

HOPE FOR HISPANIC PATIENTS IN THE CONTEXT OF HOSPICE
THE IMPACT OF NARRATIVES OF FUTURE ORIENTED STORIES OF HOPE
IN THE EXPERIENCE OF ANTICIPATORY GRIEF
FOR HISPANIC ROMAN CATHOLIC HOSPICE PATIENTS
IN THE FORT WORTH AREA

by

Alberto O. Magana

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APPROVED BY

THESIS PROJECT COMMITTEE:

DR. JORETTA L. MARSHALL
Director

DR. BRYAN FEILLE
Reader

DR. JEFFREY WILLIAMS
Associate Dean for Academic Affairs

DR. NANCY J. RAMSAY
Dean

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ABSTRACT

Research shows that ethnic minorities access hospice care less often than Caucasians. In part this issue has been attributed to the lack of cultural competence among hospice staff. The purpose of this pastoral theological study is to examine how pastoral caregivers can work more effectively by attending to cultural context of Hispanics in the United States. The project examines the meaning attached to the stories of hope for six Roman Catholic Hispanic hospice patients in the Fort Worth area in order to find out how their belief system about the future has an impact on their anticipatory grief or waiting experience.

In order to establish the context, this project introduces the pastoral challenge by identifying the Hispanic population in the United States and the cultural problems they face at the end-of-life. Second, the project describes the pastoral theological method and research design proposed by James and Evelyn Whitehead, who suggest three stages of the theological method (attending, assertion, and action) and three sources of information (experience, tradition and culture). Third, a dialogue between the three sources of information proposed by the Whiteheads and the experience of the participant patients. The written project is organized according to how the patients experience and interpret their stories of hope in three different ways: as fullness of life, as ambiguous-multiple future stories with limited life, and as future stories with no life. This project concludes by suggesting that the use of narrative theory is a helpful approach for pastoral caregivers in order to maintain culturally sensitive conversations with Hispanic patients at the end-of-life while being mindful of how their future stories have an impact on hope during the waiting experience.

CHAPTER 1

IDENTIFICATION AND CONTEXT OF THE PASTORAL CHALLENGE

INTRODUCTION

My work in the Roman Catholic Church, in hospitals and with hospice patients has given me the experience and the possibility to improve my pastoral care skills. First, I was ordained in the Roman Catholic Church. I had the opportunity to work for 5 years in a parish setting. Second, I trained for two years in a hospital setting to become a chaplain where I was introduced to hospice services. During my years working with hospice patients, I encountered that not only do some patients experience difficulty in understanding the value and meaning of hospice services, but also some healthcare providers are faced with the challenge of finding ways to explain their values and services. As a result of my observations, I identified the need of exploring the following questions: How might hospice employees provide services attuned with cultural and spiritual beliefs? In what ways can hospice present its value as care at the end-of-life when some patients and families prefer to avoid the use of end-of-life language and include in their discourse continuity-of-life and the expectation of a miracle? Imagine being challenged with the following situation.¹

A Hispanic female is admitted at one of the local hospitals with a diagnosis of cancer. After receiving some aggressive treatment, her doctor delivers the bad news about the limitations of medicine and he makes a referral to hospice services in order to ensure that this patient

¹ Although this situation reflects real lives, this case has been created to illustrate the need of a conceptual system that allows healthcare providers to engage in meaningful conversations beyond the dominant medical discourse.

receives palliative care as she waits for the end-of-her-life. This patient has been living with her adult sons for the last 10 years and they have a close relationship with one another. This patient and her family are Christians and they maintain an image of a God who has the power to heal and raise the dead, but also a God-Judge who can send anyone to hell. The family members agree with the doctor's suggestion about hospice services, so they take the patient home. While they wait for hospice they also wait for a divine intervention and they expect a miracle. Because the patient and family recognize that medicine has very little to offer at this time to prolong her life, faith and togetherness are values that help them to deal with this very complicated situation.

When the doctor expresses the lack of medical resources to find a cure for their mother, this family turns to the God that they know through the Bible. The oldest son encourages the rest of the family to maintain their hope and faith because he is convinced that in the Bible, God healed the sick and restored life. All the efforts, prayers and conversations from this family are focused on the expectation of God's intervention and of a miracle. The practices of engaging in prayers, lighting candles, and anointing with oils different parts of the body, are the family's way of making sure they are doing their part to be good receptors of a miracle.

The patient and her family understand the limitations of medicine and they are not asking for aggressive treatment; however, the expectation of a miracle from God becomes the central theme of any conversation and they report that they will continue with this belief. All the arrangements are done for hospice staff to meet with the patient and her family to discuss hospice values and services, and to determine if this patient is appropriate for hospice. The first interaction between a hospice staff and one of the sons takes place at the bedside of the patient. During this intervention, the expectation of a miracle is expressed by the son and supported by the family's Christian faith. The family's decision is not to sign any "Do not Resuscitate Order"

and they refuse to make any funeral arrangements because they want to leave the door open for a miracle to happen. At this point, the patient is already unresponsive and her vital signs indicate that the patient will not last for a long time. Considering all these elements, the first assumption of the hospice staff is: “they are not appropriate for hospice because hospice is to provide end-of-life care and this family is invested in continuity-of-life; they are in denial.”

The conversation among the hospice staff continues to explore ways to help this patient and family. The patient’s son, who is now the decision maker, decides to go further by formulating the question: “If we go with hospice, can we still continue to pray for a miracle?” That question challenges the hospice staff and makes them wonder if this is the time to make use of the medical discourse and inform this young man that his mother is close to the end-of-her-life and a miracle is not going to happen? Upon reflecting on the story of this patient and her family, the hospice employees formulate the following questions: Is there any conceptual discourse or ways to engage in conversations that can be helpful to support patients and families when they face similar situations? How do hospice chaplains properly engage in conversations with patients and families when they choose to face the end-of-life using a belief system which does not allow them to maintain conversations about dying and death using the conventional or traditional discourse?

Considering this complicated situation and acknowledging that there is not a conceptual framework within the hospice perspective that can assist the chaplain, I began to ponder the question on how to present hospice services without giving the impression that hospice values are opposed to the cultural belief systems of patients and families. The experience that some patients have faced alongside the challenge for hospice providers to be more culturally sensitive and competent, has led me to formulate this Doctor of Ministry research-project. My intent is to

explore a number of questions considering that most hospice employees, view death as a loss, end of relationships, and a failure to cure the body: What are the best practices to support patients and their families when they face the end-of-life from a perspective that does not rely only on the conventional hospice discourse? How does the belief system of patients and families influence the way they make decisions as they face the end-of-life? How does one present hospice services that take into account the patient's belief systems and rely less on conventional hospice discourse? More specifically, in working with patients who are Hispanic, how does their belief in hope function in ways that assist people at the end-of-life? As a result of my work and observations with Hispanic hospice patients, this project examines the meaning attached to the story of hope for Roman Catholic Hispanic hospice patients in the Fort Worth area in order to find out how their belief system about hope impacts their anticipatory grief experience.

My work at Vitas Innovative Hospice Care afforded me the opportunity to carry out this project. I was granted permission by this hospice provider to conduct the research and interview six Hispanic patients. The objective of this project is to contribute to the practices of pastoral care for Hispanic patients who are terminally ill and in hospice. The project provides an understanding of how some Hispanic patients attach meaning to the narratives of their future-oriented-stories-of-hope and how those stories influence their experience in the present tense as they begin a journey of anticipatory grief, or "waiting." The project also explores how these two areas, the future-oriented-story-of-hope and the anticipatory grief experience, are interconnected. In this project the process of anticipatory grief has been changed by the concept of "waiting experience." I will talk about the importance of this language change later in this project.

Ultimately, one of the purposes of this project is to help hospice chaplains and other professional caregivers to provide support meaningful for Hispanic patients.

To understand this project, it is important to describe the demographics of Hispanics or Latinos living in the United States, and some of their cultural beliefs related to healthcare. It is also significant to explore the current development of hospice services as a model for quality and compassionate care at the end-of-life. The last component of this chapter will address the use of hospice services by Hispanics and some of the challenges that this specific group faces at the end-of-life.

After a discussion of the particularity surrounding Hispanic hospice patients in this chapter, chapter 2 focuses on the methodology and the research design for this project. I am making use of the pastoral theological method proposed by James D. Whitehead and Evelyn Eaton Whitehead. The Whiteheads suggest three stages for the theological reflection process, (attending, assertion, and decision) and three sources of information, (tradition, experience of the community, and cultural resources). After giving a short explanation of the meaning of each one of the stages of the research process, I continue with the development of the first stage, attending, as I explore the available information for each one of the three sources in developing the key concepts of anticipatory grief or the waiting experience, and hope. This section will take into consideration the Hispanic cultural aspects of patients in order to address the pastoral challenge of this project and to explore how the story of hope impacts the anticipatory grief experience.

The first stage of the research, attending, is part of chapter 2. Beginning with a description of the available information on how some parts of the Christian tradition developed

the concept of hope. I also include some personal and communal experiences from the researcher, patients and other pastoral caregivers who have made some reflections about this pastoral challenge. Chapter 2 ends with developing a new understanding of anticipatory grief as I explore the view of grief in a modern context and continue to develop the “waiting experience” in a postmodern perspective. The cultural experience of death and the influence of the Roman Catholic tradition are included in this section. A discussion of how culture and tradition have merged together is necessary in order to understand not just the grieving process or waiting experience but also to understand how death, as part of the waiting experience, is constructed. This chapter introduces how the waiting experience for Hispanics is not just the experience before death but also includes the way they anticipate their continuity of life after death.

The second stage of the research process, assertion, develops in chapters 3, 4, and 5. These chapters are assembled around the waiting experience for six Hispanic Roman Catholic hospice patients. Building on qualitative interview processes, I invited conversation with these patients about their experiences of “anticipatory grief” and the way in which they constructed narratives of future-oriented-stories-of-hope. The interviews allowed me, as a researcher, to gather patient’s stories concerning the meaningful elements of the study. More reflections will be said later about the methods and design of this research. The waiting experiences are divided into three sections, according to how the patients perceive their future-oriented-stories-of- hope: “anticipating a future full of life”, “ambiguous-multiple stories producing limited life” and “stories with no future life”. This project closes in Chapter 6 with suggestions about appropriate pastoral responses in the context of working with Hispanic hospice patients. Based on the gathered information in the attending stage and the reflection of the three sources of information in the second stage, this project concludes with Whitehead’s third stage of theological reflection

by suggesting some “best practices” for hospice pastoral caregivers engaging in hopeful conversations when the patients decide to face the end-of-life through a waiting experience that includes the narratives of future-oriented-stories-of-hope.

A. Hispanics in the United States

According to the 2010 census, the definition of Hispanic or Latino origin refers to “a person of Cuban, Mexican, Puerto Rican, South or Central American, or other Spanish culture or origin regardless of race.”² The Hispanic population increased from 35.3 million people in the United States in 2000 when this group made up 13 percent of the entire population, to 50.5 million people in 2010 or 16 percent of the entire population. More than half of the growth in the total population of the United States between 2000 and 2010 was due to the increase in the Hispanic population.³ The overall Hispanic population growth between 2000 and 2010 in the United States varied by the different growth rates of multiple Hispanic groups. For example, the Mexican origin population increased by 54 percent and had the largest numeric change (11.2 million), growing from 20.6 million in 2000 to 31.8 million in 2010. Mexicans accounted for about three-quarters of the 15.2 million increase in the Hispanic population from 2000 to 2010.⁴

Hispanics are described as a group of people with a mixture of different cultures. Pastoral caregivers, Esteban Montilla and Ferney Medina note that “the latino/a population is a poly-culture combining a heterogeneous and multicolored group of people who have diverse

² <http://2010.census.gov/2010census/>

³ Ibid

⁴ Ibid

ethnicities, languages, religions, and socioeconomic and educational statuses, yet maintain distinctive features and principles that make them “one” particular people.”⁵ The growing Hispanic population in the United States represents “Mestizo”, or the group of people whose cultures have mixed together Spanish, Native American (Nahuatl or Aztecs or any other Meso-American group), and African elements.

The increase of Hispanics in the United States often includes frequent stories of people fleeing their natural land or country of origin in order to seek a better life for themselves and their families. According to Charles Dahm, a Roman Catholic priest who has dedicated part of his ministry to work with the Hispanic community, “immigrant families react differently to their new world: some readily assimilate new customs, jettisoning the old, others struggle to preserve their fundamental values and traditions, and still others struggle to resist what they perceive as a threat to their own identity.”⁶ The majority of Hispanic immigrants who arrive to the United States come filled with hope, but sometimes they bring mistaken notions of what life is in this country. They arrive with no financial resources; the majority comes from rural areas, limited education and no English.

According to Dahm, Hispanics are part of the most undereducated segment in the U.S. population. He identifies that even when Hispanic immigrants do not have the opportunity to attend school, “they are very *educados*, (educated) excelling in courtesy, respect, and graciousness, even to the point of being quite formal with family and friends.”⁷ The majority of Hispanics who immigrate to the United States arrive following the American dream; they may

⁵ Esteban Montilla, and Ferney Medina. *Pastoral Care and Counseling with Latino/as* (Minneapolis: Fortress Press, 2006), 6.

⁶ Charles W. Dahm, *Parish Ministry in a Hispanic Community* (New York: Paulist Press, 2004),viii

⁷ *Ibid.*, 36

have limited money and education but they bring unlimited hope, a hope that allows them to work hard in order to have an opportunity to obtain a better life.

This project focuses on a culture which I represent. I know what it means to arrive to the United States following a dream but with no money, no place to live, no English, no medical insurance, and no job. In 1997 I arrived to the United States after selling an old computer so I could buy a bus ticket to travel from Guadalajara to Portland. For a period of time, I lived in the corner of a living room. I delivered newspapers in the mornings, I washed dishes for 8 hours during the day, and I attended free English classes provided by a local church in the evenings. In my experience of struggle living in the United States there was one thing I never lacked and that gave me the energy to keep waiting with a strong belief that one day my life was going to get better: hope. Hope has been a crucial piece in my life and I know the importance of keeping hope alive in the present tense. Because of hope, I was able to continue searching and waiting for a better possibility of life. It is a privilege for me, as a member of the Hispanic culture, to be able to present this research project reflecting on the experience of hope.

B. Cultural Beliefs Impacting Understanding of Healthcare

When facing end-of-life, many Hispanic patients may feel hopeless. This sense of losing hope comes from a perceived loss of options, lack of resources, and from living in a different culture or country with unfamiliar ideas and customs. As noted by Merydawilda Colon, a hospice social worker, a variety of factors may affect Hispanics when they face a terminal illness: “among those factors are beliefs about health care, death and end-of-life care, language difficulties, lack of insurance, acculturation, poverty, low levels of education and lack of

knowledge about hospice.”⁸ This experience of hopelessness contradicts the belief that some Hispanics keep alive in their minds and hearts, the fulfillment of the American dream with the hope to find a better life.

Most of the Hispanic people in the United States are Roman Catholic. However, their belief system may include the expression of some indigenous ideas that affect the way these patients perceive the cause of their illness, specifically if the patients have been exposed to low levels of education, poverty, (societal) marginalization, unemployment and violence. Another aspect related to Latinos and healthcare is the view of fatalism. Colon defines this particular belief of fatalism as, “the idea that exterior forces control the universe and the destiny.”⁹ People who share this belief acknowledge that they have to accept illness because God allows it to happen. If God allows it to happen then God will decide if the patient will be cured or not. This belief also has an effect on the way Latinos/as view death and therefore the acceptance of hospice services as the end-of-life care.

For Latinos/as, traditional religious beliefs and practices are known as “popular religiosity.” Dahm explains that popular religiosity “is popular not because it is necessarily widespread but because it is born of the people, an expression of their culture.”¹⁰ This popular religiosity sometimes is not well understood not only by the Church in the United States, but also by pastoral caregivers. Mark Francis, a Catholic professor of liturgy and Aruto Perez-Rodriguez, a Roman Catholic priest, refer to popular religiosity as a group of popular rituals that “grew up alongside official rites of the church and reflect a worldview comprising elements from Spanish,

⁸ Merydawilda Colon. “Hospice and Latinos: A review of the Literature. *Journal of Social Work in End-of-Life and Palliative Care*. Vol. 1 2006, 33

⁹ Ibid.

¹⁰ Dahm, 151

Native American, and African cultures.”¹¹ These practices or rituals which form part of popular religiosity help Hispanics to maintain a connection with the Holy providing a source of unity and healing, offering hope for a better future and strength. This popular religiosity reflects spirituality so intertwined with the culture, including cosmic as well as personal dimensions. This particular spirituality is called *mística* or *mystique* by the United States Conference of Catholic Bishops. The Bishops defined this term as “a sense of the presence of God, which serves as a stimulus for living out one’s daily commitments. In this sense, the transcendent God is present in human affairs and human lives.”¹² Unfortunately, this phenomenon is not always recognized and sometimes is seen as an absurd expression of faith when it can be a true expression of people’s belief and committed Christian life.

Hispanic theologian, Ada Maria Isasi-Diaz claims, “it is thanks to *religion popular* that Christianity is a vital force in many families and communities serving not only as the principal tool for catechizing, but also as the vehicle for ministry among Hispanics.”¹³ Some Hispanics understand religion, spirituality and connectedness with God as practices they learn not only in the community of faith, but also from the teaching of the *abuelita* (grandmother) who is in charge of part of the education process to make sure that the values and traditions are taught from one generation to the next.

Different surveys and studies in the last 20 years have shown that “one of the key elements of Hispanic identity is religion as manifested in *religion popular* and not necessarily

¹¹ Mark R. Francis and Arturo Perez-Rodriguez. *Primero Dios: Hispanic Liturgical Resource* (Chicago: Liturgy Training Publication, 1997), 7

¹² NCCB. “National Pastoral Plan,” *Hispanic Ministry*, 1987, 68

¹³ Kenneth G. Davis and Yolanda Tarango, Ed., *Bridging Boundaries: The Pastoral Care of U.S. Hispanics*, (Scranton: University of Scranton Press,2000), ix

church affiliation and participation.”¹⁴ This concept of popular religiosity as I described it above includes different practices, rituals or celebrations that reflect the way Hispanics perceive their reality and the way they see life and death. Illustrative of these celebrations are Feats of our Lady of Guadalupe, Day of the Death, *Posadas* (highlighting Mary’s experience in the final days of her pregnancy), Novenas (nine days of prayer for different occasions such as following the death of a family member) or to request the help of a saint when someone is sick, street processions, commitment to a saint or virgin Mary, blessings of places and people, among others. For some Hispanics religion, expressed by popular practices, is an expression of faith and it is a way of understanding the mystery of life within the Christian context.

Under this perspective, hospice services can be presented if we take into consideration the following questions: When from a medical perspective there is no more treatment, where do Hispanic patients and families turn for healing? How can pastoral caregivers maintain meaningful and respectful conversations with Hispanic patients which include continuity-of-life instead of end-of-life? How can hospice providers be a companion in the journey of life for Hispanic patients and help them to integrate their biological existence with their spiritual identity taking in consideration their *mistica* or popular religiosity? These questions will be addressed in this research project providing an understanding of how hospice as an end-of-life model can provide meaningful support for Hispanic patients if we take into consideration the manner in which they interpret life as well as their spirituality, religion, or faith. To facilitate an understanding of hospice services, it is helpful to turn to the importance and value of hospice as an end-of-life- model of care and how hospice, as an institution, is in the process of developing and creating new ways to better serve patients from all different cultures.

¹⁴ Ibid., ix

C. Current Hospice Development

During the 1960s, some professional caregivers began to question the medicalization of the death-event as a loss of the personal-human-experience. They noticed that the medical system sometimes did not deal very well with the needs for the dying. Robert Buckingham, one of the professional caregivers at that time and one of the founding fathers of the hospice movement, pointed out that, “physicians in this culture are trained to cure and not to care. When cure becomes impossible, their typical response is to leave the patient alone and tell the family that they have done all what medical science can do.”¹⁵ As human beings, doctors also want to provide a successful cure for their patients, so death becomes a problem to be solved and enemy to be defeated. The hospice concept represents a return to humanistic medicine, taking care of patients in their own environment, surrounded by family and friends, and the view of the patient as a person not as a number or a diagnosis. With this new approach, the person facing a terminal illness is permitted to die with dignity.

Alongside this new approach, changes to our perceptions of the death process have also occurred in the American society. People are moving away from the denial of death to finding safe environments that allow them to explore their own understanding of death and to process this reality in their own terms. In order to function as an effective hospice care institution, hospice services require considering the needs of the patients and their families as the first priority. Both, the patient and family are treated together as unity, wherein “the patient needs to be listened to, cared for, and supported. The same applies to the family.”¹⁶

¹⁵ Robert W, Buckingham, *The complete Hospice Guide*, (New York: Harper & row, Publishers, 1983), 1

¹⁶ *Ibid.*, 5

While Hospice functions as an institution, it does not try to force the patients and their families to fit and accommodate themselves into the values of the institution. As one of the formative thinkers about Hospice noted long ago, “hospice care adapts to meet these varied individual needs, rather than adapting patient and family to an institutional program.”¹⁷ However, sometimes hospice caregivers have not developed the cultural sensitivity necessary for working with Hispanic patients and they fail to understand the needs of the patients and their families. As a result, they fail to adapt hospice services to the needs of the patients. The Hospice foundation of America recommends that professional caregivers can be truly helpful only if they understand the importance of the cultural dimensions surrounding the patient and family, noting that “if professional caregivers wish to render effective assistance, they will need to offer it in ways that are professionally and culturally competent.”¹⁸ This recommendation is relevant because culture is understood as a way of life. This way of life includes values, beliefs, and attitudes that affect the understanding of dying and caregiving experience; therefore, those values, beliefs and attitudes will frame treatment decisions.

Hospice was created as an alternative to dying alone in hospitals. Although hospice provides options for the patients and their families in their dying process, hospice also uses the conventional medical discourse. Carol Lorraine Hedtke, a social worker and family therapist who has been working for hospice for a number of years, challenges hospice language by noting that:

Those grieving are assessed for symptoms of anticipatory grief or referred to as in denial or needing closure. Physicians still head the professional hierarchy. While hospice

¹⁷ Ibid.

¹⁸ Kenneth J. Docka and Joyce d. Davison, Ed, *Caregiving and Loss: Family Needs, Professional Responses* (Washington: Hospice Foundation of America, 2001), 140

professes to offer a multi-disciplinary orientation, the discourse of medical assessment and intervention permeates the conversations.¹⁹

In my own personal practice with hospice, I see that as inter-disciplinary teams we continue to use traditional approaches of death and grieving. As professional caregivers, we help people to accept the reality of death by encourage them to acknowledge the loss and get in touch with their feelings created by the grief. We encourage people to say their goodbyes to a dying patient. To those who are dying, we help them finish their unfinished business so they can die in peace. During the inter-disciplinary team meetings we assess the bereavement process of each family and use the terms “normal”, “risk”, or “complicated” grief to determine the level of understanding and acceptance of the reality of death. During the condolence call which follows the death of the patient, we have the tendency to focus only on the loss of the loved one. All these current hospice practices are opposed to the premises this project holds: each individual has his or her own experience of the meaning of dying and death and they are affected by the way they construct their story of hope. Therefore, there is not a normal way of grieving that applies to everyone; because culture plays an important role there are multiple approaches when we talk about death.

In her article in *The Journal of Social Work in End-of-Life and Palliative Care*, Colin makes a strong recommendation that health care providers be attentive to the stories of patients and families about life, death and dying. Colon recommends that “they should continue to actively listen intellectually and emotionally to the unique stories of patients and families. It is in those stories that rest cultural elements that are vital to the genuine understanding and delivery of

¹⁹ Carol Lorraine Hedke, *Folding Memories in Conversation: Remembering Practices in Bereavement Groups* (Dissertation Ph. D Program) Taos Institute, University of Tilburg, 2010, 45

the most appropriate end-of-life care.”²⁰Hospice practices need to incorporate new approaches to listen to the stories by giving the opportunity for patients and families to name their own meanings in the dying process, including allowing for different ways to experience grief. Hospice provides palliative care and recognizes the holistic view that a patient’s needs inseparably intertwine the physical, psychological and spiritual areas of their existence. In pursuing this holistic care, pastoral caregivers need to be aware that the patient is the knowledgeable expert in his or her own life. Professional caregivers can proceed from a standpoint of “not knowing” how best to help and engaging in professional conversations. One of the tasks for hospice professional caregivers – including chaplains – is to find opportunities to accompany and guide the patients and their families in their journey, so they can construct and experience their dying process in ways that are unique. Because of diverse cultural contexts, a normal way of dying or a normal way of experiencing grief does not exist.

D. The Use of Hospice by Hispanics

The use of hospice programs has grown enormously in the recent years. Although the use of hospice services has been positive, only a portion of terminal patients receive hospice care. Research shows that ethnic minorities access hospice care significantly less often than Caucasians. Hospice providers have long understood that hospice services are disproportionately utilized by Caucasians compared to racial and ethnic minorities. Although Hispanics are the largest minority population in the United States, they are under-represented in hospice at the national level. According to the National Hospice and Palliative Care Organization, the

²⁰ Merydawilda Colon. “Hospice and Latinos: A Review of the Literature.” *Journal of Social Work in End-of-Life and Palliative Care*. Vol. 1 2005.

percentage of hospice patients by ethnicity in 2009, shows that 94.7 percent were Non-Hispanic or Latino origin and only 5.3 percent were Hispanic or Latino origin. This percentage of Latinos admitted in to hospice does not resemble the 16% of the entire population in the United States reflected in the 2010 census.

It is clear that Hispanics under-utilize hospice services. These statistics suggest that the admission of Hispanic patients to hospice programs remains low. While there may be many explanations for this phenomenon, two particular questions emerge from these kinds of reports. At the forefront of this phenomenon is a question about what keeps Hispanic patients from approaching hospice programs in the first place? With this question, pastoral caregivers are challenged to decide if hospice is a model of end-of-life care that truly appeals to Latinos and their traditional culture, norms, and rituals? This research project does not directly answer that question but rests with a second question: Once Hispanic patients have been referred to a hospice program, how does the pastoral caregiver make services more culturally sensitive and accessible to their understanding while making sure the care they receive more appropriately matches their cultural contexts?

Assuming that hospice is a model of end-of-life care for Latinos, how might pastoral caregivers present and adapt those services in an integrated manner so that hospice values support the values of this particular group? While there are many aspects to this latter question, this particular project will focus on the delivery of hospice services for a growing Hispanic population in the United States. The premise is that by examining how these patients experience hope in the midst of their dying, we will also discover some ways pastoral caregivers can provide meaningful and culturally sensitive support. This project does not anticipate creating a universal procedure or intervention that can be applied to all Hispanic hospice patients. The cultural

complexity and diversity among Hispanics in the United States will not permit the creation of a single approach for the understanding of their dying experience.

Pastoral caregivers face the question of how to present hospice services to patients and families who refuse to talk about the end-of-life or who do not want to use the conventional language to describe death and dying. What kind of language can pastoral caregivers use to talk about end-of-life without being disrespectful to the values, culture, and belief systems of patients and families? The truth is that there are many gaps in our understanding of attitudes toward end-of-life care among Hispanics. There is no universal remedy for improving the ethnic and racial sensitivity of hospice services because every patient presents a unique set of personal, familial, and cultural circumstances. Yet hospice needs to have a conceptual framework to improve the services they provide for patients from different cultures and belief systems and reduce the difficulties or challenges that these patients face.

Illustrative of the challenges that Hispanic patients face when they have to make end-of-life decisions is the lack of understanding of the concept “hospice” when this term is translated into Spanish as “hospicio.” This translation often creates confusion among many Hispanic because “hospicio” means an “inpatient infirmary setting similar to a nursing home,”²¹ in contrast to the focus of American hospice services on home care. “Hospicio” was created in Mexico to provide care and shelter for the disadvantaged like orphans, the handicapped, old people, and chronic invalids who did not have any family, or when their families were unable to take care of them due to the complexity of their illness or lack of resources. Considering this perspective, “hospicio” is understood by many Hispanics as care for the hopeless.

²¹ Carolyn E. Adams, Kathryn Horn, and Julia Bader. “Hispanic Access to Hospice Services in a Predominantly Hispanic Community.” *American Journal of Hospice and Palliative Medicine* 23, no. 1 (January/February 2006) 10

For some Hispanic families “accepting hospice as end-of-life care implies that their family member will not be cured since hospice is a service for individuals who are dying.”²² For some patients and families, that way of thinking creates a spiritual problem because those ideas represent giving up hope. Attitudes toward palliative care among Hispanics are intertwined with culturally based beliefs about the role of the family in caregiving and religious or spiritual beliefs. For Mantilla and Medina, “spirituality, religion, and faith are central to Hispanic families’ survival and resilience.”²³ These three concepts are better understood if they are seen as an undivided whole. They are all about relationship and intimacy with the transcendent, the self, and others. “This web of relationships is what Latino/a families have historically used to face adversities, celebrate achievements, and make sense of their existence.”²⁴ At the end of life, Hispanics make a connection and utilize all these different concepts as they express in different ways their human hopes and divine Hope. For Hispanic patients and families, “spirituality and connectedness is an integrated part of their daily functioning and that tending to the whole person within the community context is essential for the healing process.”²⁵ In my experience, working with Hispanic hospice patients, I have seen how the concept of family includes friends and neighbors and they get together not just to support each other, but to help the patient and family to keep their hope and faith alive.

Increasing hospice services to various Latino groups may require different approaches including the modification of hospice philosophy in order to meet their needs. For example, one approach is to focus on the stories of hope and the influence of those stories in the waiting

²² Ibid.

²³ Montilla, 18

²⁴ Ibid.

²⁵ Ibid.

experience. In order to accomplish the goal of this project – which is ultimately to assist pastoral caregivers and chaplains in working with Hispanic hospice patients- I draw upon the theological reflection model proposed by Catholic theological educators, James D. Whitehead and Evelyn Eaton Whitehead. Turning to their methodological resource is helpful as the next step in this project.

CHAPTER 2 PASTORAL THEOLOGICAL METHOD AND RESEARCH DESIGN

Roman Catholic practical theologians, James D. Whitehead and Evelyn Eaton Whitehead, propose a theological method which includes examining three sources of information through three different stages of theological reflection. The model moves a chaplain from thinking about an issue to discerning some appropriate and helpful pastoral responses to the questions that arise. The Whiteheads consider “Christian tradition, the experience of the community of faith and the resource of the culture”²⁶ as the three sources of information required for an effective pastoral theological method.

Three stages describe the process in which the three sources interact with each other in order to formulate an adequate pastoral intervention to any particular issue. The stages are: attending, assertion, and decision for action. In what follows, I describe each one of the sources and the stages. This method is helpful in this project because it provides the sources of information that can help me to respond faithfully and effectively to the identified challenge of providing culturally sensitive care for Hispanic hospice patients. The first stage, attending, includes the gathering of information from each one of the three resources named above: the Christian tradition, the experience of the community of faith, and the resource of the culture. Attending, however, takes two forms. First, in this chapter I will attend to the three sources largely through a review of significant written resources in the fields of pastoral theology, care, and counseling.

However, the second major way of attending is to listen more fully to the stories of Hispanic hospice patients. The stories will be more fully represented in chapters III, IV, and V as

²⁶ James D, Whitehead and Evelyn Eaton Whitehead, *Method In Ministry* (Minneapolis: The Seabury Press, 1980),13

I engage the dialogue between the sources of chapter 2 and the stories of Hispanic patients in Hospice. This movement is described by the Whiteheads as assertion; “dialogue among these sources of information in order to clarify, challenge, and purify the insights and limits of each.”²⁷ The goal of assertion is to place the data (historical, contemporary, and the voices of patients) into context and in dialogue with each other in order to begin the process of discernment and clarification of the insights prior to making an effective pastoral decision.

After discussion of the data and the information from these three sources, I move to the third stage, decision for action in chapter VI. In this chapter I examine some of the conclusions and implications of the research project with the purpose to provide an adequate practical application for pastoral caregivers in the context of hospice. Answering the question of how the narratives of future-oriented-stories-of-hope influence the waiting experience of Hispanic hospice patients ultimately leads toward particular best practices or options as one moves into the work of chaplaincy and care.

A. Explanation of the Stages for the Pastoral Theological Method

1. Attending

The first stage in the Whitehead and Whitehead method, attending, is the starting point whereby the concerned is identified, the question is formulated, and the information seeking begins. This stage searches for information available in three sources: tradition, experience and culture. Listening skills through narrative perspective are required alongside the ability to

²⁷ Ibid., 2

explore with a non-judgmental attitude, demonstrating openness to receive more information and to respond with empathy and accuracy. “The effectiveness of this first stage of theological reflection depends on my ability to explore the information available in the three sources.”²⁸ My role as a chaplain, using Whitehead’s suggestion is “as the one who helps to discern God, already present.”²⁹ Attending of my own experience requires my capacity of self-awareness, which includes the recognition of my own internal ambiguities in life. My skills also require me to be open enough to learn from the patients, from their own experience, to recognize that God is also present in them, to be sensitive to their expressions of faith and religious traditions, and to pay close attention to the dominant cultural discourses making an influence in their life.

During the first stage of the theological reflection method, I sought out relevant information regarding dying, death, and hope from tradition, from experiences of communities, and from the culture. These key concepts are needed to illustrate how the meaning attached to the story of hope for Roman Catholic Hispanic hospice patients impacts their waiting experience. The attending of tradition includes examining the development of the concept of hope from the Christian perspective, and the connection with life after death. In addition, because of the Hispanic context, I also explore theologies of the poor and liberation theology. I attend to the cultural information by exploring traditional and postmodern understandings of dying, death, and grief, including the cultural influence on the discourse in the Roman Catholic system.

Through the attending stage I also gathered information about the context and the meaning of dying, death, and hope from the patients themselves, from a Roman Catholic tradition, and from modern and postmodern cultural influences. Through interviews I explore

²⁸ Ibid., 23

²⁹ Ibid., 82

anticipatory grief or waiting experiences with six Hispanic hospice patients who are facing end-of-life and seeking for the meaning they attach to their future-stories-of-hope. This stage actually starts in chapter 1, as I outlined the development of my question and research, and continues in this chapter as I reflect on some of the influential aspects of the work of others. .

2. Assertion

The second stage of theological reflection is assertion. The three sources of information are important in the way they relate to each other; they are not isolated, but intertwined. The assumption is that “God is revealed in all three sources.”³⁰ Therefore, tradition, experience and cultural information are all equally valid and contain an important piece of information which complements the others. According to the Whiteheads, assertion is “the act of witnessing to the world that we have heard,”³¹ that we have new information and we want to share it with others. Assertion is a stage in which the researcher carefully attends to the gathered information from tradition, experience, and culture. In the case of this project, I explore how the meaning attached to the stories of hope impact the anticipatory grief experience. As the Whiteheads suggest, this means “bringing the data into contact”³² with each other. Assertion implies an attitude and a behavior. An assertive attitude depends on the perception of my own experience, needs, and purposes; therefore, this attitude involves self-awareness, self-disclosure, and self-worth. This attitude can be expressed as a behavior permitting flexibility and dialogue when disagreement

³⁰ Ibid., 23

³¹ Ibid., 90

³² Ibid., 95

and conflict arise.

Assertion, as the second stage of the theological reflection method, helps put together the findings from the three sources of information gathered in the first stage. The data from the interviews, which reflects what the patients are facing as they are in the waiting experience, engages in dialogue with the development of the Christian theology of hope, derived mainly from Catholic and liberation theology perspectives. The discussion is complemented by the contribution and influence from the cultural information including a postmodern view of death. Cultural information provides an understanding of dying, death and life after death by the modern world and by medical discourse. Sociology contributes to the discussion of cultural information by examining the values and assumptions that belong to the Hispanic culture. This second stage helps to evaluate how the development or understanding of the future stories of hope communicate with the present in people's lives and how it influences the way Hispanic hospice patients understand their dying process. In this project, the step of assertion develops in chapters III, IV, and V and includes significant attention to the stories and narratives of the people whom I interviewed.

3. Decision

The third stage in the method outlined by the Whiteheads is that of making a decision about something, or engaging in an appropriate pastoral response to something. As the three sources of information interact with each other in dialogue, they give rise to new insights. For the Whiteheads, "the challenge of the third stage of the method is to translate the insight into

action.”³³ The question to be answered in this stage is how does the insight we have gained from consulting the three sources of information lead to action? Thus, the purpose of this theological method is to engage in a process of reflection prior to any intervention. The new insights from the stages of attending and asserting are transformed in the concluding chapter into reflections on helpful practices for pastoral caregivers in the context of hospice with Hispanic patients as a way of providing meaningful support for patients and their families.

During this third stage, I integrate the previous stages and determine some of the ways in which patients understand or construct the future-story-of-hope, paying attention to the influences of their future stories on the waiting experience. From there I formulate appropriate interventions which allow patients to have greater choice and use of their agency in discerning how they want to die and the story they want to construct or maintain in that waiting period. As the project unfolds, it will become evident that good pastoral care for some distressed patients and for those patients encountering the waiting experience includes the opportunity to reconstruct a meaningful story of hope. In the same way, I want to offer to them the option of constructing open-ended futures filled with possibilities, moving away from despair and hopelessness in the present moment.

One of the goals of any pastoral care provider is to nurture hope in times of despair. This project contributes to pastoral care by providing an understanding of how the meaning attached to the future story of hope influences the waiting experience from a Hispanic perspective. As I am finding out how these two areas are interconnected, I am helping myself as a hospice chaplain and other professional caregivers to provide support that is meaningful for Hispanic patients. If the meaning attached to the story of hope is affecting the waiting experience in a way

³³ Ibid., 24

that patients face some undesirable distress, then professional caregivers have another option to intervene by supporting them in the process of “re-arranging their perceptions” about the story of the future they envision. The conclusion of the project in chapter VI offers some new possibilities for pastoral care.

B. Sources for the Pastoral Theological Method

Before moving into the stories of the patients themselves, it is important in the attending stage of the pastoral theological method to gather information from each of the sources proposed by the Whiteheads: tradition, experience, and cultural information. As we turn to tradition, the development of the concept of hope from a Roman Catholic tradition is helpful in reflecting on pastoral responses to Hispanic patients in Hospice. In this chapter I continue with the second source as I gather resources on human experience originated from my own observations of several years working in hospice, gathering the patients experience through an interview process, and inviting other pastoral theologians and caregivers to share their own experience on issues related to hope. The last section of this chapter deals with the third source, cultural information. In this section I discuss the limitations of the use of the traditional understanding of death and continue to develop the concept of the waiting experience in a postmodern world. This section also contains an examination of the view of death from a Hispanic perspective and describes how the Roman Catholic tradition, as a cultural system, has influenced the understanding of death for this particular ethnic group.

1. Catholic Tradition on Hope

The first stage of the pastoral theological method, attending, invites me to explore tradition as a first source of information. Christian tradition is understood by Whitehead as the revelation from both the Old and New Testaments, but it also includes the history of the church, teachings, and decisions of the church that date across two millennia. More specifically, I am interested in what the tradition says about hope since it represents part of the central experience of Hispanic hospice patients. Since all the participants in this study are Roman Catholic, I reflect on a specific Christian perspective of hope within the Roman Catholic tradition. Within this Catholic perspective, I am also making use of a theology that reflects on the conceptualization of salvation, suffering, oppression, and poverty since some of the participant patients experienced these in their own cultural environments as members of a third world country. For this reason, the Magisterial teaching of the Catholic Church and the perspective of liberation theology, particularly as it focuses on keeping hope alive in the midst of suffering, are beneficial to accomplish my goal in this project as I engage in the first stage of the process, attending.

According to the Roman Catholic tradition, from the time of St. Paul, “hope has traditionally been understood together with faith and love as the modalities which describe Christian existence.”³⁴ Hope, faith, and love are referred to as theological virtues because the object of these virtues is the divine Being. The divine Being enters our souls as permanent habitants or dispositions. These theological virtues are not acquired by repetition of an act; God pours them directly into our souls. Faith and hope are viewed, by some contemporary theologians, with equivalent meaning to describe the Christian life. Christian life has been seen

³⁴“Hope” *Collegeville Catholic Reference Library*. CD-ROM, version 2.0. Collegeville, Minnesota: The Liturgical Press

as *status viatoris* or “Being on the way,” and hope has been placed as the virtue that human beings need in the journey of life to face the difficulties of the present, keeping in mind an eschatological perspective. This acceptance of the arduous present and the anticipation of a better future require a patient's expectation and confidence in a God who will provide for them what they need to reach the desired point of arrival which is eternal happiness.

Pope Benedict XVI with the purpose of defending love, hope and faith from the challenges in the modern world, has written two encyclicals. The title of the first one is *God is Love*, and the second one continues a line of thought he began in the previous one as he focuses on *Saved by Hope*. The Holy Father teaches that love and hope are closely related in the journey of the spiritual life because according to him, love of God involves hope or trust in God. Pope Benedict XVI makes reference to the words of Saint Paul (Rm. 8:24 New American Standard): “In hope we are saved” affirming that “salvation has been offered to us in the sense that we have been given hope, trustworthy hope, by virtue of which we can face our present.”³⁵ The Pope, following different passages in the New Testament, links hope and faith and makes the assertion that as human beings, we are on a journey toward a goal. This journey is sometimes arduous, but hope is the ingredient that helps us to live and accept that reality.

For Josef Pieper, a German Catholic philosopher who wrote about these three theological virtues, theology has borrowed the *status viatoris*³⁶ from one of Paul's epistles, Phil. 3:13, “brothers, I for my part do not consider myself to have taken possession. Just one thing: forgetting what lies behind but straining forward to what lies ahead.” According to Pieper,

³⁵ Benedict XVI, *Encyclical Letter Saved in Hope* (San Francisco: Libreria Editrice Vaticana, 2008), 7

³⁶ Josef Pieper, *Faith, Hope, Love*, (San Francisco: Ignatius Press, 1984), 92

“Christ is the actual foundation of hope and the actual fulfillment of our hope.”³⁷ It is the foundation because Christ has entered as a human being into our own internal frail reality and has made it firm and strong. It is the fulfillment of the promise because when we say in hope we are saved, we mean that by believing in Jesus, we are saved even though we do not see the fulfillment of the entire promise in this life but we have the assurance of salvation.

Segundo Galilea, writes about the spiritual journey of hope from the perspective of liberation theology. For Galilea the realization of our hope reaches its best intensity here on earth through prayer and he describes hope as “the security to obtain, possess, and enjoy what we cannot see.”³⁸ He makes a distinction between historical hope and theological hope. Historical hope is the one that can be projected into the future based on what we can see, but theological hope requires faith to believe with a strong conviction that the promises that God has made will be fulfilled. However, those promises which we do not see in the present have already begun to be a reality because of the Spirit living within us. Therefore, “God is not only the future of humankind, but also the substance of its present. The saving love of God does not only welcome us into eternal life; this love is poured out each day over us, although veiled in faith, which leaves room for hope.”³⁹ Hope from the perspective of liberation theology includes the promise of God for a better future, but also the opportunity for a better present. God is already within us to guide us into the future but also to sustain us in the difficult present so we can choose to live a different life now.

Pope Benedict XVI affirms that “the present, even if it is arduous can be lived and

³⁷ Ibid., 106

³⁸ Segundo Galilea, *Spirituality of Hope* (Maryknoll: Orbis Books, 1988), 4

³⁹ Ibid., 8

accepted if it leads towards a goal.”⁴⁰ Pain and suffering are part of life, but life is a journey toward new possibilities which can bring salvation, freedom, and happiness. Thus, hope is based on the dialectic interpretation of the Cross and Resurrection of Jesus. Jurgen Moltmann, a Christian Theologian, corroborated his ideas with other theologians to reach a greater understanding of the Christian theology of hope from the perspective of the cross. For Moltmann, “Christian hope is not founded on the isolated event of Jesus’ Resurrection; Cross and Resurrection therefore inseparably belong together and interpret each other.”⁴¹ The contradiction between the Cross and Resurrection is the same contradiction of the human life and the life that God promises to make. The cross and resurrection indicate a meaningful connection between suffering and hope. On the cross God showed us how He is open to suffering and love.

Moltmann's theology is also considered as a theology of liberation, though not in the sense that the term is most understood (focused on the preferential option for the poor). Moltmann not only views salvation as Christ's preferential option for the poor, but also as offering the hope of reconciliation to the oppressors of the poor. If it were not as such, divine reconciliation would not be sufficient. For Moltmann God is not disconnected from the cosmos because:

God suffers, God allowed himself to be crucified and is crucified, and in this consummates his unconditional love that is full of hope. Christian hope knows that all suffering is in God, and in his faithfulness in suffering he proves that he is not apathetic deity, detached and unmoved. He is the suffering God, the crucified God. God is not only distantly future, he is present in suffering.⁴²

In the midst of our suffering we can anticipate a future filled with possibilities because God

⁴⁰ Benedict XVI, 7

⁴¹ Ryan A. Neal, *Theology as Hope: on the Ground and Implications of Jurgen Moltmann’s Doctrine of Hope* (Eugene: Pickwick Publications, 2008) 43

⁴² *Ibid.*, 61

promises new life. Our human hope can describe a future anticipation based on our understanding of a God who is reliable and faithful and who calls us into a better life in the future. If the present tense is filled with pain and uncertainties, we must remember that in the Suffering God, our suffering realizes the resurrection so we can live on this slippery earth with an attitude that is open to new horizons of hope.

Hope, from the perspective of the tradition presented in this project, can be understood as the assurance of the love and presence of God in this world inviting us to experience a better future that we do not yet possess but can be achieved. We have the potential to start the construction of that anticipated future even in the midst of uncertainties and struggles because we have a God who knows how difficult life can be. We have a God that is available to give us courage and strength for the journey. Thus, God is in the future while also in the present. God offers a new life but also the opportunity to live a hopeful life now. This understanding of hope assists in the exploration of how the concept of hope located in the future influences the experiences of hospice patients as they move through a journey of pain and suffering, but also a journey of hope.

2. Human Experience:

Individual and Communal Awareness of a Pastoral Concern

The second source for the pastoral theological method is experience and it refers to the minister's and the community's awareness of a specific pastoral concern. Experience can overlap with cultural information and Christian tradition. The Whiteheads understand experience to be "the set of ideas, feelings, biases and insights which a particular minister and community bring to

a pastoral reflection.”⁴³ This set of ideas includes religious traditions and cultural participation as it is available within the individual minister and within that specific community. This is the unique participation and understanding through the filter of the individual or community as the information is presented, received, and assimilated. Experience includes my own observations about the waiting experience of some patients and connection with the story of hope, the experience of the patients captured in the interviews, and the experience of others who have identified a similar concern and have started a reflection process.

The starting point of this project comes from my participation in the context of hospice care as an individual and as a member of an interdisciplinary team. During my work with hospice, the interdisciplinary team identified a ministerial concern related to the waiting experience for the Hispanic patients in the area of Fort Worth. Hospice caregivers wanted to be able to have conversations with Hispanic patients about end-of-life so they could address the issues of advance directives and funeral planning, but some patients refused to engage in these conversations, preferring to have conversations about hope. The problem emerged for both, hospice caregivers and for some patients. Hospice caregivers wanted to do their job by helping them to prepare for the anticipated death but for some patients and families having these conversations in a direct way meant a lack of respect and sensitivity.

My own experience in a hospice setting includes the observation that patients and families are confronted on a daily basis with challenges that become a threat for their anticipated death. For those with beliefs in the afterlife, it is comforting to know that there is a place waiting after death where all human suffering will be driven out. It is my belief that human beings are not just spiritual, but earthly material; therefore, there is a part of us that clings to the earth and

⁴³ Whitehead, 52

wants to remain in the place which is familiar to us and in the presence of our loved ones.

The dying process can create different reactions and experiences in the present. It might create fear of the unknown and resistance to isolation. The way in which we see our future might be the way we deal in the present with our crises. Theologian and pastoral caregiver, Andrew Lester, postulates that “human brokenness always has a future component; we must find ways to investigate issues in a person’s future stories that could serve as clues to understanding the problem.”⁴⁴ Hence, in order to capture the experience of the dying process, this project includes conversations about the experience-future, not only the temporality on this earth, but also the life after death.

How can we put together the past, the present and the future into one story that makes sense and gives meaning to our life? The experience of each individual can be captured and reconstructed in multiple ways, which could include elements that the patient may choose. The experience-past is gone, but this story may have some forgotten meaningful episodes that can be brought to life again. The experience-future does not belong to us yet, but we can work to construct even those moments which we know may not happen because of our temporality on this earth. If the event does not occur, it can remain in our memories. The experience-present is here, but that is where the past and the future can converge to create a different story for patients and families. The present struggle can become the opportunity for families to stay together, recreate stories from the past, and reconfigure the hope for the future through the introduction of new ways of connection.

In order to hear the future stories and their impact on the waiting experience, I interviewed six self-identified Catholic Hispanic patients. The interviews were conducted by

⁴⁴ Andrew D. Lester, *Hope in Pastoral Care and Counseling* (Louisville: Westminster John Knox Press, 1995), 106

drawing upon narrative counseling, which emerged principally from the work of Michael White and David Epston. The use of the narrative approach provided a helpful structure to create a safe, respectful, and nonjudgmental environment for all the patients who were invited to share and elaborate on their own story. “Narrative approaches to counseling invite clients to begin a journey of co-exploration in search of talents and abilities that are hidden or veiled by a life problem. The client is engaged as an active collaborator in the reconstruction of something of substance and value.”⁴⁵ Through the use of the narrative approach, I was able to maintain conversations and to develop meaningful stories with the patients. The conversations were organized through the following interview process with the purpose of exploring the patients’ stories about the dying experience.

a. Interview Process: Gathering of Patients’ Experiences

The experience of the participant patients is part of the second source of information. The qualitative research instrument for this study incorporated a series of open-ended questions with the goal of gathering the specific experience of six patients. The questions were divided into reflections on four aspects of their experience: waiting experience, stories of hope, belief systems, and some deconstruction questions with the purpose to explore stories past, present, and future. The general scope of the question can be found in the Appendix. The questions were answered in one session but some of the patients requested to have a second intervention. Interviews were transcribed from the audiotapes and summarized prior to data analysis. Building on qualitative processes, I looked for experiences of anticipatory grief and ways patients

⁴⁵ Gerald Monk, John Winslade, Kathie Crocket, and David Epston, *Narrative Therapy in Practice: The Archeology of Hope*, (San Francisco: Jossey-Bass, 1997), 3

construct the narratives of future-oriented stories of hope. The interviews allowed me to gather patients' stories concerning the meaningful elements of the study.

The research population comprised Mexican, Mexican-American, and patients from Central America living in the area of Fort Worth. The criteria for inclusion required that patients be Hispanic, fully alert, bilingual, and Roman Catholic. The decision to target only Hispanic Catholics (mainly from Mexico) for this study was based not only on the fact that they are the largest Latino population in the United States, but also because most of the Hispanic patients admitted into hospice services in the Fort Worth area are from Mexico. The participants of this research include three Mexicans, two from Central America, and one Mexican American.

During the interview process it was difficult to maintain the role as the researcher, especially when patients were sharing sensitive issues in which strong emotions emerged. The first reaction I faced in situations like that was to provide emotional support, comfort to the patient, and fix the problem. I wanted to focus immediately in the emotional state and move away from story development; however, I had to keep in mind that I was there not as a chaplain for these patients, but as a researcher temporarily setting aside the role of comforter as their chaplain or social worker. My goal during these interviews was not to fix any identified problem or to provide emotional and spiritual support, but to obtain data. Most of the interviews were done in private with the patient alone, but two of the patients requested to have their families with them during the interview. At first I was hesitant, thinking that their responses would be influenced by the presence of their family, but this was not the case. At the end of the interview these two patients and their families had journeyed together on a road that they had never shared before. Sharing those powerful stories of pain, suffering, and hope helped them to build a meaningful relationship and to have a more genuine communication with each other, as they

expressed in conversations after the interview. The interviews demonstrated that healing takes place through connectedness.

In all six interviews, patients were glad to participate in this research and to be part of a legacy for other patients and for their families. Patients answered freely some of the questions without any hesitancy or resistance, but they struggled with others not knowing what to say or had difficulty accessing certain pieces of experience. These interviews show that some Hispanic hospice patients indeed have a need to talk about death and dying. Asking questions through the narrative approach was an effective way to accomplish this goal because this approach includes the framework of co-exploring their personal story within the cultural context alongside the development of multiple stories that are meaningful to them. The summary of the interviews for each one of the participant patients will be presented in the following chapters as I engage the second stage of the method, assertion.

b. Communal Awareness of the Waiting Experience and Hope

All patients, whether they express a relationship with God or not, face a waiting experience from the moment they hear the “bad news” of their terminal diagnosis to the end of their lives or the experience of death. In a postmodern approach, the waiting experience is explored from diverse perspectives creating different meanings for each individual. This is one of the reasons why I decided to move away from the language of the anticipatory grief process, as a medical term, and use the waiting experience instead. The waiting experience is part of the journey of life; this journey has a starting point in the past and includes an arrival point that exists in our imagination in the future dimension. Although the entire journey of life could be

interpreted as the waiting experience arguing that human beings live in the present interpreting the past and waiting for the not-yet, in this project I am referring to the waiting experience as the final phase of the earthly life. This phase starts when the patients hear the bad news about their terminal condition and it continues toward the experience of death.

This project has the goal of demonstrating how the waiting experience in the present is influenced by the way each one of the patients construct the narratives of future-oriented-stories-of-hope. The past, present, and future merge together in the creation of meaning in the dying process. The way these patients chose to answer the questions related to the waiting experience and how they have been affected by their terminal illness, was through the story of hope. Hope is a significant aspect for these patients in the waiting experiences confirming what some contemporary researchers have said in their pastoral experience about the role of hope as a functional aspect of survival for the human experience.

Hope is a fundamental aspect of the human experience in general. To hope is to anticipate a desired outcome in light of a complex and complicated experience. The subject of hope has been present as a basic tenet of the Christian faith since the origins of Christianity. As such, hope has been discussed from both theological and psychological perspectives. Academicians and clinicians such as psychologists and psychiatrists have examined hope from a psychological perspective, attempting to answer questions related to the role of hope in human cognition, development and experience. These different perspectives postulate that hope is a functional aspect of human experience. Pastoral theologians examine hope in the context of one's relationship with the transcendent God. From this perspective theologians are answering questions related to meaning and purpose of life in relationship with God who offers to be a companion in the human journey with the promise of a redemptive future. Professionals, such as

pastors and chaplains, have examined hope from yet another perspective as they are uniquely positioned to examine the intersection of the meaning of hope with the experience of hope.

Academicians, theologians and professionals have, to a lesser extent, offered some reflections of the experience of hope taking in consideration the cultural differences. To look at any aspect of faith without locating it within an ethnic perspective leaves the possibility of offering answers to questions that apply to the dominant majority. Minorities often experience faith and hope differently from the dominant majority. This is the case for Hispanic patients and the purpose of this project is to find out how hope is experienced by them during the dying process. Including an examination of this experience is imperative to thoroughly answering any question about faith. This project suggests that ethnicity and faith tradition particularly make a difference in the waiting experience, which includes the construction of the experience of the stories of hope.

Several clinical studies have been conducted and books written involving the concept of hope and the way people cope within the reality of their illnesses. Hope has been identified as a vital ingredient for enhancing quality of life, for providing energy to accomplish goals, and for encouraging health, coping, and healing.

In 1994 C. R. Snyder published his work on psychology of hope and proposed a model of hope that involves the perception of how our goals are accomplished. Snyder's understanding of hope is based on how we think about reaching those goals. The concept of hope that he presents is "the sum of the mental willpower and waypower that you have for your goals."⁴⁶ Willpower is the mental energy that we need to move from point A to point B. Waypower is the mental plan which guides the person to reach their goals. From this perspective, human beings are on a

⁴⁶ C. R. Snyder, *The Psychology of Hope: You Can Get There From Here* (New York: The Free Press, 1994) ,5

journey toward a destination. To understand hope from Snyder's perspective means to have "willpower" and "waypower" so we can achieve our goals. Hope is the energy that allows human beings not just to survive during the waiting experience but also provides the sustenance to continue in their journey and arrive to the anticipated destination. Hope is part of the human experience and provides sustenance to move into the future dimension of time consciousness.

A theological perspective on hope is fundamental for both the pastoral care provider and for the dying patient. Hope from this perspective can provide an understanding of life, death, and everlasting life. Some books, articles, and studies have been written from a pastoral theological perspective with the purpose of illustrating how hope produces power to provide meaning to our suffering in this life and in life after death. Even though hope has been seen from different points of view, there has not been enough said to describe how fundamental hope is for human beings, especially by pastoral theologians and counselors. According to Robert L. Carrigan there is a "lack of conceptual model or psychology of hope for pastoral theology."⁴⁷ Carrigan argues that although hope has been present since the first Christian communities in which St. Paul interjected hope, love and faith as the pinnacle of all human expectations, hope has not received the necessary attention by pastoral theology. Carrigan questions the lack of attention and wonders why such an important subject in the human existence has been neglected. This project is an attempt to address Carrigan's concern in pastoral theology.

Carrigan, a professor of pastoral care, has conducted research as a pastoral theologian and acknowledges the importance of hope for the survival of human beings, agreeing with the

⁴⁷ Robert L. Carrigan, "Where has Hope Gone? Toward an Understanding of Hope in Pastoral Care." *Pastoral Psychology* 25, no. 1 (September 1976). <http://www.springerlink.com/content/q845531543047808/> (accessed May 5, 2010), 1

statement: “without hope there cannot be healing and without hope humans cannot survive.”⁴⁸

Carrigan makes a distinction between a genuine hope, which is based on trust in God’s love, and particular hopes or goals which sometimes becomes just an anxious desire. This distinction will be addressed when I describe the data of three specific patients in chapter 4. For Carrigan hope is “the expectation that the love we have known in Jesus Christ will continue to express itself as the meaning and fulfillment of life. Even though our individual hopes are destroyed, this pervasive hope can never be taken away.”⁴⁹ This attitude of trust in God’s love can give the patients the ability to look beyond their own desires and help them to live with confidence that God will continue to be present in their life even when the desires to be cured do not seem to become a reality.

Prior to Carrigan, a Catholic theologian, Father William Lynch, S. J. worked with various ideas about “hope,” and he also acknowledges that little has been written in this significant area for human beings. According to Fr. Lynch , “hope comes close to being the very heart and center of a human being.”⁵⁰ Fr. Lynch’s work on the topic of hope includes the description of different forms of hope and hopelessness and relates these concepts to the origin of mental illness. For Lynch, hope is the basic understanding that there is a way out of difficulty and that things can work out. This vision of hope will be addressed in chapter 3 with the stories of Raul and Antonia. In Lynch’s words, hope is “a sense of the possible” and involves three ideas: “What I hope for I do not yet have or see; it may be difficult; but I can have it –it is possible.”⁵¹ Lynch’s concept of hope points out the notion of future story which is the main focus on my project.

⁴⁸ Ibid.

⁴⁹ Ibid., 11

⁵⁰ William F. Lynch, S. J., *Images of Hope* (Notre Dame: University of Notre Dame Press, 1974), 31

⁵¹ Ibid., 32

Donald Capps, professor of pastoral theology, makes an effort to explore “the role that pastors play as the agents of hope.”⁵² He reflects on the nature of hope and how it influences our daily lives. Capps also acknowledges that theologians have not done enough reflection about hope, and he presents the matter of hope from the perspective of a Christian understanding of the self. Capps is convinced that future visioning and revising the past are essential activities to maintain hope. For Capps, human hope originates in life through relationships and experiences as we are growing up. This understanding of hope will be also addressed in chapter III when I present the data for Raul and Antonia. Some of the participant patients will agree with Capps’ argument as they describe how they were able to construct their concept of hope. Trust, patience and modesty are the “life-attitudes” necessary for the development of hope. The concept of hope for Capps includes having the “assurance that all will be well, that when others sink they will feel the solid ground beneath them, and that when their lives have fallen apart, the Christ is even then at work to make them whole.”⁵³ The work of Capps has been influenced by the writings of William Lynch and Jurgen Moltmann, a renowned Protestant theologian.

Moltmann's theology of hope is a perspective with an eschatological foundation and focuses on the hope that the resurrection brings. As such, Moltmann proposes that through faith we are bound to Christ, and therefore have the hope of the resurrected Christ. For Moltmann, there is an inseparable link between faith and hope. “Hope is nothing else than the expectation of those things which faith has believed to have been truly promised by God.”⁵⁴ Human beings did not receive the promise of everlasting life here on earth but a life of participation of God’s

⁵² Donald Capps, *Hope: A Pastoral Psychology*, (Minneapolis: Fortress Press, 1997), 1

⁵³ *Ibid.*, 4

⁵⁴ Jurgen Moltmann, *Theology of Hope: On the Ground and the Implications of a Christian Eschatology* (Minneapolis: Fortress Press, 1993), 20

eternal life in heaven. This understanding of hope illustrates the importance of maintaining conversations about the content of the promise attending particular attention to the way each one of the patients is anticipating the fulfillment of the promise and the construction of the sacred story which will be included in chapter 3.

Lester reaffirms that hope has been somehow neglected. Lester also makes an effort to answer the questions formulated by Carrigan--“why is it that those of us in pastoral theology are not dealing with so important a topic”⁵⁵--by saying that the failure is because pastoral theology has not developed a “theological anthropology or understanding of the human condition that provides an adequate frame of reference for addressing the subject of hope.”⁵⁶ For Lester, hope is the “configuration of cognitive and affective responses to life that believes the future is filled with possibilities and offers a blessing.”⁵⁷ This research will show how for some patients the stories of hope are stories filled with life and possibilities helping them to live in freedom in the present tense.

Howard Stone and Andrew Lester wrote an article based on previous works that both have utilized before. They continue to support the importance of hope and how pastoral caregivers need to offer specific care and counseling methods that will reassure hope in people who are facing struggle; this reassurance of hope can be applied in patients who are facing the waiting experience. They place hope in the future dimension arguing that “only the future holds promise, the hope of something better, a chance to grow.”⁵⁸ Attending to this recommendation of

⁵⁵ Lester, 3

⁵⁶ Ibid.

⁵⁷ Ibid., 62

⁵⁸ Howard Stone and Andrew Lester, “Hope and Possibility: Envisioning the Future in Pastoral Conversation” *The Journal of Pastoral Care*, 55, no. 3 (Fall 2001), 259

the importance of hope in the future dimension, this project has the intention of contributing to the practices of pastoral care by providing a conceptual framework that can be useful for chaplains when dealing with Hispanic hospice patients.

As I continue to explore the concept of hope, it is clear that this concept was significant for these participant patients. Hope has been linked with the concept of faith and it has been placed within the eschatological dimension of Christian hope. This understanding of hope enables the individual to find meaning and strength to deal with difficulties in the present time or waiting experience, with the belief that the promise of a better future can be fulfilled. When the patients are able to achieve this connection between present and future they create their sacred story which allows them to confront the reality of death.

During the waiting experience, I related the manner in which some patients experienced despair at the end-of-life, including hopelessness, depression, loss of meaning, suicidal ideation, and desire for a hastened death. Lester affirms that “when people are wounded, and in need of healing, confused and in need of guidance, overwhelmed and in need of sustaining, alienated and in need of reconciliation, or trapped and in need of liberation, it should be obvious that hope and despair are major psychological and theological dynamics.”⁵⁹ For Lester, when patients are suffering, they may be worried more about the future rather than the past or present. Exploring the future, where hope is located, can be a helpful tool to identify the nature of the current suffering. “Hope or its absence in despair is the basic psycho-spiritual dynamic with which the pastoral caregiver must contend, particularly when attending to a crisis.”⁶⁰ For the purpose of this research, the focus of the interview is on narratives of future-oriented-stories-of-hope. Each one

⁵⁹ Lester., 1

⁶⁰ Ibid.

of the six patients have the opportunity to share their own construction of this concept of hope in a profound way which allows them to include the stories of their own death and life after death.

3. Cultural Information

The third source for the pastoral theological method of Whitehead and Whitehead is to draw upon cultural information. For the Whiteheads, “cultural information includes both historical and contemporary aspects of a culture, aspects which influence Christian self-understanding.”⁶¹ Those aspects include the philosophical, political, sociological, and religious systems or traditions which have influenced, both negatively and positively, the thought, doctrine, and teaching of the Christian perspective and human life. In this project, I take into consideration the developments regarding the concepts of death and grief starting from a modern perspective and continuing into a postmodern understanding of death, while I also continue to explore the influence in the discourse of death by the Roman Catholic tradition as a cultural system.

A postmodern view of dying, death, and grief requires a different understanding that embraces the unique experience of each individual and moves away from the development of a global grief theory that can be applied to everyone. This approach is based on the premise that every culture has its own values, beliefs and understandings. Furthermore, there are not only differences between cultures but also differences between individuals within the same culture. These individuals may have different interpretations of the meaning of their cultural environment. In the case of Latinos/as, these interpretations may have been influenced by factors

⁶¹ Whitehead, 20

like country or origin, region within the same country, or the contact with other different cultures. All these elements combined with some socio-cultural dynamics from a specific region such as values, attitudes, norms, and beliefs may contribute to the way each individual understands his/her own story and attach meaning to that story. The traditional modern language of “anticipatory grief” provides an entry into thinking about the concepts of death in our culture using the conventional-medical discourse of dying and death. At the same time the next section provides more reasons why I prefer to change the language from anticipatory grief to waiting experience.

a. Anticipatory Grief in a Modern Context

The term “Modernism” represents the dominant ways of thinking originated a few centuries ago. This period is characterized by the dominance of scientific ways of thought and intellectual perspectives. Modernism has influenced theories and practices in medicine which in turn have an impact on cultural understandings of dying and death. Modern perspectives of death have been constructed as a medical event where biological existence takes over the spiritual dimension of human existence. The modernist approach to life emphasizes goal directedness, efficiency, and rationality. In psychology, modernism created the metaphor of human functionality as a machine. When applied to grief, this view suggests that “people need to recover from their state of intense emotionality and return to normal functioning and effectiveness as quickly and efficiently as possible.”⁶² To accomplish this goal, modern theories

⁶²Margaret Stroeber, Mary Gergen, Kenneth Gergen, and Wolfgang Stroebe, “Broken Hearts or broken Bonds?” in *Continuing Bonds*, ed. Dennis Klass, Phyllis R. Silverman, and Steven L. Nickman (Washington: Taylor and Francis, 1996), 32

of grief suggest that there are certain steps and actions that the individual will need to follow. The process of grief, as a result, assumes a linear movement which contains stages or tasks toward a final stage where the individual will accept the loss of the loved one and move on with the normal life, forgetting about the meaningful relationship with the deceased.

Death is often seen by Western modern cultures as a powerful episode where human beings have no control. Grief, in the same way, is seen as a painful process with not many options for healing. As professors and researchers on death, Dennis Klass and Phyllis Silverman suggest, “the view of grief most accepted in this century holds that for successful mourning to take place the mourner must disengage from the deceased and let go of the past.”⁶³ Modern grief psychology has suggested that prior to death, the patients and their families should engage in a process that will prepare them to face the “end.” This process, known as “anticipatory grief,” was used for the first time in 1944 according to William Worden who argues, “the term anticipatory grief was coined by Lindeman in 1944 to refer to the absence of overt manifestation of grief at the actual time of death in survivors who had already experienced the phases of normal grief and who had freed themselves from their emotional ties with the deceased.”⁶⁴ This concept is generally accepted and along with it, the assumption that there is a pre-death condition or process for the dying patient and the family anticipating the experience of separation.

During this process professional caregivers facilitate practices using the language that marks death as the end of existence. These practices encourage individuals to get ready to face the death-event which will occur in the future. There are some metaphors that provide the

⁶³ Phyllis R. Silverman and Dennis Klass, “Introduction: what is the problem?” in *Continuing Bonds*, ed. Dennis Klass, Phyllis R. Silverman, and Steven L. Nickman (Washington: Taylor and Francis, 1996), 4

⁶⁴ William Worden, *Grief Counseling and Grief Therapy: A Handbook for the Mental Health Practitioner* (New York: Springer, 1991), 108

structure for the performance of different rituals like “saying good bye” or “completing unfinished business.” When individuals refuse to engage in this process or practice, they are diagnosed as “in denial.” On the other hand, when some patients express their anticipatory grief with practices beyond what is categorized by the medical discourse as “normal grief,” then professional caregivers label those patients as suffering “complicated grief.”

One of the tasks that hospice professionals focus on is to manage all the symptoms that patients and families experience. One of those symptoms is anticipatory grief which is measured based on how the staff perceives that the patient and the family are reacting. When the patients are admitted into hospice services there is a component for education directed to the entire family. At Vitas Hospice, we have a two-page flyer explaining anticipatory grief. This handout includes information regarding grief with the purpose to make the family aware of what they can expect. This flyer gives expert advice of what grief is with the purpose to help the family to be watchful in case they experience any of those symptoms. Anticipatory grief is an accepted term which alerts hospice professionals of the existence of any risk-condition about what is about to come in the near future. The intention of this intervention is to provide education for the patients and families about what they may expect but also this practice is to set the guidelines of what “appropriate grief” is supposed to be before and after death.

As mentioned in previous chapters, for many years the concepts of death and grief have been dominated by modernist discourse. Many of these medical perspectives reduce the death-event to a mere biological existence. Under this perspective, patients and their families follow a conventional pattern of the meaning of grieving: facing the reality of death, accepting it and letting go of the relationship with the deceased. This modern discourse suggests that death is not only the end-of-life but also the end-of-relationships. However, in terms of death and grieving,

there is not one theory about death and grieving that applies to everyone. As a Professor of Family Social Services, Paul Rosenblatt suggests:

New anthropological studies of dying, death and grief suggest that there is no one grief theory or one psychology of ego defenses that applies to everyone. Majority-culture American social scientists and human service practitioners may have been unintentionally ethnocentric on ways that have made it difficult to understand and deal with realities of people from other cultures.⁶⁵

Therefore, if all cultures and even individuals from the same culture may grieve differently, the concept of “normal grief” may not exist just because each individual has a different view and understanding of the meaning of dying and death. “Regardless of the particular way that a culture chooses to answer the questions of death, the questions seem to be pretty much the same: What is the meaning of death of human existence? Why do we die when we do, and what happens to us after we die? Is there a life after death, and if so, what is its nature?”⁶⁶ All these questions have been present through history and have been answered from different perspectives.

For the nature of my research I focus on a post-modern view of grief which recognizes not only the loss but also the continuing bond of life after death and which promotes culturally embedded practices. This project takes seriously the role of cultural context in examining grief and loss from a post-modern perspective considering that the grieving experience is unique for each individual. For these reasons, I avoid the use of the concept of anticipatory grief and I build this research through the development of the “waiting experience” concept.

⁶⁵ Paul C. Rosenblatt, “Cross-Cultural Variation in the Experience, Expression, and Understanding of Grief,” in *Ethic Variations in dying, Death, and Grief*, ed. Donald P. Irish, Ketheen F. Lundquist, Vivian Jenkins Nelsen (Philadelphia: Taylor and Francis, 1993), 13

⁶⁶ Elisabeth Kubler-Ross, *Death: The Final Stage of Growth*, (Englewood Cliffs: Prentice-Hall, 1975) , 31

b. Waiting Experience in a Post-Modern Perspective

Individuals respond to dying, death and grief according to what they have learned at home and within their own culture. For Elisabeth Kubler-Ross, “The problem of death is a universal question. But the answer to that question differs among cultures.”⁶⁷ In the same line, Therese Rando affirms that “any work with people in the areas of loss and death must take into account their social, cultural, religious/philosophical, and ethnic backgrounds.”⁶⁸ Every culture has different concepts that create meaning for their waiting experience or for the dying process and what happens after death. The idea that all cultures should merge into a new one in which the main ingredients will be taken from the dominant culture is not very helpful in a postmodern world. Some people make the choice to become bi-cultural, others become multicultural, but others prefer to maintain their own culture. There is no melting pot anymore where we put all the elements together and become one culture. Each culture deserves to retain its uniqueness and to be respected by the others. Usually, a dominant culture has the tendency to interpret or translate, into its own perspective, the manner in which other cultures or ethnic groups perceive reality, in this case, dying and death.

A postmodern perspective provides a different way of understanding the waiting experience that the patients and their families face at the end-of-life. Two family therapists and researchers in postmodern theory, Jill Freeman and Gene Combs, provide a helpful explanation of the difference between modernist and postmodernist perspectives, “while modernist thinkers

⁶⁷ Ibid., 27

⁶⁸ Therese A. Rando, *Grief, dying, and Death: Clinical Interventions for Caregivers*. (Champaign :Research Press, 1984), 5

tend to be concerned with facts and rules, postmodernists are concerned with meaning.”⁶⁹ From a modern perspective, the meaning of grief is to be reconstructed based to the concepts already established as a norm by dominant discourse. From a postmodern perspective, there is no norm to be followed, the meaning is constructed from a personal experience and can be reinterpreted from different angles providing for the individual empowerment and authorship about his or her own story.

To have a postmodern perspective means to adopt a personal understanding of reality, as Freedman and Combs suggest: “realities are socially constructed, they are constructed through language, organized and maintained through narrative; therefore, there are no essential truths.”⁷⁰ Considering these suggestions we can argue that there are many options for how any given experience can be understood or interpreted. This approach not only provides the opportunity to focus on the loss and pain, but also gives the freedom to explore the meaning attached to the dying process in order to create different possibilities of experience and knowledge. Pastoral caregivers, instead of providing guidance and teaching in the grieving process, facilitate the co-exploration of this particular experience through guided questions that facilitate the telling of the story. Each individual constructs his or her own story and the story can be developed from different perspectives creating multiple stories. It is important to facilitate these conversations with the dying patients because as Hedtke and Winslade propose, “the way we construct death and grief in our talk makes a big difference to how we experience it.”⁷¹

A postmodern approach includes practices which give agency to the person to re-connect,

⁶⁹ Jill Freedman and Gene Combs, *Narrative Therapy: The Social Construction or Preferred Realities* (New York: Norton & company, 1996), 22

⁷⁰ Ibid.

⁷¹ Lorraine Hedtke and John Winslade. *Remembering Lives: Conversations with the Dying and Bereaved*. (Amityville, New York: Baywood Publishing Company, 2004), 39

re-frame or create new knowledge using their own resources as the starting point. This is done in order to find meaning in moments when their belief system is not enough to provide meaningful answers to the existential questions. These conversations can be accomplished through the use of narrative metaphors. Hedtke and Winslade argue, “If we are shaped by stories as much as by realities, then it is also possible for us to shape our experience differently through telling the story differently.”⁷² So, if as narrative theorists suggest we acknowledge that we have options in the way we want to tell our story, the meaning of dying and death can be seen and experienced from different perspectives. We not only have options to re-interpret the meaning of dying and death, but we also have flexibility in how we want to face the waiting experience.

Taking into account that “professional conversations with the dying and bereaved are going to concentrate on the relationship between personal experience and the narratives that are informing that experience,”⁷³ the patients and their families will benefit by sharing those personal narratives that are most useful and meaningful to them. These conversations help them to confront the reality of death and to explore their understanding of what happens after death; by doing so, they can choose how they want to be remembered and how they want to maintain a relationship with those they love even after death.

It is when relationships are allowed to continue even after death that human beings are seen as more than physical bodies. The spiritual dimension is emphasized and used to maintain transcendent relationships that surpass the reality of death. This dimension sometimes is forgotten when we use discourses that see death as our enemy that destroys the human existence. However, because we have a spiritual dimension, death has the power to destroy our physical

⁷² Ibid., 41

⁷³ Ibid.

bodies but not to destroy relationships.

For the purpose of this research, I focus on elements from narrative theory that can be applied to the waiting experience. This postmodern approach allows the researcher to maintain conversations exploring the meaning of dying and death from the particular point of view of each individual using the language, discourse, and understanding that each patient prefers. Under this narrative approach, the views of each one of the patients are validated and accepted unconditionally with a nonjudgmental response. The emotions experienced by the patients are welcome but they are not the primary focus as they are considered a reaction based on the discourse. If the discourse can be reframed, the emotions and reactions can be changed as a result of the construction of a different discourse. A narrative approach provides the framework to maintain meaningful conversations with the dying empowering them to exercise their own agency and at the same time helps them to understand that their own experience of grief is not linear and it is not limited to one, but multiple interpretations. A postmodern approach to death and dying also takes into account the cultural context of the patients and the caregivers. In the case of this project, it means attending to the particularities of the Hispanic culture that allows them to construct a unique waiting experience at the end-of-life.

c. Death from a Hispanic Perspective

In this project we are focusing on a culture which I represent in my own life experience. For twenty-eight years I lived in my country of origin Mexico, and my first experience of death occurred when I was 6 years old. This experience took place in a rural context with the loss of my grandmother. The narrative or story that I remember includes not being told what to expect

during the viewing which lasted 24 hours. It was an experience of fear and mystery. The whole community gathered together to support the family. Women cried passionately, praying the rosary several times. Men were standing outside talking to each other and drinking coffee or tea with tequila. No music was allowed to be played within the entire community and women were told to wear something black. The burial took place 24 hours after the death because there was not enough money to pay for the embalming of the body. The smell of the flowers, burning candles, and the body created a unique atmosphere of fear, sadness and discomfort. Grief was not taught, but experienced. That experience sometimes was unprocessed and remained as a shocking revelation creating extreme feelings of fear toward death and to the place where the person expired.

In my experience, faith was very important in the celebration of death. Almost everyone in the community shared the same faith tradition, Roman Catholic. In this tradition we were taught that different rituals were needed in order to assist the deceased person to get into heaven and to provide support for the family. First, prayers needed to be said constantly, asking God for forgiveness for the sins of the deceased. It is a Catholic belief that the person has to go through a process of purification before entering heaven. The period of purification (purgatory) is determined by how the person lived his or her life but there is also a belief that prayers can help the person to get out of purgatory.

Considering the belief of purgatory, the whole community shared the responsibility of offering prayers constantly with the hope of giving the deceased person a better chance to enjoy eternal life. Second, after the burial, a period of intense grief needed to be followed for nine days. During this time family and community gathered together at evening time to pray the rosary with a double intention: to support the family and to ask God for the forgiveness of the

sins of the deceased. The gathering usually took place at the home of the deceased, especially in small towns or rural areas. In the area where the coffin was placed during the viewing, a cross was fashioned with ashes. Third, at the end of the nine days of intense mourning, the cross was picked up and taken to the cemetery to be placed by the grave. During all these rituals, different expressions of grief were also appropriate, such as crying aloud, fainting, holding the coffin, asking to the deceased over and over, “Why did you go? Why did you leave me?” or other expressions of disappointment.

My narrative of death also included fear. On the walls of some homes I remember paintings representing purgatory and hell. Those were intended to be motivations to remind the living that we all needed to live a good life in order to avoid those places of punishment. As a result of all these cultural experiences, I constructed a concept of death as a mysterious, scary, and powerful enemy which we must keep at bay. I learned that it was not good to talk about death because that would imply opening the doors so death could come in.

As a culture, Hispanics maintain a close familiarity with death. Historically, before the Spanish Conquest, the Aztecs practiced ritual human sacrifices:

The Aztecs were a warlike people and they made a ritual out of death. Shedding blood in the act of killing, and then smearing it on the hair and on the faces of the priest who performed these rites, were part of the bizarre aftermath of the wars the Aztecs waged against their neighbors.⁷⁴

Aztecs made a cult of death and believed that a dog would transport the souls of the dead to the afterlife. Aztecs associated the yellow flower (zempasuchitl) with death and used this flower to decorate graves. Death rituals included yellow flowers, the presence of skulls, the exhibition of dead bodies and displays of blood; all these rituals were included in ceremonies of killing thousands of people captive in war.

⁷⁴ Younoszai, 71

When the Spaniards arrived, they brought their own similar rituals. Although the Spaniards were scandalized by those Aztecs rituals, “they regularly paraded statues of Christ thought the streets with blood flowing freely from the torn wounds on his head, the sword thrust into his side, and the nails pounded into his hands and feet upon the cross.”⁷⁵ The idea of martyrdom was present in both cultures; Catholic saints and the martyrdom of victims of the Aztec Wars of the Flowers. The celebration of Day of the Dead “represents a wedding of two historical realities: the pre-Columbian Day of the Dead and All Souls’ Day on the Catholic calendar.”⁷⁶ During this celebration death is represented as a living being, doing everything that the living can do. Also families light a candle during the night and prepare the favorite foods of the deceased. The light of the candle shines to help them find the way home where food is waiting.

It is believed that if the deceased person does not get a candle or food, he or she could be feeling sad as they see that their family does not remember them anymore. Death is seen as a companion and as part of life. These cultural practices and beliefs inform that death and life, from Hispanic perspective, are connected to each other. The belief of the existence of this relationship provides comfort to the living knowing that there is a continuation of life after death and a way of communication between both realities.

Death and bereavement among Hispanics generally follow the pattern of the Catholic rituals in combination with some cultural traditions prior to the Spanish conquests. These combined traditions provide the elements that allow them to maintain a close relationship not only with each other at time of death but also with those who have preceded them into the eternal

⁷⁵ Ibid., 72

⁷⁶ Ibid., 73

life. Before proceeding to explore the waiting experience for each one of the participant patients, it is important to understand how the Roman Catholic tradition, merged with the cultural context, informs the waiting experience of these patients.

d. Influence of the Roman Catholic Tradition in the Understanding of Death

When I was a child, I remember my grandmother praying every night “for a good death.” I could perceive she was afraid of dying or afraid of having a bad death. What does it mean to have a good death? How can we determine what makes a good or bad death? Conversations about death are not usual conversations in which we sit and discuss our different views. This is not even a usual conversation in the Catholic tradition. A Roman Catholic theologian, Henry Nouwen, agrees that “when the church speaks about death, it is often about the hereafter, about heaven or hell, or about everlasting life.”⁷⁷ For Nouwen, conversations regarding death and dying are not part of our Catholic tradition and when the church teaches about these matters, it is done using the language of anticipation where the arrival place becomes the main point. For some Hispanics then, the waiting experience becomes the anticipation of a future beyond death with the possibility of receiving a reward or a punishment.

The Catechism of the Catholic Church regarding death mentions different possibilities of life after death by arguing that there will be a judgment after we die and the place that will be given to us will be a result of that judgment. The Catechism teaches that:

Death puts an end to human life as the time opens to either accepting or rejecting the divine grace manifested in Christ. The New Testament speaks of judgment primarily in

⁷⁷ Henri J. M. Nouwen, *Finding My Way home* (New York: The Crossroad Publishing Company, 2001), 125

its aspect of the final encounter with Christ in his second coming but also repeatedly affirms that each will be rewarded immediately in accordance with his works and faith.⁷⁸

The Catholic Church affirms that there is judgment after death as well as a reward according to how a person has lived their life. The catechism continues explaining that: “Each man receives his eternal retribution in his immortal soul at the very moment of his death, in a particular judgment that refers this life to Christ: either entrance into the blessedness of heaven through purification or immediate and everlasting damnation.”⁷⁹ Based on this teaching, there are three possible places where we can be after death: heaven, purgatory or hell. Those places will be assigned after the judgment depending on the acceptance or rejection of Christ; in other words, the judgment will be based on works and faith.

Taking into consideration this Catholic teaching, can a Catholic Hispanic patient be certain of having a good death if death is linked to the life that he or she has lived? Who can be certain of being admitted directly into heaven if the sinful human condition gets in the way? Following the Catholic teaching, there is a place of purification where the soul can get prepared for the entrance into heaven, “all who died in God’s grace and friendship, but still imperfectly purified, are indeed assured of their eternal salvation, but after death they undergo purification, so as to achieve the holiness necessary to enter the joy of heaven.”⁸⁰ For another Catholic priest, Fr. Cochem, there are three principal reasons why people fear death:

First, because the love of life, the dread of death is inherent in human nature; secondly, because every rational being is well aware that death is bitter and the separation of soul and body cannot take place without inexpressible suffering. Thirdly, because no one knows where he or she will go after death or how he or she will stand in the Day of

⁷⁸ United States Catholic Conference, *Catechism of the Catholic Church* (Vatican: Libreria Editrice Vaticana, 1997), 1021

⁷⁹ *Ibid.*, 1022

⁸⁰ *Ibid.*, 1029

Judgment.⁸¹

How then are we to overcome our fear of death and be assured that we will have a place in heaven? How, as human beings, can we obtain the confidence that our death will give new life, new hope and new faith to the people we love, and not be another cause of pain, suffering, and sadness?

Henry Nouwen offers an answer to those questions. Nouwen did some reflection on what it means to die well as he argues, “I trust that, like everything else I have lived, my attempt to befriend my death will be good not only for me, but also for others who face a similar challenge. I want to die well, but I desire others also to die well.”⁸² For Nouwen dying well means to befriend his own death and prepare himself to live well. The first task, according to him, is to become a child again, “this might seem to be opposite to our natural desire to maintain maximum independence. Nevertheless, becoming a child, entering a second childhood is essential to dying a good death.”⁸³ Being a child again means being dependent again because life is experienced from dependence to dependence.

The view of dependency through life is inspired by a mysterious God able to reveal to us that the life of Jesus was a journey from the manger to the cross. Jesus was born in dependence and died depending on other people’s decisions. Nouwen claims that Jesus “came as a child and died as a child, and he lived his life so that we may claim and reclaim our own childhood and thus make our death –as he did his- into a new birth.”⁸⁴ For Nouwen, experiencing dependence in

⁸¹ Martin Von Cochem, O.S.F.C., *The Four Last Things: Death, Judgment, Hell, and Heaven*. [www..Catholictradition.org/classics/4last-things.htm](http://www.Catholictradition.org/classics/4last-things.htm) (accessed December 2, 2011)

⁸² Henri J. M. Nouwen, *Our Greatest Gift: A Meditation on Dying and Caring* (New York: Harper Collins, 1995) 5

⁸³ *Ibid.*, 14

⁸⁴ *Ibid.*, 15

this life often is interpreted as slavery but “dependence in God leads to freedom”⁸⁵ and this freedom can lead to confidence. Confidence can help us to live well knowing and accepting that God is in charge and God has the power to hold us safely, and whatever happens in our daily life, we have the confidence that God will be there to take care of us.

When we live the waiting experience in fear, we are not free to choose because “fear takes away our freedom.”⁸⁶ However, according to Nouwen, we do not have to live in fear and we can choose to live in freedom “when we can reach beyond our fears to the One who loves us with a love that was there before we were born and will be there after we die, then oppression, persecution, and even death will be unable to take our freedom.”⁸⁷ As human beings, we have the power to choose how we want to live our waiting experience. We can choose to live in fear or in freedom, as Nouwen suggests, “we can choose to claim our divine childhood and trust that death is the painful but blessed passage that will bring us face-to-face with our God.”⁸⁸ This concept brings the joy of knowing that we are loved and we are part of the human family. We are not alone in this world and we will make a passage to the new life united with others.

A good death, according to Nouwen, includes the concept of solidarity with others, being aware that death will reach out to every single human being on earth. When we focus on the power of death to separate us from the people we love, then death can be a sad and painful event. “If we grow in awareness that our mortality, more than anything else, will lead us into solidarity with others, then death can become a celebration of our unity with the human race. Instead of

⁸⁵ Ibid., 16

⁸⁶ Ibid., 17

⁸⁷ Ibid

⁸⁸ Ibid, 18

separating us from others, death can unite us with others; instead of being sorrowful, it can give raise to new joy. Instead of simply ending life, it can begin something new.”⁸⁹ Death is a human event that will contribute to the fullness of life and will ensure the unity of the human race in heaven.

When we develop a sense of solidarity and a sense of belonging to a bigger plan, or part of the whole creation, we can live in the freedom of the children of God, having close to our hearts the One who created us, loved us before we were born and will continue to love us after we die. This belief can help us to understand that this life is “just a little opportunity for us during a few years to say, I love you too.”⁹⁰ We are chosen to live and be part of this creation. We are special because we belong to a sacred family. “The mystery of God’s wonderful love is that you come with it into the world and it blesses you whether you know it or not. Your life is in God’s universal embrace of the whole human family.”⁹¹ God created each one of God’s children and called them to be part of one family and one day the whole family will be reunited but in heaven.

In this chapter I have discussed a movement from anticipatory grief in a modern context to an understanding of grief that respects the personal and the cultural perspective of each individual creating a unique waiting experience. In the case of the Hispanic population, the Roman Catholic tradition is blended with the cultural context creating a unique understanding of the reality which is expressed through diverse rituals. The Roman Catholic tradition provides the theological framework that allows Hispanics to transform the modern understanding of

⁸⁹ Ibid, 27

⁹⁰ Nouwen, *Finding My Way home*, 130

⁹¹ Ibid, 132

anticipatory grief into a waiting experience. In the Spanish language “to wait” (esperar) means “to hope;” therefore, for some patients there is not such a process of anticipatory grief because from the moment when they hear the bad news they start living an experience of waiting which means they start an experience of hope.

It is clear to see that life and death are together and connected to each other; however, even though Hispanics maintain an awareness of the reality of death and an understanding that life continues after death, for the most part, they are afraid of dying. This fear of dying makes them do everything possible to postpone the reality of death. All of the participant patients in this study are influenced in some way by the teaching of the Catholic tradition. In the Hispanic culture, not everyone is connected to a local church, but everyone is somehow affected by the teaching of this tradition which is merged in a deep level with the cultural interpretation of life and death. Therefore, a Catholic tradition in some Hispanic countries forms an integral part of the cultural context. Taking in consideration this cultural integration between the Catholic tradition and cultural beliefs, this project incorporates seriously the understanding of death for the Catholic tradition.

The first part of this project includes chapter 1 and 2. In this section I identified the pastoral challenge and I set up the context for the research question of how the narratives of future-oriented-stores-of-hope impact the waiting experience. I continued to explain the pastoral theological method and research design through three stages and three sources of information suggested by the Whiteheads. I engaged in the first stage of the process which gathers some of the available information with the purpose of understanding the goal of this project. I concluded with the first stage of the method.

Now, I move to the assertion or second stage where I bring the results of the data into dialogue with the sources of information. The next three chapters contain the data and the three sources of information with the purpose of demonstrating how the story of hope is connected to the waiting experience. The three sources of information interact with each other proving a helpful conceptual framework for pastoral caregivers facilitating and understanding of how the sources of information contribute to the construction of the patient's stories.

CHAPTER 3 WAITING EXPERIENCE WITH STORIES OF HOPE: “FULL OF LIFE”

This chapter marks the beginning of the assertion stage of the theological reflection method. In this chapter I present a summary of interviews with Raul and Antonia whose waiting experiences are examined together because both of them construct a story of hope that articulates a future full of life. This understanding of hope affects their waiting experience in ways that make them live the present to its fullness, enjoying their life, spending time with family, and accepting the fact that they are facing an incurable illness. For the purpose of my research, the assertion stage draws upon the available information from the three sources discussed in chapter II (tradition, experience, and culture) and engages in dialogue in order to explore how the meaning attached to the story of hope for Raul and Antonia impacts how they live through the waiting experience and how the sources of information contribute to the construction of their stories.

All of the interviews for this project were conducted in Spanish and the questions were designed to co-explore and co-develop the waiting experience by using a narrative approach. As noted earlier, the questions include three major tiers (see appendix for the questions), the first of which is to invite patients to describe their present, which I refer to as experience-present. In this section the focus is on their description of the effects of the current crisis, from the moment when the doctor delivers the bad news and the beginning of the waiting experience. The second tier of questions focuses on experience-future, inviting the patients to use their imagination to describe what happens next, what happens after death, and to describe the anticipated arrival point in their journey. The third group of questions is designed to explore the experience-past, encouraging the

patients to share how they constructed their own narrative and to evaluate how this understanding has been useful in their journey. The results of the interviews are organized according to experience-present, experience-future-and experience past in order to identify how the future stories of hope are connected to the waiting experience and to facilitate the visualization of how the participant patients get to that understanding of hope based on the experience of the past.

All of the participants in this project shared narratives of experience-past, experience-present, and experience-future. Because the goal of this research is to explore how the construction of the stories of hope affects the waiting experience, the data is organized according to three ways in which the patients experience their stories of hope. This current chapter explores future stories of hope that envision the fullness of life. I am presenting the stories of Raul and Antonia in this chapter because they envision the fullness of life in the future story. In the next chapter I will present the stories of three patients whose stories of hope are ambiguous and multiple producing a vision of limited life. In chapter 5 I will present the stories of another patient who envisions his future stories of hope with no life at all.

A. Patient's Experience

1. Raul's Waiting Experience and Story of Hope

Introducing Raul

Raul was born in Texas but he considers himself Hispanic because his parents are Hispanic, Mexican origin. He grew up in South Texas, suffering discrimination and poverty but

having a very supportive family. He attended a Catholic elementary school and he remembers one of the nuns who was very helpful in the construction of his belief system. During this interview, Raul asks if his wife can be present because he wants her to hear what he has to say. As soon as I enter, Raul gets ready to share his story. He has been waiting for me so that he can share his story. When he opens the door he immediately shares how grateful he feels to participate in this study and starts sharing the beginning of his struggle, when he first got sick.

Experience-Present

Raul describes his waiting experience as coming from above. He says, "God has a purpose for me. When I got so sick I was taken to the hospital but God did not take me. God gave me more time, that's why I am still here." Raul is convinced that God is in charge of directing his life toward a purpose that he did not yet know. He asks God to reveal to him what his purpose is and why he is still alive after being close to dying at the hospital. Raul believes that God is in charge and the role of a human being is to accept God's plan. "God gives us choices and my choice is to accept whatever it is God has in store for me." Raul is not afraid of dying, nor does he experience any unwanted feelings or reactions in his waiting experience. Raul is content with his life. The waiting experience for Raul is a message from God announcing that his end is coming sometime soon and, therefore, he needs to prepare. This patient is not fearful of dying and he is not anxious to know how his future is changing.

The purpose of the waiting experience is to wait in hope. Raul said, "you do not push God, you just wait. I heard those words when I was a child; now I just sit and wait because I know that God is in charge and one day God will show me what to do." Raul mentions that in order to have a way to live in this life and to be with God, it is necessary to connect the heart

with the mind and the spirit. Raul responds to questions like, how do you make those connections, and what you think happens when you are able to connect them? With this response:

When you connect those three, you have shown that there is hope. And you get there when you learn how to forgive all what happened in your past. You need to have a good thought about yourself and people. You have to learn the language, follow the rules and work hard for what you want. I hope I am doing right. I had to change the way I was living, the way I was thinking, and the way I was feeling, that was important to have some healing. So now I am just waiting for God to give me more instructions. I want my life to be better. It is difficult because I had so much anger built up inside of me. But I had confidence in myself and I was able to stand side by side with a white man and I accomplished the same things. I had to work three times harder in order to accomplish the same things because my color, the limitations of the language, the difference of the skin color but I did it. I feel very good and proud for what I did.

Raul is feeling proud because he was able to understand the things that he needs to do in this life and he shows confidence that he is doing the right thing as he waits for God to give him more instructions. For Raul the waiting experience implies confidence in a God Who knows what it is best for him and Raul accepts whatever God has in store for him.

Experience-Future

Raul has a strong conviction that to enter heaven we must not be ugly with one another; we must deserve it. Raul believes that he has done his part by being kind to himself and with those around him; therefore heaven is for him. Raul describes a narrative of a future story of hope with the certitude that he will be with God in heaven and with his parents. He views his life as a journey. Raul says:

We are on the road and we go one way, all of the sudden you got to go in a different way. God is responsible for everything and I accept whatever He sends my way. God gives you choices and my choice is to accept what He offers. Life is not easy, but in the middle of struggle you have to have hope because God will show you the way soon.

This patient learned from his father that God does not like ugly, that statement meant for him that it is necessary to have some virtues in order to please God and to be in heaven. His father told him, “There is a place for everyone in heaven if you follow your religion. You never judge a human being by the color of the skin. Everyone has the same rights that you do, so you do not take that away, that’s not your place.” Raul is convinced that he is following his religion, so heaven is for him.

Raul expresses also his belief that when he arrives into heaven, his father will be there to receive him. That belief gives him confidence that everything will be fine after death and as a consequence, his waiting experience is an experience of hope and confidence in a future full of life, accepting whatever God has in store for him.

Experience-Past

Raul has a conviction of what “to wait” means. He learned about waiting when he was attending Catholic school and one of his teachers, who was a nun, told him, “You do not push God. God will let you know when you are ready to hear it.” Because of this belief, Raul waits patiently until that day when God will reveal in more details why his life was saved a few months ago when he was close to death. Raul believes that God does not like “ugly,” meaning that God is not happy when people mistreat each other. Raul experienced prejudice, poverty, suffering, and discrimination when he was growing up, creating some resentments toward some people. According to Raul, some people were ugly to him and his family just because of the difference of language and skin color. Raul was able to find some peace and resolutions to his struggles in life, and he believes that in moments when human beings are angry, God is there just waiting for us to reconcile. “In this life nothing is for free, human beings have to earn it,” he

says. The same principle applies to life after death.

While we will look more closely at some of the underlying themes of Raul's story later in this chapter, it is clear that the future story of hope is producing the fullness of life for him, even though he wants to know what God has in store for him, he accepts his human limitation and he enjoys his present life in the best possible way. Raul learned from the past how to wait and how to trust and how to live his waiting experience in hope.

2. Antonia's Waiting Experience and Story of Hope

Introducing Antonia

Antonia is a 70 year old female from El Salvador, living with one of her sons. She has 5 sons, all living in the same area where she lives. Antonia did not have the opportunity to go to school or to have any religious education. What she learned came from her grandmother, who rescued her from an abused environment when she was a child. During the interview, Antonia describes stories of violence, poverty and oppression. Antonia, in the same way as Raul, requests to have her family present during the interview because she wants them to hear what she is ready to share and she has not told them.

Experience-Present

When the doctors tell her about her terminal condition, she immediately starts having mental conversations with God. "God is in charge, not this doctor." Antonia reports that she cried once when she heard that there was no more treatment for her, but in her crying she asked God to give her strength to keep living and the will to keep standing. Antonia remembers what

her grandmother taught her: “If you want God to forgive your sins, you have to suffer.” Antonia makes a movement from trusting in her doctor to accepting her terminal condition on the basis of the value of suffering. Antonia asks God for more time to spend with her family, but at the same time she acknowledges that God is in charge and one day God is going to ask her to go to heaven.

Antonia is not afraid of dying. She believes that life with God is precious and God is always with us. “I learned from my grandmother that God is always with us taking care of us when we are suffering, so I am not fearful.” Antonia applies the same principle to her waiting experience. She acknowledges that it is a possibility God is not changing her dying situation, but she feels confident that God is there with her, taking care of her and that belief gives her confidence to enjoy the fullness of life with her family. Antonia asks God to give her more time to be in this world, but at the same time, she knows that a place in heaven is waiting for her because of all the suffering she had to endure as she was growing up. For Antonia, the words of her grandmother keep resonating in her mind, assisting her to find meaning to her suffering and to find courage to continue living with dignity in the present tense and maintaining hope alive in a better future after her death.

Experience-Future

The narrative of future hope is based on trust, faith, and confidence. Antonia, says, “I have asked God to give me more time, but I am not scared of dying.” She is not sure how she would use her time if God responds to her petition in the way she is expecting. However, she answers the question, what would you do if God gave you more time with this: “To be with God,

to devote my time to God.” This led me to wonder why it is so important to be with God and to devote herself to God in this life? She responds by explaining how grateful she feels for all of what God has done in her life. This patient needs more time to be with God in this life.

I find myself wondering why she has that desire to be with God in this life? She reports: “I am 70 years old now, and every night I ask God to help me keep living. I would like to be younger again and go more often to church because I do not think I have gone enough.” After that statement I ask if she believes that it was necessary for her to go more often to church in order to be with God. After a short period of silence, she responds: “No, suffering has been part of my life and my grandmother, the only person who loved me when I was growing up, once told me, ‘You have to suffer so God can forgive you and you can go to heaven,’ I have not forgotten those words.” After reflecting on the questions, Antonia realizes that for her it is not necessary to go more often to church so she can stay connected with God because she already feels connected. Antonia is able to make sense of her narrative based on what she learned and experienced about suffering when she was growing up. The experience of suffering is providing a connection with God and with her family giving meaning to her waiting experience as she waits in confidence to be with God after her death.

Experience-Past

Antonia describes her childhood in the following way:

When I was a child I asked God to help me and God did help me. God did not change my suffering situation but God gave me the strength and courage to endure it. As a child my life was a life filled with pain, violence, and suffering because my parents split up and I had 13 siblings. My mother was so poor that she had to give each one of us away. They gave us away like puppies. I went to live with my uncle who treated me very badly. They hit me very often. They made me work very hard at a very young age. All that I did at

that time in the middle of my suffering was asking God to help me. One day my grandmother knew the way my uncle was treating me and she rescued me. After that I went to live with her and she taught me how to trust in God. I learned that God was with me in my suffering and he would give me the strength. God did not change my poverty and my situation but God gave me the courage to continue.

The experience-past for Antonia is an experience of suffering but because she had a significant relationship when she was a child she is able to construct a helpful story of life. She reports that she was able to keep hope and faith alive trusting in a God who is able to be with us in our struggles and suffering. The experience of suffering is the connecting point for Antonia and she feels confident that God not only understands her suffering but God is also at her side. She believes that God will reward her in heaven because all the suffering she has endured in this life. How is Antonia able to keep her hope alive and enjoy the fullness of life when all she sees is hopelessness? This question will be discussed in the integrative section. It is helpful now to move to the integrative work of the assertion stage in theological reflection.

B. INTEGRATION OF DATA: EXPERIENCE-TRADITION-CULTURE

The stories of Raul and Antonia capture the dimension of their complex waiting experience and the power of hope to overcome any difficulties in life. In the complexity of their lives, they describe the waiting experience and the meaning for the future oriented stories of hope based on how they learned from experience-past. As I continue with the assertion stage, I turn now to the discussion of the meaning of hope for these particular patients with the communal experience of some pastoral caregivers and theologians. I include a Christian narrative perspective as part of a cultural-religious system and the understanding of hope by drawing upon aspects of a Christian cultural-tradition and liberation theology. I will describe the

value of the construction of the sacred story and I will discuss how the experience of suffering is an opportunity to increase our hope and enjoy the fullness of life instead of living an experience of powerlessness and resignation.

1. Functional Religious Experience: Creation of the Sacred Story

Raul and Antonia's personal waiting experience shows the importance of hope for survival in their daily lives. Both of these patients interpret the concept of hope from different perspectives, but both experience the fullness of life as they wait for their final hour. Raul and Antonia are not afraid of dying and they feel a close connection with God and with others based on their capacity to hope. The waiting experience of Raul and Antonia supports what Lester affirms: "How a person thinks about and feels toward the not-yet is crucial to physical, emotional, and spiritual health."⁹² Hope is located in the future dimension of human temporality but this understanding is originated in the past; Raul and Antonia understood the concept of hope because of what they learned in the past from significant relationships in the context of faith, helping them to construct a sacred story based on some specific aspects of the Christian life. This allows them to confront the reality of death through the creation of their sacred story. For a Christian person, the future dimension becomes crucial for the construction of the sacred story within the context of religious faith. Lester argues that "for those with a religious identity, these faith stories make meaning out of religious experience in the past and also form stories about what they expect in the future."⁹³ The religious experiences from the past for Raul and Antonia

⁹² Lester, 59

⁹³ Ibid, 39

has a great influence in the shaping of their religious identity and gives them a conceptual frame which they use to construct their stories of hope and those stories are functional for them.

According to Lester, from a Judeo-Christian tradition, the understanding of the sacred story includes the participation of major or theological hope which “is rooted in the character of God, the Creator, and the Redeemer of the universe.”⁹⁴ As Christians we believe that the “God who created us and sustains us is primary characterized by love. The experience of love is manifested to us though human touch or meaningful relationships. The creation and the incarnation reveals the nature of the self-giving live.”⁹⁵ God in Jesus Christ gives us the reason to hope for the not-yet of our future. This is a trustworthy God who is able to keep promises. Our hope is based on this relationship with this trustworthy God who loved us first and invites us to maintain a close relationship. God is at our side, God has plans for us, and God has taken care of us and will continue to take care of us even after we die. This is the experience for Raul and Antonia as the prophet (Jer. 29:11) proclaims: “For surely I know the plans I have for you, plans for your welfare and not for harm to give you future and hope.” Antonia and Raul know that God was, and continues to be, at their sides. They understand that God has a plan for them and they wait with confidence and trust.

The story of hope, according to Lester is communicated through the development of Christian narratives or sacred stories. The development of sacred stories tied to the Christian identity can face different challenges in our present world when we do not see the whole sacred story and perceive only a particular aspect. This is not the case for Antonia and Raul. Antonia believes that suffering is a requirement for the forgiveness of sins and a place in heaven. Raul

⁹⁴ Ibid., 65

⁹⁵ Ibid., 66

waits patiently for God to show him a plan of action. This project does not focus on the judgment of the construction of the sacred story as right or wrong; analyzing the doctrinal righteousness is not the goal. Instead this project focus on the meaning attached to the stories as an important component for the creation and understanding of the sacred story, and the impact that this understanding has in the waiting experience. A particular view of Christian identity is understood by Raul and Antonia with this Christian identity provides answers for their questions. Their sacred story functions in the way they feel confident, allowing them to enjoy the fullness of life.

Why, for Antonia, does suffering provide the assurance of a place with God? Why, for Raul, is connectedness required to be a good receptor of God's grace? According to the experience of Christian narrative theologian, George Stroup, there are a number of symptoms influencing the construction of the Christian narrative or identity: "The curious status of the Bible in the church's life, the church's loss of its theological tradition, the absence of theological reflection at all levels of the church, and the inability of many Christians to make sense out of their personal identity by means of Christian faith."⁹⁶ We understand the Christian faith and make meaning of it according to what is accessible to us. Sometimes we only have limited access to the narratives of Christian faith, but with those limitations some patients are able to construct a functional sacred story.

When patients are not able to access those elements of the Christian faith to construct a hopeful sacred story they can face a challenge. This challenge gets complicated when some people do not have a connection to any local community of faith or they do not have a significant trusting relationship that can help them to construct their sacred story. If this is the case, it will be

⁹⁶ George W. Stroup, *The Promise of the Narrative Theology: Recovering the Gospel in the Church* (Eugene: Wipe and stock Publishers, 1997), 24

difficult for patients when facing end-of-life to find their Christian identity based on a previous religious experience. Raul and Antonia are fortunate because they are able to construct their sacred story in a way that their Christian identity is functional by providing a connection with themselves, with others, and with God. Raul and Antonia experience life with a hopeful attitude and a certain belief that one day they will be participating of God's life.

Raul attended a Catholic school and the teaching of one of the nuns, "you do not push God," was helpful for him. Antonia had an experience of suffering, but the teaching of her grandmother about the link between suffering and forgiveness of sins helped her to construct a solid Christian narrative. Are these narratives considered right or wrong? From the perspective of narrative theory this classification is not a priority because what matters is the meaning attached to the story they have constructed. If some patients construct a specific Christian narrative which provides meaning and fullness of life for them, it deserves to be respected and nourished by pastoral caregivers.

For Stroup, "Christian hope is based not on a repetition of the past but on the expectation of a future in which God's promises in the past will be consummated in new and unexpected ways. Christians look to the future not simply as a repetition of the past, but as the final, yet undisclosed meaning of the past and present."⁹⁷ Christians are required to look to the future for the fulfillment of their narrative identity in the yet uncompleted narrative of God's history in this world. "It is Christian memory in the past that prompts Christian hope in the future."⁹⁸ Because all human life is stored in our memory, we must give shape to our sacred story or religious

⁹⁷ Ibid., 258

⁹⁸ Ibid., 259

experience through “narrative structuring.”⁹⁹ Our stories or core narratives not only include past experiences but also include stories about the way in which we think our future is moving. Each human being has created sacred stories that express their unique experience of faith. These stories have the potential to become core narratives which will be an important component of our belief system.

For Raul, the words from his father, “God rejects ugly,” become part of his core narrative which informs him how to behave and how to be a Christian. For Antonia, the words of her grandmother, “you need to suffer to receive forgiveness of sins in order to be with God,” become one of the main components in her story of suffering and give her confidence in the certainty of life after death. For both of them, these core narratives are meaningful and powerful. Raul and Antonia are not questioning the veracity of their belief system. They make every effort to honor those significant relationships from the past as they show by the way they face the waiting experience that life must be lived at its fullness.

Christian narrative gives a priority to the future tense and focuses on how each individual understands their sacred story. As Stroup explains, “the future which Christians anticipate is the future of the God to whom they are related in their narrative history, and although that future may be new and unknown, Christians trust in the faithfulness of God who is celebrated and confess in the Christian memory.”¹⁰⁰ Therefore, it is important to know what kind of God we have experienced in our life and the God we think we will meet at the end-of-life. The God we confess and proclaim with our way of living will be the same who will meet us at the end-of-life. For Antonia, God had been her companion in her suffering as she was growing up. Now during

⁹⁹ Lester, 39

¹⁰⁰ Stroup, 259

her waiting experience she has the strong confidence that God is going to be there, taking care of her.

From a narrative perspective of theology, the sacred story that we construct is about the God who is love. The question then becomes, how do we know the identity of this God? Have we experienced in life a God who is loving, merciful and forgiving? Or have we experienced a judgmental God who will execute justice at the first moment when we meet Him face to face? Most likely we get to know God based on the experiences of God of those with whom our formative years are spent. Raul understood God through the vision of his father and his teacher; Antonia from the understanding of her grandmother. The God that Raul and Antonia know is experienced through their significant relationships. Both, Raul and Antonia experienced pain and suffering in the past created by people around them. They could have developed a negative image of a God who is distant and who punishes people. How did Raul and Antonia come to understand that God is at their side, comforting them and taking care of them? One of the values of the use of narrative approach is to explore Raul's and Antonia's participation in the construction of their own sacred story and to learn how they have come to know this perspective of God.

According to Stroup, "the narrative identity of Christian individuals and communities is reinterpreted by means of the narrative identity of Jesus Christ, a narrative that culminates in the passion and the cross."¹⁰¹ But that is not the whole story; there is more. The life of Jesus does not end in the pain and suffering that Jesus endured on the cross. "It is the resurrection that has enabled Christians, both those in the first century and those in the twentieth, to identify Jesus of Nazareth as the crucified Messiah, and it is the event of the resurrection that links Christian

¹⁰¹ Ibid.

memory to Christian hope.”¹⁰² Both Raul and Antonia faced suffering in their experience-past; however, they understand that although on this earth we do not yet see its full realization, as human beings we live within God’s promise of a good end. They keep hope alive based on their experience of suffering. The challenge that we face as human beings is how to live in hope even as we surely do not live to see the promises of God finally fulfilled before our eyes and when all we see is pain and suffering.

Liberation theology offers an answer to that question by asserting that people take care to help one another down from their crosses of suffering in a consolidated effort of solidarity that points directly to the resurrection. A Roman Catholic theologian, Paul G. Crowley, who writes about the connection of the suffering Christ with hope, suggests: “when the cross is understood as the concrete embodiment of the divine entrance into the real, it can be served as a foundation for hope.”¹⁰³ Thus, we get to hope going through suffering because God, in solidarity with the human race, entered the mystery of suffering as a human being. In response to God’s generous act, human beings are also called to help each other and show solidarity in the experience of pain and suffering.

For another Roman Catholic theologian Galilea, Jesus offers eternal life and that eternal life begins here. As human beings we do not have to wait to be with God to participate in God’s eternal life. The construction and participation of eternal life starts here and now in this imperfect world. However, because of this imperfect world, the vision of eternal life can become vulnerable to the temptation of hopelessness in the midst of suffering. According to Galilea, “the full manifestation of this eternal life, in the resurrection, belongs to a future that passes through

¹⁰² Ibid.

¹⁰³ Paul G. Crowley, *Unwanted wisdom: Suffering, the Cross and Hope* (New York: Continuum, 2005),16

our own death. This future no one has seen, but it is hoped for, because of the promise of the Christ accepted in faith. Hope is the certitude about what faith promises.”¹⁰⁴ The promise begins in the present and it is accepted by faith but the reign will be manifested in the future. Christian hope allows us to live here and now in the ambiguity of the experience of suffering and the promise of eternal life. Hope looks to the future in the light of the promise, in the light of eternal reward, and the goal of hope is eternal happiness. Reward implies struggle, effort and a willingness to remain strong in hope.

The idea of a reward in heaven after the cross helped the martyrs to maintain hope when there was no hope because God is not only the future of human beings but also the support for the present. (Mt 6:25-26) affirms that God will provide us with everything we need in the present to reach the future promise:

Therefore I tell you, do not worry about your life, what you will eat or drink; or about your body, what you will wear. Is not life more than food and the body more than clothes? Look at the birds of the air; they do not sow or reap or store away in barns, and yet your heavenly Father feeds them. Are you not much more valuable than they?

Raul and Antonia manifest possessing this understanding and confidence in a God who provides, who knows what they need, and who is always at their side. Part of Christian hope is the call to have confidence. For Galilea, “hope is lived as a waiting for what has not yet arrived, and as confidence that God gives us everyday everything necessary for the wait in such a way that the wait is anticipated step by step.”¹⁰⁵ The waiting and confidence are inseparable and they either grow or deteriorate together. Living in hope does not mean that all our problems will find a solution or that we will never suffer or get sick. As Antonia says, “God did not change my

¹⁰⁴ Galilea, 6

¹⁰⁵ Ibid., 9

suffering when I was growing up, God will not change my illness.” However, Antonia understands that “the promise of God does not deal primarily with temporal goods. The promise deals with human dignity and its growth toward eternity.”¹⁰⁶

When we are able to trust God with confidence, acknowledging that God is in charge and God is directing our lives now and in the future, it is an expression of faith in a loving God. Our final hour always arrives in this world but if we trust enough, if we have enough confidence, we will not have to be worried about how that hour will arrive or when. In Raul’s words, “we do not push God, we just wait.” That will require that we recognize that “Christ is the Lord of history and rules over it, on his own terms, not ours, often in mysterious ways.”¹⁰⁷ Hope in the promise of God gives us the assurance of the triumph of good over evil, of justice over injustice, “but we do not know that the promise will be realized in terms of history.”¹⁰⁸ The ultimate reason for our hope is the conviction that God loves us now and forever unconditionally. Because of that love, according to Antonia, God will be our companion in our journey of suffering. If we do not reject his love we can have a future where we can fulfill our happiness and experience life.

The construction of the sacred story allows Raul and Antonia to participate in God’s life during their waiting experience and they are able to face the reality of death without fear. The sacred story provides fullness of life for both of them even after death and they wait with confidence for the full realization of the promise which they accepted by faith.

¹⁰⁶ Ibid., 10

¹⁰⁷ Ibid., 11

¹⁰⁸ Ibid.

2. Suffering: An Opportunity to Hope

It is important to discuss the influence of a Catholic tradition as a cultural system in the way some people interpret life. In some Hispanic countries the teaching of the Catholic Church has merged with some cultural beliefs, creating a system that provides answers and meaning to the precarious life style in which they live. This is the case of the meaning of suffering from a Christian perspective in a third world country. From the perspective of liberation theology, the mystery of evil is the temptation against hope but at the same time it is the opportunity for us to prove that we have hope. Again, Galilea notes that “the paradox is that evil of the world is one more confirmation of the existence and providence of a God of love and is one of the reasons for hope.”¹⁰⁹ Therefore, whenever we experience bad times in life, it is the time to prove that we are men and women of hope because “hope increases when less is seen.”¹¹⁰ Confidence makes the difference between living a life of absurdity and a life of hope. When we live a life with confidence we are capable of accepting a life filled with mystery and evil, living according to that, “the promise does not pretend to eliminate evil from us, but rather to give evil meaning in the light of a destiny of total good.”¹¹¹

According to Moltman, the cross is the site of God’s direct entry into the realm of human suffering. He affirms, “the Trinitarian relations, especially between the Father and the Son are revealed in the cross itself, for in the suffering Jesus, God the Father himself suffers. In the cross, the incarnate God is present in every human being who suffers and draws near to everyone who

¹⁰⁹ Ibid., 17

¹¹⁰ Ibid.

¹¹¹ Ibid., 18

is forsaken.”¹¹² The cross is the real participation of God in our experience of suffering. The path of the cross is also the path to our hope. “Christian hope in an unrealized future can include the connection that things here below will only get worse before they get better, just as human beings cannot redeem themselves, human history cannot be redeemed by human beings.”¹¹³ Christians are called to be realistic and accept their own human condition and reality as it is rather than to evade it through a false religious piety. Raul and Antonia are realistic about their health condition; they know that one day is going to be their last day and they accept it. Sometimes patients believe that having enough faith means that God will provide for us the miracle that we are expecting for and we will see some of this narrative in stories in the following chapters. However, for Antonia and Raul, hope is not an excuse to avoid the acceptance of the reality of pain and suffering that comes from dying, but an opportunity to live in freedom.

Crowley argues that it’s better to confront the reality of suffering, which includes the acceptances of our own mortality and somehow deal with it. He formulates the question in this way as he reflects on the experience of suffering: “how to go through it without losing a sense of hope, or more precisely, how to find hope within the crucible of suffering?”¹¹⁴ For him resignation in a sense of powerlessness or the refusal to accept what is happening is not the Christian solution. Crowley’s argument is that the cross leads to hope because it involves not only the unequivocal reality of pain and suffering but also includes “the relationship between the cross and the incarnation and the resurrection, between both the hope-filled divine entrance into

¹¹² Crowley, 68

¹¹³ Ibid., 91

¹¹⁴ Ibid., 11

human life, and the final victory of God's love over suffering and death."¹¹⁵ The cross of Jesus illustrates the hard reality of living in this life when we face pain and suffering. "The cross does not ask for masochism, but does force us to face what we must face in life. It is in the facing of the real, the concrete, in going through it, that we become something other than what we once were, and that we thereby can move toward the promise realized."¹¹⁶ For Moltman, the cross is the place of God's real participation into human suffering. The relationship between the Father and the Son are revealed in the cross itself for in the suffering Jesus, God the father also is suffering. "On the cross then, the incarnate God is present in every human being who suffers and draws near to everyone who is forsaken."¹¹⁷

Antonia grew up in a third-world country where she and her family experienced suffering in many different levels, mainly caused by poverty. Antonia reports that she experienced God's presence during her suffering and she learned to endure this suffering by believing that God was taking care of her even in the experience of poverty. Raul did not grow up in a third world country surrounded by poverty, but he also experienced oppression, discrimination and humiliation. Catholic spiritual writer, Richard Rohr, defines the poor person as "one who either temporality or permanently finds herself or himself in a situation of weakness, dependence or humiliation. It is a state characterized by a lack of means. The poor do not have the means to accomplish the ends they desire."¹¹⁸ Why is the experience of suffering significant for the construction of the concept of hope? Because, as Galilea notes, "Christian hope is the

¹¹⁵ Ibid., 127

¹¹⁶ Ibid., 12

¹¹⁷ Crowley, 68

¹¹⁸ Richard Rohr, *Job and the Mystery of Suffering* (New York: The Crossroad Publishing Company, 1998),

fundamental guarantee that human beings in any system, any condition, in any trial or apparently hopeless situation, can preserve integrity and dignity, can maintain the spirit free and with love, can reach their destiny.”¹¹⁹ This guarantee of hope relates in a remarkable way to those who lack human expectations in the basic form: “the poor, those who suffer, the abandoned. Hope is offered to them as the greatest richness of their lives, at times, the only richness.”¹²⁰ This is a vivid sign that hope has the power to sustain us even in the midst of suffering and oppression. The stories of Raul and Antonia are vivid signs of the power of hope.

How did the experience of suffering help Raul and Antonia in the construction of their story of hope? Both grew up in a Catholic environment; therefore, they were influenced by the Catholic teaching as a cultural system. The catechism of the Catholic Church teaches:

The cross is the unique sacrifice of Christ, the one mediator between God and humankind. But because in His incarnate divine person He has in some way united himself to every human being, the possibility of being made partners, in a way known to God, in the paschal mystery is offered to all. He calls His disciples to take up their cross and follow Him, for Christ also suffered for us, leaving us an example so that we should follow in his steps. In fact Jesus desires to associate with His redeeming sacrifice those who were to be its first beneficiaries.¹²¹

This teaching is an invitation to accept our own suffering as Jesus did, dying on the cross, suffering and accepting God’s will. In The Apostolic Letter of John Paul II *On the Christian Meaning of Human Suffering*, The Pope declares the power of suffering by making reference to (Col. 1:24) “I am glad that I can suffer for you. I am pleased also that in my own body I can continue the suffering of Christ for his body, the church.” This joy comes from finding the meaning of suffering and from knowing that other people can be blessed or helped when one

¹¹⁹ Galilea, 36

¹²⁰ Ibid.

¹²¹ Catholic Church, *Catechism of the Catholic Church*, # 618

understands the salvific meaning of suffering. This understanding brings to the believers both meaning and hope, knowing that God is not merely tolerating human suffering, or healing suffering, but God is participating in it with us. As Rohr reminds us about the meaning and value of suffering, “we seem to believe that this suffering is even life-giving and redemptive. It’s quite amazing.”¹²² This understanding of the value of suffering gives Antonia an opportunity to experience life as she waits in confidence for her reward in heaven.

I consider that life is not a problem to be solved, but a mystery. Suffering is part of that mystery and our task is to learn how to live fully and consciously in the presence of the mystery where sometimes we do not have answers to our questions. Faith allows us to live in a shaky position so that we have to rely upon another Greater Being as we discover how powerless we are. According to Rohr, “faith does not mean having answers, it means being willing to live without answers. Cultural faith and civil religion tend to define faith poorly and narrowly as having certitudes and being able to hold religious formulas.”¹²³ Expressions like “if you have enough faith God will remove your suffering,” “God knows what is the best for you,” or “there must be a reason for your suffering” force individuals to either live under the pressure to have a strong faith so their suffering is eradicated or to experience resignation and powerlessness knowing that God is allowing this suffering; therefore, we do not have the right to complain or the courage to cry, as Jesus did.

Rohr continues arguing that, “even when Jesus sat looking down on Jerusalem and crying over it, the last thing he needed was a pious soul to run up to him and say, -now Jesus,

¹²² Richard Rohr, *Job and the Mystery of Suffering* (New York: The Crossroad Publishing Company, 1998)

¹²³ *Ibid.*, 74

don't cry. It is all in God's perfect plan."¹²⁴ Trusting God does not mean that we will never suffer or will have to deal with trials and tribulations. Trusting in God in the midst of our human suffering does not mean that we have to endure all kinds of sufferings, especially those coming from human oppression. For Crowley, there is a difference between the acceptance of suffering with passivity and resignation and accepting suffering with hope in the resurrection. Crowley states "isolation of the cross can lead to a spirituality of masochism and passive acceptance of certain forms of suffering, such as the misery following upon economic and social injustice, the sources of which must be challenged."¹²⁵ Not all forms of suffering must be accepted; as human beings we have the capability to challenge certain situations and improve our human condition. If suffering can be challenged and changed, we must make use of our agency and power to improve the quality of our life. Accepting all forms of suffering can lead to oppression and resignation. It means accepting just the crucifixion but forgetting about the resurrection.

We are free to question God in the midst of our suffering but we may not get any answers because God owes us nothing. God is God and we are God's creatures. There are some forms of suffering that we can change but there are others where we are completely powerless, just for the simple reason that we are human beings in a journey, in the process of perfection and "the wayfarer is not to evade the challenges, the struggles, the difficulties, and dangers of life, but to accept, make his way through, and grow in them."¹²⁶ When we accept the human condition which includes the reality of suffering, suffering has the potential to give us an opportunity to grow and to increase our hope.

¹²⁴ Ibid., 60

¹²⁵ Crowley, 70

¹²⁶ John Navone, *Towards a Theology of Story*, (Slough, England: ST. Paul Publications. 1977), 63

As human beings we may question why the just person suffers and we may correlate suffering with sin. Some Catholics may have the idea of the retributive justice, “we expect retribution of God and of one another: we do this much bad and expect that much punishment. Our horrible doctrine of purgatory was a perfect example of poorly understood retributive justice.”¹²⁷ In the Catholic tradition, there has been a classical distinction between God permitting suffering, and God causing suffering.

Some Catholics affirm that there is a kind of suffering caused by our human freedom. Crowley refers to that kind of suffering as “clinical states of disease usually brought on in part as a result of acts involving the exercise of some degree of human freedom, although the degree of human freedom varies widely from one person to another.”¹²⁸ In situations like these, because human freedom is involved, some claim “the physical and spiritual suffering brought by some diseases is self-earned, and further even ordained by God as a kind of judgment for sin.”¹²⁹ According to Crowley, Rahner refused this kind of judgment and the language of causality which affirms that sin leads to suffering, or by implication that suffering is the consequence of sin and experience of divine judgment. For Rahner, “God is responsible for the whole of creation in freedom, a claim which includes not only the possibility of evil and suffering, apparent and real, natural and moral, but also the possibility of grace given and received in the heart of sin and suffering.”¹³⁰ This view, Crowley continues, opens the door for hope in a God who has the power to be present in the heart of the suffering itself. “God does not stand outside of suffering,

¹²⁷ Rohr, 34

¹²⁸ Crowley, 82

¹²⁹ Ibid.,

¹³⁰ Ibid., 83

but is found within it. Suffering simply cannot be mapped out according to schemes that would pit divine justice against human sinfulness, or that would place God outside the world of suffering itself.”¹³¹ God is present within every human existence; a presence which includes the experience of human suffering. This perspective recovers the cross as a symbol of hope for all who are suffering and need to find hope in order to be led to a new dimension of life.

Taking in consideration the influence of a Roman Catholic tradition, the personal and communal experience of some theologians in the understanding of the cultural context, we can learn how the experience of suffering for Antonia and Raul became an important component of their sacred story. Both Antonia and Raul had the option of accepting suffering from the place of passive resignation centered on the pain of the cross, but they chose instead to construct a different interpretation for their story of struggle and suffering. They firmly believe that God is at their side even present in the experience of suffering when they were growing up. They opted for the construction of a sacred story which allows them to see beyond the crucifixion and focus on the promise of a loving God who is offering the fullness of life even when all they see around them contradicts that promise. Antonia and Raul are facing the waiting experience as they wait not just for their death but also for the enjoyment of the participation of a life with God. A dying patient can fit the description of the poor, as previously defined by Rohr, (one who either temporality or permanently finds herself or himself in a situation of weakness, dependence or humiliation). Antonia and Raul have the advantage to be a witness of hope “because to the degree that they cling to hope, they can move already here on earth toward the happiness and dignity promised by God,”¹³² and experience the fullness of life as they wait in faith and hope for the fulfillment of the promise of eternal happiness.

¹³¹ Ibid.

¹³² Galilea, 38

CHAPTER 4
WAITING EXPERIENCE WITH STORIES OF HOPE:
AMBIGUOUS-MULTIPLE STORIES PRODUCING LIMITED LIFE

As noted in the previous chapter, some patients approach the waiting experience with confidence in God allowing them to maintain a sense of fullness of life. Others, however, carry an ambiguous waiting experience with multiple future stories of hope. As I continue in the assertion stage of theological reflection and method, I will explore the stories of Pedro, Jose, and Maria and describe how the ambiguity of their waiting experience with mixed emotions creates a perception of a limited life for them. For these three patients, family becomes the corner stone in their waiting experience and story of hope. Pedro, Jose, and Maria are concerned about how the waiting experience affects their families and how their families will be able to survive after their death. They make every effort to continue living because they want to support and equip their families before the waiting experience is over.

The waiting experience for these three patients involves feelings of fear and suicidal thoughts, and the story of hope is a story with multiple arrival points at the end of their journey. Many of these patients do not have their extended families in this country. They often request hospice to advocate for them so at least part of their family can travel and spend some time with them before their death. This chapter introduces the three stories of Pedro, Jose, and Maria and then turns to the integrative aspect of assertion by placing the stories in conversation with the three sources of tradition, experience, and culture.

A. Patients' Experience

1. Pedro's Waiting Experience and Story of Hope

Introducing Pedro

Pedro is a 41 year old man from Central America diagnosed with cancer. Pedro lives with his sister who is a single mother and who has two children. Pedro is separated from his wife but he takes care of a 3 year old son. Pedro's sister lost her job and Pedro is unable to work; therefore, they are facing financial issues. Pedro's family members (parents and brothers and sisters) are in Central America. They live in poverty so they are unable to travel to the United States to support him.

Experience-Present

When I ask Pedro questions about the effects of the current crisis, he reports:

I have no money, no medical insurance, when the doctor told me that I was not going to receive more chemotherapy because I did not have money to pay for it I was very angry. I felt abandoned by these doctors because of my financial situation, but at that moment, I said to myself, 'my life will end on God's terms, not with yours.

Pedro reports that he feels helpless because he does not have money to pay for more treatment, but when he hears the bad news, he starts to engage in hopeful conversations with God asking for help, and a miracle to cure his body. After this conversation with the doctor this is how Pedro describes his waiting experience:

I felt so bad, I got depressed, I was just thinking that the cancer was going to progress and I was going to die. Since I did not have the money to pay for more treatment, I had to find resignation and accept my death. I thought about my son and I kept asking God for help. At the beginning I was only thinking that I was going to die, but I tried to live a normal life. Sometimes I feel good but other times I want this suffering to end. I ask God to give me strength so I can work and provide for my family, so I go to work as often as I can.

Pedro describes that sometimes he wants his life to end but other times he feels good.

When I invite him to expand upon and develop the feeling-good-story by asking “What is helping you to feel good?” he replies:

I feel good when I have people around me, when they visit me, when they try to help me. I feel good when I see my son next to me; I gain strength to keep going. I feel good when I think about my family and how they need me to protect them. But when I am alone I cry and I think about my death.

The waiting experience for Pedro includes mixed reactions and emotions. Sometimes he feels strengthened and hopeful, but other times he feels fearful and hopeless. Sometimes he wants to continue living but other times he desires an end to his life. Pedro suffers some episodes of loneliness and abandonment, during which time thoughts of suicide emerge, he reports. Sometimes Pedro is fearful of dying because he is not sure that the way he lives his life will allow him to enter into heaven.

Experience -Future

Pedro thinks about his immediate future and he is concerned about his family. When he first heard the bad news of his diagnosis, his questions were: “Who will take care of my son? Who will support my sister?” In the midst of his fear and struggle, Pedro starts to have conversations with God, asking him to have more time so he can continue taking care of his family and to see his son grow up. The story of hope starts to develop when he hears the bad news but at this time, fear is the dominant story and the story of hope is not strong enough. Pedro focuses on human hopes at first and on the need to get well so he can continue to have a role in his family.

During the interview Pedro reports a different story from the more hopeless one as he says: “now I feel different; I understand better this illness; I can see clear now, but at the

beginning it was very scary and dark.” Using Pedro’s terms, there is a movement from darkness to clarity, from misunderstanding to understanding. At this point I ask Pedro the question, “How did you arrive to this point of clarity?” He answers, “I learned to trust God, to put my life into God’s hands, and if God wants to take me, God’s will be done.”

Pedro is also opening the doors to discussions during the interview about the meaning of his own death and life after death. Using Pedro’s language, “when we die, God is taking us, and it is God’s will.” To expand this narrative of hope, I ask Pedro two questions: “Have you imagined the day when God will decide to take you? How would that day be?” Pedro says, “I have not been able to discern death. When I think about death I get scared. Sometimes I prefer not to sleep because I am afraid of not waking up. But this does not happen very often.” At this point I am curious about what is making Pedro afraid of death. Pedro responds, “I do not know if I have done good actions to deserve to be with God.” For Pedro death is an opportunity to be with God but he is not sure if that means he will be with God or not. As I invite him to expand on his belief, Pedro continues saying that life after death depends on how we live our life; nobody is sure about having a place with God. This leads me to ask: “What would you prefer to experience when God takes you?” Pedro responds by saying, “I would like God to tell me, ‘Welcome home, this place is for you.’ I think everyone has to pay for the wrongdoings. I do not think God will reward us if we have done bad things.”

For Pedro good works are necessary to assure a place in heaven. Heaven is a possibility but also a place of judgment. In which place will Pedro be? He is not sure which one he will experience, but he verbalizes which one he prefers. Sometimes he feels encouraged and believes that he will have a chance in heaven, especially when his friends or hospice employees visit with him. When he is alone, the fear of death gets stronger because the story of hope becomes

unclear. Pedro has a preferred story of God welcoming him into heaven by saying, “This place is for you.” This narrative can be developed with the help of a caregiver. What would it take for Pedro to feel welcome by God? What are some examples of good deeds that Pedro has done or will need to do in this life? Is Pedro just focusing on the story of failure, disappointment, pain, and death and forgetting all the other stories that show how Pedro is concerned about taking care of his family? Those are helpful questions to continue developing Pedro’s alternative stories that can contribute to a more hopeful future.

Experience-Past

Pedro has been influenced by the Church’s teaching on salvation which teaches of three possible places after judgment: heaven, purgatory or hell. The story of hell is not developed and he denies thinking about it, even though he acknowledges it as a place of punishment if one has not lived a good life. When I ask Pedro how he learned this story, he replies, “At home, when I was growing up”. This is part of his understanding as he was growing up. His parents taught him to fear God with statements like, “If you do not behave, God is watching you and God will punish you.” Pedro is interpreting that it is a possibility that God will punish him after death because he is thinking about all the different situations when he did not behave. If punishment is part of his belief system, it means that God will not allow him to enjoy the fullness of life and he will go somewhere else to pay for his mistakes.

2. Jose's Waiting Experience and Story of Hope

Introducing Jose

Jose, another relatively young man with a young family, is also diagnosed with cancer. Jose is from Mexico and has been bedridden for several months. His wife sells food outside a manufacturing plant to provide for the family. Part of Jose's family is in the United States and the other part is in his own country. Jose expresses his desire to see his family together but this process has been very difficult because of the immigration laws. Jose's story represents "multiple stories" because he lives in the ambiguity of his future life thinking about the possibility of not entering into heaven but going to another place.

Experience-Present

When Jose hears his doctor delivering the bad news about the limitations of treatment, he hears the doctor saying that his life is coming to an end very soon. At that time Jose does not know what to think or what to do. When I ask Jose how this illness has changed his life, he replies that, "this is a process that one has to suffer to be with God." Then, Jose continues explaining how this illness is producing something positive: "one thing I have noticed is that my family is getting together and closer to God, everyday my brothers and sisters come and visit me. My sister from Mexico came to see me, my father is coming very soon and I hope that my other sister will also come from Mexico. God has been good to me." At first Jose said that suffering is necessary to be with God. Then he adds that his suffering is producing good fruits (Jose is smiling as he is telling the story of suffering producing good fruits). I ask Jose the meaning of seeing his family together, and he responds, "I want them to be together, so when I am not here

they can help each other. I think that if they have faith in God it will be easier for them. My family has not been together and some of them are not close to God; that worries me.” Jose’s mixed emotions emerge as he says:

I am tired of being in this bed all the time, sometimes I feel good, when I see my family together, but other times I feel like I am moving backwards. There are some things that cross my mind when I am alone, I feel down. Suddenly some ideas come to my mind and I think that I need to get closer to God because I feel afraid when those ideas come to my mind.

Jose keeps saying, “some ideas” but he is unable to name them. I continue exploring those ideas by asking him different questions such as, “Do you have a name for those ideas? Do these ideas talk to you? If they do, what are they saying to you?” Jose is silent for a moment and then he replies, “I get down when I think about them, I feel scared; that’s when I try to think something good, but those ideas keep coming and I think about the end of the world and the end of the world for some people.” I ask Jose whether, “Those ideas that make you feel down are about the end of the world and how the world ends for some people when they die?” “Yes,” he answers, and continues by saying, “when I think about that I try to avoid it; when I think about that is when I need someone to be here and to read the Bible and to talk to me about God.” Jose is talking about when some people die but he refuses talking about his own death. Jose mentions that he gets down when he thinks about those ideas, and he does not want those ideas with him. He prefers to replace those ideas with ideas about God.

The waiting experience for Jose includes the emotional pain created because he is unable to provide for his family. He prefers to die but he does not want his family to suffer his death. Jose feels depressed at times, and he does not like being alone. When he is alone Jose thinks about death, which only depresses him further. At those times the understanding of death is very confusing for Jose and he is afraid of the consequences of his actions after death. Jose believes in

heaven, but he also believes that heaven is not for everyone.

Experience-Future

Jose expresses a concern about his family after his death and he wants to make sure they would be able to handle it. Jose is also talking about death in an impersonal manner. The question I formulate to expand on that story is, “sometimes you think about people whose world has ended. What do you think happens to them when their world ends?” Jose responds, “I do not know, it’s very confusing; I just know that when I think about that I feel down. When I feel down I ask God to help me.” I ask, “What kind of help are you asking God?” He responds, “I tell God, your will be done, whatever you choose for me.” My next question is to explore what Jose would prefer. “What would you like God to choose for you?” Jose responded, “To take me with him because with God we have everything.” I ask, “What do you imagine being with God looks like?” Again, Jose does not have easy access in developing that story, “I do not know, but it must be something good” he responds. When I inquire of Jose if he has imagined the place where God is he says:

It must be a nice place, and I am not sure how good one can be to enter heaven. I am not sure if one can be there or not, I do not think I have done something wrong to deprive me from heaven. Since God gave me this illness, I have tried to be a better person. I do not know if I will be with God but I know that Jesus came to rescue the lost sheep. But I do not know if Jesus will rescue me or not. I have been praying, watching the religious channel, I know I have not done enough.

I ask Jose if he knows of another place where he can go if he does not have a chance to be with God. He mentions, “Hell.” Immediately he notes, “I do not think about that, it is not good; that is why I need to get closer to God, to see if I have a chance.” Jose is thinking that what awaits him is a chance to participate of the fullness of life in heaven or a chance to receive

punishment in a different place, hell or purgatory.

Experience-Past

Jose believes that God gave him this suffering so his family can get together and he feels good about that. Jose's suffering has a meaning. Jose is using that suffering to get closer to God and to get his family together; however, the vagueness of not knowing for sure if he would have a chance to be with God or not is creating confusion in the present tense. Jose is trying to do everything he can to get closer to God. The influence of the teaching of the Catholic Church in the Hispanic culture about salvation is creating a conflict for Jose. For Jose having family together, being closer to God, and accepting suffering are important in order to have a place with God. Jose constructed this belief system from the teachings of his mother. Jose is trying to do everything that his mother told him so he can have a chance of being with God.

Jose is facing his waiting experience with mixed emotions and unwanted ideas that come and go. Jose does not feel happy for having those ideas and mixed emotions. When Jose experiences fear is when he thinks about his death and the possibilities of life or punishment for him after death. He is not sure if God will welcome him in heaven so he can enjoy the fullness of life. He believes he might go to another place where he needs to pay for what he has done wrong, or he might not have life at all by being in a place of eternal punishment. The future stories of hope for Jose include multiple stories affecting his waiting experience, in a way that he lives in ambiguity and with limited life.

3. Maria's Waiting Experience and Story of Hope

Introducing Maria

Maria is a young married woman with, two under-age kids and one married son. Maria is from Mexico, her parents are dead but her siblings are alive in Mexico. Maria had a close relationship with her parents when they were alive and this relationship continues to be significant after their death. Maria is trying to get a humanitarian visa for her two sisters so she can see them before she dies. Maria is actively involved in a local church she attends regularly and participates in a prayer-support-group on weekly basis. We see in her story is also the experience of mixed emotions with multiple stories of hope producing limited life.

Experience-Present

When doctors tell Maria the bad news of no further treatment, her mind is numb. At that time she decides not to hear what the doctor is saying. Maria reports, "at that moment my mind was a blank and I started thinking on a miracle; I started talking to God, creating the idea of having a miracle. This idea was giving me strength day and night; that was my hope." Maria is asking God to cure her body magically. Her main concern is for her four year old daughter, so she is asking God not just to give her more time, but to cure her completely. Maria says that she was depressed for a while at the beginning, but after a period of time she develops other feelings like guilt and confusion. "At the beginning I demanded a miracle and I was very angry; but I have learned to talk to God in a different way. I used to tell God what to do and how to do it. I used to ask God: 'What have I done to deserve this punishment?' But I do not do that anymore."

Maria's thinking changes over time, from asking God to cure her body, to asking God for

just a little more time to do what she needs to do in order to get ready. However, when her pain and suffering increases, she asks God to take her to heaven. Maria reports feeling confused with having those desires to be with God and leaving her family. At the same time Maria does not want to disappoint God for not wanting to be in heaven, as she prefers to stay here on earth and support her family. Maria reported that her depression returns for two reasons. First, Maria wants to see the rest of her family (sisters) who still reside in her native country, but they are unable to travel due to the denial of travel permits by the US Border Patrol. Second, she is worried about her husband and children. The family is facing some challenges due to some misunderstandings and Maria feels that it is her responsibility to help to solve the problems. Maria says:

I feel very sad and I cry when I see my sons and my husband with all their problems and I am just here, creating another problem for them, unable to help them. I wish I could have more time to help them, I am afraid to die and leaving my family torn apart. When I feel like this, I looked at my little daughter, she is like an angel for me, and she makes me to get up and keep fighting.

Maria faces her waiting experience with emotions that change constantly and make her feel vulnerable. Maria is concerned about her family and wants to do something in order to help them to solve their problems. Maria thinks that she is a problem for her family and sometimes wants to terminate her life but at the same time she does not want to abandon her family because she knows that will create a problem for them.

Experience-Future

In order to explore the narrative of experience-future I express curiosity about the statement, “God is punishing her with this illness.” I wonder aloud about the image of God that she has constructed. I invite her with the question, “Do you think that God is punishing you?” She immediately responds, “No, I don’t think God wants us to suffer; I do not think that God is

sending this illness to me; at the beginning I used to think that, but not now.” I continue developing this new story and I ask, “How did you come to understand and change your image of God?” She replies, “I think it has been very helpful to participate in the church. I joined a prayer group. I feel their love and support. When I feel sad and depressed, I tell God that I am in his hands and I ask for forgiveness for not being patient.”

In her discourse Maria is introducing the belief that being impatient is a sin, so Maria tries to move away from that specific sin. She feels that the right thing to do is to accept God’s will without complaining. When I ask, “What would you like God’s will to be?” she responds by saying, “I want to continue living in this world but at the same time I do not want to continue living in all this suffering. When I am not feeling well I think that it would be better if God took me at that moment to end my suffering. I just think about it; I have never verbalized that idea, but I know that God listens anyways. I want to go but at the same time I do not want to go.”

I ask, “How having those desires at the same time is affecting you?” She responds:

It is very confusing. I do not know which side to take. That’s when I feel guilty because I feel I am disappointing God for not wanting to be where God is, but at the same time I feel guilty because I am disappointing my family. I am alive today and I know that I have to take advantage of my life until the last day instead of having desires to be with God.

For Maria death means “the last day.” I decide to explore the meaning of “the last day” by asking, “Have you imagined how that last day will be for you?” She responds, “Yes, I am afraid of death but sometimes I think that death can be a solution to a bad and long illness, also it is delivering my family from the burden of taking care of me.” For Maria death is a solution for her problems and for her family because she believes that her family is having a hard time taking care of her. Maria adds, “I am afraid of being alone in a small place underground, I have told my husband about this but he does not want to hear it, so I prefer to be cremated.”

Maria is having conversations about her funeral preferences. This is very interesting because usually Hispanic patients do not want to have those conversations until death occurs, but Maria is sharing what she would like to have and she is giving the reasons.

After this explanation of death, I encourage Maria to think about what she believes would happen after the scary event of death. Maria responds:

I have dreamed about it (smiling). I have seen my parents when I am entering into heaven, they hug me, we have a long conversation, we are so happy. I know they are in heaven and I know I will see them when I get there. In my dreams they have told me not to be worry that everything will be fine. I am not sure if I deserve to have those beautiful dreams because I am a sinner and I have heard the church saying that God does not like sinners but I know that those people are the ones that God loves the most.

Maria maintains conversations with her dead parents; they are encouraging her not to be afraid. Maria sometimes focuses on the fear of death making her feel depressed but then she is able to move beyond death and see the place where her parents are not just waiting for her but encouraging her. Maria believes that the fullness of life is a possibility for her, depending if she is able to accomplish the things that she needs to do in this life. Maria believes that she is a sinner and she expresses some fear when she thinks about the possibility of not having the fullness of life with God. However, Maria is questioning the influence of the teaching that “God does not like sinners,” by creating a different story about “God love sinners.” This story is not strong enough yet to assure Maria that even when she has sinned she will be forgiven and enter into heaven.

Experience-Past

Maria is talking about a discourse that she heard in her growing up, that “God does not like sinners.” At the same time, Maria is deconstructing that belief by affirming that according to

her experience sinners are the people whom God loves the most. Maria shares two stories, one story of hope, love, and connection, and the other one of sadness, disconnection and misunderstanding. In following with the advice that her parents gave to her: “you do not take your sins to the tomb,” I ask Maria, “Which story would you like to take with you?” Maria says without hesitation:

I want to take with me the story of hope, love and connection. Every day I ask God to guide me so I can find the way to know what to do; I want to go well prepared. I want to be able to reconcile my family with one another and I want to reconcile myself with them. I think God already has forgiving me but God wants me to confront those situations that I have done wrong and fix them. My father taught me to have faith and trust. He went to church, he prayed every day, and he died singing. I know that in heaven he continues singing and praying for me.

The waiting experience for Maria has not been easy. It has been filled with emotions of fear, anxiety, powerlessness and disappointments but at the same time she has experienced love, support, and assurance from a community of faith, from her daughter, and from her dead parents. Maria is afraid of dying but she wants to be in heaven with God and with her parents. Maria is not sure if she will be able to accomplish all what God is asking her to do as a way to prepare herself to enjoy the fullness of life. Maria faces some anxiety as she thinks that her time is getting shorter and she is not done with all her good works. The waiting experience for Maria is a time of preparation for herself so she can deserve to be in heaven. This preparation includes reconciliation with some family members and also the need to prepare her family for their survival after her death.

B. INTEGRATION OF THE DATA: EXPERIENCE-TRADITION-CULTURE

For Pedro, Jose, and Maria, it is important to make a human effort in order to be with

God. Family-relationships are important for the support of these three patients in their suffering condition. For Pedro, Jose and Maria, the waiting experience has been a difficult journey. They experience confusion in the waiting experience as they face multiple and uncertain stories in the narratives of hope. They move from feeling good and wanting to continue living to feeling sad and fearful and wanting to die. The stories of hope for Pedro, Jose, and Maria show that hope is dynamic and changes over time. They report that at the beginning they focused on their human hopes but over time they are able to experience a different kind of hope, a hope that allows them to accept their dying and the possibility to experience the fullness of life. For Pedro, Jose, and Maria the possibility of participation of the fullness of life after their death depends on the preparation during the waiting experience.

The possibility of not being forgiven by God could imply that they will have to be in a different place away from heaven so they can pay for their sins before enjoying the fullness of life. These different places where people are sent, according to the influence of a Roman Catholic tradition are: heaven, purgatory, or hell. During the integration of the data I will discuss how hope changes over time and it is nurtured as described by these three patients. I will also discuss the meaning of salvation and I will describe how the influence of the teaching of the Catholic church about this matter affects the way some Hispanic patients understand the connection of the fullness of life after death, with good works as one human response.

1. Nurturing Hope in Ambiguous Waiting Experience

The waiting experience for Pedro, Jose, and Maria is an experience of uncertainty caused by the existence of multiple stories. Sometimes they feel good, but other times they experience

suicidal thoughts and moments of hopelessness. They want to be with God but they want to stay in order to have more time with their families. All of these three patients, when they heard the bad news, start conversations with God hoping for a divine intervention to prolong their life in order to continue taking care of their families. They start a process of the waiting experience with the construction of human hopes.

Theologian Rahner acknowledges the existence of two kinds of hope and he gives to each one of them an equal value. Rahner affirms, “We have the major hope in God’s kingdom, in God’s absolute future, the future which we can never fully realize in history, but equally we have minor hopes based on this major hope.”¹³³ Minor hope is also known as natural, human, or finite. Major hope can be theological, divine, or transfinite. Both types of hope, minor and major, can be connected and can talk to each other. There must be a connection between finite hopes and transfinite or theological hope in order to be able to create our sacred story. As Lester notes, “transfinite hope undergirds and informs finite hope.”¹³⁴ If we have only finite hopes and the transfinite hope is not developed or does not form part of the core narrative, we may be tempted to elevate finite hope to transfinite hope. If this is the case, patients might be looking for other alternatives to be treated when facing a terminal illness, seeking a second or third opinion, or using other options for healing because they do not have the ability to confront the reality of death. When “the finite hope takes the form of a sacred story, but without God as the central character”¹³⁵ death does not form part of the story; therefore, death needs to be avoided.

For Roman Catholic theologian and philosopher Josef Pieper, natural hope or hope from

¹³³ John J O’Donnell, *Karl Rahner: Life in the Spirit*, (Rome: Gregorian, 2004) ,125

¹³⁴ Lester, 66

¹³⁵ *Ibid.*, 79

the inside, expresses our earthly desires for objects, dreams, or goals in life. Pieper argues that “natural hope blossoms with the strength of youth and withers when youth withers.”¹³⁶ This kind of hope focuses on prolonging a long future here on earth and on achieving our goals.

Theological hope, or the outside hope, goes beyond the material world providing for human beings the notion of a long future beyond this earthly life, taking us to the anticipation of an open-ended future. Imagining an open-ended future is basic to maintaining hope.

For Lester, “the deepest level of hope is an open-ended trusting stance toward existence that perceives a future horizon that transcends the finite hopes expressed in our specific objectives.”¹³⁷ It would appear that at first the vision of an open-ended future was not the case for Pedro, Jose and Maria. They were asking for a divine intervention to prolong their existence here on earth and they were unable to have their theological hope in place so they could see that life continues even after death. Hope as a journey and a human reality originating from the inside and reaching out can be used with the purpose of sustaining human beings to make the transition from biological existence in this earthly life to a spiritual existence that reaches beyond death. Jorge, Jose, and Maria experienced this transition as they considered that their existence was more than biological and they expanded the understanding that the spiritual existence also has a value.

The journey for Pedro, Jose, and Maria is a journey with two elements or two stories pointed out by Pieper: “the absence of fulfillment and the orientation toward fulfillment.”¹³⁸ In other words, one element is related to the human imperfection, with the desire to continue on this

¹³⁶ Pieper, 40

¹³⁷ Lester, 64

¹³⁸ Pieper, 13

earth and the second element is the internal desire or natural orientation to achieve fulfillment, to the happy outcome of this pilgrimage, to be with God. In this life, according to Pieper, human beings progress toward fulfillment by affirming that “hope like love, is one of the very simple, primordial dispositions of the living person. In hope human beings reach with restless heart with confidence and patient expectation toward the not-yet of fulfillment, whether natural or supernatural.”¹³⁹ This reaching out comes from the inside of us. For Lynch, “hope is truly on the inside of us but hope is an interior sense that there is help on the outside of us.”¹⁴⁰ If we are moving in a journey toward the future, in hope there is a future; “if there is a future to which we can look forward, we can endure all things in hope.”¹⁴¹ Hope becomes the vehicle which will take us toward the future.

For Galilea, “hope is the security to obtain, possess, and enjoy what we cannot see. Hope is the firm conviction that the promise we know by faith will be fulfilled.”¹⁴² Part of the promise is that we will have eternal life, but that eternal life begins here on earth with limitations. “The full manifestation of this eternal life, in the resurrection, belongs to a future that passes through our own death. This future no one has seen, but it is hoped for, because of the promise of Christ accepted by faith.”¹⁴³ Therefore, hope is the conviction of eternal life that faith promises us. Galilea talks about firm conviction and the security of having eternal life, something that we cannot see yet, but we will after death. However, Pedro, Jose, and Maria, are not certain of

¹³⁹ Ibid., 27

¹⁴⁰ Lynch, 40

¹⁴¹ Ibid., 70

¹⁴² Galilea, 4

¹⁴³ Ibid., 6

obtaining that eternal life; they are afraid because that promise is not clear for them, and the result is they carry multiple stories. The multiplicity of stories makes me wonder how their faith affects their stories of hope? Or is the Christian identity affected by the way they interpret the Christian narrative and promise of salvation, or sacred story?

According to Stroup, Christian identity is created around the narrative of the cross, but the cross is not the final event in the identity of Jesus. The story of the cross has to be interpreted only in relation to the other event of the narrative, the resurrection. Stroup affirms that “the memory of the resurrection of the crucified Christ compels the Christian community to look to the future in hope and anticipation of the consummation of Christian narrative.”¹⁴⁴ A crisis of the Christian identity could affect the identity of the patient if the Christian narrative is not interpreted in its entire event. We could focus on the stories on the Scripture if we see it as a narrative that does not need interpretation in the present. We could say, the God of the Bible has cured the sick and raised the dead, and if we have enough faith God can do the same for us. For Stroup, “Christian identity is neither simply a repetition of the past nor a construction unrelated to the past but the result of faith’s struggle to extend Christian narrative into a new and unforeseen future.”¹⁴⁵ Based on an understanding of the God of the Bible who cured the sick, I can interpret that Pedro, Jose, and Maria were expecting a divine intervention to prolong their existence and cure their bodies because God has done it before and they kept the door open for a repetition of the story.

Lester reminds us that, “each individual has created stories that express personalized

¹⁴⁴ Stroup, 260

¹⁴⁵ Ibid., 261

understanding of religious faith.”¹⁴⁶ Those stories are created based on what we have learned as we are growing up, what we have experienced in the past but also they include the future guiding the journey into tomorrow. From a narrative perspective, the sacred story in the future that empowers life in the present “is about the God-who-is-love.”¹⁴⁷ However, not everyone experiences the same kind of God, because we get to know God in different ways, and most of the times we know a particular image of God based on the understanding of God that our parents or significant people instill in us. Thus, there is no guarantee that a person can have an understanding of a loving, forgiving, and merciful God when that person does not have the means to get to that knowledge. As a result the future narrative which provides the energy for hope may not include all the elements that a patient who is facing end-of-life needs in order to find meaning for his or her dying experience, and to find continuity of life after death. As Lester argues, “hope must be grounded in trust that the God-who-is-love will keep the promises made, rather than in expectation that God will initiate certain events or actions.”¹⁴⁸ Following Lester, I formulate two questions to explore Pedro, Jose, and Maria’s narratives of hope: What is their understanding of that promise? And, what kind of God do they trust?

If we anticipate suffering in our future, we are uncertain of God’s promises, and we think that a kind of punishment after death could be possible, most likely we will suffer difficulties in the present tense such as fear or anxiety. For Lester, “awareness of potential future suffering is the ingredient that transforms the situations into crisis. At the heart of those crises is the fear and

¹⁴⁶ Lester, 39

¹⁴⁷ Ibid., 40

¹⁴⁸ Ibid., 67

anxiety related to projected alteration of the future story.”¹⁴⁹ Therefore, from a pastoral theological perspective, “threats to ones future story make one vulnerable to despair.”¹⁵⁰ Pedro, Jose and Maria are afraid of death but also they are afraid of what will happen after death. They struggle to accept their declining condition when they are unable to have access to their sacred story. For them, knowing that the end is close created unwanted feelings. They believe that they need more time in this life to make sure they can have a place with God. They experience hope but the way they understand it is not helping them to see the fullness of life.

Galilea affirms that “hope comes exclusively from God but it is revealed to us wrapped in human events.”¹⁵¹ From his perspective, human beings do not possess hope in a complete form because it looks to a full realization in the future. However, even when we do not possess it fully, we can experience it in the present and therefore we can educate it, nourish it, or make it grow. The stories of Pedro, Jose, and Maria show how hope can be changed by meaningful relationships. For Galilea, “hope is educated by human experience. Without them, hope does not develop.”¹⁵² These patients report that having the support from family, friends, or community is an important element for them to help them feel better. The experience of these patients also shows how the lack of support or the fact that their families are unable to travel from their own country increases the intensity of their unwanted feelings.

Similarly, Galilea makes an interesting point by explaining how hope can grow with any human experience. It can grow when we experience true love, fellowship, or friendship, hope can also grow when we experience failure and disappointments from the people we trust. The

¹⁴⁹ Ibid., 45

¹⁵⁰ Ibid.

¹⁵¹ Galilea, 45

¹⁵² Ibid.

growth is different but both can contribute to the development of hope Galilea continues, affirming that “the human experiences of fullness and consolation nourish hope when we recognize in them the anticipation of the promised happiness and well-being.”¹⁵³ This experience of growth is when everything looks good in life, when we are achieving our goals, when our relationships are helping us to anticipate the happiness we will achieve in eternal life. The other one, “crosses and desolation nourish hope as purification and crisis that lead to maturity,”¹⁵⁴ are also an opportunity to hope. How is this possible? For Galilea, hope can grow stronger when less is seen; “in life the bad times more than the good times are times of hope because hope increases as less is seen.”¹⁵⁵

Whereas in the stories of the previous chapter where hope was experienced in fullness of life, hope grows even in the darkness for Pedro, Jose, and Maria allowing them to have a glimpse of the meaning of experience of hope. Yet their waiting experience produced limited life because the promise of heaven was ambiguous for them creating fear and uncertainty. During the conversations Pedro, Jose and Maria acknowledge that they do not need to have everything in order to experience the fullness of hope. They do not need to have all their families together. But this growth does not happen easily or automatically. Galilea continues arguing that sometimes the experience of the cross and desolation destroys hope, but also the experience of fullness and consolation has the potential to destroy hope. When everything is going well in our life, we may focus only in the present and forget about the future promises. When we experience frustrations and failures we have risk living in despair and disconnection from the theological experience of

¹⁵³ Ibid., 46

¹⁵⁴ Ibid.

¹⁵⁵ Ibid.,17

hope because “success and failures are two sides of the same temptation against hope.”¹⁵⁶ Pedro, Jose, and Maria experience both, failures and success; sometimes they feel good, other times they are fearful. In both situations hope can grow and help them to maintain the vision of an open-ended future.

For Lynch, “hope cannot be achieved alone. It must in some way or another be an act of community, people develop hope for each other, hope that they will receive help from each other.”¹⁵⁷ In the same line, for Lester, hope is communal and relational; “hoppers have roots in some community with which they identify and with whom they feel bounded. Whether the community is their own family and friends, or a larger entity such as a nation or a church, hoppers feel a connectedness with it.”¹⁵⁸ Connectedness is a value that Hispanic people bring to this country. Montilla notes that, “Hispanics are born, reproduce, grow, unfold, mature, and die in community. Because of their gregarious nature, they need the community in order to receive the healing power of relationships.”¹⁵⁹ These three patients said, “At first, I was mad, and I was asking God for a miracle to heal my body but that changed overtime.” They expressed that the change occurred when they were involved fully in a community. When they felt like part of a group, some of them had the opportunity to see their families who were in another country at least for a few days, others joined to prayer groups in a local church, while others felt the medical staff as part of their family.

For Hispanics, “connectedness is an integrated part of their daily functioning and that tending to the whole person within the community context is essential for the healing

¹⁵⁶ Ibid., 46

¹⁵⁷ Lynch, 24

¹⁵⁸ Lester, 95

¹⁵⁹ Montilla, 18

process.”¹⁶⁰ The value of togetherness provides information to answer the question of why some Hispanic patients, when they are sick or facing end-of-life, have hospital rooms full of people? Some patients who do not have their immediate family in this country request medical letters for the immigration office hoping to get a parole visa for their relatives. Togetherness provides healing as hope increases.

2. A Journey with Multiple Arrival Points: Meaning of Salvation

The waiting experience for Pedro, Jose, and Maria is a story of multiple stories and their narrative of future-oriented-stories-of-hope also are journeys with multiple arrival points. This section is written not with the intention to correct Pedro, Jose, and Maria’s view of salvation but with the purpose to describe the influence of the Catholic tradition in the cultural understanding of the Hispanic population. The exploration of the issue of salvation will provide a better understanding of the construction of the stories of hope for these three patients. According to their stories, the journey has an arrival point for these patients with different possibilities: heaven, purgatory, or hell. Pedro, Jose and Maria understand salvation as a gift from God but they also believe that to be in heaven they need to have good works; therefore it is difficult for them to have the certainty of salvation. Their stories represent attending to the Catholic teaching and the question of what we need for salvation. We Catholics cannot say with certainty, “I Have been saved;” we wish we could have the assurance of salvation. We cannot presume that, “all I have to do is accept Christ as my personal Savior, and it’s done.” Catholics think of salvation, ultimately, as a process that is begun with faith and baptism. Most Catholics are able to speak of

¹⁶⁰ Ibid., 18

specific events, such as the first time they truly understand that Jesus is Lord. Many are able to tell specific stories of experiences of the Holy Spirit. Many have wonderful stories of healings, consolation, and miracles. To speak of "having been saved," in the past tense, is something Catholics tend not to do unless we are speaking about our baptism, at which time we were first justified.

Rahner writes a reflection about the tension between being justified and the continual sinful condition. Rahner claims that "the Christian is a sinner because of the ingrained self-love which inclines him to sin, at least venial sin and to habitual imperfection. Yet the Christian is also justified because Christ's grace within him contends against his human sinfulness."¹⁶¹ Under this dynamic, human beings are sinners who always maintain the hope of escaping away from that sinfulness, trusting in the mercy of God. Rahner continues, "Even when justified, human beings remain in pilgrim. We are on a pilgrimage in the faith. We possess God only on the ground of hope."¹⁶² However, our sinful human condition does not allow us to be certain of our salvation. As human beings "we place our hope in the grace of God, but we can never do this proudly and self-assuredly with a theoretical certitude of salvation."¹⁶³ We are just sinners, but at the same time, we are in the process of becoming perfect as we are in search of perfection. As human beings we are allowed to live in ambiguity as Pedro, Jose, and Maria do. But in the middle of that ambiguity we can keep our hope alive by believing in the possibility of participation of the fullness of life. This reality depends on our capacity to trust and hope.

In the Catholic tradition there is an understanding that the Christian "is nothing but

¹⁶¹ Gerald A. McCool, *A Rahner Reader* (New York: The Seabury Press, 1975), 310

¹⁶² *Ibid.*, 311

¹⁶³ *Ibid.*, 310

nothingness and that left to himself he is nothing but sin. Wherever he discovers something good in himself he must acknowledge it as a causeless free grace of God.”¹⁶⁴ Related to the issue of whether one can lose one’s salvation is the question of whether one can know with complete certainty that one is in a state of salvation. Even if one could not lose one’s salvation, one still might not be sure whether one ever had salvation. Similarly, even if one could be sure that one is now in a state of salvation, one might be able to fall from grace in the future because of our sinful condition. It looks like Catholics live every moment in terror and fear created by the probability of losing salvation since Catholics recognize that it is possible to lose salvation through mortal sin. However, one can be confident of one’s present salvation. This is one of the main reasons why God gave us the sacraments to be used from the moment we are born to the moment we die.

Sacraments provide visible assurances that God is invisibly providing us with God’s grace. One can also be confident that one has not thrown away that grace by simply examining one’s life and seeing whether one has committed mortal sin. Catholics can express this confidence “by saying that he is always and of himself a poor sinner and always someone justified by God’s grace as long as he does not close himself to this grace of God by disbelief and lack of love.”¹⁶⁵ The saints have confessed themselves as sinners and that act brought them to a position where they could receive God’s love and grace. For Rahner, “in this consciousness of their own sinfulness they discovered in themselves that miracle which means that God fills our hands with his glory and makes our heart overflow with love and faith;”¹⁶⁶ Therefore,

¹⁶⁴ Ibid., 312

¹⁶⁵ Ibid.

¹⁶⁶ Ibid., 313

recognizing before God our sinful human condition helps to make that person justified, a holy, just and blessed member of the family of God.

By looking at the course of one's life in grace and the resolution of one's heart to keep following God, one can also have an assurance of future salvation. Paul speaks of this situation and says (Phil. 1:6), "And I am sure that he who began a good work in you will bring it to completion at the day of Jesus Christ." The Catechism of the Catholic Church affirms that "our justification comes from the grace of God. Grace is favor, the free and undeserved help that God gives us to respond to his call to become children of God, adoptive sons and daughters, partakers of the divine nature and of eternal life."¹⁶⁷ Grace is a participation in the life of God given to us on the day of our own baptism. This participation in the divine life depends only on God's gratuitous initiative. The catechism continues, "The grace of Christ is the gratuitous gift that God makes to us of his own life, infused by the Holy Spirit into our soul to heal it of sin and to sanctify it. It is the sanctifying or deifying grace received in Baptism. It is in us the source of the work of sanctification."¹⁶⁸ The catechism affirms that God provides for us sanctifying grace or habitual grace, which is a stable and supernatural disposition that perfects the soul itself to enable it to live with God, to act by his love:

The preparation of man for the reception of grace is already a work of grace. This latter is needed to arouse and sustain our collaboration in justification through faith, and in sanctification through charity. God brings to completion in us what he has begun. Certainly we also work, but we are only working as a response to God who works ahead of us. It has gone before us so that we may be healed, and follows us so that once healed, we may be given life; it goes before us so that we may be called, and follows us so that we may be glorified; it goes before us so that we may live devoutly, and follows us so

¹⁶⁷ Catholic Church, *Catechism of the Catholic Church*, #1996

¹⁶⁸ *Ibid.*, #1999

that we may always live with God: for without him we can do nothing.¹⁶⁹

Faith and works of charity are needed for God's children to be able to participate in God's life as a human response out of gratitude for what God has done for us, not as a human requirement to enter into heaven. Justifying faith produces good works. "But faith never receives forgiveness of sins on account of love or works. The believer cannot love at all unless the heart is confident of forgiveness through Christ. Once the confidence is in the heart, love follows."¹⁷⁰ Therefore, there is a connection between a living faith and good works. St. Teresa de Avila affirms and witnesses with her life the fruits of a genuine love of God acknowledging that "the Lord does not look so much at the magnitude of anything we do as at the love which we do it."¹⁷¹ The Catholic church teaches that "every man after death, his immortal soul receives his eternal retribution in a particular trial that refers his life to Christ, either through a purification, either to immediately enter into the bliss of heaven, either to immediately condemned forever,"¹⁷² and concludes this teaching with the words of San Juan de la Cruz: "In the afternoon we shall be judged on love."¹⁷³

To the question, "Are you saved?" Catholics following Paul's teaching could reply, "In hope we were saved" (Rom. 8:24). This indicates an action that took place in the past, in the day of Baptism; but also we are being saved in the present and as work in progress due to our sinful human condition. We have the hope that we will be saved in the future because we have

¹⁶⁹ Ibid., # 2001

¹⁷⁰ George Anderson, Austin Murphy, Joseph A. Burges, *Justified by faith* (Minneapolis: Augsburg Publishing House, 1985), 196

¹⁷¹ Philippe De la Trinite, "God of Wrath or God of Love" in *Contemporary Catholic Thought*, ed Barry Ulanov (New York: Sheed and Ward, 1963), 280

¹⁷² Catechism of the Catholic Church # 1022

¹⁷³ Ibid., #1022

confidence in a merciful God who wishes everyone to be saved. The goal as Paul writes at the end of his life is to have the confidence to say, "I have fought the good fight, I have finished the race, I have kept the faith. Henceforth there is laid up for me the crown of righteousness, which the Lord, the righteous judge, will award to me on that Day" (2 Tim. 4:7-8).

The stories of Pedro, Jose, and Maria represent the struggle of many Hispanic hospice patients who have difficulty living with ambiguity who face the reality of death because of the fear of what could happen to them after their death. The teaching of the Catholic Church represents a strong influence in the cultural understanding affecting the way these patients embrace their faith and construct their story of hope within the sacred story. In this chapter, I explored how in the midst of ambiguity it is possible to maintain hope and experience the fullness of life. The reason behind my decision to explore the understanding of salvation from a Catholic perspective corresponds to the influence and power of this catholic discourse merged within the cultural context affecting the waiting experience of many Hispanic patients.

During my conversations with Pedro, Jose, and Maria I did not intend to change their belief system by telling them "you are wrong in the way you are interpreting your sacred story." I explored the meaning of salvation for each one of them and I listened carefully to hear what they were not saying looking for contradictions to their story of suffering. By my questioning they were able to access new stories in order to create a different understanding of a God who is loving and merciful and who loves sinners. We discussed the importance of good works and they acknowledged all what they had done in their lives, such as helping their families in so many different ways. This process gives them the opportunity to develop another story about themselves.

CHAPTER 5
WAITING EXPERIENCE WITH STORIES OF HOPE:
“NO FUTURE LIFE”

In the previous chapters, I explored the waiting experience for some patients who understand the future story of hope with the fullness of life and also I described how for others, the understanding of the story of hope is ambiguous and produces limited life. Now I will engage in conversation with a patient whose future story of hope has no life but punishment.

Jorge’s waiting experience is a story of sadness, depression, and limited life. He feels lonely because he thinks that nobody cares about his life. The story of hope is a story of hopelessness with the belief that after death there is only nothingness and punishment. Jorge is convinced that he does not have even a minimum chance to have life after his death because of all his actions in this earth. Jorge’s story of hope represents what I have come to call “no future life.” By that I mean Jorge is certain that God is mad at him for all the mistakes he has done in life, therefore, eternal punishment is waiting for him.

A. Patient’s Experience

1. Jorge’s Waiting Experience and Story of Hope

Introducing Jorge

Jorge is 58 year old man from Mexico. Jorge has been married three times and all ended in divorce and violence. He lived with a son with whom he does not have a close relationship. According to the son, he is taking care of his father because he wants to do it, thinking that this is

his responsibility; but they do not have a father-son- relationship.

Experience-Present

Jorge does not find any reason to continue living, but he is fearful to die because he does not know what to believe about what occurs after death. Jorge cannot accept the harsh reality of what his doctor is saying in that there is nothing more to be done. Jorge reports, “at first I did not want to believe anything about my illness. I felt normal like any other person, but then little by little I started to experience pain and I said to myself, this is not normal. I started to believe that I was really sick and I was going to die.” Jorge is feeling fearful, lonely, and lost. His dying is a solution for his life and at the same time it is his biggest problem. Jorge’s family is scattered and he does not have any meaningful relationships to support him in his waiting experience.

Experience-Future

Jorge wants to believe in life after death but he says, “I do not know what to believe, nobody taught me anything, now I feel lost. After I die, everything is over. Life is done, I will cease to exist.” He explains, “if there is a heaven, I do not think it is for me. We should behave properly and forget about evil, but evil attracts more evil and I have regrets of not doing good things, but nobody was there to guide me for the path.” Jorge has some vague ideas about life after death but they are not strong enough to sustain him during his dying process. Jorge says, “many times I am scared of the transition of leaving this life and entering into death. I am trying to learn about this process of entering into this new world but I do not know what to do and I do not have anyone to help me, I just need someone to help me.”

In the middle of his fear, Jorge keeps saying, “I hope someone can help me and teach me

what to believe.” In order to expand what Jorge wants to believe, I ask him, “What would you like to believe?” He answers, “I want to believe that there is life for me after my death; that there is a chance for me to be with God.” When I ask Jorge to imagine the day he is entering to meet God, he is terrified and just answers by saying, “I do not know.” After several questions Jorge is able to access this source of information and he expresses what he would like to hear from God as he enters into heaven: “Welcome home.” Jorge needs to construct his belief system from scratch and he is aware of the need for the construction of his belief system. He needs someone to guide him. What would it take for Jorge to construct a belief system? He already mentions that he wants to believe that there is life after death, and that he wants to hear the voice of God telling him, “welcome home.”

Jorge has no access to the creation of any sacred story because his interpretation of his sinful condition is taking over his life. During the conversation, I ask Jorge to imagine what God would ask him to do in order to welcome him home. He responds by saying: “I will have to ask for forgiveness.” Jorge shares the story of his struggles and he mentions his desire to have forgiveness and reconciliation. This becomes part of his belief system which he did not have access before this conversation. In our conversation we discuss different images of God that include a loving, forgiving, and merciful God to contrast the story of a punishing God capable to send anyone to a place of eternal condemnation and deprive anyone from the enjoyment of life.

Experience-Past

According to Jorge, being lost and confused about the dying process and life after death is a result of the lack of guidance from? He recounts, “I have the regret of not doing good things. I could have lived a better life but I did not have anyone to guide me on that path.” Jorge is

fearful. He is aware of his many errors in life as opposed to those good things he has accomplished, and for him, God would not be happy and might even terminate his existence as a result of his actions. Jorge explains that his parents did not teach him what to believe and he just learned on his own how to live his life. Now that he is dying he realizes that he did not make the right choices.

Jorge is facing a waiting experience with the certitude that there is not even the minimum chance for him to participate of God's abundant life. Jorge is lonely and feels lost. As he waits in bed for the last day of his life he lives in fear because according to him, he is a sinner and deserves no life at all. In the next section I will discuss how a patient who perceives a closed-ended future is most likely to face despair.

B. Integration of the Data: Experience-Tradition-Culture

Jorge is living in fear his waiting experience, feeling abandoned. He does not have any meaningful relationships. He is afraid because he does not think his future story is providing life, but punishment for him. Jorge complains because he did not have anyone to teach him how to make the right decisions, but even when he is living in hopelessness he is facing his waiting experience with hope. Jorge hopes that someone can help him to find reconciliation and build his belief system. Jorge has an unwanted future story of hope and he is asking for help so he can change it. I will discuss the effects of living in hopelessness and the impact of the tradition/cultural influence of the Roman Catholic Church regarding a God who will make us pay what we have done wrong and will send us to hell if we die without being reconciled.

1. Unwanted Waiting Experience: Hopelessness

Jorge not only perceives a change in the future story as he sees his body declining and gets closer to death, but he also perceives a complete loss of the story of hope after he dies. According to him, when he dies, there is nothing for him. When there is not more future or no other future story has been put in place, Lester notes that, “they may actually experience a taste of despair.”¹⁷⁴ This could happen when we invest our time in developing other kinds of projects so that we forget to develop the sacred story, and as a result, “when there is no more future, life becomes scary and despair.”¹⁷⁵ For Lynch, hopelessness is experienced when we think there is no more future ahead of us creating a “sense of the impossible.”¹⁷⁶ This way of feeling creates a sense of no goals, no reason to live and there is a disconnection from everything; “the present moment has no connection with the next, I therefore I do not move, it’s something like death.”¹⁷⁷

When someone is facing hopelessness, that person assumes that there is no help, no internal resources that he or she can use. As Lynch notes, “frequently, when someone feels this way, he is really demanding that someone else do things for him.”¹⁷⁸ This is seen in Jorge’s repeated statement that, “I need someone to help me, to teach me, to guide me.” He felt as if he had no resources to use and everything was futile to him. According to Donald Caps, one of the reasons a person experiences despair (one of the major threats to hope), is related to their

¹⁷⁴ Lester, 75

¹⁷⁵ Ibid.

¹⁷⁶ Lynch, 48

¹⁷⁷ Ibid.

¹⁷⁸ Ibid., 50

perception of time; their time is too short, it is not enough. Another reason to experience despair is, “when looking back on periods of one’s life, or perhaps the whole of ones’ life, and realizing that there were years or decades, that were essentially wasted or misdirected.”¹⁷⁹ For this patient, the experience-past is the reason for his despair because of all the things he felt he did wrong and because he had nobody to guide him on how to live his life. His despair was also related to his future because he knows he is dying soon and he does not have enough time to demonstrate a change in his behavior. As a result, he thinks that there is no hope at all for him.

Despair may be expressed in two forms: “It might be projected outward in the form of disgust directed against other persons or in situation, or it may be deeply internalized in the form of depression.”¹⁸⁰ For Lester, despair also includes some form of depression, as he notes that despair “is primarily related to a cognitive and effective and affective response to spiritual problems rooted in or leading to negative perceptions about the future. Despair is an internal frame of reference convinced that the future is closed down, unchangeable, and meaningless.”¹⁸¹ Jorge understands that he does not have a future, or better said a hopeful future, because all he sees is punishment and death.

Negative God images have an impact in the way we perceive or understand the Christian narrative and the promise of salvation. I mentioned previously how Nouwen argues that “when we can reach beyond our fears to the one who loves us with a love that was there before we were born and will be there after we die, then oppression, persecution, and even death will be unable

¹⁷⁹ Donald Caps, *Agents of Hope: A Pastoral Psychology* (Minneapolis: Fortress Press, 1995), 100

¹⁸⁰ *Ibid.*, 105

¹⁸¹ Lester, 73-74

to take our freedom.”¹⁸² However, Jorge developed an image of a God who will be a judge more than a loving and caring God. Lester maintains that “those who feel that God is out to teach them a lesson, keeps a record of their sinful actions, and accuses and condemns them will feel despairing.”¹⁸³ Jorge is fearful to meet God face-to-face because he believes that God will ask him for an account of his actions in this life. As Lester notes, “when people feel that God is upset with them, they find it difficult to be hopeful. Their God is related to law rather than grace.”¹⁸⁴ Lester and Nouwen agree that those who live this life aware that God loves them have a better chance to think “that God calls them into a positive future.”¹⁸⁵ Jorge’s understanding of God does not include the image of a loving God who is capable to love God’s children unconditionally regardless the living situation. As a result, Jorge’s future is negative and does not allow him to see any possibility to have life after his death.

2. The Fear of Hell: Limited Life

Chapter II included a discussion of how the Catechism of the Catholic Church regarding death mentions different possibilities of life after death by arguing that there will be a judgment after we die and the place that will be given to us will be a result of that judgment. The Catechism teaches that:

Death puts an end to human life as the time opens to either accepting or rejecting the divine grace manifested in Christ. The New Testament speaks of judgment primarily in its aspect of the final encounter with Christ in his second coming but also repeatedly

¹⁸² Nouwen, *Our Greatest gift*, 17

¹⁸³ Lester, 82

¹⁸⁴ Ibid.

¹⁸⁵ Ibid.

affirms that each will be rewarded immediately in accordance with his works and faith.¹⁸⁶

The Catholic Church affirms that there is judgment after death as well as a reward according to how a person has lived their life. The catechism continues explaining that “each man receives his eternal retribution in his immortal soul at the very moment of his death, in a particular judgment that refers this life to Christ: either entrance into the blessedness of heaven through a purification or immediately, or immediate and everlasting damnation.”¹⁸⁷ Based on this teaching, there are three possible places where we can be after death: heaven, purgatory or hell. Those places will be assigned after the judgment depending on the acceptance or rejection of Christ; in other words, the judgment will be based on works and faith. According to Jorge’s narrative, he is afraid of receiving eternal punishment.

Taking into consideration this Catholic teaching, can Jorge be certain of having a life after death if death is linked to the life that he has lived? Following the Catholic teaching, there is a place of purification where the soul can get prepared for the entrance into heaven, “all who died in God’s grace and friendship, but still imperfectly purified, are indeed assured of their eternal salvation, but after death they undergo purification, so as to achieve the holiness necessary to enter the joy of heaven.”¹⁸⁸ How then are we to overcome our fear of death and be assured that we will have a place in heaven? How, as human beings, can we obtain the confidence that our death will give new life, new hope and new faith to the people we love, and not be another cause of pain, suffering, and sadness?

In the Scripture, we see Jesus forgiving sinful people as a sign of his Father’s nature,

¹⁸⁶ *Catechism of the Catholic Church*, # 1021

¹⁸⁷ *Ibid.*, 1022

¹⁸⁸ *Ibid.*, 1029

compassion and forgiveness. Jesus forgives sins in the name of God and he also forgives those who have hurt him on a personal level. Jesus preaches a message announcing how God is merciful, compassionate, and loving. A Roman Catholic priest and psychotherapist, Patrick Brennan, affirms what he thinks God wants from us “a contrite heart. We are to humble ourselves and seek the forgiveness of those we have hurt.”¹⁸⁹ Brennan recommends the use of reconciliation because he considers it as a process to grow in God’s grace. However, Brennan thinks that in the story of the Prodigal Son (Luke 15:11-31), as a story of reconciliation, Jesus captures the nature of human condition.

For Brennan, “the Prodigal Son’s decision to return is prompted by a number of factors: pain, hope for a new beginning, shame, guilt, and to some degree, sorrow.”¹⁹⁰ The decision to return is made with the purpose of easing the pain he caused himself. Jorge is afraid of not having life after death and his motivation for reconciliation might be influenced by the fear of eternal condemnation. However, as Brennan expresses it, “part of the good news of the parable of the Prodigal Son is that God’s grace can take imperfect motivation and transform it into something greater.”¹⁹¹ At the end we belong to God and God will find ways to assure that all God’s children can have a chance of eternal life. Jesus testifies and proclaims (John 6:38-40), “For I have come down from heaven, not to do my own will but the will of him who sent me. And this is the will of him who sent me that I should lose nothing of all that he has given me, but raise it up on the last day. For this is the will of my Father that everyone who looks on the Son and believes in him should have eternal life, and I will raise him up on the last day.”

¹⁸⁹ Patrick Brennan, *The Way of Forgiveness*, (Ann Arbor: Servant Publications, 2000), 12

¹⁹⁰ *Ibid.*, 33

¹⁹¹ *Ibid.*

Jorge is able to have access to his belief system. His plea of “I need someone to help me what to believe” was a way of saying I need someone to help me have access to my belief system. Jorge was able to access his belief system as he acknowledges that he needs forgiveness and reconciliation in order to have a chance to be with God. Jorge knows what to believe and he knows what he needs to do. The fear of eternal condemnation became the core future narrative and influenced his waiting experience by making him believe that he had no future and no opportunity to have eternal life.

C. ASSERTIONS: FULLNESS OF LIFE, AMBIGUOUS-MULTIPLE STORIES WITH LIMITED LIFE, NO FUTURE LIFE

During the assertion stage which included chapter 3, 4, and 5, I explored with the patients their understanding of the future-oriented-stories-of-hope with the purpose of finding dialogue between the waiting experience and the sources of information. The results of the interviews show that the participant patients construct their stories of hope based on their unique understanding of what happens after death. The participant patients report that the stories of hope can be visualized in three different ways: Fullness of life which means participation in God’s life in heaven; limited life with ambiguous and multiple stories which include three possibilities after death, heaven, purgatory, or hell; stories of hope with no future life but eternal punishment in hell.

The waiting experience of each one of these patients is affected by the way they interpret the future story of hope. The patients who envision the fullness of life in their future are able to enjoy their life in the present with their families and wait with confidence for the last day of their

life on earth and the continuation of life in heaven. The patients who envision a future life with multiple stories face the waiting experience with mixed emotions due to the fact they do not know for sure which story will be their arrival point in their journey. For the patient whose future story is lost and includes no life but punishment, his waiting experience is filled with fear, sadness, and hopelessness.

Why do these patients interpret their future stories of hope in so many different ways? Different factors may have been affecting their interpretations. Some patients did not have a significant relationship as they were growing up to teach them and guide them. Others did not have their extended families in this country as they are in the process of dying, which is a significant part for the experience of healing for Hispanics. Another element contributing to the differences in their responses was the age of the patients and the existence of young children under the care of the patients. And one more element which I want to mention is the influence of the teaching of the Roman Catholic Church in some Hispanic countries in the form of experience, tradition and cultural information. Some Hispanic patients do not need to go to church to have an awareness of how life and death should be interpreted because the powerful discourse of the church is seen as experience, tradition and culture merge together affecting the construction of the core narratives for Hispanics. I am moving to the last chapter of this research project, decision for action. This chapter will transform the insights gained through the entire process of this research into action or pastoral response with the purpose to provide helpful interventions for chaplains working with Hispanics in the context of hospice.

CHAPTER 6 PASTORAL RESPONSE

The third stage of the pastoral theological method developed by Whitehead and Whitehead is to arrive at a decision or pastoral response. Such a decision is a result of the interaction of the three sources of information giving rise to new insights. In other words, the task of the third stage of the method is to translate the insights into action. The question to be answered in this concluding chapter is: How does the insight I have gained from consulting the three sources of information, including the narratives of the patients whom I interviewed, lead to action?

In an effort to explore how the meaning attached to the story of hope for Roman Catholic Hispanic hospice patients impacts their waiting experience, I made use of narrative theory with a group of six patients. This, in dialogue with information from the sources of tradition, experience, and culture, lead to new insights about practices for pastoral caregivers. In the context of hospice the objectives of a pastoral caregiver is to offer meaningful support for patients and nourish hope. The results of this research project provide a helpful resource for chaplains in order to offer meaningful and sensitive pastoral care for Hispanic patients.

The assertion stage of this project shows that some Hispanic patients construct their future-oriented-stories-of-hope in three different ways, each shaped by an understanding of the stories of hope that have an impact on the waiting experience of the participant patients. The three different ways run parallel to their vision of their future experience. The three ways of moving through the waiting experience present in the participant patients with whom I spoke include: embracing the fullness of life, living with ambiguous-multiple stories that produce

limited life in the present, or living with a sense of hopelessness and no life.

In this chapter I want to summarize my findings and offer some concrete suggestions for pastoral caregivers who want to bring cultural sensitivity to their work with Hispanic hospice patients. The conclusions of this written project are organized under four headings: Summary of my findings, the value of maintaining narrative conversations at the end of life for Hispanic patients, the limitations of this research and questions for the future, personal reflections, and helpful interventions for pastoral caregivers in the context of hospice.

A. Summary of the Findings

This study should be considered an initial exploration on the influence of the narratives of future-oriented-stories-of-hope in the waiting experience for Hispanic Roman Catholic hospice patients. The results of this study indicate that hope is a significant dynamic for Hispanic patients when facing end-of-life, and hope is a human and divine dynamic affecting their lives in different ways. Some Hispanic patients are positively affected by the way they maintain their human hopes in communication with their divine hope. These patients are able to integrate both, human and divine hope, within their sacred story, giving them the opportunity to enjoy the fullness of life not only in the future dimension of time consciousness but also during the waiting experience located in the present tense. Other patients express some difficulties in experiencing the fullness of life because they are dealing with some concerns not only in the present tense but also in their anticipated future, creating for them a waiting experience with limited life. For one patient in this study, the waiting experience is one of fear and hopelessness because the story of hope is a dreadful story of punishment with no possibilities of life. Based on my own

observations, I argue that experience-future affects experience-present in a significant way, but also experience-past plays an important role because it informs both, experience-future and experience-present.

The waiting experience for the participant patients varied according to their construction and understanding of the concept of future-oriented-stories-of-hope. The responses of these six Hispanic hospice patients indicate that the story of hope is often constructed by envisioning life after death in different ways: fullness of life, limited life, or no life. This study also shows that the construction of the future stories of hope are influenced by the experience of love and trust that these patients witness from the past, as they learned from their families or other significant relationships. The patients who believe with confidence that they will have the abundance of life after their death are able to live the waiting experience also with the fullness of life. This confidence, as they describe, is a result of experience-past where they begin to construct a helpful belief system which allows them to find meaning for the waiting experience and to survive in the midst of struggles.

The patients who anticipate their future story of hope with a possibility of limited life face the waiting experience with mixed emotions of fear and confidence. Sometimes they acknowledge that they will have the fullness of life after death so they try to live their waiting experience with confidence and love. When the possibility of having life gets dark, they face a waiting experience of sadness and fear. These particular patients believe that the life they will experience after their death will depend on the accomplishments in the past and present life. But the fact that their life is coming to an end creates unwanted feelings, especially when they think that they will not have enough time to do what they believe they need to do to guarantee the experience of the fullness of life.

For another patient, the story of hope does not include the remote possibility of life after; therefore the waiting experience for him is filled with fear. Because the story of hope for this patient does not promise any life but punishment, he lives in despair trying to find a last minute reconstruction for his unwanted future story. However, even though this patient lives his waiting experience in hopelessness, he still keeps his hope alive as he waits for someone to show up and help him reconfigure his belief system so he can avoid the idea of facing punishment and no life after death.

The waiting experience for these six patients shows a strong connection with the future dimension of time consciousness as they face the end-of-their-biological-existence in the present tense and start the transitional process of experiencing the continuity-of their-spiritual-life through hope. The gifts of narrative conversations can assist patients and pastoral caregivers in reflecting meaningfully on the waiting experience.

B. Value of Narrative Conversation for Hispanic Hospice Patients

According to the results of this research project, the participant patients are able to maintain meaningful conversations that allow them to share their understanding of the waiting experience. Having conversations through narrative approaches, these patients explore the anticipated future stories and find confidence in describing the meaning of their waiting experience, the understanding of death, and their belief about life after death. It is interesting to note that all the participant patients requested to continue conversations in a second interview, suggesting the possibility that they might find help and comfort in maintaining this kind of conversation. While I do not have proof that the patients found these conversations to be

extraordinary in thinking about their future story, I do wonder if the project does not highlight the importance of a narrative approach in conversations with hospice patients.

By the use of hopeful narrative conversations, patients have the option of maintaining meaningful discussions with the pastoral caregiver about their spiritual journey and their relationship with God. These conversations empower the patients to explore their journey of life from their own cultural perspective in search of gifts, talents, and abilities in order to rediscover and reinterpret their participation in the construction of their own identity. During these conversations the patients find comfort as they are able to find meaning for their waiting experience through the dynamics of hope. At first they seem to focus on ways to prolong their biological existence in this earth, but when they find a way to understand that the spiritual existence is also important they transition to a different dimension allowing them to live in freedom, confidence, and acceptance. It is also possible, through the narratives of these patients, to see how theology and popular religion make a difference in their constructions of the future. As the patients explore their own belief system and construct their stories about what they have learned from the teaching of the church, from their cultural experience or from popular religion they can assess what it is helpful or what it is creating conflict in their waiting experience.

Through the use of narrative conversations, patients are able to describe their own journey which includes not only the past but also the perception of their future. Within the context of a non-judgmental but trusting relationship with the chaplain as the researcher, some patients are able to maintain conversations about their funeral arrangements and advance directives without hesitancy. Some patients also complain that their families do not engage them in this kind of conversation and whenever they want to express their need to have these conversations they are ignored. A hospice chaplain trained in narrative theory can provide a

helpful conversation partner when families, for whatever reason, are not able to participate in the planning of funerals of advanced directive.

All the participant patients report that there is something they need to do in this life in order for them to have a place with God. Their hope is based on their ability to do here and now what they think is their responsibility. Some patients show that they are ready and have done their part, others are in the process. For some the priority is to fix the problems with their families and to help their families remain together, while for others it is the experience of suffering, or the need to reconcile with the self, with God, or with others. Narrative conversations allow patients to explore their own journey including past, present, and future. Through the use of imagination, the patients can access the story of hope and evaluate if the way they have constructed the story of hope allows them to enjoy the fullness of life or not. In the same way, when patients have the opportunity to create their story and re-interpret it, they can put in perspective the things they need to do and take credit for those they already have accomplished.

Raul, Antonia, Pedro, Jose, Maria, and Jorge acknowledge the existence of life after death. Some of them anticipate with confidence that they would have a chance to be with God and with their loved ones who died before them; those conversations become a source of strength and encouragement for them. However, for some other patients their chances to be with God are based on how they live their life and some are really concerned: "I do not know if God will forgive me, I want to have more time to do what I need to do, I have done so many things wrong that God will not give me a chance to have new life." Five of the six patients, when asked about the meaning of a life with God after death, were able to construct a story of comfort describing what they believe heaven is and how they would enjoy being there with God and with their loved

ones. It seems that in maintaining this kind of conversation, patients gain access to hidden stories that provide comfort and contradict the story of fear, pain, and no life after death. When their imagination does not let them access these comforting hopeful stories they take time to reflect on the questions so they can create those stories that reframe their identity as they are able to change the perception of their reality.

For two patients the-future-oriented-story-of-hope is a story with an open-ended future filled with meaning and possibilities. These two patients, when invited to share their stories, have no difficulties accessing their future narratives. When guided by questions, these two patients create a sacred story which provides answers and meaning to their living and dying. They share those stories with energy showing a sense of empowerment and pride for their survival even when life was not easy for them. One of these patients starts sharing his story from the moment he opens the door and requests the presence of his wife. He is not fearful of dying and he expresses total confidence that he has done his part and he is ready to accept God's participation in his life. He shares also the joyful anticipation of encountering his parents in heaven. This patient enjoys the sharing of his past-present-future-stories and he requests another opportunity to continue those stories.

The second patient with a waiting experience full of life connects her experience of suffering with the expectation of a better life in the future and acknowledges God's presence in her suffering from childhood; however, she has some difficulty accessing the sacred story or divine hope. She addresses this issue by saying that she wants to have more time here on earth to be with God, during the conversation she makes the connection between her human and divine hope having access to her sacred story and she realizes that her dying will provide an opportunity to be with God. She requests her family be present so they can hear what she has to say. When

this patient shares her story of pain and suffering and how she is able to find hope, her family is in tears saying, “I never knew this about her.” From my perspective, this conversation moment becomes a sacred moment for the patient and the family. By the end of this conversation, both the patient and the family express gratefulness for having the opportunity to achieve connectedness through the construction of their family narrative. This family is able to interpret that they have received the gift of life thanks to the endurance and hope that this patient was able to maintain as she was growing up. This patient died two days after the interview. The family expressed that because of the opportunity they had to hear this patient’s story, they feel comforted and experience a deeper connection with her and with each other.

For three patients the story of hope produces limited life in the future and in the present. Sometimes they are fearful and have suicidal thoughts. They have difficulties accessing their future narratives. They worried about their families who are in other countries, and they have the need to do something to prepare for their death. They live with the knowledge that they are running out of time and that seems to create some fear. For these patients, life after death is limited and has the possibility of punishment, as they learned from the Catholic teaching about the doctrine of hell and purgatory. They are not sure if they have enough good works to assure them a place in heaven and they anticipate meeting a punishing God instead of a loving and merciful God. The fear of suffering in this life and finding suffering in the next life becomes a threat for their experience-present. During the conversations with these patients, they had the opportunity to access their sacred stories and to explore other options that led them toward a more open-ended future. At first, it was difficult for them to converse about a future filled with possibilities; their answers sometimes were limited to things like, “I do not know, I have not thought about it.” However, when they are able to access the future stories, they were able to

develop and expand their stories and move toward joy and strength to the point that they were able to say, “I am not afraid anymore, if God is taking care of me and my family now, God will take care of me and my family after I die.” Considering these conversations I affirm that when patients are able to access their sacred story, they are empowered to manage conversations regarding dying and death.

For one patient, hope is absent and life is not an option. He acknowledges that there is hope but not for him because he thinks he does not deserve it. He does not have any significant relationships in the past, present, or in heaven waiting for him. This patient, with a closed-ended future and with a future story of punishment, lives in fear and hopelessness from the moment he knows he is facing a terminal illness. Nobody has been there for him to teach him how to live, he reports. He is certain that he will be punished for all his mistakes here on earth. For this patient it is necessary to start from the beginning, creating a trusting relationship first because he does not have any recollection of the meaning of a trusting relationship. This patient completely blocks his future story from his level of consciousness.

Yet, while he is very reluctant in his responses he keeps saying, “I need someone to help me, so I can prepare myself.” This suggests that even in his hopelessness he is living in hope that part of his story might involve a God who is there for him in his illness, giving him a chance to repent and ask for forgiveness. He realizes that he still has time to prepare and he is surprised when he has access to his belief system which he learned from popular religion and informs him: “to be with God you need to repent and ask for forgiveness.” He responds, “Is it that simple? Can God forgive me for all I have done without any punishment?” Conversations about God’s image as loving and forgiving begin to develop, giving him the opportunity to construct an open-ended future with the possibility of having a new life instead of punishment. Narrative conversations

with Hispanic hospice patients facilitated the co-exploration and re-interpretation of their sacred story allowing to talk about the inevitable pain of death. When these conversations included the cultural context, the patients were able to construct a story that embraced the continuity of life after death.

C. Limitations of this Research

The development of a new way of thinking and presenting hospice services attuned with the patient's cultural diversity needs further research and further attention. This research focuses on a small sample of Roman Catholic hospice patients in the area of Fort Worth; however, the Hispanic culture is a complex culture which includes different countries and diverse understandings of religion, faith, and spirituality. The results of this research could have been more accurate if the sample size was enlarged but for the purpose of this project, a small sample was chosen in order to capture the richness of the connection between the waiting experience and the construction of the stories of hope in the qualitative analysis. This project was limited by the time period in which the interviews were conducted and by the terminal condition of the patients. Most of the patients admitted into hospice remain there for only a short time; therefore the interviews had to be done in one-hour-sessions.

This study does not provide information about the applicability of this project to all Hispanic hospice patients in the United States or in the area of Fort Worth, or to other cultural contexts. However, this project does provide an initial consideration about the positive use of hospice services when the cultural context of the patients is taken seriously. It is not clear from this project how persons from other cultures might live into the waiting experience. In other

words, while the study has limitations due to context, time, and number of people in the interview population, it still raises implications for the work of pastoral caregivers in this context.

D. Personal Reflections

Before moving onto a consideration of specific actions pastoral caregivers might take with Hispanic patients in hospice, I would like to add how this project has an impact on my personal life and my understanding of theology as a result of my involvement in this project. As a Catholic chaplain and endorsed by the National Association of Catholic Chaplains, I have reflected on the meaning of being Catholic and how the influence of the Catholic teaching can affect the lives of all those who claim themselves to be Catholics. First, as I had the opportunity to listen to the patients' stories I felt strong reactions of discomfort for being part of a system which sometimes preaches a message of oppression, seemingly forgetting that the Gospel is a message of liberation and Good News. I observed patients terrified because of the teaching of the Roman Catholic Church about hell, purgatory, good works for salvation, and the understanding of a God who will ask each one of us for an account of our actions at the moment of our death in order to determine if we deserve everlasting life or punishment.

I am aware that God is actively present in the tradition of the Roman Catholic Church, but I also learned that God is equally present in the cultural context of the patients, in their personal experience, and in the experience of other theologians and pastoral caregivers. God is not a God who can be limited by any cultural tradition, Church teaching, or personal experience

because God is more than rules, particular teachings, and earthly regulations. Jesus in (John 6:37-40) proclaims:

All that the Father gives me will come to me, and the one who comes to me I will certainly not cast out. For I have come down from heaven, not to do my own will, but the will of Him who sent me. This is the will of Him who sent me, that of all that He has given me I lose nothing, but raise it up on the last day. For this is the will of My Father, that everyone who beholds the Son and believes in Him will have eternal life, and I Myself will raise him up on the last day.

If Jesus is proclaiming a God who is willing to do everything possible to make sure that all God's children have eternal life and not cast out, why the Church has the authority to determine who goes to heaven and who deserves punishment? As a Roman Catholic chaplain I do not have the power to change the teaching of the Roman Catholic Church on issues concerning to the dying Catholic patients, but I do have the responsibility to become an advocate for these patients and help them to reach a place where they can experience the freedom from any system of oppression so they can live and die experiencing love, forgiveness, and compassion. God does not know limits and God is not bounded by any particular interpretation of Church tradition. God is limitless and God will find ways to make sure that all God's creation has the same opportunity to enjoy the fullness of life. The Roman Catholic teaching is not the tradition of the Church, it is only an interpretation of a particular tradition, a version of the truth; therefore, the Roman Catholic teaching becomes only a tradition of the Universal Church that can be challenged, transformed, and reinterpreted by the patients as they face the waiting experience because they deserve the freedom to experience the unconditional love of God and the opportunity to enjoy everlasting life.

E. Conclusion: Helpful Interventions for Pastoral Caregivers

Finally, I would like to suggest 5 aspects about pastoral care with Hispanic hospice patients in order to facilitate more appropriate interventions for hospice chaplains. Pastoral caregivers need to be aware of the importance of the cultural context and how the understanding of the stories of hope influence in the waiting experience. It is possible to provide meaningful support for Hispanic hospice patients by giving them the opportunity to share their own journey which originates from past, continues toward an anticipated future, and merges in the present.

First, it is clear from this study that Hispanic hospice patients turn to “hope” as something that allows them to find healing and to maintain conversations about the continuation-of-life after physical death. However, the understanding of the concept of hope is complex and it is different for each one of the patients. For some patients their narratives of future-oriented-stories-of-hope are not helping them to confront the dying experience, creating fear, depression, or anxiety rather than providing meaning, peace, and continuation-of-life. Pastoral caregivers can maintain meaningful and respectful conversations with their patients in order to help them remember their sacred story, to find a new meaning to the story they have, or to co-create one story together in the event they do not have any.

Second, drawing upon narrative theory can assist pastoral caregivers and hospice workers to present hospice services from the perspective of hope. Narrative theory allows pastoral caregivers to have an understanding of how patients construct their narrative of future-oriented-stories-of-hope and how these stories are affecting their waiting experience. Hospice services provide palliative care and they recognize the holistic view that a patient’s needs are inseparably intertwined with the physical, psychological and spiritual areas of one’s life. In pursuing this

holistic care, pastoral caregivers need to be aware that the patient is the knowledgeable expert in his or her own life. Patients are seen as the courageous victor rather than the victim of an incurable illness. Through the use of narrative theory, specifically externalizing conversations, pastoral caregivers can map the effects of the current situation locating the problem outside the patient instead and considering the patient as a problem. Pastoral caregivers proceed from a humble standpoint of “not knowing” how best to help and engaging in professional conversations encouraging the patients, who are the experts, to share their stories and to determine how the patients are affected by the interpretations of their own stories.

Patients are the authors and experts of their own lives. The telling of the story to a non-judgmental professional caregiver enables the patients to construct new meanings that may alleviate their suffering by identifying their own resourcefulness in diminishing the current challenge. By their questioning, pastoral caregivers provide for the patient an opportunity to explore various dimensions of their stories giving them options to re-interpret those stories as they choose.

Narrative theory postulates that our stories constitute our reality and identity. We, human beings, make meaning through language. The ways we tell our stories speak about ourselves. If our narrative is not being helpful, we can change the narrative in order to change the reality. When dying patients are only focused on their painful dying story in the present, pastoral caregivers can help those patients to access stories that are already there but hidden, so these patients can open the door to the creation of hopeful stories in the future. Through narrative, pastoral caregivers can ask questions to call forth hopeful scenarios, giving the patients the option to construct their future narratives from a different perspective and to challenge their religious beliefs influenced by a tradition of the church, cultural knowledge or by any other

personal experience. If the patients realize that their current narrative is not supporting them in their living and dying, patients can then have the freedom to reframe their identities by reframing their stories.

Third, chaplains have the ability to support patients while they are facing the waiting experience and they need to be aware that the patients can be fully understood and cared for only if we, as chaplains, attend to the future stories. When patients acknowledge the limitations of medicine but opt to create a future story of hope as a way to find meaning in their distress, hospice providers can support them in their journey toward the future, with the awareness that the understanding of hope for the patients plays a significant role in the waiting experience. Chaplains need to have in mind that any kind of hope is hope, regardless if it is human or divine. Hope can be expanded, transformed, and redefined but not taken away. People can move on from the understanding of transitional/finite hope to a deeper, transcending hope that prevails even after death. Our job, as pastoral caregivers is to help these patients in the process of transition so they can create a sacred story where their human hopes are connected with the divine hope integrating, as part of that sacred story, the dying experience.

During my conversations with these six patients the concept of hope was explored, affirmed, accepted, respected, and as a result, a process of reframing the concept of hope took on a new level of consciousness. Hope is a human dynamic. “Hope is both transforming and transformative,”¹⁹² and the role of hospice pastoral caregivers, is to be a companion for patients through a changing course of hope that often moves from an initial hope for cure, through the hope for care, and arriving to a hope for the fullness of life in the kingdom of God.

While journeying with people through their waiting experience and their sacred stories,

¹⁹² Deborah Geweke. “Hope in Hospice? Accompaniment of the Spirit through Life’s Journey.” *Word and World* 30, no. 1 (Winter 2010) 82

chaplains have the opportunity to explore the divine images that open new doors of hope and healing or terror and death. Through guided conversations, these participant patients realize that God is at work in the ambiguity of their lives, always calling them to keep hope alive even when darkness surrounds them. If pastoral caregivers give attention to narratives of future-oriented-stories-of-hope, they may be able to understand better the patients' struggles and the nature of their needs. By doing so, pastoral caregivers may have new opportunities to help patients to modify the impact of the unwanted waiting experience by redefining the unwanted future story of hope.

Fourth, through meaningful narrative conversations that include questions of exploration of their own journey which includes the past, patients can explore some missing and meaningful components of their stories so they can develop a new sense of identity as they create new understanding of life-events and relationships. A narrative approach allows patients to live in ambiguity and uncertainty by proclaiming that there are many faces to one particular event or situation and encourages them to choose the side of the story they prefer to construct without considering if what they choose to believe is right or wrong. Through guided questions those patients can find a way to connect their stories-past, stories-present, and stories-future to the larger story that constitutes their own identity giving them the ability to see their life from different perspectives and new possibilities of life.

Fifth, hospice chaplains have the opportunity to establish a trusting relationship, showing respect for the patients' values and taking every opportunity to demonstrate to our patients that hospice is about life, compassion, and hope. One of the tasks for hospice pastoral caregivers is to find opportunities to assess patients' travel stories and accompany them on their journey so they can construct and experience the many faces of love, hope and healing. Pastoral caregivers have

the opportunity to co-assess the patients' travel story with the purpose of finding out together if the anticipated destination is the one that the patients want so they can enjoy the fullness of life.

To conclude with this project, I affirm that the future-oriented-story-of-hope impacts the waiting experience of Hispanic hospice patients in a significant way. According to the results of this research project, when some Hispanic patients hear the bad news about their terminal condition, the move away from the anticipatory grief process and start a waiting experience which includes some cultural elements that are meaningful for their survival. Some Hispanic hospice patients transform the waiting experience into an experience of hope that changes over time and transforms the patients allowing them to enjoy the fullness of life in the midst of their struggles. At the end, hospice patients have the right to experience freedom instead of fear, as suggested by Nouwen in a previous chapter, so they can have the ability to choose the way they want to die, the story they want to construct about themselves, and the way they want to continue experiencing life after their death regardless the influence of any religious creed or cultural belief. Through the exploration of the story of hope, narrative conversations facilitate the process of helping the patients to experience that freedom so they can enjoy the fullness of life not just in heaven, but during their waiting experience.

I strongly suggest that it is important for pastoral caregivers to have an understanding of the cultural context when providing pastoral care for Hispanic hospice patients. Narrative theory provides the framework to co-explore the context and assess the journey of life with these patients so pastoral caregivers can join them in their journey without taking the role of the expert. If pastoral caregivers show cultural sensitivity in their questioning, the patient and the chaplain will find a helpful way to understand each other and walk together during the waiting experience. Chaplains can assist patients in the re-construction of a sacred story which will allow

them to face the reality of death even when a church tradition, cultural knowledge, or personal experience limit their understanding of an open-ended future filled with possibilities of enjoying the fullness of life in heaven.

APPENDICES

APPENDIX A.1

PATIENT'S QUESTIONARE

Magana Doctor of Ministry Project
Texas Christian University 2010

Date: _____

A. Experience of Anticipatory Grief

1. How do you describe what is happening to you now?
2. How is this affecting you and what are you experiencing?

B. Future Story of Hope

3. Do you have any hopes?
4. What does "hope" mean to you?
5. How do you see your future?
6. How does your future change over time?
7. As you think of your future, what feelings or emotions are you experiencing?

C. Belief System

8. Do you see God in your story?
9. What role do you think God is playing?
10. When looking towards the future, what image of God do you keep in mind?
11. What do you think will happen to you when you die?

D. Deconstruction Questions

12. How did you come to understand "hope" in the way you do?
13. How did you learn or experience death for the first time?
14. What kinds of emotions, or feelings, come to you as you remember those experiences?

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