in order to obtain information and participants for my study.

Participant observation and one-on-one interviews were my primary means of data collection. The one-on-on interviews took place at the center in a location somewhat away from the group to avoid distractions. Although privacy was attempted, because of the commotion of the center, complete privacy was very hard to achieve.

Overall, I spent about 5 months visiting the women doing one-on-one interviews, participant observation, but also spending time to get to know them. During the interview sessions, either notes were taken or information was audiotaped or both.. Additionally, daily participant observation notes were taken.

Interview Guidelines and Possible Interview Questions

The questions asked were of an open ended format so that a conversation can take place between informant and researcher. The questions fell into four categories: (1.) General knowledge about hospice, (2.) Use of curanderos or folk medicine, (3.) Religious beliefs, fatalism and the Western idea of “health replacing salvation”(Good, 1994) or what is referred to the soteriological, and (4.) Familismo which incorporates the idea of “taking care of our own. A sample interview agenda can be found in Appendix A.

A fact sheet about hospice was provided to the informants and translated into Spanish for ease of reading by those who were more comfortable with Spanish. A Consent Form was also provided and offered to the women in both Spanish and English. When questions arose about translating hospice, *Hospicio* was the term advised for use. This is what translators and Spanish speakers believed would provide the best translation of Hospice for the Spanish speaking population. As a researcher, I anticipated some difficulties with language; but through the use of an interpreter, I attempted to override difficulties and maximize exposure to informants.

Field Work Hurdles

My field work efforts included a number of hurdles that impacted many aspects of my study. I am hoping that this personal reflection on field work gives a model of some possible hurdles to be expected when doing fieldwork with an ethnic sample and some possible solutions.

As I began this study, I was determined to do field work which included interviewing human subjects. I have come to find that field work is not such an easy task. At times, I felt as though I was making no progress and thought about giving up and just

doing a literature review. However, my belief in personal narratives and the importance of the other's voice drove my thesis idea forward.

Initially, I started my field work trying to contact community leaders in hopes of finding people who would be interesting informants for my study. I left the desk and books and headed out into the field. My initial high hopes became more and more deflated by the lack of responsiveness of community leaders to the point that I felt hopeless. What was I doing wrong? Why was I unable to convince others of the intentions of my study?

It was not until I spoke with a representative from the Julian Samora Research Institute (JSRI), Michigan State University-East Lansing, Michigan, that I became enlightened on the importance of researching different cultures. Although I had thought that I had an understanding of the people I intended to study, I felt as Wittgenstein (as quoted by Geertz) said, "We do not understand the people. We cannot find our feet with them" (Geertz, 1973). I needed to communicate with them in a way which encompassed much more than talk in order that I could "find my feet with them". I needed to establish a relationship which treats the other as a partner in the conversation.

As Refugio Rochin, the director of the Julian Samora Research Institute (JSRI), pointed out not only do I need to present my ideas, but I need to present myself. The importance lies not only I knowing the people or the "other" but also knowing oneself. Social science must accept responsibility for its observations as acts of witness that commit the scientist as a person (Murphy, 1987). This all can be achieved by interacting in constant conversation. Some important helpful tips for doing research with Mexican Americans are as follows: (1.) To let them know a little about my background, (2.)



Explain to them my intentions of the research, (3.) Let them know how my research may help them, (4.) Let them know how important they are for my study, and (5.) Do not assume anything just because they are considered Mexican American. These suggestions may seem to be common sense to some; however, they may have been so common sense that I had been overlooking them in my initial presentation of myself to potential informants.

This advice lead me to do some research on the methodology of doing ethnographic research with Mexican Americans. The literature suggested the importance for the researcher to understand allocentrism, power distance, interpersonal relationships and *simpatia* (Marvin, Gerado, Marin and Barkind, 1991). Because of allocentrism, the literature goes on to say that interpersonal relationships within Mexican American groups are nurturing, loving, and intimate. Therefore, the importance of designing a research project which makes explicit the need for friendly interactions between researchers and informants and methods which enhance friendly contact is essential.

Another characteristic of research with Mexican Americans one needs to take into consideration is power distance. Power distance suggests that what is called “*respecto*” is something that also must be taken into consideration if one intends to do a research project with Mexican American people. *Respecto* connotes the need for respect of the social power of the participants. Also related with power distance is the suggestion of sitting close with the participants in order to become in a sense intimate and personal. *Simpatia* also should be taken into consideration if one wants to do good ethnographic research in the Mexican American community. *Simpatia* emphasizes the need for behaviors promoting smooth and pleasant relationships. The goal is to achieve harmony in

interpersonal relationships. As a script, *simpatia* moves the individual to show a certain level of conformity and empathy for the feelings of other people (Marin and Marin, 1991). It is suggested that if coffee or snacks are offered in order to express proper *simpatia* one should accept. Also what is known as *la platica* or small talk before and after will help to strengthen the feeling of *simpatia*.

These suggestions from both the literature and the community leaders like the Director of Julian Samora Research Institute (JRSI) gave the researcher insight into the importance of the presentation of self as the researcher. The newly acquired insight gained from my research helped “get my foot in the door” and openly talk with people in the Mexican American community. I strongly believe that the information on how to conduct interviews for narrative studies can also help the Western medical health care providers and hospice care providers realize the importance of social interaction and actions.

My second day at Christo Rey Community Center confirmed the benefits of getting to know how to socially interact with an ethnic population. Consequently, I found that before I began discussing my research it was essential to engage in *la platica*. Some people required more than others. I spent this whole day almost engaging in *la platica* in order to let the people of the community know that I was interested in their stories. I talked with those who were fluent in English and found out those who were not. Other people from the center volunteered to help me with the language barrier which I found to be beneficial.

Facing my field work hurdles enabled me to gain insight into the importance of presentation of the self. One cannot assume that the traditional curanderos, familismo, or

fatalism are the reasons behind the underutilization of hospice service without hearing narratives from the Mexican American people. One must learn how to interact socially in order to comfortably converse with the Mexican American people in order that their voice can be heard.

Description of the Five Primary Participants: "The Teachers"

Maria is 70 years of age. She is happily married and has been for over 50 years. She was born in Mexico but has lived in America for 60 years. As a young person, she came to Lansing at the age of 22 and has lived here ever since. Her predominant language is Spanish, but she can understand and speak some English. I would characterize Maria as a very giving and sensitive woman. Her sweet and kind manner is reflected in her bright and cheery smile. Although others spoke of Maria's hard life, a humble Maria never complained. Maria is a very spiritual person she uses her strong religious beliefs to pray for herself as well as everyone around her. She stated several times that religion "keeps my spirit alive".

Christina is 87 years of age. She is a widow of many years. Her birthplace is Mexico, but has lived in America for 50 years. She speaks fluent Spanish and English. In order to survive, "I had to learn to language," stated Christina. Christina's wisdom is a quality that everyone at the center admired. Her soft white hair and little girlish smile, although precious and delicate, commanded attention from everyone whenever she spoke. She is a plump little woman whose grandmother like stature encourages everyone who knows her to take part in a hug. Some of the women even call her Mom. Christina is not shy about speaking her mind. However, she is also content just listening to the people around her converse. This was confirmed by her statement, "I have ears like deer in order



to listen to everything that is going on.” Her warmth is easily absorbed and her life experiences are inspiring to hear.

Olejio is 61 years of age. She was born in Texas, but lived in Mexico for 5 years before coming to stay in America. She lives with her two sons. She speaks Spanish occasionally, but generally speaks English. One of the youngest of the group, Olejio is more Americanized than most of the other older women. She understands that she is living in the American society; however, she tries very hard to keep her Mexican heritage. Her voice is soft and the expression on her face somberly expresses permanent sadness. Conversely, she loves to talk and shows considerable facial articulation when telling a story. By talking with Olejio, one can tell that she is very intelligent and has a wide range of opinions.

Margaret is 78 years of age. She was born in Mexico and is a widow of about ten years. She lives alone in an apartment next to Christina. Her main language is Spanish, but she can speak some English. I used an interpreter to help in our interview. By the tough look of her skin and the deep lines on her face, one can tell that she has lived a long and hard life. When addressing my questions, her eyes never left mine. She was very intense, but always in the end had to bring about a bit of humor into the conversation. She cherishes her friendship with Christina and always sits by her at lunch.

Anna is 47 years of age. She was born in Mexico, but came to America when she was about two years of age. Her job at the community center is to help out in the kitchen. She is a short statured women with strikingly beautiful eyes and a stunning smile. Anna told a story much different from the others. Her husband recently died of cancer and used hospice in his final days of life. She was very emotional in telling her story. To talk about

it brought her much pain. I am very grateful that she was able to be so intimate.

These women were my teachers. I could not have done my study without their insightful stories and wisdom. I realize; however, that there is always a concern regarding human subjects. The concern is if they are telling the truth or simply obliging the person conducting the interview. Personally, I found that after a relationship was established, the women were much more open to my questions and gained a trust in me. Consequently, trust begets honesty and I believe that the women spoke with much sincerity.



Chapter Three

Research Findings

In this chapter findings made in respect to the women's narratives on death and dying are reported. A variety of cultural factors could have been discussed; however, only three of the most prominently mentioned in the literature which I have reviewed will be examined. The prominent rationale for not utilizing hospice according to the literature is the alternative use of curanderos or folk medical beliefs, familismo or what is referred to as "taking care of our own", and fatalism or the religious belief that there is little an individual can do to alter fate. Let us now consider these three factors in greater detail.

Folk Medical Beliefs (Curanderos)

Folk medical beliefs among Hispanics were considered one of the most important variables leading to the underutilization of health services (Tajalli, 1984). However, there is controversy surrounding the use of folk healers and the extent of which Mexican Americans actually use them (Marin and Marin, 1980). Yet, even with this reported question of the use of curanderos, folk medicine is still used as a common way of explaining underutilization of health services by hospice literature. According to a recent article from the hospice literature, it is common even in the U.S. for Mexican Americans to seek out curanderos rather than physicians (Beechem, 1995). In another hospice article, it is quoted from Falicov (1982) that while nearly all Mexican Americans are

Roman Catholic, “sorcery, witchcraft and ancient herbal lore exist along with Western medical practices and beliefs.”

Historically, folk medicine came about from folk medical lore of medieval Spain which was then refined in Mexico. Folk medicine in general is based on health as a matter of chance; Magic and bewitchment may cause many illnesses (Weaver, 1976). The general practitioner of Mexican folk healing is called the curandero. The curandero is a spiritual leader with healing powers. Cuaranderismo stresses the significance of interpersonal relationships and the curandero is perceived by patients as more than a practitioner. According to Clark (1970), people know that the curandero is one of them and that she\he really cares what happens to them. It is believed that he\she sincerely has their welfare at heart.

The faith healer is referred to in most of the literature as a main source of care for Mexican Americans (Beechham, 1995; Fallicov, 1982; Crowley, 1993). Even though the tradition of curanderos may still be strong in Mexico, it is not as frequently used, or even heard of by Mexicans Americans. A recognition that these forms of healers exists is important, but to what extent each Mexican American elder group and their families utilize them is not known. (Talamantes, Lawler, and Espino, 1995)

The hospice literature has attributed the underutilization of hospice by Mexican Americans to the use of curanderos (Beecham, 1995; Crowley, 1993). However, I found that by speaking to the Mexican American women that the use of curanderos is a belief of the past. Curanderos are no longer widely used. The assumption that Mexican American’s believe in curanderos is an over generalization of their population.

“Most people do not even know what they are. I have seen some bad examples on T.V. There are not many around here and if there are they are just out to take your money. They promise you good health for \$50 or so but they are really just after your money. The only one with the power to heal is the Lord. He can give doctors the power to heal and medicine the power to heal but he is the one with the power. No curandero can compare to that.”(Maria)

Fatalism and Religious Beliefs

Fatalism is the second category which I discussed with the women. Fatalism refers to the belief that there is little an individual can do to alter fate. The idea of fatalism parallels a strong faith in God. In other words, it is God who controls fate. In an article from the hospice literature, former Surgeon General of the U.S. Public Health Services, Antonia C. Novello, M.D. is quoted saying “Hispanics are fatalistic. We’ve been taught that you live, you suffer, you die. That’s the way life is.” The idea has never been presented that if you go to the doctor early, you won’t have to suffer pain or discomfort.(Crowley, 1993) How strongly do the Mexican Americans in Lansing, Michigan believe in the idea of fatalism? In order to test this question for its legitimacy, narratives of Mexican Americans elderly women in Lansing, Michigan were used. The conclusion is that the Mexican American women with whom I spoke had very strong religious feelings. Fatalism and the idea that God controls fate was a belief shared by the majority of the women with whom I spoke. The women spoke with much emotion on the topic. For example, the informant whom I have named Olejio burst out into tears when she began discussing prayer and her spiritual belief in God.

Also, as an addendum to fatalism there exists in the Western medical system a phenomenon referred to by Good (1994) as the “soteriological”. Soteriological is defined



as the idea of suffering and salvation. In reference to the Western medical model, it is the needed reflection in medicine which shows that in our “post-modern times, “health replaces salvation” (Good, 1994) Soteriological is a belief which opposes the idea of fatalism. The fatalistic belief is that God controls life and death. Life is eternal and one must die to reach everlasting salvation. The soteriological on the other hand is a concept of Western medicine and of Western society which states that health is what is important. One should not die if one can live by the help of modern medicine. These two ideas are somewhat conflicting. The soteriological looks at death as a correctable deficiency (Callahan, 1993). Fatalism looks at death from the perspective that life cannot be life without death being integral to it.

“We have life and life and death and death. In death we are going to die, but we are going to live after. Jesus says we have to die, but we will have life after.”(Maria)

The popular Mexican American religious belief accepts death as natural; as a must. The soteriological looks at death as a possible, but avoidable event in the eyes of modern medicine. The modern medical belief is that life can be prolonged. It fits within the Western culture’s strong support of technological medicine and the idea to ease suffering at all cost by the medical system. The hospice philosophy shares a common goal. This hospice goal is to humanize care for the dying and their families and to introduce new forms of medical technology to ease the pain of death.(Siebold, 1992) Mexican Americans fatalistic views do not fit with the soteriological and; therefore, do not fit with the hospice philosophy. There is no need to ease suffering artificially for as one lady said:

“God would not let me suffer.”(Margaret)

The belief that God would not let someone suffer makes the hospice philosophy hard to grasp for the Mexican American women. In other words, their fatalistic views represent the belief that God controls everything. There is no reason to find another way to deal with death and suffering because only God controls how and why you die.

“I have suffered just by living life. Suffering in death is not different. Just as I pray to help ease my day-to-day suffering’ I would pray for my suffering in death. The bible says that you have life until you are 70. After that you have free life. If I die now I am ready, because I have already lived life. I am just enjoying my free time. There will be no need for me to fight for life now. When it is my time, I will go.” (Christina)

In the women’s mind there is no need for an organization such as hospice, because God would not give them suffering that one could not handle. There is no need to fight for life. When God calls you, it is your time.

I found that, when talking about religion, the women had much to share. Their religion helped them through every facet of their day-to-day lives. Also, in times of illness, God was given as the main source of support. They do not see dying as a problem or suffering as something which needs to be alleviated. Whereas, the soteriological view of Western medicine and hospice sees suffering as a problem; something which needs to be eased. According to the Mexican American women; God takes care of these things.

However, the Mexican American women do not disregard the medical system all together. For example, they did say that when they get extremely ill they will go to the hospital and seek help. They went on to say that it is God who gives physicians and medicines the power to heal.

“Everything comes contaminated, but your body cures it automatically. With medicine and prayers one can get better. Medicine comes from the help of God. If the doctor says that they cannot do anything, then the person wants to die. Prayer is what is most important. Without God, we cannot do anything. Without God, we would not be living.” (In tears) (Maria)

The hospice philosophy stresses the importance of comforting the patient and the family facing the end of life. The Mexican American women find no need for extra help in comforting. They have learned from the help of the Bible and God. They take comfort in God. There is no need for something like hospice. In their minds, the idea of hospice is neither good nor bad. To them the hospice philosophy is a concept which is not desired by their culture. Religion keeps them strong.

The hospice philosophy portrays the idea that death and pain are conditions which need to be alleviated. However, the Mexican American women do not share this outlook of the problem. As one women said:

“Pain is in the heart, not something a pill can take away.” (Maria)

Therefore, a conflicting definition of the meaning of pain and suffering between the hospice philosophy and the Mexican American women’s narratives is seen. There are no discrepancies to be eased, or problem to be solved when it comes to pain, suffering and death according to the Mexican American women. The Mexican American women do not need to find an outside way to deal with death. It is something that only with the help of God can be eased.

An interesting finding of my study showed that although the women talk very strongly of their religious beliefs and their apathetic feelings toward hospice. If there was a



dire need of help taking care of a dying family member, maybe hospice could be used.

“My sister in law needs help taking care of her mother. She just cannot do it on her own. I think that hospice may be helpful for her.” (Margaret)

However, the majority of the women did not share this acceptance of hospice and were honest in saying that they did not see a “need” for hospice.

Overall, the women’s religious beliefs were what kept them going. Religion gave them the support and strength to be not afraid of death. They believe that God would not promise eternal life if he didn’t mean it.

“In death we are going to die, but we are going to live after. She knows that Jesus and God say that we have to die, but we have hope that we will have life after. A life after death. God has conditions. You have to do what he wants if you are to have eternal life. I do not fear death. I used to go to the hospital and tremble. Now, because of my faith in God, I don’t.”(Maria)

The belief that these women have in God is very strong. God is like a medicine that they use to help cure them of their illness and free them from contamination from the world.

“Every morning I wake up and use the bible. I place it on my eyes and ask for healthy eyes, then I place it on my ears and ask for good hearing and then I place it on my ears and ask for good hearing, then I place it on my “box”.”

She explained her “box” to be her upper body cavity which holds her heart and arteries. She asks God to clear her arteries of any blockage so that everything will flow correctly. With a laugh she says,

“Then I ask for a stomach like I had when I was twenty. I use the bible all the way down to my feet. I also place the bible over my bed so that I don’t have a contaminated bed. There are bad things in the air and I want to be protected from them.”(Christina)

These narratives about religion and fatalism present the Mexican American women's perspectives on death and dying. They show the conflicting definitions of death and suffering between hospice and their own religious beliefs. Both the Mexican American women and the hospice philosophy believe in the universal goal of a "good" death, but it seems that their definitions of "good" are conflicting.

Familismo

One of the most important culture-specific value of Mexican Americans is the family (Moore, 1970). Familism (also called familismo) is a cultural value that involves individuals' strong identification with and attachment to their nuclear families and strong feelings of loyalty, reciprocity and solidarity among members of the same family (Triandis, 1982). The concept of familismo incorporates the ideology of "taking care of our own". However, the practice of familismo may not be as strong as once thought. The family networks among the aged no longer constitute the "romanticized" extended family so often described in the ethnic literature (Beecham, 1995; Clark, 1959; Crowley, 1993; Kalish, 1976; Saunders, 1954; Talamantes, Lawler, Espino, 1995).

Historically, the family provided all levels of support for the aged. Yet, in today's society, Mexican American families, like many families, are experiencing various forms of structural change as they attempt to adjust to an advanced technological society (Williams, 1990). The traditional extended families are breaking up and the elders are becoming more independent. Independence is now a large part of the Mexican American elderly culture. The close knit family is breaking up and the children are forced to move away for economic reasons. Therefore, the elders worry who is going to take care of them if they



fall ill. Considerable anxiety is felt in relation to their care from both the elders themselves as well as the children. Naturally, the children feel a strong filial responsibility to take care of their parents; however, financially it could create a risk that may become detrimental to the caregivers family.

There now exists a struggle between obligation and financial survival. There is no indication that the familial network structure provides definite assistance for terminally ill elders. Therefore, I hypothesize that the underutilization of hospice should not be strictly linked to the ideology of familismo. The literature, which eludes to familismo and “taking care of our own” as the main ideology of the Mexican American culture, needs to hear the voices of the people in order to understand the modern struggle of living within today’s technological society. As the Mexican Americans become more acculturated into the Anglo American society, the idea of the family seems to change; and with it a new way of life is being established. Customs, traditions, and beliefs are now fluid entities which can only be known by speaking with the people of the community.

The hospice literature places much emphasis on the idea of the Mexican American family (Beecham, 1995; Crowley, 1993; Talamantes, Lawler, Espino, 1995). Consequently, family unity is suggested as one of the main reasons why Mexican Americans do not use hospice. Other studies agree that family relationships among the elderly are significant; however, they tend to disagree about the extent of family support of Latino elderly (Sanchez, 1995). Recent literature on the Mexican American family; however, criticizes the perpetuation of the stereotype that the family unit is cohesive, strong, and capable of fending off all external threats to individuals (Sanchez, 1995). Mobility and acculturation have separated the Latino family from the elderly.

Subsequently, the elderly frequently end up living isolated lives in urban barrios.

(Sanchez, 1995).

I found by talking with the women at Cristo Rey that the family is still an important element. Nevertheless, they are aware of the changing society in which they and their family live. For example, the younger generation is becoming more mobile and often moving far away. One woman talks about how spread out her family is now:

"My family is all over; one in Illinois, two in Texas and one in Florida. All over. They call and write, but seldom visit. Here, my daughter takes care of me. Most of us live in nursing homes. It is O.K. to live alone because we know that there is someone nearby to help us. I do fine living by myself."(Olejio)

Although the nuclear family is moving apart, the women still rely on them for transportation and care. In times of illness, the women still say that they rely on their family to take care of them.

"I wouldn't need something like hospice because I live with my son and he takes care of me. We are proud of our culture and we do not need anyone to help us take care of our family. America tries hard to take away our culture, but there are some good things that need to be kept like our close family. We may not be as close, but we still call and talk. Even in death, our family is there. What more do you need! If one feels betrayed by their family in times of need, then they are already dead."(Margaret)

Anna interestingly says:

"When I am on my death bed, I do not want my family to see me suffer. I saw my husband die. It was very painful. I do not want my kids to go through that pain."(Anna)

There are conflicting views about the family caregiving role. On one hand, the family is valued and significant, yet; the reality of the Mexican American family is that it is not as close as people would like it to be. Elderly are living alone and other institutions are assuming greater roles (Beckett, Dungee, and Anderson, 1991; Becerra and Shaw, 1976; Torres-Gil, 1978). The elderly women confess that they are comfortable living alone, but still rely on others for help. These helpers are not only family but neighbors.

"If there is an emergency, there is a cord I pull and it summons the medical people. The apartment complex helps take care of me. I know that when my time comes, I will be able to let everyone know. Just pull the string and help will arrive." (Christina)

These narratives show that the nuclear family traditionally associated with Mexican Americans is changing.

How does this impact hospice use? Although the family is changing, the talk is still of "taking care of our own". The realization of this changing tradition is recognized by the Mexican Americans, but seldom comfortably acknowledged. The Mexican Americans I spoke with are struggling to hold on to their traditional beliefs of close family unity. To them, hospice represents a threat which places their feeling of tradition in jeopardy.

"When one comes to America, one has to change their ways to fit into a new culture. But the good parts of our traditions are still important. For example, the family is still an important element of our culture. Hospice came to our church. I would not want something like that because it would interfere with the family. It pushes the family out. We take care of our own. It is our obligation to take care of our family ourselves" (Margaret).

Margaret gave me an example of how some Mexican Americans are giving in to the American culture and losing their family unity. While she tells the story, the tears and

anger can be seen on her face.

"My sister-in-law's mother became very ill. The doctors said that she was going to die. The family was very sad and prayed very hard for her. She somewhat recovered, but still needed medical help. The daughter decided to put her in a nursing home. (tears) How could you do such a thing the other family members complained? It was a disgrace to the other family members to see that Mother was being put in a nursing home."(Margaret)

Here once again, the conflict arises over the struggle between the traditional obligation of taking care of their own and the reality of medical help in times of need. The women all talked of close families and friends, but they also admitted needing outside help from doctors when they are ill. However, in talking to relatively healthy elderly the major theme is that they want to share with me the traditional ways of the Mexican American family and not the idea of the changing Mexican American family role in today's American society. According to the Mexican American women with whom I spoke, there is no need for a service such as hospice because the family, in spite of difficulties, is perceived as significant.

However, according to Sanchez, (1995) there definitely appears to be a conflict with expectations and the perceived ability of the family structure to meet these needs (Sanchez, 1995). Therefore, it is not peculiar that the women did not speak much about the negative aspects of the changing role of the family. They were not eager to admit to the idea of a change in family unity. Because often a conflict exists between what is known and what is admitted.

Chapter Four

Discussion

Overview

This study examined the question of why Mexican American elderly women in Lansing, Michigan do not use hospice by using an interpretive approach. Thus far, narratives including the use of thick description, have been presented. The narrative and thick description categories of the proposed interpretive approach brought into existence the Mexican American women's true feelings about death and dying.

As a portion of the title of this study, "*En Sus Proprias Palabras*", suggests, the women's personal narratives were presented in "their own words". The narratives were taken in the context from which they were given; the Mexican American community in Lansing, Michigan. Every word, gesture, and symbol in the tradition of Geertz's thick description was taken as apart of their culture. The narratives gave confessions about the Mexican American women's lives which helped me "find my feet with them." (Geertz, 1973)

From the "said" discourse, I was able to explore the assumed generalizations about Mexican Americans "barriers" to hospice which is discussed in the literature. Some of the findings supported the literature; for example, the idea of fatalism and

familismo. In favor of this support, the Mexican American women spoke, not only in words, but also in gestures and emotions, regarding the importance of their family and religious life. Therefore, the narratives revealed that the hospice literature does have some merit in pointing towards the concept that family and religion are important to the Mexican American culture.

However, the hospice literature reviewed did not look at the changes in the Mexican American traditions brought about by assimilation into mainstream Western society. This included the aspects of the breaking up of the Mexican American close knit family unit because of industrialization and the changing values of industrialized Western society. Also, other assumptions in the literature, including the Mexican American's use of curanderos as a reason for the underutilization of hospice, were proven false in this particular population. Although some women expressed using herbal medicine, essentially curanderos are a thing of the past.

"Barriers"

The hospice literature makes evident the cultural differences of Mexican Americans and refer to these cultural differences as the best explanation of the underutilization of hospice. These cultural differences are referred to as "barriers" to hospice care (McDonald, unknown; NHO, 1994). Conversely, I argue that there are no "barriers". A "barrier" is "a boundary or limit something that separates or holds apart; something immaterial that obstructs or impedes" (The American Heritage College Dictionary, 1993). Therefore, I interpret "barriers" as being a physical road block which obstructs one from doing something they want to do. It is not apparent that a "barrier" to hospice exists according to the women of the Mexican American community with whom I



spoke. Nothing is stopping them from using the service. The dilemma is that the Mexican Americans do not feel that there is the need for this kind of help.

Narratives were provided as examples relaying the message that the Mexican American women are not seeking out the use of hospice services. On the other hand, they told about the Mexican American women's struggle to understand the hospice's philosophy of death and dying and examining if the philosophy fits within the context of their cultural understanding of death and dying. The narratives gave truthful evidence from the words of the informants about their feelings on hospice and its service. The narratives also helped to confirm or reject certain hospice literature claims. Although some may not find narrative examples useful, most anthropologists believe that it is small scale and qualitative types of information that have become the hall mark of the science, more than compensated for the missing statistical larger focus that other social sciences use (Barrett, 1991).

By using narrative and thick description, I was able to "cut the culture concept down to size" (Geertz, 1973). The cultural concept given by the literature tried to give a "most complex whole" approach to the Mexican American culture. The women's daily rituals, and commentary helped to cut the assumed complex whole idea down to size; therefore, "insuring its continued importance rather than undermining it". (Geertz, 1973). The Mexican American narratives I obtained supplied meanings from the Mexican American women's own perspective setting forth their understanding of hospice and death and dying.

Moreover, interpreting with "thick description", or the "said" of social discourse, I have come to the conclusion; that hospice is a concept which is not part of the Mexican

American women's "said" social discourse. In other words, hospice does not yet have meaning for the Mexican American elderly women. The narratives of the elderly women presented a struggle of the Mexican American women to understand the concept of hospice. Until that concept is understood, it is hard to report if hospice is needed by Mexican Americans in the Lansing community. Consequently, it is hard to analyze cultures "said" or narratives when a common meaning is not shared.

Cultural Relativism

The assumption that Mexican American's use of hospice is a "problem" or that there are "barriers" can be refuted by using the theory of cultural relativism. Cultural relativism gives ownership for meanings to the actors whose words and actions they belong to. The women's "thick descriptions" of death, dying, family care giving and religion give, in their own words (*en sus propias palabras*), beneficial narrative data. The use of narratives from a cultural relativistic view provides insight for research into exactly where the "problem" may lie. But is the underutilization of hospice by Mexican Americans necessarily a problem?

By speaking with the Mexican American women I have found that there is no "problem". The underutilization of hospice by Mexican Americans is not a "problem", but an example of the need for understanding cultural relativism. The hospice literature tries to define reasons why Mexican Americans are not using hospice, but soon forget that hospice fits under the Western medical philosophy of comfort care. Comfort care and spiritual help of the dying patient are concepts ethnocentrically believed to be beneficial for the Mexican American culture. However, hospice was created out of a "way to meet a need" (Siebold, 1992). The Mexican American women do not share the constructed



“need” for hospice. The humanistic approach to terminal care which focuses on pain medication, such as morphine, attempts to ease the physical pain and suffering of dying, whereas the Mexican American women are more interested in easing the spiritual pain and suffering of death and dying. In other words, these Mexican American women have their own framework which enables them to understand and accept death.

If the hospice philosophy is examined in relation to the framework of the Mexican American women in this study, it can be determined that a common definition of proper death is not shared. To the Mexican Americans, the hospice philosophy is insignificant and does not fit in their cultural framework of death and dying. The Western culture that accepts hospice, is part of a society which “ finds itself without a creedal or mythic framework in which to understand life and interpret death”. (Wass, 1979) The hospice philosophy struggles with the question of who has control over the process of dying - the individual or medicine? Without struggling over the question of control, the Mexican American women believe that it is the individual and the individual’s relationship with God which will help them in the dying process. They do not see the need for a medically enhanced method of dying.

However, when examining the differences of the hospice philosophy and the Mexican American philosophy of death and dying it must be made apparent that a healthcare culture is being compared with a ethnic culture. The hospice helathcare culture is a culture which by being afiliated with modern medicine has a different lifespan orientation leading to different beliefs on death and dying. Although, hospice claims to accept death, it is still a healthcare culture which has been ingrained with the idea to sustain life at all costs. The life span of hospice and the point when life surrenders to

death is different from the Mexican Americans concept of life and death. The lifespan orientation of a healthcare culture compared to an ethnic culture has two different perspectives. The Mexican American culture has a concept of the lifespan which incorporates more than just birth, life, and death. The Mexican American women spoke of a continuum in which there was life after death. Therefore, note the difference between the cultures and realize that a healthcare culture is being compared to a ethnic culture in which both have different orientations on the concept of a lifespan.

The underutilization of hospice is not necessarily a "problem" or the "barrier" to which the literature refers. It cannot be taken as generalized assumptions of every group of Mexican Americans. In order to argue such a position calls for the use of certain aspects of cultural relativism. Cultural relativism is a general term which is sometimes misunderstood in its intent. To clarify my position I am taking cultural relativism to be "a philosophy which, in recognizing the values set up by every society to guide its own life, lays stress on the dignity inherent in every body of custom, and on the need for tolerance of conventions though they may differ from one's own. Instead of underscoring differences the relativistic point of view brings into relief the validity of every set of norms for the people whose lives are guided by them, and the values they represent." (Herskovits, 1949) The cultural relativism argument appropriately denotes that the voice of the Mexican American is heard in order to understand why Mexican Americans in Lansing, Michigan are not using hospice.

The cultural relativism argument also challenges the hospice literature's description of cultural "barriers" to hospice care. Only by using cultural relativism can we analyze the Mexican American beliefs about death and dying. "The natives, they advise, should be

assisted to develop the potentialities of their own cultures and to lead lives of their own, rather than to acquire our Western culture, which they cannot understand or appreciate adequately" (Bidney, 1953). In other words, the Mexican American women of Lansing, Michigan who do not use hospice should not be viewed as being constricted by a "barrier", but realized for the development of "the potentialities of their own cultures". Until the women are able to incorporate the idea of hospice into their culture, and understand and appreciate the purpose of hospice will they begin to request the services of hospice.

Yet, when requests are denied and Mexican Americans wanting to use hospice are finding themselves unable to utilize its services can the term "barriers" be used to describe the situation. Until then, hospice caregivers need to relate to particular Mexican American groups from a culturally relativistic framework. By using a thesis of cultural relativism and narrative ethics, relationships are formed and Mexican American individuals cultural beliefs are understood as well as educating both hospice caregivers and Mexican Americans about the respective beliefs and purposes of each other's cultures.

In presenting my argument for cultural relativism I propose that the Mexican American culture needs to be viewed from its cultural context. In order for hospice caregivers to understand the underutilization of hospice by this particular culture calls for educating itself about the targeted culture. Becoming students of a particular culture, by the use of narratives, the hospice caregivers can become educated about the beliefs of death and dying from the perspective of the Mexican American teacher.

In this argument for cultural relativism I want to add a twist. Traditionally, cultural relativism as a theory is used for cross-cultural studies. Yet, this particular study



looks at Mexican Americans and their acculturation into American society. Mexican Americans represent a culture with its own beliefs and traditions trying to co-exist within American society. Therefore, I believe that there are what I refer to as "generals" which are shared between the Mexican Americans culture and hospice. "Generals" is a term which is used to incorporate a shared ideal but one which can be defined differently by different cultures. "Generals" is used in place of "universals"; for the use of "universals" connotes a much more encompassing notion of shared ideals. In defining "generals", I must point out that there is a general term or ideal which is shared but which is defined differently. "Generals", on the other hand, are those least common denominators to be extracted, inductively, from comprehension of the range of variation which all phenomena of the natural or cultural world manifest. For instance, morality and aesthetic emotion are criteria for truth as "generals". "Every culture supplies its own different content to them depending upon the specific historical development of such a culture." (Herskovits, 1949). However, a "general" such as death with dignity can exist. It is defined from the context of each individual culture. Just as different languages define concepts differently with a variety of phrases or words, a "good" death is defined differently by hospice and by the particular group of Mexican Americans in Lansing, Michigan.

Because of the pluralistic society in which we live and the close interaction of cultures, the idea of "generals" is able to exist. It is the general idea of a "good" death which I believe has led the hospice literature to look past the underlying question of why Mexican Americans do not use hospice. It is the hospice's intention to supply a service to everyone which is believed to uphold a natural way of dying. However, by overlooking cultural relativism the hospice literature does not discuss that there may be populations

who do not see the hospice service as a necessity for a "good" death. This is the focus by which the hospice literature and the hospice caregivers are formulating their concern. They believe that everyone should have the chance to die with dignity. Yet, as cultural relativism indicates the hospice's definition of a "good" death is not necessarily shared by the Mexican American culture in Lansing, Michigan.

It is quite possible that the Mexican Americans already have an informal system of hospice which provides their culture with a "good" death. Therefore, just as the narratives of the elderly ladies showed, there exists a belief in the elderly Mexican American population of Lansing, Michigan which refutes a "need" for hospice. In a close knit community where family and neighbors are easily accessed, there is no need for outside help.

Although the nuclear family is tending to grow apart, the women that I spoke with still believe in the use of the family as a support system. Family members are seen to be dependable and reliable. There is a sense of duty toward each other. They appear to be willing to give, often with the idea that they themselves might be in the position of needing family help in the future. High familial integration with the family network will lead individuals to first seek help (curative measures) within the family except when illness is very serious (Giachello, 1985). Mexican Americans are more prone to act on "need" for health care; whereas, Americans tend to prescribe to the philosophy that when you feel the slightest pain go to the doctor. "Medical needs are the strongest predictors of health services utilization for the Mexican America population" (Giachello, 1985).

Mexican Americans also traditionally illustrate elderly women of the community as caregivers more commonly known as *la abuela*. (Facio, 1996) The *Chicana* caregivers



provide the necessary care for ill family members. The Mexican American elderly women have expectations in relation to their gender and age. Their nonacceptance of hospice may be explained by their traditional obligatory role of caregiver, grandmother and spiritual leader. Therefore, they see the need to be strong, religiously and physically, for the sake of their people. Quite possibly it is this existence of an informal system similar to hospice which the Mexican Americans feel is sufficient in dealing with illness, death and dying. If the closely knit Mexican American community already has an informal hospice service set up where no morphine or pain medication is used then hospice's philosophy of comfort care to relieve pain may not be needed. Once again to question becomes a question of need. Do the Mexican Americans of this particular population "need" or desire hospice care?

A "good" death as an end is a shared ideal however; what constitutes a "good" death calls for the use of cultural relativism. Hospice must try to understand death and dying from the perspective of the Mexican American.

The general value of both cultures is that everyone should die with dignity. "There are some moral rules that all societies will have in common, because those rules are necessary for society to exist" (Rachels, 1986). Although a common general is shared, the interpretation of the general concept of a humane death may have different meanings in different cultures. "Cultures may differ in what they regard as legitimate exceptions to the rules, but this disagreement exists against a background of agreement on the larger issues" (Rachels, 1986).

Humane death is a shared moral universal by both hospice and the Mexican American women. One might be inclined to believe that this common shared moral value

is good reason for the use of hospice by Mexican Americans. However, humane death or death with dignity is defined differently by the two cultures. The definitions of humane death, taken from the information gathered from the narratives of the women in the Mexican American community in Lansing, Michigan, does not include the need to ease pain by the use of medicine, the need for spiritual help, the need for a caregiver to help in the death process, the need to support the family member as well as the patient, or the need to understand death and to be not afraid. The Mexican American women's strong religious beliefs and family ties establishes a working framework to deal with death and dying. This framework does not include the need for a service like hospice.

Although in general there may be a shared philosophy of death with dignity, pluralistically different cultures may define death with dignity differently. It is the difference in what a humane death means in relation to the society that defines it which helps to explain why Mexican Americans do not use hospice. As one woman confessed:

"A "good" death to me would be to fall asleep peacefully. (Christina)

Christina also talked about what death means to her in a way which exemplifies the different definitions of a humane "good" death.

"I do not need any medicine when I die. I want to die the way the Lord wants me to die. When it is my time, it is my time. I will endure any pain which comes along with my illness for it is the final step for my reaching eternal life. Dying is not such a bad suffering for we have suffered our whole life. The strong person can handle the pain and suffering for according to the Lord it is O.K. to have pain. Pain makes me find peace in God; this is why there is pain. It is not meant to be eased by medicines in the final days. For if your time has come, then let God take over your body and do what he pleases." (Christina)

However, overall the women shared with hospice a universal moral value; the need for a humane "good" death.



"I do not want to die violently in crime or anything like that. I want to die a death which God has chosen for me. I can be taken by illness or strife, but not by the hands of another human that is not in God's plan. Even cancer is natural for it is the wishes of God that controls things like that."(Maria)

The definition of cultural relativism is the view that no one culture is better than another. "Anthropologists now agree that each culture must be examined in terms of its own structure and values, instead of being rated by the standard of some other civilization. This anthropological principle can lead, it is true, to relativistic or pluralistic philosophy- a belief in many values rather than a single value system." (Kroeber, 1950; Kroeber and Kluckhohn, 1963; Keesing, 1958; Foster, 1962). Therefore, no one narrative scheme is better than another. The hospice philosophy's value of "good death" cannot be compared within the Mexican American's philosophy of "good death". One can only make a comparison between persons and cultures with respect to narratives if and only if a common problem is shared. The information that I have gathered from the narratives supports this point. The Mexican American women's stories explain a different lifestyle that cannot be interpreted in comparison to the idea of the "good" death which is indoctrinated in the hospice philosophy.

The conclusion that I have reached in researching the question of the underutilization of hospice by Mexican Americans is that there is no absolute answer to this question. The best answer one can get is to talk to the people and report by "thick description" the narratives in order to understanding their meanings of family caregiving, death, dying and religion from their own cultural perception. Therefore, if and only if, a common problem is shared, can a common solution be found. Hospice for these Mexican



Americans does not fit into their definition of "good" or even "needed".

"As a total way of life ours may not be preferable to others, and we need not try to turn them into copies of Western civilization." (Hatch, 1983) How can we compare one culture to another from only one culture's viewpoint? This is why I am arguing that the only way we can objectively look at the problem of the underutilization of hospice is by documenting the narratives of the people being studied. Therefore, with thick description the "said" of social discourse and the meanings of a culture can be known. Documentation or as Geertz says "inscription" is the key to understanding another culture's point of view. Comparing the Mexican American women's view with the hospice philosophy is not possible because a common problem is not shared.

A narrative view better enables hospice researcher the ability to study a culture different from the Western American culture. The "narrative view" says that there can be no comparison between cultures. There are only narrative schemes explained from a particular person in a particular culture. One might wonder how and why the question of Mexican Americans and the underutilization of hospice should be addressed in a way which can be beneficial? The significance lies in the realization that there are culturally specific narratives which define the problem of death and dying differently.

Take for example "John" a born and raised in western America has been diagnosed with cancer. John is very afraid of dying. He feels like he is not ready to go. He always thought that he would just die in his sleep with no pain. The pain of cancer has been great for him. Emotional pain as well as physical pain. Hospice is offered to him as a way to help him in his last dying days. He accepts hospice. He doesn't want to go through any pain and wants the health caregivers to help his family take care of him. He does not want

to burden them with his care. For him, hospice is providing a "good" death. In comparison, Maria a women from the Mexican American community is also diagnosed with cancer and has been given that prognosis of less than six months to live. She believes that it must be her time and prays for eternal life. The cancer can be overcome by prayer, and, if it cannot, it is just pain which can be overcome. For example, one women said when asked about pain:

"it (pain) is just something happens in life -'halgo de dios'. When one is born, you cry for they must face a world of suffering; however, there is no need to cry when one dies for they are leaving the suffering behind in order to enter a world where there will be no suffering." (Maria)

Overall, the elderly Mexican Americans women with whom I spoke were not afraid of death. "In the final hours of death, you have God and your family. They can cure any pain of the inside, which is the worst pain. Pain is everything. Spiritual pain, emotional pain like one is losing oneself and there is also physical pain" Therefore, the "good" death using the narratives of the Mexican American ladies tell a story which defines the "good" death in a different way from the hospice philosophy. One cannot compare the feelings about hospice from the Western view and the Mexican American view. There is a shared "general" goal of attaining a "good" death, but a common shared definition of a good death does not exist. Consequently, there is no shared concept of the problem. Therefore a shared common solution cannot be made.

Hospice is a philosophy that fits into the western idea of a "good" death quite nicely, but trying to impose this idea onto another culture is not an easy task. It will take time for the Mexican American culture to adopt their definition of hospice and what it



means to them. Socially, hospice is a new word that needs to be defined by their culture before it can be used. Once it is defined as an essential need by the Mexican American culture, then it may possible be considered as a beneficial service.



Chapter Four

Conclusion

General Implications

In this study, I investigated the question of why Mexican American elderly women in Lansing, Michigan do not use hospice. I applied an interpretative approach including the use of narratives from elderly women in the Mexican American community in Lansing, Michigan, the use of thick description as a descriptive tool for analyzing the narratives, as well as an argument which calls for the thesis question to be examined from a cultural relativistic framework. By utilizing these methods, I speculated reasons as to why Mexican Americans do not use hospice services as described in the hospice literature. The results interpreted from the narratives of the elderly women revealed that the use of curanderos is no longer an issue; however, familismo and fatalism are still held in high regard.

Subsequently, the question asked: How do these assumed cultural factors relate to the use of hospice? Here an argument for the use of cultural relativism was discussed. The resulting conclusion is that although Mexican American cultural factors may be different from the mainstream Anglo American culture, there are strong values of family and fatalistic beliefs that do not necessarily set up “barriers” to hospice. Where the

literature refers to these cultural traits as "barriers", the authors have set forth a paternalistic view that hospice should be utilized by everyone.

Everyone should die a "good" death. However, this argument does not take into consideration that the Mexican Americans may define a "good" death differently and see no need for the assistance of hospice services. By understanding the Mexican American's cultural beliefs of death and dying from the context of their own culture, hospice may be able more clearly understand the needs of the Mexican American people. Hospice needs to listen to the Mexican Americans people and allow them to become teachers. Hospice caregivers may learn that there are different ways of dealing with death and dying which are also after the same end; a humane and dignified death.

Overall, there is a need to recognizing plurality of culture. One needs to view each culture as having various beliefs defined from the content of their own culture. Cultural relativism is not a static concept. As one may, realize Mexican Americans come from a Mexican heritage and may have traditions and beliefs instilled in them to varying degrees. By living in America, American ideals are now also becoming part of their heritage. The Mexican American culture will always be changing as new generations are born and mature. Although the heritage will tried to be preserved, the pluralistic society in which we live will force acculturation.

The argument which I have made about the nonexistent "need" for hospice may only be a generational set of beliefs. Given time and the proper education about hospice, Mexican Americans may also come to share the "need" for hospice services and appreciate their purpose. For example, in an interview with Anna she told me about her positive experience with hospice. Her husband died of cancer, but used hospice in his final days of



life.

"It was a positive experience. I would not have done it any other way. At first I did not know that he had choose to use hospice. I thought he would try treatment, but he did not want life support because that is prolonging death in a way which is unnatural.

It was very painful for me to see him suffer. I needed help because of my emotions. I was not able to be as strong as I would have liked. I could not ask for friends' or neighbors' help because he did not want anyone to know of his illness.

Our relatives did not believe that there is such thing as a cancer that can kill someone like that. I don't think they believed that he was sick enough to die. They never even came to visit. To him, death was something he did not think anyone should see. I prayed all the time and hoped for a miracle, but believed that God wanted it that way. It is like he has new life now. He is Gods child. God was anxiously awaiting his arrival in heaven. Now, he is living his new life in heaven."(Anna)

I then asked Anna if she would use hospice in the same situation.

"I had a very positive experience with hospice. As I said before, I could not have gotten through the pain without the help of hospice. But I would not want my children to have to see me die. It would be to painful for them".(Anna)

Anna's narrative showed that a certain amount of traditional cultural beliefs still exist like the belief in fatalism and obligation to her husband. Because of her age and her assimilation into American society, Anna accepts help and does not see hospice as an infringement on her heritage. Anna's story is a prime example of how the "need" for hospice may change with the generations. Therefore, in my previous argument I discussed that one cannot talk of "barriers" because there is no shared definition of the "need" for hospice. As hospice begins to interact with the Mexican American culture and the Mexican Americans begin to learn about hospice, the plurality of culture may allow them

to become knowledgeable about each other.

In summation, I believe that possible shortcomings of this research should be understood. It is very possible that the women that I interviewed were not as honest as I would have hoped. Some women may have wanted to give the impression of having a stronger beliefs that they actually had. What one says and what one does are two different issues. However, if they confessed these strong traditional cultural beliefs to me then a hospice caregiver may also experience the same dilemma.

Areas for Further Research

For further research on this topic one may need to interview a larger sample, but due to the timeline of this study, I was unable to accomplish such depth. This study focused primarily on the three cultural factors curanderos, familismo, and fatalism. However, other sociological factors such as economics, availability of help and support systems, and language obstacles also may effect the use or disuse of hospice and are areas that present valid topics for research..

It may be the case, that the only difference between an informal Mexican American hospice and the Anglo American hospice organization is hospice's affiliation with biomedicine and the use of pain medication. I believe, the use of medication in hospice care is another area of further research. Questions focusing on the medicalization of hospice and its affiliation with the Western biomedical system compared to the Mexican American's lack of need for pain medication should be addressed. As stated earlier an existing informal Mexican American hospice, whose philosophy parallels the hospice philosophy, may already exist in the Mexican American community. However, the fact that hospice is affiliated with biomedicine may result in the underutilization of its services

by Mexican Americans.

There are possibilities for numerous thesis questions to be developed from the Mexican American's point of view: For example, Why is there hospice and what is its purpose? or more specifically, Why would you need an outside service to help one die?. A study which has the time and resources to become better acquainted with the Mexican American culture will be able to research such questions.

The effect of the narratives could have been enhanced by interviewing those who are suffering from a life threatening illness or have recently been involved in a situation where a loved has fallen ill with a life threatening illness. Because of time restraints, I was unable to gather a population of Mexican Americans with this criteria. The benefit of a study such as this would be to examine the effect of pain on a person's perception of the "need" for a service such as hospice. One's perception of the situation can change when actually faced with a life threatening illness.

This thesis study can be a resource for hospice caregivers, as well as representatives of the Mexican American community, as a tool for understanding the variations of care for those who may be faced with a life threatening illness. We live in a pluralistic society, which "emphasizes the persistence of ethnic cultural patterns while at the same time conforming to a common culture in which all can communicate" (Negy and Woods, 1992). Hopefully, the uniqueness of the Mexican Americans culture can be preserved while also achieving a common bond of communication where hospice and Mexican Americans are equally able to understand. With such plurality, I see this challenge necessary in order for the survival of communities, such as the Mexican American community in Lansing, Michigan, who are struggling to keep their heritage alive

as well as trying to fit in with the norms of American society.

Why don't elderly Mexican American women in Lansing, Michigan use hospice?

Based upon my small sample, I found that there was not a perceived "need" for hospice services. However, as the acculturation of the Mexican American community progresses hospice services may become an increasingly meaningful option for dealing with death and dying.

There seems to be a real need to interface the philosophy of hospice with the Mexican American perception of its own ethnic approach to death and dying. A reasonable method to address this need would be a concerted effort to form interpersonal relationships with the people of the Mexican American community. The most promising method to address this is to form an interpersonal relationship with the people of the Mexican American community. By gathering comprehensive narratives from individuals within the community, a better understanding of their beliefs can be attained and an organization, such as hospice, can begin to understand the rationale by which they can provide meaningful service to the Mexican American population.

Hospice needs first to understand and, secondly, to educate the Mexican American community. Therefore, in order for hospice to become a useful service utilized by the Mexican American community hospice caregivers need to educate the ethnic community about their purpose while also realizing the cultural context from which death and dying is being understood. In conclusion, I believe that hospice may become a service utilized more frequently by the Mexican American community, but only when its philosophy and purpose is defined and has meaning for the Mexican American people.

APPENDICES

APPENDIX A

Interview Agenda

Age

Where born

English/Spanish native language

Tell the informant a little about my study in so far that it is a study about the underutilization of Hospice by Mexican Americans in Lansing Michigan.

I will ask you about your life experiences referring to three categories: family, religion, and folk healers "curanderos"

FAMILY

First just tell me how you ended up here in Lansing, Michigan?

How long have you lived in America?

Are you close with your family?

Are you married?

What is a typical day like for you?

Does your immediate family live close in location to you?

Who would you depend on if you got sick?

When medical decisions are made do you make them individually?

Would you want the doctors to tell you if you had a terminal illness like cancer?

Do you feel obligated to take care of your own family members?

Has anyone close to you fallen ill to a terminal illness?

If so what happened? Who was involved?

RELIGION

Do you consider yourself very religious?

What are your beliefs on death and dying in relation to the church?

How does God play a part in dealing with illness?

What do you think about fate? Do things happen for a reason?

Is illness a punishment from God?

Would you go to the doctor as a way to prevent suffering and pain?

If one is struck ill should one seek help from Doctors to help ease pain and suffering?

If you were to fall ill would you look to the church for support?

Where would you feel most comfortable being in your final days of life? At home or in a hospital with close family or alone? Who do you want to be a part of your death?

What do you think about the idea of the afterlife?

What are your thoughts about death?

Are you afraid of dying?

How would you describe pain?
What does it mean to suffer?

CURANDEROS (folk healers)

Have you used curanderos or folk healers?
Are there any curanderos in the areas?
Do you have any folk remedies that you uses at home?
Do you believe that folk remedies work better than medicine from the doctor?
Would you fell more comfortable with a curandero if one was available?
Do you feel comfortable going to the doctor?
How do you communicate with the doctor? Do you have a close relationship?

HOSPICE

Go over Hospice information sheet
So, Hospice may not be good for you?
Do your views on death and dying fit with the Hospice philosophy?
Does Hospice seem like something that you would benefit from if you or someone close to you was diagnosed with a terminal illness?
Did you know about hospice before today?
What are some things that might make you apprehensive of using Hospice?
Do you feel comfortable with caregivers coming into your home helping to care for you or someone close to you with a terminal illness?
Why do you feel that many people in your community do not use hospice?

APPENDIX B

¿Qué es Hospicio?

- **Acerca del Hospicio**

Hospicio es una manera de cuidado especial para las personas quienes padecen de una enfermedad no curable. El énfasis es cuidar, no curar. Se centra en ayudar las personas para aprovechar al máximo cada hora y cada día durante lo que le queda de vida proveyendo confortabilidad y alivios del dolor.

- **¿Qué tipo de personas asisten el Hospicio?**

Hospicio está asistido por un conjunto extensivo de profesionales en la salud que puede consistir de un médico, enfermera, trabajador social, consejero espiritual y otros terapeutas.

- **¿Dónde queda Hospicio en todo esto?**

Hospicio cree que la esperanza es un ingrediente esencial para nuestro sentido de bienestar, proveyendo soporte y dirección mientras que su enfermedad progresa y su forma de esperanza cambia manteniendo su calidad de vida.

- **¿Cuándo es apropiado el Hospicio?**

Hospicio es una decisión apropiada cuando la meta de tratamiento es comodidad y control del dolor y síntomas físicos garantizando su calidad de vida.

- **¿Es Hospicio un lugar? ¿Puedo ser cuidado en casa?**

Hospicio no es un lugar, sino una filosofía de cuidado la cual afirma la vida y existe para proveer soporte y ayudas para personas en la última fase de su incurable enfermedad para que vivan lo más completamente comfortable como sea posible. Todos los programas de Hospicio enfatizan ayuda en la casa, a pesar si es casa propia o casa de cuidado.

- **¿Puedo seguir estando cuidado por mi doctor?**

Si. Hospicio anima a usted a seguir con su doctor. El Hospicio conjunto coordinará su cuidado con el (ella). Si no tiene un(a) doctor, el personal del Hospicio lo asistirá en identificar y seleccionar un doctor.

- **¿Qué pasa cuando necesito estar hospitalizado?**

Los programas de Hospicio certificados tienen acceso a las unidades de internados, los cuales están diseñados para satisfacer sus necesidades graves. Cuando es apropiado y necesario, la ayuda interna se puede proveer en un edificio de Hospicio.

- **¿Podrá mi seguro cubrir el Hospicio?**

Los servicios de Hospicio generalmente están cubiertos por casi todas las normas de seguros. El personal del Hospicio le ayudará a determinar la extensión de la cobertura

médica. **Nadie sera negado de los servicios por la incapacidad de pagar.**

- **¿Puedo salir del Hospicio?**

El servicio de Hospicio es nuestra decisión. Usted podrá mejorarse o estabilizarse hasta un punto donde ya no es necesaria la ayuda del Hospicio. Sin embargo, si su condición cambia, usted será elegible para proseguir los servicios del Hospicio en un tiempo después.

- **¿Cómo puedo obtener servicios?**

Para residentes de Michigan, se puede contactar con: Michigan Hospice Organization al número telefónico 1-800-536-6300 para más información y una lista de programas de Hospicios disponibles en nuestra área.

Servicios adicionales que se pueden incluir:

- El control del dolor y otros síntomas físicos
- Asistencia con ayuda personal y actividades de la vida diaria proveída por profesionales de salud, incluyendo ayudantes de salud que pueden visitar la casa o atendentes de casa.
- Soporte para sus seres queridos, por ejemplo, consejo en técnicas de ayuda y también consejos de luto
- Breve periodos de cuidado para internados por control sintomática
- Acceso directo telefónica al personal de Hospicio 24 horas diarias, 7 días a la semana
- Voluntarios preparados para proveer ayuda y compañerismo para usted o para proveer soporte a su atendente de cuidado
- Coordinación de: medicamento, terapia, provisiones, y equipo en casa

Esta información fue tomado del folleto Michigan Capital Healthcare Home-based Services- Visiting Nurse Services: Hospice – *Is Hospice an Option for Me?*

APPENDIX C

Forma de Consentimiento

Mi nombre es Lisa Topoleski. Estoy trabajando en un estudio el cual va a ser el fundamento de mi tesis maestrial en el programa Interdisciplinario en Salud y Humanidad. Se le ha solicitado a usted participar en este estudio investigatorio explorando las razones del por qué los mexicanoamericanos no usan el Hospicio. Mi estudio se llama "Barreras Culturales frente al Hospicio: El problema de la inutilización del Hospicio por la parte de los mexicanoamericanos en Lansing, Michigan". La participación incluirá una entrevista informal de media hora a una hora, que será grabado si usted está comodo con el uso de grabación de voz. Si usted decide no ser grabado se tomará notas. Esta información será interpretada para los propósitos del estudio.

Cuando se usa relatos en el ensayo investigativo en ningun tiempo se usará su nombre, para asegurar privacidad. Después de ser interpretados, los casetes serán borrados.

No hay ningunos riesgos o costos para usted. Las preguntas estarán a su disposición en cualquier momento ante, durante, o después de la entrevista. Puede cancelar o parar la entrevista en cualquier momento.

Por participar voluntariamente en este estudio usted está dando su consentimiento del uso de la información que después será usado como parte de la investigación que se publicara. Se aclara otra vez que su identidad jamás será revelada y que no hay ningun riesgo para usted por haber participado en este estudio. Gracias.

Su firma: _____

Fecha: _____

Lisa Topoleski B.S.
Masters Candidate
Michigan State University
Interdisciplinary Program in Health and Humanities

APPENDIX D

What is Hospice?

- **About Hospice**

Hospice is a special way of caring for a person whose disease cannot be cured. The focus is on care, not cure. Emphasis is on helping the person to make the most of each hour and each day of remaining life by providing comfort and relief from pain.

- **What kind of people run Hospice?**

Hospice is run by a comprehensive care team of health care professionals which may consist of a doctor, nurse, social worker, spiritual counselor and other therapists.

- **Where does hospice fit in?**

Hospice believes that hope is an essential ingredient to our sense of well-being, providing support and direction as your illness progresses and the focus of hope shifts to maintaining your quality of life.

- **When is hospice appropriate?**

Hospice is an appropriate choice when the goal of treatment is comfort and management of pain and physical symptoms to ensure quality of life.

- **Is hospice a place? May I be cared for at home?**

Hospice is not a place, but a philosophy of care which affirms life and exists to provide support and care for persons in the last phase of incurable disease so that they might live as fully and as comfortably as possible. All hospice programs emphasize care at home, whether in an individual home or supportive care residence.

- **May I continue to be cared or by my doctor?**

Yes. Hospice encourages you to retain your primary doctor. The hospice team will coordinate your care with him/her. If you do not have one, hospice personnel can assist you in identifying and selecting a doctor.

- **What happens when I need to be hospitalized?**

All certified hospice programs have access to inpatient units designed to meet your intermittent acute care needs. When it is appropriate and necessary, inpatient care may be provided in a hospice-contracted facility.

- **Will my insurance cover hospice?**

Hospice services are usually covered by most insurance policies. Hospice staff will help

you to determine the extent of your medical coverage. **No one is refused services for inability to pay.**

- **Can I leave hospice?**

Hospice service is our choice. You may improve or stabilize to a point where hospice care is no longer needed. However, should your condition change, you may be eligible to resume hospice services at a later time.

- **How can I obtain services?**

For residents of Michigan, Contact the Michigan Hospice Organization at 1-800-536-6300 for further information and a listing of hospice programs available in our area.

Additional services may include:

- Management of pain and other physical symptoms
- Assistance with personal care and activities of daily living provided by health care professionals, including home health aides or home attendants
- Support for significant others such as guidance in caregiving techniques as well as bereavement counseling
- Short term inpatient care for symptom control
- Direct telephone access to hospice staff 24 hours a day, 7 days a week
- Trained volunteers to provide help and companionship for you or to give your primary caregiver support
- Coordination of medications, therapies, supplies, and equipment in the home

Information taken from Michigan Capital Healthcare Home-based Services-Visiting Nurse Services: Hospice -- *Is Hospice an Option for Me?* brochure

APPENDIX E

Consent Form

My name is Lisa Topoleski, I am working on a study which will be the basis for my Masters Thesis in the Interdisciplinary Program in Health and Humanities. You have been asked to participate in a research study exploring reasons why the hospice alternative is not utilized by Mexican Americans titled "Cultural Barriers to Hospice: The problem of the underutilization of hospice by Mexican Americans in Lansing, Michigan". Participation will include an informal interview averaging 1/2-1 hour which may be tape recorded if you are comfortable with the use of voice recording. If you choose not to be recorded, field notes will be taken. This information will be interpreted by the researcher for purposes of the study. When using narratives in the research paper at no time will your name be used in order to insure confidentiality. After interpreted, the audiotapes will then be erased.

There are no risks or costs to you as an individual. Questions are always welcome at any point before, during, and after the interview. You may cancel or end an interview at any time.

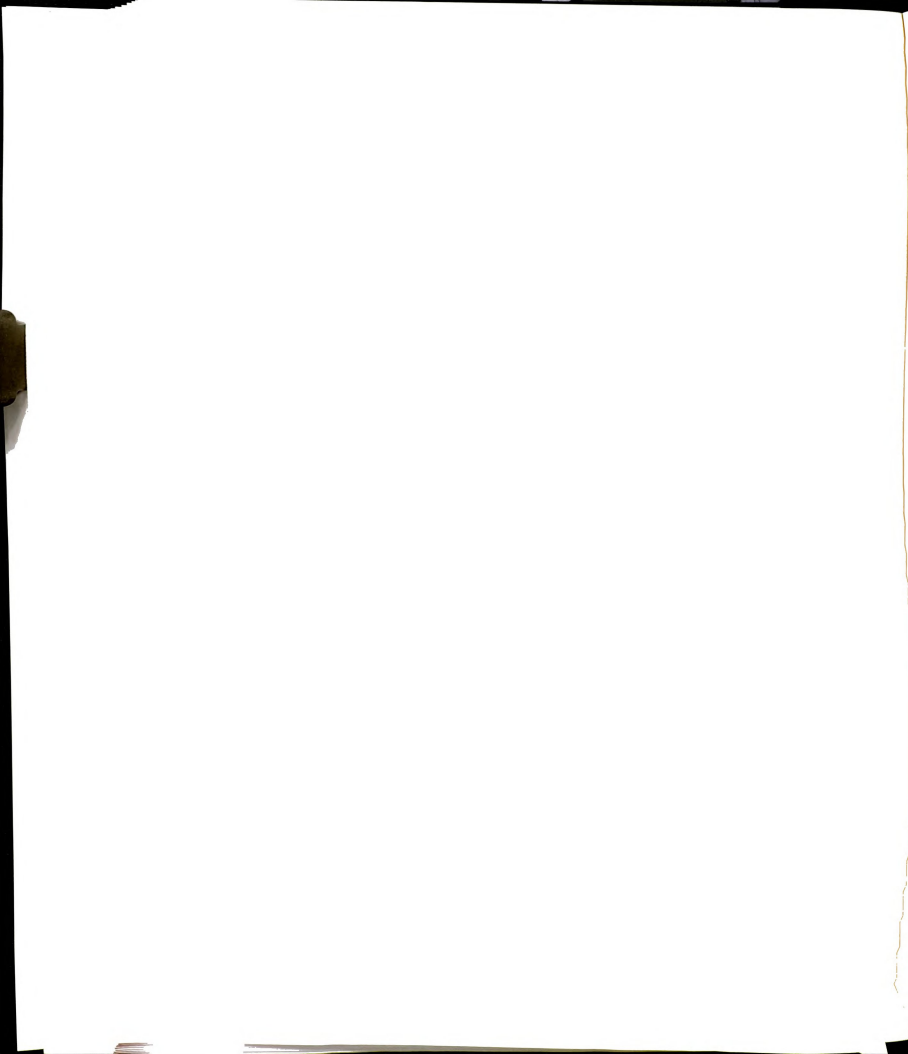
By voluntary participation in this study you are consenting to the use of information from the interview to be used later as part of possible published research. Once again at no time will your identity be revealed and that there is no risk to you whatsoever by participation in this study.



Signature: _____

Date: _____

Lisa Topoleski B.S.
Masters Candidate
Michigan State University
Interdisciplinary Program in Health and Humanities

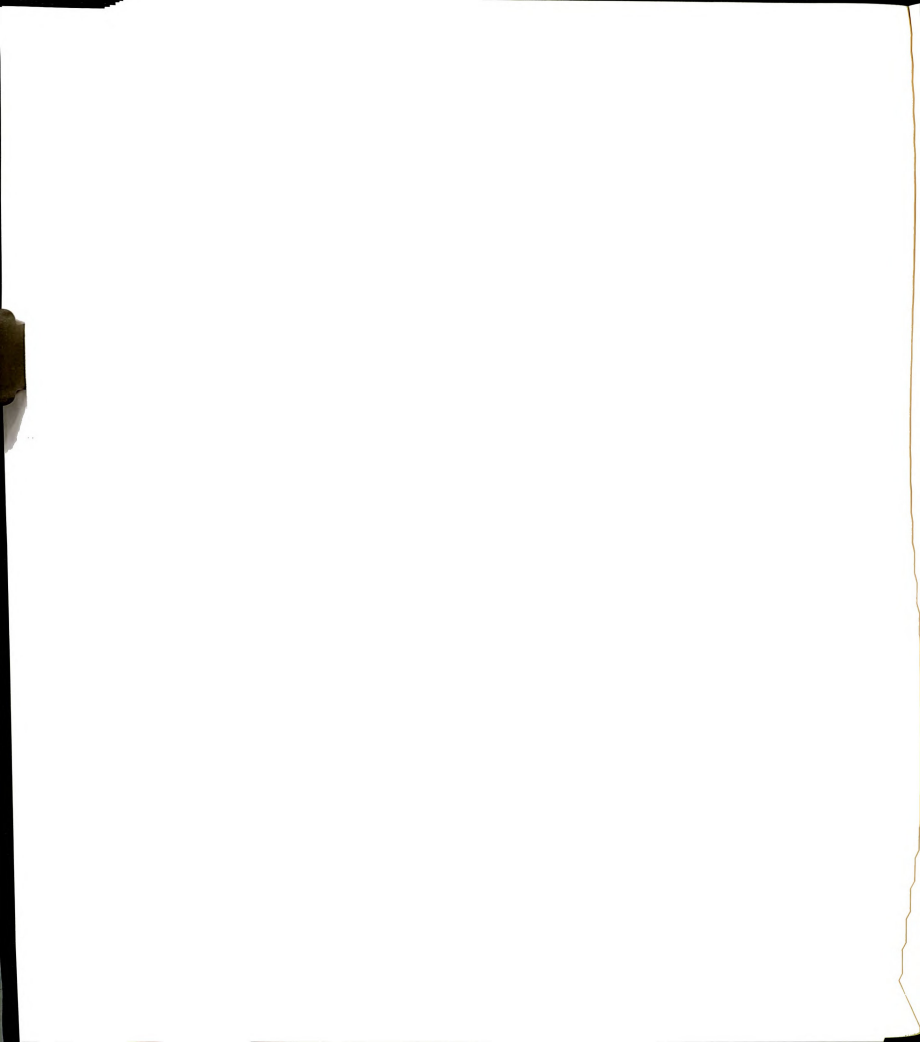


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