

UNIVERSITY OF CALIFORNIA

Los Angeles

Medical Decision-Making among
Foreign-Born Latino Elders with Multiple Chronic Conditions

A dissertation submitted in partial satisfaction of the
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by

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ABSTRACT OF THE DISSERTATION

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Background and Significance: Patient-centered care is based upon the fundamental focus of the clinician creating a dialogue with patients to assess their preferences and engage in medical decision-making. Medical decisions are multidimensional, dynamic and complex and the process may vary given the sociocultural differences presented by the growing Latino elderly population. To be patient centered, we must understand how patterns of engagement, cultural concepts of illness and faith play in meeting elder Latino immigrants needs and preferences and how clinicians may more effectively interact with this patient population. This study identifies typologies of decision-making with foreign-born Latino elders with multiple chronic conditions who are enrolled in an integrative geriatric health care program. Three separate yet interconnected research aims include how patients engage medical encounters (aim 1) using their cultural concepts of illness (aim 2) and their faith (aim 3). Methods: This study used qualitative

methods influenced by grounded theory to conduct three in-depth interviews in Spanish per respondent over 9 months with a convenience sample of 13 Latino immigrants (39 total interviews) from Central America, South America or Mexico. All had multiple chronic conditions and participated in PACE (Program of All-Inclusive Care for the Elderly), an integrated medical care program for nursing-home eligible Medicaid-Medicare recipients. Interviews were audio-recorded and transcribed verbatim in their original language. All audio-recorded field notes and memos were also transcribed verbatim. The interviews explored participants' medical experiences, paying attention to the patients' patterns of engagement during medical encounters, their illness experiences and their faith in God. Data was analyzed using an interpretative lens based on a grounded theory constructivist approach. Findings: Foreign-born Latino elders' decision-making processes were made within a cultural context and were unique to each person. Decisions followed a pattern described by a proposed model that involved balancing a fear of perceived results with or without medical intervention and hope both in medicine and God. Personal and vicarious experiences, knowledge, available resources and, most importantly, cultural beliefs, values and norms informed the pseudo cost-benefit analysis of perceived risk and benefits. Regardless of type of medical decision, therefore, some criteria held more influence than others at any one time, yet all were included in the decision deliberation process. *Aim 1*: Latinos engaged the medical encounter using three types of engagement and communication: technical, social and emotional. Participants were most likely to engage in medical encounters in social and emotional ways. Trust increased with level of patient-doctor relationship (*good doctor, person of trust, advocate*). *Aim 2*: Immigrant elders held on the traditional belief on the importance of maintaining the human body in a state of balance and harmony to avoid disease yet still believed in biomedical treatments. Biomedicine and traditional

remedies often functioned to complement one another. *Aim 3:* Faith was not found to serve in direct opposition to medical care treatments, except for mental health disorders when mental illness was perceived to be caused by the accumulation of social and life stressors. Given the belief that God is in control, faith indirectly influenced decision-making. Faith was particularly magnified in times of crisis where critical decisions were contemplated. Faith served as a coping mechanism most often manifested through prayers and helped to create meaning to life's circumstances (e.g., death, miracles), including legitimizing the doctor's actions as part of God's overall plan serving as the "hands of God." Like medicine, faith provided hope. Conclusions: Multiple chronic conditions pose many challenges, including the questions of how to provide patient-centered care in the context of competitive health care priorities for diverse populations. Study findings contribute to practice-based conversations, particularly around the implementation of patient-centered care in specialized populations. The outcomes of this descriptive research project serve as building blocks to larger hypothesis-testing investigations of older adults and decision-making.

The dissertation of Rosana Leos Bravo is approved.

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DEDICATION

*This dissertation is dedicated to God,
my spouse Jesus, and our children Kailani and Jeremiah.*

*And, for my parents, in-laws, my brothers, my sister— a prayer warrior, the Leos, Guerrero,
Bravo and Chaffino families, compadres and friends who uplifted me.
Finally, to all of you who are to come after me. You can do it!*

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People often say it takes a village to raise a child.

The same can be said about a poor Latina from East Los Angeles.

It took a community to get a PhD!

"For nothing is impossible with God." ~Luke 1:37

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PRESENTATIONS

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Wallace, S.P. “Healthy Aging Partnerships in Prevention Initiative (HAPPI).”
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CHAPTER 1.0: INTRODUCTION

The focus of this study is to identify typologies of decision-making with foreign-born Latino elders with multiple chronic conditions enrolled in integrative geriatric health care programs. Multiple chronic conditions affect the health and well-being of older adults. The effects of having multiple chronic conditions are more prevalent in communities of color. The enactment of the Affordable Care Act (ACA) has propelled efforts to implement patient-centered care in America's healthcare system. Patient-centered care is based upon the fundamental focus of the clinician creating a dialogue with patients to assess their preferences. However, passing of the ACA alone will not ensure the patient is engaging in the decision-making process as is often assumed. Medical decisions are multidimensional, dynamic and complex. Relatively few studies consider decision-making processes in foreign-born Latino elders with multiple chronic conditions and Latinos in particular who have poorer quality of life outcomes. We need to understand what modes of communication may be more productive to meet elder Latino immigrants needs and preferences, and how clinicians might communicate in more effective ways with this patient population.

1.1 Multiple Chronic Conditions

Chronic health conditions replaced infectious diseases the most common threat to the lives, health and well-being of Americans more than half century ago. In 1949, the American Hospital Association, the American Medical Association, the American Public Health Association and the American Public Welfare Association joined forces to make "a concerted attack on what is in essence the nation's major health problem." A report by the *American Journal of Public Health* in 1947 reported that chronic diseases were the leading cause of death

in the United States and were responsible for at least 60 percent of all disability (1947). This situation has only intensified in the last 60 years.

Chronic conditions continue to increasingly affect the health and well-being of older adults. In 2010, the six leading causes of death for those 65 years and older were all chronic conditions (Centers for Disease Control and Prevention & Injury Prevention & Control: Data & Statistics, 2014). Chronic conditions are not always the cause of death; however, in 2010 they accounted for more than 88 percent of all deaths for older adults (Centers for Disease Control and Prevention & National Center for Chronic Disease Prevention and Health Promotion, 2014; Murphy SL, Xu JQ, & KD., 2013).

Issues of assessment and the lack of standardization with multimorbidity are currently areas under debate in the field of aging (Yancik et al., 2007). According to the National Institute on Aging Task Force on Comorbidity National Institute of Aging states that "the health status of older individuals is affected by the accumulation of biological dysfunction in multiple systems" (Yancik et al., 2007, p.276). For the purpose of this dissertation, multimorbidity is conceptualized as defined by the United States Department of Health and Human Services. Chronic conditions are those that "last a year or more and require ongoing medical attention and/or limit the number of activities of daily living." A representative definition for multiple chronic conditions (multimorbidity) is the coexistence of two or more chronic conditions, where one is not necessarily more central than the others (C.M. Boyd & Fortin, 2010).

Living with chronic health conditions is an ever-increasing reality for the majority of older Americans. According to a report on a nationally representative sample of Medicare beneficiaries, nearly 80 percent had at least two chronic conditions and more than 60 percent had at least three chronic conditions (DuGoff, Canudas-Romo, Buttorff, Leff, & Anderson, 2014). A

study found that 85 percent of the United States health care dollar is spent on people with chronic conditions. This conservative percentage excludes expenses incurred during end-of-life care (Anderson, 2010).

People with multiple chronic conditions are at increased risk for mortality and poorer day-to-day functioning. A review found that as the number of comorbidities increase an individual's quality of life decreases, and the likelihood of death increases (Fortin et al., 2004). A study found it increasingly difficult to care for patients with multiple chronic conditions. Managing multiple chronic conditions can mask, interact, or compound with one another and make the treatment process for any one disease more difficult (Bower et al., 2011). Common diseases often present themselves atypically in older people and many physicians may not have the skill sets necessary to evaluate geriatric patients (R. D. Adelman, Greene, & Ory, 2000). A classic example is the changes in thermoregulation with age, so older adults may not get a fever when infected. Another example is thyroid disease, B12 deficiency and/or depression may often go overlooked when an older patient arrives at the medical encounter complaining of cognitive dysfunction and the clinician attributes such decline to age. Even more difficult to track in an older patient with severe osteoarthritis and limited mobility, for example, is coronary artery disease with classic signs of chest pains or shortness of breath on exertion. Treating one disease at a time is easier than trying to treat multiple chronic conditions (Bower et al., 2011; C. M. Boyd et al., 2014; Zulman et al., 2014), which increases the likelihood of a patient engaging in multiple medical encounters.

1.2 Multimorbidity by Race/Ethnicity

Multiple chronic conditions are a problem in the aged, in general, but in particular, chronic conditions affect people of color in different ways than their white counterparts. A recent

national assessment of health and functional status among racially and ethnically diverse Medicare beneficiaries showed that the prevalence of multimorbidity (more than three chronic conditions) was not significantly different among most groups. Elders of racial/ethnic minority backgrounds, however, were found to be a higher risk than non-Hispanic whites for a broad range of adverse health and functional outcomes (Ng et al., 2014). Latinos, for instance, are at increased risk for diabetes and cardiovascular-related conditions, which lead to poorer quality of life and a higher incidence of a number of chronic conditions left to manage. An increase number of multiple chronic conditions lead to higher dosages and concentrated time periods with medical encounters to help in their management.

1.3 Medical Encounters

Multiple chronic conditions are those that necessitate ongoing medical attention. Human interaction is a fundamental tenet of medical care, which is often delivered in an examination room where a “medical interview” is conducted, and medical practitioners and patients are assumed to interact. The increase in medical encounters is bound to provide additional opportunities for the engagement of medical decision-making, as far as the patient and/or family wish to be involved. A study conducted by the Pew research center found that people with multiple chronic conditions prefer to engage clinicians rather than resort to obtaining health information through other sources (e.g., Internet). Preliminary findings from the Pew Internet Health Tracking Survey conducted from 2007-2012 showed that 8 percent of adults with two or more chronic conditions preferred getting information, care or support from a practitioner or other health care professional for consultation on a health issue compared to 31 percent who preferred receiving information, care or support from others who had the same health condition

(Pew Research Center, 2014). For this reason, there are an increasing number of patients requesting to see their primary care doctors.

However, duration of office visits and the single-disease focus during medical visits are issues of concern – particularly for geriatric patients with multiple chronic conditions. In the last 15 years, the United States medical system has been set- up for a physician to see returning patients at 12-16 minute intervals and new patients for 45 minutes to one-hour initial visits (Fiscella & Epstein, 2008; Mechanic, McAlpine, & Rosenthal, 2001). This in itself is a problem with older adults suffering from multiple chronic conditions, since their medical conditions often affect multiple organs. The lack of time for medical visits and single-disease focus have been shown to displease older adults (Barnett, Shale, Elkins, & Fisher, 2014). Time-constrained and single-disease focus medical visits will only increase the frequency a patient necessitates seeing a clinician to ensure specific conditions are being properly managed. Treatment of geriatric patients with multiple chronic conditions is further complicated by the potential adverse drug risks inherent in polypharmacy and particularly in older persons. In addition, older patients have more extensive medical histories than younger patients. Many geriatricians acknowledge that it may take two to three visits to assess the geriatric patient adequately (R. D. Adelman et al., 2000). Multiple visits often require arranging transportation, parking fees and transit time, which constitute disincentives for appropriate and timely medical management.

Medical encounters are important aspects of medical decision-making. Aside from the individual characteristics that define the clinician and the patient, the medical encounter is multidimensional. The “encounter” for this project is conceptualized as having three overlapping components: (1) patient engagement, (2) patient-clinician relationship and (3) patient-clinician communication. The three overlapping constructs have the potential to influence patient

decision-making (Figure 2.1). An umbrella-like construct that creates the context for these elements is the medical decision-making models of care. The tenets of these models, implemented in practice, modify modes of medical interactions. For instance, the way a doctor interacts will dictate how the relationship and communication patterns relate and in turn how a patient engages. The interaction and balance of these elements play a role in how a patient and practitioner interact with one another.

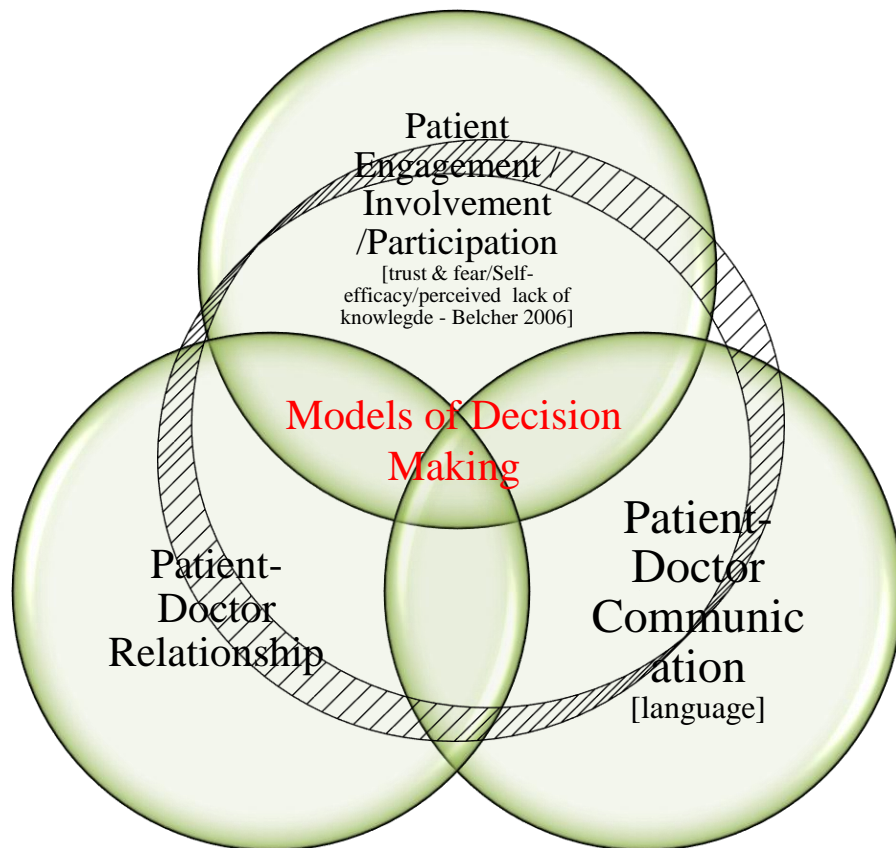


Figure 1.1: Conceptual Framework of Medical Encounter Construct

1.4 Overarching Research Question, Aims and Sub-aims

This study identifies typologies of decision-making with foreign-born Latino elders who have multiple chronic conditions and are enrolled in an integrative geriatric health care programs by studying three separate yet interconnected research aims are: patterns of engagement, cultural concepts of illness and a patient's faith.

How do foreign-born Latino elders with multiple chronic conditions make medical decisions?

Specific Aim 1: What are the patterns of engagement in medical decision-making?

Sub-Aim 1: Under what circumstances are older adults choosing to include or exclude family in the decision-making process?

Specific Aim 2: How do patients' cultural concepts of illness influence medical decision-making?

Sub-Aim 1: How do patients' perceptions of their medical conditions influence medical decision-making?

Specific Aim 3: What role does faith play in medical decision-making?

Sub-Aim 1: How does a patient's faith shape medical decision-making?

Sub-Aim 2: Under what circumstances is faith most likely to be included?

CHAPTER 2.0: BACKGROUND AND SIGNIFICANCE

The medical decision-making literature is multidisciplinary. Decades of research and theory on the judgment and decision-making of physicians and patients use various conceptual models. The following statement by Schwartz and Bergus (2008) and endorsed by the Society of Medical Decision provides a comprehensive definition of medical decision science:

Medical decision science is a field that encompasses several related pursuits. As a normative endeavor, it proposes standards for ideal decision making. As a descriptive endeavor, it seeks to explain how physicians and patients routinely make decisions, and has identified both barriers to, and facilitators of, effective decision making. As a prescriptive endeavor, it seeks to develop tools that can guide physicians, their patients, and health care policymakers to make good decisions in practice.

- (Schwartz & Bergus, 2008 (Medical Decision Making: A Physician's Guide, Cambridge University Press) preface, pg. xiii)

Normative decision-making researchers teach us how one “ought to make decisions.” Their primary focus is on how to make effective, “good” and correct decisions. The problem with normative is that it is the ideal. It assumes that people are rational agents and make rational and logical decisions. A prescriptive decision-making researcher aims to develop tools to facilitate “good” decision-making. It describes how a person should make decisions (Bell, Raiffa, & Tversky, 1988). The problem with prescriptive is that the way in which the data is presented or the way one frames the problem will bias the person’s thought process and the outcome will be affected.

My research is descriptive and seeks to describe “how” decisions are made without a valence-based judgement. Not the “ideal” but the lived reality. Most research in decision analysis has the concept of a “good” decision versus a “bad” decision. A good decision is one whose outcome is considered positive or effective. A bad decision is one whose outcome is negative or ineffective, and may at times be harmful. My research does not seek to categorize decisions as

good or bad. My assumptions are that people do not always make the most logical or rational decisions, especially in emotionally heightened situations as can often occur in medicine (both by clinicians as well as patients and families). People make decisions based on what they know (often based on incomplete or limited information), who they know, and the resources they have available to them. In addition, decisions are dynamic, contextually dependent, and with perceived time constraints and urgency.

Medical decision-making for the purposes of this project is defined as the process that leads to an action-oriented behavior that is observable and relates to managing multiple chronic conditions.

2.1 Rationale for Understanding Medical Decision-Making

The Affordable Care Act, also known as Obamacare, was passed by Congress and then signed into law by President Obama on March 23, 2010. With the enactment of the law, efforts to implement patient-centered care for the nation's health system have increased. Financial incentives are being provided by the Centers for Medicare and Medicaid Services to encourage providers to apply tenets of the patient-centered care model (California Healthline, 2014; Neergaard, 2015). One of the major principles of the model is to capture patient experiences. Exploring patients' medical care experiences is important, since they are a major contributing factor in shaping their future medical decisions. Two classic medical decision-making studies suggest that patients' past medical experiences influence personal decisions about future treatments (Kahneman, Fredrickson, Schreiber, & Redelmeier, 1993; Redelmeier & Kahneman, 1996).

Medical decision-making in general has been extensively studied, but not in geriatric populations with multiple chronic conditions. Historically, medical decision-making has been

studied in singular areas, such as European American populations, and focused on a particular disease or disease-type such as cancer (Chawla & Arora, 2013; J. N. Katz et al., 2011; Salloch, Ritter, Wascher, Vollmann, & Schildmann, 2014; Strull, Lo, & Charles, 1984), and a discrete and often dichotomous decision outcome (e.g., receipt of radiation or not) (Belcher, Fried, Agostini, & Tinetti, 2006; Laba, Lehnbohm, Brien, & Jan, 2014). The few research projects looking at medical care decision-making in older adults are qualitative in nature (J. N. Katz et al., 2011; Salloch et al., 2014), and/or conducted on international populations (Adams, Price, Tucker, Nguyen, & Wilson, 2012; Bastiaens, Van Royen, Pavlic, Raposo, & Baker, 2007; Galesic & Garcia-Retamero, 2011; Laba et al., 2014; Salloch et al., 2014).

Historically, in the United States, medical decision-making has been evaluated on Caucasians, particularly in studies of patients' preferences for their level of engagement and decision-making (more discussion on this in a later section). One study with cancer patients in New York found that patients in their sample desired information and involvement in treatment decisions; however, most of their sample was Caucasians (Elkin, Kim, Casper, Kissane, & Schrag, 2007). Another study found that patients wanted to be more involved, but 64 percent of their sample were Caucasians from Oklahoma (Peck, 2011). Another study evaluating approximately 4500 healthy white Midwesterners in their mid-60s found 80 percent wanted to make decisions independently valuing independence (Moorman, 2011).

Research often considers specific conditions to explore medical care decision-making (Balneaves, Truant, Kelly, Verhoef, & Davison, 2007; Beaver & Booth, 2007; Chawla & Arora, 2013; S. J. Katz, Belkora, & Elwyn, 2014; Salloch et al., 2014; Strull et al., 1984; Zikmund-Fisher et al., 2010). One of the most frequently used diseases to study decision-making is cancer. Decisions around cancer differ from decisions around multimorbidity. First, receiving a cancer

diagnosis is different than receiving a diagnosis of a chronic condition. The perception one has in hearing the word cancer almost always equates to a potential death sentence, whereas a diagnosis of diabetes may also cause grief for the implications of managing the condition, but not for its perceived fatal course. For this reason, cancer-related decision-making is contextually unique from decisions around most other common chronic condition management due to the perceived severity of the diagnosis, the potentially fatal course and complexity of cancer treatments. Cancer treatment decision-making is often a family affair compared to an individual preference-based decision. Second, decision-making studies often center around one particular condition at a time. Few studies focus on the complexities of studying the decision-making process on multiple chronic conditions.

Medical decision-making studies often focus on discrete and dichotomous outcomes (Belcher et al., 2006; Laba et al., 2014). Decision-making studies with geriatric populations are most notable in the death and dying field, particularly in end-of-life care. Several studies have been conducted on the end-of-life decision-making processes using various units of analysis: at the physician level, at the individual level and at the family level. These studies have been conducted to advance knowledge in end-of-life decision-making research to adequately serve the dying population (Bito et al., 2007; Foster & McLellan, 2002; Haley et al., 2002; Johnson, 2008; Kwak & Haley, 2005; Rosenfeld, Wenger, & Kagawa-Singer, 2000). End-of-life care decision-making is dissimilar from decisions on multiple chronic conditions. Treatment for end-of-life care is unlike accepting a treatment option for knee replacement surgery. The potential outcome for one is life or death, while the option for the other is perceived improved quality of life (Shrank et al, 2005).

The recent surge in medical care decision-making literature internationally, especially in Germany, may be due to the passing of the “Law to Improve the Rights of Patients” *Patientenrechtegesetz* in 2013 (Meltendorf & Meltendorf, 2013). The issue of the patient’s level of engagement in decision-making is intensely debated in terms of the legal statutes and clinical practice. The German government is endorsing issues of patient participation by funding research and training programs on shared decision-making (Harter et al., 2011).

2.1.1 Explanatory Model of Illness and Medical Decision-Making

A myriad of factors influences medical decisions. One of these factors is the manner in which people perceive illness. Illness is socially constructed, and not solely the result of biology. Studies in this area were highlighted by the seminal work of the medical anthropologist and psychiatrist Arthur Kleinman (1978) who coined the term "explanatory model of illness" which is a phrase used to capture the idea that individuals exist in a context that influences the way they think about, identify and experience illness (A. Kleinman, 1978; A. Kleinman, Eisenberg, & Good, 1978). An individual’s explanatory model, whether biomedical or otherwise, will impact the way people make medical decisions.

Research on immigrant health and ethnomedicine demonstrates that cross-cultural differences exist in the explanatory model of illness. A study on Mexican American college students in a social work program in Southern California found that 84 percent received services of an indigenous/folk/spiritual healer (Lopez, 2005). Hispanic mothers with young children from the Yakima County in Central Washington State were interviewed to explore how they made treatment decisions for their young children. The study found that “some [illnesses] are not of the clinic. [Josefina]” (Andrews, Ybarra, & Matthews, 2013, p.386). The preceding quote indicates

there are some conditions that biomedicine is unable to treat effectively; in this case, and traditional healing methods are sought in place of biomedicine, for example *empacho* (indigestion or a gastrointestinal obstruction) in the Latino community.

Although Hispanic families may use traditional healers, and treatments (e.g., *sobador*, *curandero*), they may prefer biomedicine for specific ailments. Medical pluralism has been widely documented, and generally one medical system dominates (Leslie, 1980; Poss & Jezewski, 2002). Ethnographic interviews with 25 older adult Mexicans living in Texas talked about folk healing and its influence on health care behaviors. Researchers found interviewees treated serious injuries and major health problems with biomedicine; however participants continued to rely on traditional folk healing as a viable alternative (Applewhite, 1995). Similarly, explanatory models of Mexican Americans along the border with diabetes were elicited, and it was found that most families prefer biomedicine as the dominant model. However, researchers' findings were further complicated by trying to explain why and how patients made medical care decisions (Jezewski & Poss, 2002). Aiming to identify the patterns of the various health belief systems is a continuing challenge (Baer, 1996). Research with Latinos residing in the United States describes their health beliefs as an intricate system. Health is thought of as a state of harmony between the individual, nature and the cosmos, and society. In an attempt to simplify the complex health system and to describe the observed variability within-groups and between-groups of Latinos, researchers termed the system *Curanderismo*.¹

Given the complexity of the way sociocultural aspects may affect patient perceptions of illness and illness causation, eliciting a patient's explanatory model would prove fruitful for medical practitioners seeking to understand a patient's medical care decisions. The explanatory

¹ *Curanderismo* refers to the health practices that exemplify this historically influenced worldview about the sources of illness. Further descriptive explanation of the history is out of the scope of this dissertation, for additional information (see (Valdez, 2014).

models of the patient and the physician may contradict one another, making it a perfect situation for miscommunication and misunderstandings during the medical encounter and a potential burden on the medical care decision-making process. A patient's preferred way of explaining illness may contradict the practitioner's preference. Consequently, a lack of appreciation to cultural diversity and beliefs by medical practitioners may arise. A study was conducted to identify the decision-making process that 72 clinicians working in a university hospital in the Netherlands used when choosing drugs of preference. Researchers found that biomedical variables predicted prescribed treatment regimens in 53 percent of the cases (Denig, Haaijer-Ruskamp, Wesseling, & Versluis, 1993). It is important to recognize that unlike Westernized clinicians, patients may not always use biomedical measures and logic to make medical decisions. As research shows, it is important to assess a patient's explanatory model of illness, but it is of equal importance to assess an individual's faith in medical decision-making (discussed below).

2.1.2 Faith and Medical Decision-Making

An individual's faith in God may play a significant role in medical decision-making. Most Americans believe in some form of Higher Power. In a 2011 Gallup poll, more than nine in 10 Americans reported a personal belief in God. This number is only slightly lower from the 1940s when Gallup first asked the question. According to the 2011 poll, belief in God was lower among younger Americans, Easterners and liberals. "Despite low rates of religious observance in many industrialized countries, there is widespread interest in practices that people envision as both 'scientific' and 'spiritual.' Many Europeans and North Americans are looking for something more than modern medicine to help them. Most people who say they are 'spiritual but

not religious' or who have stopped going to church believe in God or a higher power and may be open to receiving prayer. People go where they expect to find help, and when churches or medical practitioners do not offer hope of healing, people go elsewhere" (Brown, 2015, p.11).

According to the 2011 Gallup poll, among those 59 years and older, 94 percent believed in God. Many individuals believe in the power of prayer; more than 80 percent believe prayer has a healing effect (Barnett et al., 2014; Brown, 2015; Levin, 2009 for review). Personal belief in the power of God is pervasive; for this reason, an individual's faith in God should not be ignored in studying medical care decision-making, especially during the medical encounter. Discussions around issues of faith during the medical encounter have been traditionally linked to spirituality and religion. Conversations about faith, especially within the medical field, tend to make professionals who are trained only to focus on empirical evidence uncomfortable. Current research in this area demonstrates a movement to broaden the term faith to be more inclusive to lessen tensions in the field. Using qualitative analysis through the lens of Margaret Newman's *Health as Expanding Consciousness*, Dyess (2011) conducted a concept analysis on the word "faith" primarily to assist specialty nurses working in faith community nursing. Dyess (2011) found "four key attributes of faith focusing on beliefs, foundational meaning for life, living authentically in accordance with beliefs and interrelating with self, others and/or Divine" (Dyess, 2011, p.2727). She found faith was individually defined. It appeared to be broader than spiritual practices and religious rituals and "became the very foundation that enabled human beings to make sense of their world and circumstances." Her analysis "broaden[ed] the use of the term beyond the traditional understanding of a religious denomination" (p. 2729).

Literature around faith and medical decision-making are problematic due to the lack of cross-study comparison stemming from conceptual variation in the operationalization of faith-

based terminologies, such as spirituality, religiosity and beliefs. However, there are studies that address the issues of decision-making and faith, especially with high profile diseases such as cancer. For instance, White and Verhoef (2006) explored the role of spirituality in cancer management by men with prostate cancer who had declined conventional treatment in order to use alternative treatments (White & Verhoef, 2006). They found that individual spirituality influences all aspects of the cancer experience and most participants intensified personal use of spiritual practices after the diagnosis. Silvestri (2003) asked oncologists, advanced lung cancer patients and patient caregivers to rank the importance of factors that may influence their treatment decisions. Faith in God was ranked second only to the recommendation of the medical oncologist by patients and caregivers while the physicians ranked God last. The physicians felt that a patient's faith in God should be the least important factor when deciding therapy (Silvestri, Knittig, Zoller, & Nietert, 2003). However, patients and caregivers placed major weight on faith on the course of their cancer experience – even more than the ability of the treatment to cure the disease.

Literature on the role of faith in God in cancer care or EOL medical decision-making is prevalent. However, there is a dearth of literature on the role of faith in God in medical care decision-making with people with multiple chronic conditions. Parks (2014) identified psychosocial factors influencing decision-making among African Americans' and Latinos' preferences for knee or hip replacement surgeries. Mental calculations made in patients' decision-making processes included reliance on faith and spirituality for guidance (Parks et al., 2014).

Perceptions of a patient's faith can also influence the practitioner's decision-making process (Jaul, Zabari, & Brodsky, 2014). If a physician is aware of the patient's level of faith, the

physician may be more cognizant on issues of whether to suggest certain end-of-life care options (e.g., do-not-resuscitate order; hospice, food withdrawal). A physician who is receptive to their patients' faith and incorporates their patients' faith in their treatment recommendations, practices an essential tenet of patient-centered care – listening and responding to patient's needs and preferences.

2.2 Patient Participation in Medical Decision-Making

Patient-centered care and patient-practitioner interaction research have long trajectories contributing to current thinking (M. Stewart et al., 2014). A patient/family-centered model of care assumes a patient/family group actively engages in the medical encounter and the decision-making process. The assumption is particularly true for people with multiple chronic conditions, where treatment decisions can often be revisited and reversed with minimal detrimental repercussions, unlike more imminent life-threatening diseases (Montori, Gafni, & Charles, 2006). However, medical research on the preferences of older adult patients on the *level of participation* in medical decision-making is limited and findings are mixed (Levinson, Kao, Kuby, & Thisted, 2005; M. Stewart et al., 2014). There is even less literature on Latinos and especially older Latinos in the area of understanding medical decision-making associated with multiple chronic conditions.

This section will focus on discussions around the participation of older patients in medical decision-making, and the following two separate but interconnected subsections will focus on components of the patient-practitioner interaction: the patient-clinician relationship (2.3) and patients' communication issues with medical practitioners (2.4). While these concepts are inter-related, they are not identical. Never the less, the medical decision literature often uses the terminology interchangeably. An attempt is made to untangle the ideas and obtain a better

grasp of the unique aspects of the relational elements that may play an integral component among foreign-born Latino elders.

Shared-decision making as will be described in greater detail in the subsequent sections assumes the patient and the clinician share decision-making power (Roter & Hall, 2006). One set of studies around older patient participation in decision-making argue that older adults have strong preferences for shared decision-making (Peck, 2011). Other studies conclude, however, that not all older adults wished to participate in shared decision-making. The patients were reported to be less involved during the medical visits and generally participated less during the encounter than younger people (Bastiaens et al., 2007; Frosch & Kaplan, 1999; Galesic & Garcia-Retamero, 2011; M. G. Greene, Adelman, Charon, & Hoffman, 1986; Say, Murtagh, & Thomson, 2006). Studies have shown some older adults prefer their clinicians maintain a high-level of control in the realm of medical decisions (Arora & McHorney, 2000; Mansell, Poses, Kazis, & Duefield, 2000; Teh et al., 2009). Whether these set of studies “observed” less involvement due to participants’ attitudes towards medical practitioners (e.g., deference to authority) or their actual desire for a lesser degree of involvement is still open for discussion, as are how patients’ worldviews and perspectives influence their understanding of “involvement.” For instance, Baestians et al (2007) explored the views of people over age 70 on their involvement in their primary health care in 11 different European countries and although they found that the participants did want to be involved in their care, older adults’ definition of involvement was focused on the "caring relationship, 'person-centered approached', and 'receiving information' rather than on active participation in decision-making." Similarly, Teh et al. (2009) found that although some prefer to let their providers make the decisions, having mutually respectful patient-provider relationships is important to older adults.

Context-based factors also potentially contribute to patients' preferences for decision-making involvement, which are less supportive of older adults preferring to engage in a paternalistic-like model of care, where all decision-making is made by the clinician on the patients' behalf. Older patients' preference levels of participation in medical decision-making may be influenced by multiple factors including, demographics, health status and types of diagnoses and decisions (Arora & McHorney, 2000; Mah, Muthupalaniappen, & Chong, 2016; Mansell et al., 2000; Say et al., 2006; Tariman, Berry, Cochrane, Doorenbos, & Schepp, 2010). Types of diagnoses and types of decisions associated with such diagnoses create multiple preferences for decision-making involvement. Cancer patients and those with recent severe heart disease (myocardial infarction, by-pass surgery, angioplasty), for instance, have been found to wish more involvement in treatment decision-making (Degner & Sloan, 1992; Frosch & Kaplan, 1999). Research comparing the preferred and actual participation roles of patients found that adults from diverse backgrounds with cancer wanted more involvement than what occurred (Tariman et al., 2010). Similarly, Peek et al. (2009) conducted a phenomenological study among African Americans and found that patients wanted to increase their level of participation during medical visits. They found that shared decision-making was enhanced when patients felt that their physicians were accessible and available and when their perspectives were validated and acknowledged (Peek et al., 2009).

Patients' preferences for involvement in medical decision-making among older adults are dynamic in that patient preferences change throughout an individual's life course, in part due to their circumstances. The existence of context-based factors, such as severity of illness and type of decision, contribute to patients' current preference for decision involvement, which may change patients' future preference level for engaging future medical decisions. At healthier

states, a patient may choose a more paternalistic model of care, while at more ill states that preference may shift to one of patient-centered care where the clinician and the patient share a relational component where the clinician provide advice and support (Mansell et al., 2000). Patients' medical preferences vary depending on their current and previous experiences with the medical care system, their belief system and the interaction the system has on individual embedded values.

While medicine has typically approached these issues with a focus on the clinical encounter and a concern with outcomes like adherence, other disciplines like sociology and medical anthropology have also studied the conflicts between patient belief systems and medical systems and the power dynamics in patient-clinician interactions (Roter & Hall, 2006; M. Stewart, 2003; M. Stewart et al., 1999; M. A. Stewart, 1995; M. E. Stewart & Roter, 1989), which will be further discussed in subsequent sections. However, the medical literature often falls short of incorporating patient belief systems and explaining how patient values and norms play a role in medical decision-making (R. Andersen & Newman, 1973; Waitzkin, 1984). One of the most widely used models in medicine is the Healthcare Utilization framework, also known as the Behavioral Model of Health Service Use, which is helpful when aiming to understand issues around patients/families access to care from a systems perspective, but not for understanding the roles that patients' belief systems play in their medical decision and ultimately their healthcare. The model views health care utilization "as a type of individual behavior," which places the onus for help/health-seeking behaviors on the persons (R. Andersen & Newman, 1973; R. M. Andersen, 1995). Similarly, some of the medical literature on the patient-clinician communication plays a similar role where the lens is on the system and structural barriers that reinforce unequal power of dynamics and reproduce paternalistic styles of communication

without asking about the belief systems and communication styles held by patients and families (e.g., Waitzkin, 1984).

A wide range of fields of study have used discourse analysis² or a variation of it to analyze patient-doctor interactions. Unfortunately, the medical literature using discourse analysis as a tool to evaluate medical decision-making among minority geriatric populations is rare. A handful of studies using this approach with minority populations during medical consultations demonstrate its potential usefulness. For instance, Pope (2016) used audio/video recordings to capture the verbal discourse and to analyze the interaction between multiple parties within Latino populations with interpreters in pediatric primary care clinics and found common communication practices, such as omissions on the part of the interpreter affected pediatricians (Pope et al., 2016). This study helped to identify areas of communication practice improvement and potential opportunities for communication skills training. Hardin (2013) examined patient complaints and folk wisdom in the context of the patient-clinician encounter in Eastern Ecuador and was able to identify embedded and hidden meanings during the encounter, identifying the discrepancy between what the speakers stated from what the speakers truly meant (Hardin, 2013). The study helped by providing information that can be used to minimize practitioners' cross-cultural misunderstandings. Additionally, using discourse analysis provides an exceptional understanding of the process of discourse.

Despite the usefulness of studies using discourse analysis to evaluate interactions, by its nature it is unable to provide insight into the subjectivity of the people interacting. Studies that

² Discourse analysis is an approach to analyze language and discourse in social institutions. A discourse is a behavioral unit (e.g., conversation, a joke, an interview). Discourse analysis is an attempt to discover linguistic regularities through an in-depth analysis of recorded interactions. It is an effort to interpret what the speaker intended to convey and the dynamics of the interaction. The analysis often focuses on how social relations, identity, knowledge and power are constructed (Luke, 1997; Norman, 1989; Powers, 2001).

rely on retrospective reports about interactions (versus observing them) may be less accurate about what actually happened, but may offer insight into how older adults interpret what happened and how that fits into the larger worldview (Chapters 4-7).

The medical literature using discourse analysis as a tool to study medical decision-making among minority geriatric populations is rare. Within the medical literature, the study lens is often placed on the patient-clinician engagement and the scope of study is confined to the patient and practitioners' characteristics and styles of interaction, but less often on the individual, the clinician or the patient's family belief systems. In chronic disability studies comparing, for instance, the rates of hip replacement surgeries for Latinos and Whites, they found Latinos in Texas and Latino Medicare beneficiaries from Arizona, Illinois, New Mexico and Texas had lower rates than non-Latino persons (Escalante et al., 2002; Escalante, Espinosa-Morales, del Rincon, Arroyo, & Older, 2000). However, they were unable to understand the cause of the outcome. They were unsure if the disparity of services rendered to one group versus another was due to practitioner bias³ (e.g., racism) or cultural differences (e.g., medical care preferences, lack of patient involvement, or level of patient involvement) in the decision-making process. In another study, Latinos' decision-making regarding treatments for knee and back pain differed from Whites. The study found that Latinos were more likely than non-Latinos to report that knowing about adverse treatment experiences of others made them less inclined to choose a treatment. They also reported the larger importance of family and religion in the decision process of Latinos (J. N. Katz et al., 2011).

³ See LaVeist (2005) for an overview of minority health care disparities.

2.3 Patient-Clinician Relationship

The interpersonal relationship between a patient and a clinician is an important aspect of the medical interaction, especially during medical decision-making. A relationship is a bidirectional process where patients and physicians are assumed to dialogue, interact and develop a trusting relationship.

A relationship is established with two or more individuals; therefore, from an ecological perspective the relationship is influenced by all levels: individual/intrapersonal, interpersonal, organizational, community and public policy. Systemic forces due to managed care policies, and the fragmentation of the medical system (e.g., waiting time, access to consultants, ability to contact physicians, time spent with physicians) may interfere with optimal relationship development (Friedenberg, 2003). However, this project sought to address the more immediate clinical levels of the ecological forces of the patient-clinician relationship as it related to a patient's experience during medical encounters.

This section includes a brief discussion of the patient-clinician relationship as it may influence the medical decision-making process. The following are the points of discussion: (1) characteristics of the patient-clinician relationship based on the model of care (power dynamics), (2) patients and physicians' expectations of each other (power dynamics), (3) predictors of patient satisfaction, in particular age/generational effects, and (4) building trust and managing relationships.

The models of care play a significant role in the characteristics of the patient-clinician relationship, as mentioned earlier. The traditional theories of medical ethics – models by Kant, Mill, Veatch and Pellegrino – have a hierarchically-based view of the patient-clinician relationship and a tendency toward a paternalistic model of care (Freedman, 1993).

A paternalistic model of care assumes a medical practitioner is in complete control of the patient. An informed model establishes a relationship between a medical practitioner and patient; the clinician leads the communication. The physician provides the treatment, and the patient complies. The shared decision-making models are purely interactional, where the physician and patient are assumed to participate in a process enabling patients to make fully informed decisions (Charles, Whelan, & Gafni, 1999). The tenets of shared decision-making models are embodied in the Ottawa Framework for Decision Making, a paradigm used to evaluate the decision-making process (Legare, O'Connor, Graham, Saucier, et al., 2006; Legare, O'Connor, Graham, Wells, & Tremblay, 2006).

The expectations that a clinician and patient have about each other's behaviors prior to the first medical encounter influences the decision-making process. Within the context of a medical encounter, the patient and the physician have an established set of behavioral expectations they anticipate encountering during the medical interview, which implies a top down approach, "I interview you." The patient, who adheres to this model, expects the physician to behave in a predictable manner when providing technical information regarding their medical care (Kravitz et al., 1996). Physicians enter the encounter expecting the patient to behave according to Westernized cultural norms. The extent to which the expectations overlap may be related to positively or negatively influencing the decision-making process. The unspoken expectations will impact the manner that both parties aim to relate to one another.

Patient satisfaction is a method used in healthcare delivery that has been used to measure various aspects of quality of care and the patient-clinician relationship. A patient's level of satisfaction with the patient-clinician relationship has demonstrated to often influence patients' medical decisions. The practice of medicine requires technical and scientific expertise. Most

people do not have the knowledge to assess a physician's skill set, so they evaluate using other more subjective measures of care that they personally know and value (Friedenberg, 2003; Kenagy, Berwick, & Shore, 1999). The patient-clinician relationship literature within medicine seems to base its primary outcome on patient satisfaction and studying physician characteristics, physicians' personality traits, and physicians' style of interaction. For instance, Duberstein (2007) conducted a cross-sectional study of patients and clinicians from primary care practices in Rochester, New York. Patients reported being more satisfied with medical practitioners who were relatively high in Openness and average in Conscientiousness. Another predictor of patient satisfaction was patient age. Older patients assigned higher ratings than younger patients, and those with a greater medical burden rated their physicians higher (Duberstein, Meldrum, Fiscella, Shields, & Epstein, 2007). Patient age was associated with the style of interaction, which is, in turn, related to patient satisfaction. Patients' over the age of 65 were more likely to have a patient-centered encounter with their physician (Peck, 2011). Patients, in general, have been found to be less satisfied when physicians dominate the medical encounter or when the emotional tone is characterized by physician dominance (Bertakis, Roter, & Putnam, 1991).

Even more important than clinicians' characteristics are the perceived true intentions of the medical professional towards the patient's well-being, which aids in establishing trust. "Patients do not care how much a physician knows until they know how much the physician cares" (Friedenberg, 2003). Trust is a central component of the patient-clinician relationship and an important aspect of a patient's medical decision-making process. Trust is defined by Thom (2004) as the acceptance of a vulnerable situation in which the patient believes that the practitioner will act in the patient's best interests. As mentioned earlier, one of the goals for the physician during the medical interview is "to establish a relationship of mutual trust." Trust is a

vulnerable and fragile commodity difficult to acquire and it is extremely delicate (Thom, Hall, & Pawlson, 2004). Once established, often by multiple medical encounters and a lengthier relationship, it can be completely lost with one bad experience (Friedenberg, 2003). Often, the level of trust is used by the patient to judge the physician's knowledge or skill (Freedman, 1993). Trust is a major factor, particularly with certain groups of people. A recent study found that ethnic minorities are less likely to trust clinicians. Latinos were less likely than whites to trust the fiduciary ethic, technical judgement and interpersonal competence of clinicians (Sewell, 2015). However, the opposite was true for cancer survivors who preferred physician control. These cancer patients reported having greater trust in their physicians (Chawla & Arora, 2013). Trust is one of the central components in the patient-clinician relationship (Thom et al., 2004). A study by Clarke (2014) with elderly patients with multiple chronic conditions reported that participants wanted physicians who were trustworthy and open to diverse decision-making styles (Clarke, Bennett, & Korotchenko, 2014). Once trust is acquired, how do clinicians manage the relationship and maintain their trustworthiness? (Kagawa-Singer, 2013).

2.4 Patient-Clinician Communication

Communication with geriatric patients with multiple chronic conditions during the medical encounter influences medical decision-making. Although both verbal and nonverbal forms of communication exist, this section will primarily discuss aspects of face-to-face verbal communication.⁴ First, communication between a dyadic medical interaction will be defined. Secondly, a brief discussion of the power dynamics in dyadic and triadic medical interactions will follow, which include a conversation on patients' expectations and sensory/functional limitations. Finally, a symbolic interactions perspective will be presented to describe potential

⁴ See Hall, Coats, and LeBeau (2005) for nonverbal communication

issues leading to miscommunication, such as misaligned belief systems (e.g., attitudes toward aging) and discordant interpretations to a symbol (e.g., word, behavior, and the like).

Dyadic (two-person) and triadic (three-person) systems of communications between the older patient, caregiver/interpreter and the clinician are common during medical interactions.

Interpersonal communication is a two-person system of communication. The medical visit is usually a face-to-face⁵ interaction between a dyad, often in proximity, in the exchange of giving and receiving. The two people send and receive verbal and non-verbal information (Solomon & Theiss, 2013). Interpersonal communication fundamentally involves an exchange of messages (Cohen, 2014), often being the primary tool by which clinicians and patients exchange information (Ong, de Haes, Hoos, & Lammes, 1995; Street, 1991). One person generates a message to the other individual and communication follows a unidirectional path (Danziger, 1976). A three-person system of communication in the geriatric medical encounter is also relatively common. The presence of a third person during medical visits often increases with patients age and declining health status (Clayman, Roter, Wissow, & Bandeen-Roche, 2005). Twenty to 57 percent of patients over the age of 65 have a family member or friend accompany them to their medical visits (Beisecker, 1988; Prohaska & Glasser, 1996).

Multiple factors influence the communication between older-patients and physicians. Some of the most common factors affecting geriatric patients with multiple chronic conditions are power dynamics both in dyadic and triadic clinical encounters, expectations, and sensory and functional limitations (R. D. Adelman et al., 2000; Michele G. Greene, Adelman, Friedmann, & Charon, 1994). Power differences between actors during the geriatric medical encounter strongly

⁵ Interpersonal communication is not exclusively face-to-face and may include other facets such as those available through social media outlets (e.g., Facebook, Twitter, Instagram) and other electronic devices (e.g., email, texts, instant message). Such types of interactions are of importance for future studies, particularly with the emergence of electronic health records, thus this area of research will be much needed for later cohorts of older adults.

influence the older-patient and clinician communication. The distribution of power varies between dyadic and triadic medical encounters; however, traditionally the power distribution between dyadic interactions has been unbalanced. The clinician has the power of authority arising from the unequal gap in technical medical knowledge and expertise between the older patient and the medical practitioner. Often this scenario allows the practitioner control over the clinical encounter. It provides the clinician the opportunity to treat older patients as dependent and inactive actors of communication (Berger, 1985; Friedman & DiMatteo, 1979; Marshall, 1981). The unequal distribution of power could potentially result in two situations at opposite ends of the spectrum. One setting increases the likelihood that an older patient be objectified and viewed as a disease rather than a person (Friedman & DiMatteo, 1979). At the other end, the physician can empower older patients to change and modify behavior to improve health status. The physician can positively reinforce healthy behaviors (e.g., motivating, influencing), and thus increase an older patient's self-confidence on issues of disease management (Kaplan, Greenfield, & Ware, 1989).

Unlike dyads, the power distribution between triadic interactions is ambiguous due to the ambiguity of the third person's role during the medical encounter. The third person can be a caregiver, an interpreter, a family member, and/or a friend. Even though there has been a surge of older patient medical visit companions, few descriptive studies have examined the effects of third person on the patients' medical decision-making or how it impacts the care that older patients receive. Adelman (1987) has conceptualized three major roles in the third person: the advocate, the passive participant and the antagonist⁶ (R. D. Adelman, Greene, & Charon, 1987). Whatever the third person's role, research has found they can influence communication and the distribution of power between an older patient and the clinician during the encounter. The

⁶ The conceptualized major roles for the third person by Adelman have not been empirically validated.

interpreter holds a position of power in the interaction, since communication would be impossible without the interpreter's assistance (Hasselkus, 1992). Interpreters have a skill for expanding information. They can facilitate understanding between the clinician and the patient through translation and interpretation. They can influence the flow of interaction and affect the content of the medical encounter (e.g., bringing in their agenda items). Lastly, they can affect medical encounter outcomes (e.g., advocate) (O'Neil, Koolage, & Kaufert, 1988). Additionally, hybrids of roles hold additional power for decision-making. Family caregivers-interpreters hold the power of the medical history as a primary tool in making diagnoses and prescribing treatment as opposed to the physical examination and lab tests (Hampton, Harrison, Mitchell, Prichard, & Seymour, 1975). Family caregiver-interpreters can be primary resources for the medical history, and can have a major impact on the resulting diagnosis and on health care plans proposed by the doctor.

Another factor influencing older- patient and clinician communication are expectations influenced by patient and clinicians' characteristics. Patients' expectations are perceptions that the occurrence of given events is likely to happen during or as a result of medical care (Ulhman, 1984, p. 681). Patient expectations are not always communicated to clinicians. One must "take the cue from the patient. If one listens to and observes the nonverbal communication ... [the patient] will let the physician know...their hopes regarding the treatment outcome and fears about the diagnosis." (Devereux, 1992, p.1410). Roter (2006) theorizes four mechanisms of how the medical care process may be affected by patients' sociodemographic characteristics (p.57). One of them is the unintended care provided by the clinician due to ignorance of social or cultural norms. Clinicians who are largely well-educated, middle class and White are often characteristically different from their patients who are not. Waitzkin (1985), for instance, found

that middle-class subjects tend to be verbally explicit while working-class individuals tend to communicate implicitly with nonverbal signals. Waitzkin proposes that clinicians may simply not be attuned to nonverbal signals of working-class patients (Waitzkin, 1985).

Other factors influencing older-patient and clinician communication during the medical encounter are the patients' sensory and functional limitations (R. D. Adelman et al., 2000). Hearing and vision are important components of verbal and non-verbal communication. Of older adults in their 70's and 80's, 70 to 80 percent experience hearing and vision loss. Visual cues are vital during the interaction. After age 65, there is a decrease in visual acuity, contrast sensitivity and glare intolerance. Older adults who experience visual loss are twice as likely to have difficulty with basic activities of daily living (ADL) and instrumental ADLs (IADLs). Many older adults have functional limitations and problems with ADL and IADLs. These limitations may make the logistics of the medical encounter difficult. Transportation to the medical office may be so overwhelming that older adults do not go to doctor visits as often. The visit may be emotionally and physically taxing to fragile older patients. Practitioners need to adapt their medical encounters to meet the needs of their geriatric patients with limitations (e.g., expand time of medical encounter, additional lighting in addition to learning strategies to effectively communicate with geriatric patients with emotional and physical limitations).

Lastly, many issues can lead to miscommunication between the older patient and doctor during the medical encounter, such as misaligned belief systems (e.g., attitudes toward aging) and discordant interpretations to a symbol (e.g., word, behavior, and the like). Ageism is a belief "system of destructive false beliefs about older people" that is pervasive in the medical care system (M. G. Greene et al., 1986). Research on dependency in the aged argues that the negative function of dependency is a result of society's negative attitudes toward old age. In fact, many

other phenomena in aging, “are seen primarily as a product of decline and deterioration, as a loss of physical and mental functioning...an inevitable consequence of growing old” (Baltes, 1996). Similarly, interviews were conducted with the oldest elderly and the conclusion was that respondents never used the word frail to describe themselves; consequently, the notion of frailty has the potential to stereotype elders with negative effects on well-being (Becker, 1994). The literature describes examples of ageist behaviors among physicians, but few studies document the magnitude of the phenomena. Clinicians, like other members of society, are negatively affected with implicit biases and stereotypes. Studies have found that their scores on attitudes towards older persons or the poor are comparable to the general population (Marshall, 1981; Price, Desmond, Snyder, & Kimmel, 1988). Medical practitioners manifest a personal belief system on aging in many ways. For example, clinicians may discount or trivialize medical problems of older people, inappropriately attributing patient problems to the “natural processes” of aging (R. D. Adelman et al., 1987; M. G. Greene et al., 1986). They may also consider older-patients more “difficult” to deal with than their younger counterparts (R. Adelman, Greene, & Charont, 1991).

Symbolic Interactionist Perspective

According to Teutsch (2003), “it has long been recognized that difficulties in the effective delivery of health care can arise from problems in communication between patient and clinician rather than from any failing in the technical aspects of medical care” (Teutsch, 2003, p.1115).

This research uses a Symbolic Interactionist perspective to conceptualize aspects of communication because some fundamental aspects of our social experience and identities (e.g., ethnicity, age, sex) can be understood using the social interaction perspective (Mead, 1934).

Medical encounters and interactions represent social experiences. People often behave according to how they interpret the meaning of their world.

The symbol is a central concept in this perspective, and people intentionally (and usually unconsciously) use the symbols to communicate. People impose meanings on objects, events, behaviors, body language, words, and the like and will often behave based on what they believe and not what is objectively true. Communication often relies on the use of words and body language that carry meaning and the meaning is often social (Charon, 2001).

During the medical encounter, interpersonal communication is composed of two people. One actor generates a message to the other person and follows a unidirectional path (Danziger, 1976). Within this model, a social interaction takes place. Social interactions are symbolic. The symbol is a central concept to the social interactionist perspective (Charon, 2001). A symbol is a “social object used for communication to self or communicate to others and self. It is an object used to represent something else. The symbol is intentionally used. If the actor aims to use it without intention, the actor may be communicating, but it is not called symbolic (e.g., baby crying). Using a Symbolic Interactionist perspective, the messages being transmitted between the actors carry meaning. Words are symbols that stand for something; they are meaningful; they are used by actors to represent physical objects, feelings, ideas and values. Communication often relies on the use of words that carry meaning and the meaning is often social (Charon, 2001).

Acts are often symbolic as well. They are often used to transmit meaning, to communication with others. For an action to be considered a symbol, the action must have meaning to the actor who performs it. The symbols are significant for the actor who receives them but also to the user. The user of symbols uses them intentionally, not by mistake. “What is essential to communication is that the symbol should arouse in one’s self what it arouses in the other

individual” (Mead, 1934, p. 149). The person uses symbols for the purpose of transmitting meaning that they believe will make sense to the receiver (Charon, 2001). This research assumes that some aspects of miscommunication result from misunderstanding, misinterpretation or dissonance in the meaning of symbols during the interaction of the geriatric medical encounter that may potentially influence medical care decision-making.

Misunderstandings are a common side-effect of human interaction and communication. Words and actions between actors may carry different meanings and, therefore, create potential confusion and misunderstanding. One actor may misinterpret the other individual’s act or word symbolically while the actual meaning from the sender is completely different. For instance, the word cactus for the general population may just mean a desert plant. For Mexicans it means food and medicine to regulate blood sugar. In a medical context, a patient’s behavior may be misinterpreted by medical personnel. For instance, a patient missing a medical appointment may be interpreted as a lack of interest when, in fact, the patient may have simply had no form of transportation or missed the bus. Whatever the patient or doctor intentionally (or unintentionally) communicate may have one meaning to one and a different meaning to the other.

A central component of the Symbolic Interactionist perspective has the actors place themselves in the other’s shoes, something that is central to patient-centered care and patient-centered interviewing. Aiming to engage in delivering and interviewing patients in patient-care model is of supreme importance to ensure identifying common ground. Patient and clinician values and/or perspectives may differ and at times clash (e.g., practitioners’ ageist belief system has a negative function of autonomy).

In summary, a myriad factors influence effective communication between the patient and the clinician during the geriatric medical encounter that has the potential to influence decision-making processes. Adelman (2000) suggests six components of communication should be integrated into the medical encounter to develop effective and empathetic relationships between an older patient and his/her clinician. First, understand the patient perspective. Second, integrate the psychosocial into medical decision-making. Third, give attention to sensory and functional limitations. Fourth, involve caregivers in diagnosis and care plans. Fifth, communicate to the geriatric team. Finally, promote an integrated system of care delivery with potentially new and innovative care approaches (e.g., group care sessions implemented by managed care) (R. D. Adelman et al., 2000).

2.5 Theoretical Models/Frameworks of Medical Decision Making

Over several decades, the medical community has been conducting research based strategies to improve the quality of health care for patients. New and improved models of care have been discussed, developed and implemented (see letters to the editor in response to Emanuel and Emanuel, 1992; Steward, 2014). Most models of care within medicine have moved away from a paternalistic model to patient-centered care (Laine & Davidoff, 1996). Irrespective of the nuances in verbiage, the overall intention is to improve the medical care process and ultimately outcomes for patients (Vladeck & Westphal, 2012; Westphal & Vladeck, 2014).

There are several models of care that have an embedded method for medical decision-making. A brief overview of the four models will be discussed to highlight some implicit assumptions with the construct of autonomy, and the implications for communication between older patients and doctors.

2.5.1 Overview of Decision-Making Models of Care

Paternalistic Model

In the purest form of the paternalistic model, patients assume a passive and submissive role toward professional authority. They are expected to comply entirely with the physician's choice of treatment. The assumption is that the doctors will make the best treatment decision for the patient based upon their clinical expertise, and they can do so without asking the patient for their desires, additional personal information, or involving the patient in the decision-making process. There is a lack of information sharing; therefore, the patient's autonomy is removed and the doctor-patient relationship fails to exist. The flow and direction of communication are unidirectional, from doctor to patient. There is no deliberation process or equitable exchange of information (Charles et al., 1999; Emanuel & Emanuel, 1992).

Informed Model

The informed model establishes a primarily unidirectional relationship between the doctor and the patient. In the process of exchanging information, the doctor often manages the flow of communication from the doctor to the patient. The physician communicates information to the patient by unfolding all treatment options, benefits and risks. Given the gap of knowledge between the patient and the doctor, the transfer of information is primarily seen as the doctor's main responsibility to the decision-making process. This model assumes that the tasks associated with decision-making will be divided, but not necessarily equally as in the shared model, which follows (Charles et al., 1999; Emanuel & Emanuel, 1992).

Shared Model

The shared model in its purest form is interactional. Over time, several hybrids of the shared decision-making model have sprouted, but the main components of the model, with minor exceptions, remain.

The doctor and patient share all stages of the decision-making process (Charles, Gafni, & Whelan, 1997; Charles et al., 1999). There is a two-way exchange of information. The patient and the doctor share preferences for treatment and both negotiate on an agreed decision. The approach assumes both patient and doctor have an investment in the treatment decision. They build a consensus on the treatment option. There are two challenges for doctors using this model of care. First, doctors must create an environment where the patient feels comfortable expressing personal treatment preferences. Second, doctors must allow for discrepancies and disagreements, especially if the patient actively involves family or friends during medical encounters. The model assumes that the patient and/or the physician are interested in partaking in this process. In addition, the model in its purest form assumes no time limitations for all stages of interaction. However, the reality of the 15-minute (or 10 minute) office visit makes this process that much more difficult. It assumes the doctor has the interest, skill and, energy to engage every patient in this type of decision-making model of care.

Patient-Centered Care Model

A patient-centered care model, as its name indicates, centers on the individual (M. Stewart et al., 2014). Similar to the shared model, it is interactional to the degree the patient wishes. According to the Institute of Medicine (2001), patient-centered is "care that is respectful of and responsive to individual patient preferences, needs, and values and ensure that *patient*

values guide all clinical decisions” (Institute of Medicine, 2001). This type of care informs and involves patients in medical decision-making and self-management. Patient-centered care provides physical and emotional support. This model of care recognizes the patients’ concepts of illness and cultural beliefs. It understands and applies principles of disease prevention and behavioral change appropriate to diverse populations (Legare, 2013; Maizes, Rakel, & Niemiec, 2009). In essence, the patient-centered care model serves as a framework that ensures respectful communication and encourages dealing with each patient as an individual rather than a carrier of a presumed set of cultural traits. If used appropriately during the medical encounter, the physician is cognizant of the power of his technical knowledge, but humbly accepts his ignorance of his patient’s characteristics, health preferences and needs.

Although there is a significant amount of interest in healthcare settings on patient-centered care implementation, there is also an acknowledgment that one size is inappropriate for all. The hope is that it fits the majority. However, even among geriatric experts, it is commonly recognized that new models of care are required to meet the needs of older patients with multiple chronic conditions. As a result, the John A. Hartford Foundation and the Patient-Centered Outcomes Research Initiative recently announced their funding of a project to develop "a new model of care that could better meet the complex needs of older patients with multiple chronic conditions” (The John A. Hartford Foundation and the Patient-Centered Outcomes Research Institute, 2014).

Intermediate Approaches

Theoretical models of care are meant to explain the process of medical care with the idea that they will help predict patient behavior. This section recognizes that in real life, doctors may

deviate from the purest theoretical models and apply intermediate and mixed approaches during medical encounters (Charles et al., 1999).

Table 2.1: Theoretical Models of Medical Decision-Making

		Paternalistic Model	Informed	Shared Decision Making Models	
				Shared	Patient/Person/Family Centered Care
Medical Philosophy; Worldview Paradigm		Disease-centered; Doctor-centered; Empirical only	Disease-centered; Doctor-centered; patient - Student	Disease-centered; Person-centered (other models of care are beginning to be introduced)	Patient/Person/Family-centered; Disease acknowledged (other explanatory models of care are acknowledged and could potentially be included)
Physician Role		Dictator	Consultative	Consultative - Collaborative	Collaborative
Patient's Explanatory Model of Care Explored		No	No	Potentially – Not Essential	Yes - Essential
Information Exchange	Flow	Unidirectional	Unidirectional	Bidirectional	Bidirectional; Individualized; Personalized to patients' wishes
	Communication Direction	Doctor to patient	Doctor to Patient	Doctor to Patient Patient to Doctor	Individualized (teacher centered)
	Content Type	Technical	Technical	Technical and Non-technical	Technical and Non-technical
Deliberation		Doctor	Patient	Doctor and Patient (equally)	Varies.. Individualized
Primary Decision-Maker on Type of Treatment to Implement		Doctors	Patient	Doctor and Patient	Varies.. Individualized
Adapted from Charles, 1999					

2.5.2 Conceptualizations of Autonomy

The relationship between autonomy and dependence is a crucial one to examine in conversations with older adults with multiple chronic conditions. However, the various ways dependency is manifested in older adults will be first discussed. Baltes (1996) conducted research in the aged and classified types of dependency to capture a comprehensive understanding of this concept (Baltes, 1996). Baltes described three types of dependencies: structured, physical and behavioral, and argued that dependency has more than merely negative functions. Social demographers and sociologists often use structure dependency. This is dependency created by social structures in society. Physical dependency is often used by public health and medicine as it has wide clinical relevance in the development of ADL and IADLs, often to help determine the ability of an older person to live independently. Finally, behavioral dependency is a focus in the field of psychology and has three main causes: one is learned helplessness; the second, learned dependency; and lastly, selective optimization with compensation. The first two are traced to social environmental conditions. Behavioral dependency results from overly pampering. “When expected incompetence—not real incompetence—in the elderly turns care into over care it results in loss of independence due to disuse.” The last one is self-induced or self-selected and is an integral part of successful aging. This type of behavioral dependency is highly adaptive and represents not only a loss but also a gain. This is dependency that is often selected by the person. The person becomes aware of restrictions in their capacity and in their environment, and they resort to selection and compensation to maintain and optimize functioning. This section describes the relationship between autonomy and dependency, defining dependency from a behavioral perspective. Behavioral dependency is one of the dependencies most feared by the elderly (Baltes, 1996).

The way patients and doctors interpret autonomy matters, even within a patient-centered care model where collaboration and partnership in the decision-making process is assumed. Perceptions of autonomy are often value-driven, much like patient preferences and communication styles. When patients and physicians' perceptions of autonomy are dissonant, it leaves room for assumptions that could potentially lead to misunderstanding and miscommunication.

Not surprisingly, the literature in this area reveals discrepancies in findings that are likely to do with lack of clarity about and disagreement on the relationship between autonomy and dependence. There are both positive and negative conceptualizations of autonomy and its relationship with dependence. Some researchers equate autonomy with independence, implying the absence of dependency, which, in turn, conflicts with autonomy. Other researchers think of autonomy as actively shaping life in accordance with one's values (Berlin, 1969). Other people may facilitate this process, which means that dependence may enable autonomy. Lastly, another group of researchers argue that people depend on each other during the course of their lifetime, albeit to various degrees, which implies that autonomy can only be delivered through interdependence (Tronto, 1993).

Consonance between the patient-doctor perceptions of autonomy must be established to avoid possible misunderstandings and miscommunications. The American medical system has evolved into a business model with consumerist characteristics and ideas. In a consumerist society, autonomy and individuality are fundamental values, which may seem appropriate and positive features. However, the way in which many foreign-born and some ethnic groups view autonomy may not be the same. Some argue that autonomy is an individualistically-driven value that is not relevant to Latinos given their collectivist nature (Montemayor, Adams, & Gullotta,

2000). In an individualistic society, an individual is valued over the collective, while in a collectivist society the collective is valued over the individual. Although at times it is helpful to distinguish between the two camps to display predominant and opposing value systems, the dynamics of perceived autonomy on medical decision-making with older adults with multiple chronic conditions is much more complicated and multidimensional.

“Collectivist” societies do not lack the concept of autonomy. The nature of autonomy exists in both groups under various forms, but depending on whether one has an emic⁷ or an etic⁸ perspective the individual could potentially be perceived as either upholding or declining their autonomy or exercising it in different forms. The physician may unintentionally assume that the patient desires equality in engagement and that it is the patients’ right and privilege. However, many foreign-born individuals may define autonomy interdependently. That is, autonomy is getting the patient what they want with the assistance of or at least within the context of family and friends (a characteristic of collectivist societies).

Moorman (2011) assessed the proportion of older adults who prefer independent or delegated medical decision-making at end-of-life and found most wanted to make decisions independently valuing independence. However, both groups indicated that the reasons for decision-making preference was not due to a lack of autonomy but rather personal and affiliative beliefs (religious beliefs, concerns about burdening others with one’s care, the sense that one is important to and needed by others) (Moorman, 2011). Similarly, Becker (1994) conducted interviews with the oldest old and concluded that views on autonomy and aging promote a “cultural ideal” that fails to accurately reflect an elder’s perspectives (Becker, 1994).

⁷ Emic – (Insiders view) perspective from the members of the community point of view

⁸ Etic – (Outsiders view) perspective from the “experts” or dominant society’s point of view

A concept paper by Mars et al. (2008) that tackles the issues of conceptualizations of autonomy in the context of multiple chronic conditions concludes that ultimately “what matters is that people can realize what they want to realize. [They] suggest that in the context of chronic physical illness, autonomy might be conceptualized as correspondence between what people want their lives to be like and what their lives are actually” (Mars, Kempen, Widdershoven, Janssen, & van Eijk, 2008). What is important to note is that in collectivist societies many families function in this manner throughout their lifetime, so the introduction of a chronic condition for a loved one is one more issue to tackle in the already interdependent perceived autonomy.

CHAPTER 3.0: METHODS

The dissertation project is a qualitative study influenced by grounded theory. Grounded theory is “a specific methodology developed by Glaser and Strauss (1967) for the purpose of building theory from data.” (Corbin & Strauss, 2008, p.1). In general, qualitative methods are used to understand phenomena, processes, explore behaviors, perspectives and experiences (Bernard, 2006; Charmaz, 2006; Corbin & Strauss, 2008; Creswell, 2003; Miles & Huberman, 1994). This study explores the medical decision-making of a convenient sample of Latino immigrants with multiple chronic conditions participating in a specialized medical care program by exploring their medical experiences, paying particular attention to the patients’ patterns of engagement during medical encounters, their illness experiences and their faith in God. Through the influence of grounded theory principles, the collected interview data contributed to the identification and description of cultural modes of interaction with the medical system, and the influence of cultural norms in Latino elder interactions and relationship development, which in turn affects patients’ receptivity to “actively” engage in medical decision-making. To understand the process, the study involved multiple stages of data collection and the refinement and interrelationship of categories of information (Corbin & Strauss, 2008). Two primary characteristics of the grounded theory approach to analysis are the “constant comparison of data with emerging categories and theoretical sampling of different groups to maximize the similarities and the differences of information” (Creswell, 2003, p. 14). However, this researcher used Charmaz’s constructivist grounded theory approach to analysis, which is less prescriptive than those outlined by classic grounded theorists (Glaser & Strauss, 1967). Charmaz’s constructivist grounded theory approach encourages theorizing with the interpretive tradition and

provides this researcher the freedom to explore ideas interpretively (Charmaz, 2006). These methods will be further described below.

3.1 Sample and Recruitment

The objective of inductive qualitative research is to identify the uniqueness of a group including the cultural norms and behaviors. Sampling for inductive research studies are often nonrandom and purposive (Creswell, 2003). In this longitudinal study, a convenient sample of members of a PACE (Program of All-Inclusive Care for the Elderly) center were recruited. The patients were exposed to the medical system on a weekly basis, in particular to a specialized integrated medical system. Given the researcher wanted to capture the patients' medical decision-making and deliberation process in real time, these individuals' were ideal patients to follow. The participants conducted three rounds of in-depth qualitative interviews over a period of 9 months.

Study criteria included self-identified Central American, South American, or Mexican natives to capture the unique Latino elder immigrant medical experience. Although Spanish language was not an inclusion criterion, the language preference for all participants Spanish. Due to the recruitment location, all of the participants were members of GraciaMed's PACE program.

GraciaMed's PACE Program: Recruitment Setting

At the time of the first interview, participants were enrolled in an advanced care program within community health clinics (CHCs) called GraciaMed for anonymity purposes. Loosely defined, the program from which the research participants came was an advanced care program with individualized clinical care management for aging patients with multiple chronic conditions.

GraciaMed's PACE⁹ program is a Medicare and Medicaid managed-care program for adults over the age of 55. The program uses an interdisciplinary team approach to provide patients with medical, social, nutritional and rehabilitative services. The care is comprehensive and integrated, including pharmacological and non-pharmacological treatments and interventions (e.g., referral to specialists, physical and occupational therapists, alternative treatments such as acupuncture and massage therapy), screening, prevention, diagnostic tests, follow-up, and advanced care illness preparation. In order to enroll in GraciaMed's PACE program, patients must have met nursing home eligibility criteria.¹⁰ The advanced care program uses a social worker and adult day health care center model.

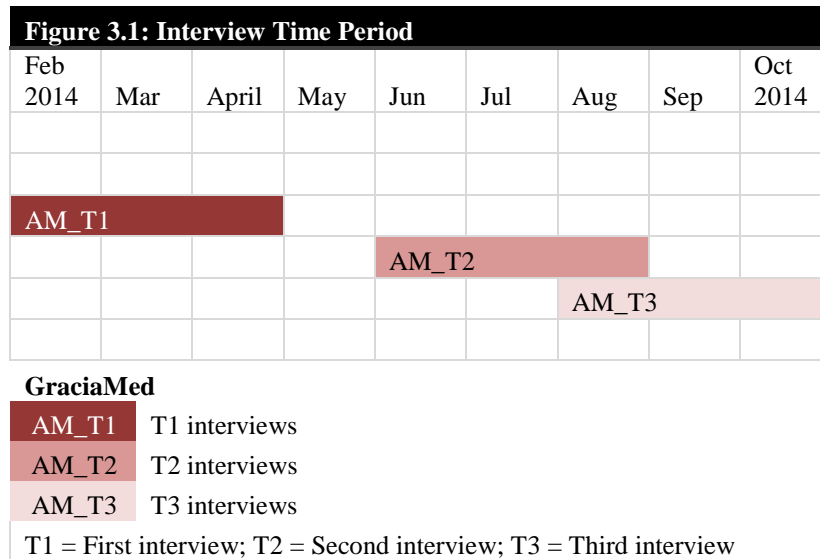
3.2 Recruitment Process and Data Collection

UCLA investigators were provided the contact information for clinic patients who expressed interest in knowing more about the project and what it entailed. UCLA investigators called these individuals to provide project information and obtain consent. If the participant agreed to be interviewed, the location and time of interview were negotiated and interviews scheduled. Most interviews took place in patients' homes and a handful opted to be interviewed at the medical facility. Three rounds of in-depth qualitative interviews were conducted with each participant over a period of 9 months (range of elapsed time between interviews was 6 to 12 weeks). Inclusion criteria for transcript analysis were that they self-identified as foreign-born Latino from South, Central American, or Mexico. None of the 13 patients refused participation in T2 and T3 rounds; however, one was lost to follow-up for T2 interview.

⁹ For more information on PACE, please go to <https://www.medicare.gov/your-medicare-costs/help-paying-costs/pace/pace.html>

¹⁰ For nursing home eligibility criteria, please see http://www.dhcs.ca.gov/services/medical/Documents/ManCriteria_26_LTC.htm

UCLA project investigator (RLB) conducted the first round of interviews in Los Angeles County between February 2014 and April 2014. The first interviews were conducted face-to-face. The duration of the interview was approximately one hour. Subsequent interviews (T2 and T3) were conducted over the phone with interviews ranging in duration between 30 to 90 minutes. All three-rounds of interviews were conducted between February 2014 and October 2014 (8 months). All interviews were conducted in Spanish and were digitally recorded with permission of the participants. There was one individual who declined permission for the first interview, but agreed for the subsequent interviews. About three months transpired between rounds of interviews (T1, T2 and T3) (Figure 3.1).



3.2.1 Sample Demographics

During the first round of interviews, most participants were conservative in self-reporting their conditions. As time elapsed and rapport- building increased, the participants more openly disclosed additional conditions, especially mental health conditions such as depression, anxiety and sleep disorders, which often carry social stigma. Other conditions were also not initially disclosed, such as those not viewed as medical problems per se, such as risk of falling (having had multiple falls and being at grave risk of falling due to mobility issues). The average numbers of medical conditions reported on Table 3.1 were based on the first round of interviews.

We interviewed a total of 24 patients from GraciaMed. The average age was 74 years (R 56-93) and 75 percent were female with people from all minority groups, predominantly being from central/south American and Mexico. A minority were African, Asian and American Indian. Twelve were monolingual Spanish speakers. Six were bilingual choosing to do their interviews in English and six were English speakers. The foreign-born Latinos within GraciaMeds population has on average 9 years of education.

Although three round of interviews were conducted with all GraciaMed sample, this study's inclusion criteria called for an analysis on foreign-born Latino elders (n=13; Table 3.1). The sociodemographic differences between native and U.S. born Latinos are minor; foreign born Latinos primarily preferred Spanish language and had a lower level of education (4.5 years vs. 9 years for U.S. born). However, the exclusion of U.S. born Latinos was based on the immigrant experience and their exposures to the American culture. Foreign-born Latino elders will have different exposures and experiences that inform their decision-making process in comparison with U.S. born Latinos. Although the value systems and worldviews between U.S. and foreign-born may overlap, the nuanced worldviews may have a slightly varying version of reality that

may in fact impact medical decision-making. Some studies have shown that cultural values (e.g., familism, Spanish language) may wane with time (Almeida, Molnar, Kawachi, & Subramanian, 2009; Taylor, Lopez, Martínez, & Velasco, 2012). Culture, as explained later, is dynamic and influences individuals as well as its influenced by it (Kagawa-Singer, Valdez Dadia, Yu, & Surbone, 2010). Cultures are embedded within social structures of dynamic interactions, where individuals impact and in turn are themselves impacted by culture (Kagawa-Singer et al., 2010). In addition to culture impact, studies by M. L. Kohn (2006) have found that social structure impacts individuals' relational behaviors. They conducted cross-national system and generally found that socioeconomic status is associated with self-direction or conformity (M. Kohn, 1989). More traditional social class structures are taught to obey authority, which locks their behavior to model after the authoritarian style of interacting with others. As one moves up in social economic status (economically or educationally), the less likely the individual will use an authoritarian model of interaction and more permissive behavior to interact with others (M. L. Kohn, 2006). One of the assumptions of this study is that the medical encounter influences medical decision-making processes – the way the patient and clinician engage (e.g., authoritarian vs. more permissive styles)¹¹ will be affected by their exposures based on their social structure. Although arguably, if using insurance status as proxy (e.g., Medi-Medi), most of the participants are deemed low socio-economic status; however, the U.S. born Latino may have other kinds of resources that may deem them equivalent to a middle-class social economic status compared to that of immigrants (e.g., language, education).

¹¹ Authoritarian conservatism. Conceptions of what is socially acceptable—at one extreme, rigid conformance to the dictates of authority and intolerance of nonconformity; at the other extreme, open-mindedness (M. L. Kohn, 2006, p. 22).

Table 3.1: Participants' Demographics	
Participant Characteristics	Latino Immigrant Patients from GraciaMed (n=13)
Age	
Mean (<i>range</i>)	75 years (65-85)
Gender	
Male	3 (23%)
Female	10 (77%)
Race/Ethnicity	
Central /South American	6 (46%)
Mexican	7 (54%)
Marital Status @ T1	
Married	3 (23%)
Widowed	7 (54%)
Separated/Divorced	3 (23%)
Living Arrangements	
Alone	3 (23%)
Family	10 (77%)
Language	
Spanish	10 (77%)
Bilingual	3 (23%)
Years in the United States	
Mean (<i>range</i>)	21 years (3-52)
Education	
Mean (<i>range</i>)	4.5 years (0-16)

3.2.2 Data Source and Instrument

These data were taken from a sample of 13 older adults over the age of 65 with multiple chronic conditions. The data were collected using semi-structured interviews that call for the use of an interview guide to direct discussion and provide probes when additional information is necessary (Bernard, 2006). The pre-screening questions and interview guide used during the interview included the following information that speaks to the research question and specific aims (see Appendix B for complete interview guide):

Demographic Information

- Age
- Gender
- Education
- Marital Status
- Language
- Foreign-born
- Years in the United States

Interview Guide Topics that Address Research Question and Aims

- Medical Decisions
 - Communication with doctor
 - Relationship with doctor
 - Family involvement in decision-making
- Explanatory Model of Illness (Kleinman, 1980, p. 106)
- Faith

3.3 Data Preparation /Data Management

For the sake of maintaining original meaning and avoiding the loss of meaning in translation, I transcribed interviews in their original language. All audio-recorded field notes and memos were also transcribed verbatim. All audio files remained in a password protected and secured drive at the UCLA Center for Health Policy Research. The interviews were uploaded to Dedoose version 7.1.3, a software that facilitates qualitative data management (Lieber, 2015). The transcripts were arranged by participant. All complete interview transcripts were read once along with the interview summaries to bring myself into the participant's world. When all three interviews were read once, I began line-by-line coding (described in qualitative data analysis section).

3.4 Qualitative Data Analysis

Prior to conducting analysis, I obtained approval from the UCLA Office of the Human Research Protection Program (IRB # 15-000208). I analyzed a qualitative dataset for 13

interviewees composed of 39¹² original transcripts in Spanish and their respective interview process documentation (e.g., written and oral interview summaries). An inductive approach to analyze interview data and interview summaries was conducted to answer the research question and aims. My aim was to deconstruct explicit reality and reconstruct implicit reality (see it from the eyes of the participants). I sought to capture the contexts within which older adults with multiple chronic conditions made medical decisions. Such an approach allows for an in-depth exploration of the individual and socio-ecological factors affecting older Southern Californian Latino immigrants' medical decision-making processes. The analysis explored factors that affected older adults' medical decision-making processes, particularly issues around the patients' medical encounters (patient-clinician communication, patient-clinician relationship, and patient engagement) and issues of faith, perceptions of illness, trust, fear, self-efficacy and perceived lack of knowledge to answer the research question and three aims.

¹² 35: 13 people across three time periods = 39 – 4 transcripts (recording refusal and one who was unable to complete all rounds of interviews).

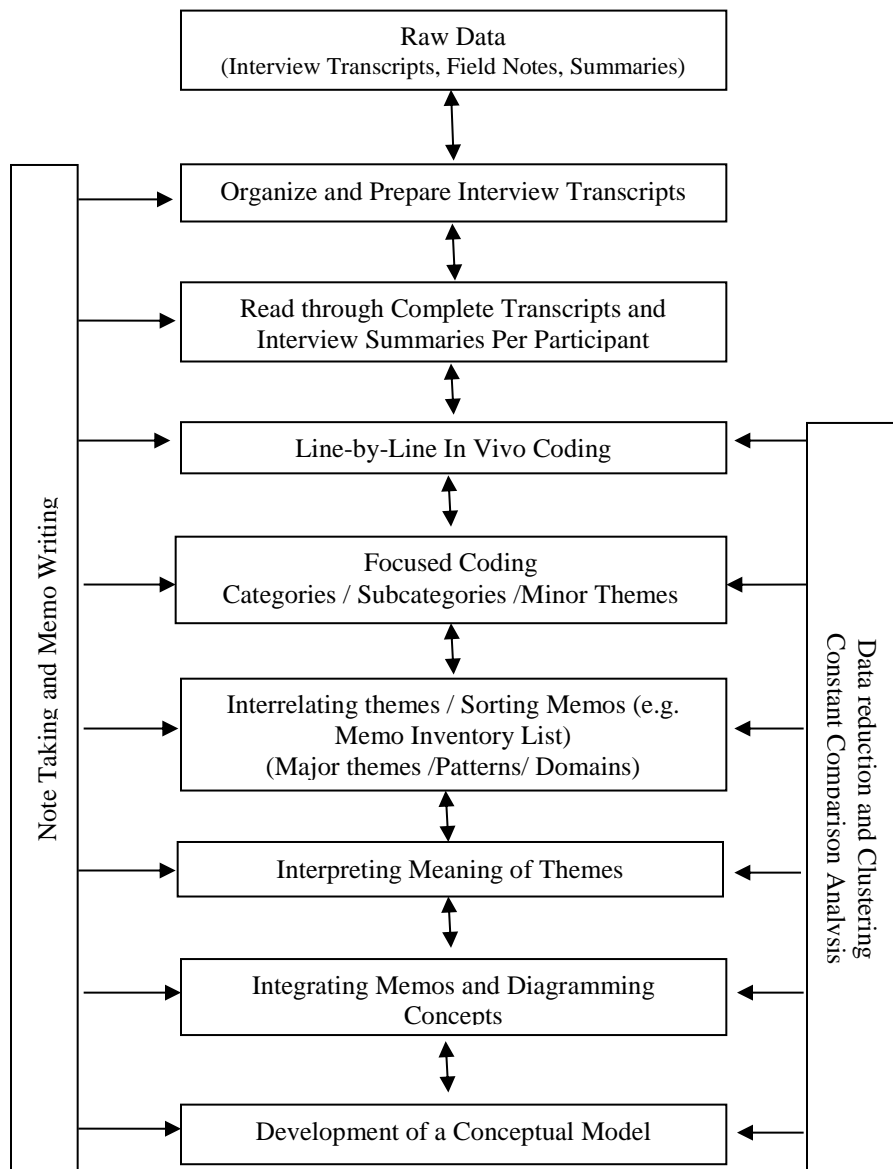


Figure 3.2: Visual Representation on the Overview of the Data Analysis

Schematic diagram outlining simplified steps to a grounded theory study. This dissertation was influenced by classic theorists of grounded theory (Glaser & Strauss, 1967); however, the analysis was heavily influenced by Charmaz (2006) constructivist grounded theory for interpretative theorizing to uncover implicit meanings and processes (p. 11).

3.4.1 Inductive Approach: Developing Domains/Model

The following describes the analysis process in a step-wise method as if there is a beginning and ending to each section. The steps are presented in such a manner for the sake of clarity. In reality, this type of analysis is an iterative process of adding and updating codes so there was a blurring between steps (Figure 3.2). In situations where multiple coders are simultaneously coding, this iterative process often intensifies and dialogue often brings resolution. In this study, I was the sole coder and during this whole process I wrote memos on any conceptual maps and questions that arose. Additional questions were resolved in consultation with the faculty advisor. In addition, I maintained methodological notes during the coding process identifying reasons for inclusion and exclusion of specific codes, categories and/or themes. In addition, I recruited two undergraduate (AR & NV) volunteers to code two transcripts.

Step 1: Initial Phase of Coding (Developing Codes)

A sample of interview transcripts were read once without the use of annotation to allow myself (the coder) to enter into the participant's world. I then began the first level of coding. I conducted five line-by-line coding by hand, which consisted of reading each line of text and assigning a code to pertinent data. A line or phrase of text was divided and assigned a code using the interviewee's own words directly from the transcript. This method of coding is referred to as in vivo coding, an important initial phase to encourage the researcher to remain grounded in the data without imposing personal biases (Corbin & Strauss, 2008). This process yielded a number of codes across all 13 interviews, and thus I developed an on-going list of codes that was subsequently condensed into higher order categories. Initiating the coding process automatically

starts the data reduction and clustering process. All transcripts were coded in Dedoose by one coder.

Step 2: Higher Level Coding (Grouping Codes into Categories/Minor Themes)

Once coding for a handful of transcripts was completed and the codebook approved by faculty advisor, I coded all remaining transcripts adding additional codes as they emerged. I grouped line-by-line codes into broader categories. Again, just like the initial phases of coding, I conducted two higher-level code schemes/broader categories to develop themes. Transcripts were read at multiple times to ensure all themes had been exhausted. Every “codebook” version has been kept to parallel the methodological notes.

Step 3: Higher Level Concepts (Grouping Categories into Major Themes/Domains)

The categories that resulted from grouping multiple codes gave rise to the development of several major themes/domains. The conceptual model was developed based on specific domains that pertained to the decision-making processes that older adults with multiple chronic conditions engaged (more on this section below).

3.5 Data Interpretation: Thinking Outside the Box

In qualitative research, the researcher is his or her own data collection instrument and thus wears multiple hats: observer, interviewer and evaluator. A researcher is also embedded within his or her own ecosocial system and somehow inter-related to the participants, even if it is just by human nature. Being cognizant that the researcher’s inherent biases, blinders and issues of race/culture are important to consider in the process of conducting research, memos were extensively used for self-reflection (Milner, 2007). During the data collection process,

precautions were taken to avoid potential biases and blinders by recording and writing personal memos on all impressions regarding the interviews especially when questions and emotions were triggered. Because I am the eldest child of Mexican immigrants and hold a Christian worldview, additional precautions during the analysis of the data were taken by increasing inter-rater reliability by having my advisor who is not of Mexican heritage provide feedback on the coding scheme.

The researcher sought to define reality as it was deemed by the participants. During the interview process, the interviewer/researcher became the student and looked to foreign born Latino elders with multiple chronic conditions as the experts. Using the themes that emerged from the coding, the researcher interpreted the data by examining explicit and implicit themes. Once an explanatory model of the decision-making phenomena, as seen across the interviews was developed, the researcher used individuals' interview summaries and compared and contrasted perspectives (Bernard, 2006). In addition, as a way to validate findings, the summary of findings table was distributed to fellow students and older adults with a similar background. They were asked to comment based on their particular situations and experiences.

In closing, this chapter summarized the methods used in this study, the reasons for using constructivist ground theory approach, the sample demographics, the recruitment setting, data collection and data analysis. The next four chapters will present the results of the conceptualized relationships discussed earlier with medical decision-making (e.g., issues of patient engagement, culture, and faith).

CHAPTER 4.0: FINDINGS - PATTERNS OF RECEPTIVITY AND MEDICAL DECISIONS

In this study, the emergent theme centralized around patients and family members aiming to have *their needs met, but often only engaging the healthcare system as far as cultural norms, beliefs and values dictated to be appropriate*. Typically, a patient/family was willing to partake in the medical decision-making process when the perceived benefits of a health-related decision outweighed any potential risks, and when a patient's/family's level of readiness for change was high. This chapter describes a general model of medical decision-making informed by economic ideas of cost and benefits analysis. However, rather than a traditional rational actor type of cost-benefit, this model is primarily driven by patients' cultural beliefs and values, which informed patients fears of the perceived outcomes. In addition to describing the general model, I describe four patterns of receptivity that patients used to engage the healthcare system. Patients' willingness patterns to participate in health encounters had a direct impact on decisions. Many factors influenced patients' receptivity to medical decision-making, including the type of program/health systems they belonged to at the time they were engaging healthcare organizations, and the types of engagement used during medical encounters. Examples of health decisions to change practitioners and medical systems are presented as well as a description of how patients and the medical system engaged using technical, social, and emotional types of engagement. I describe three types of engagements from the most technical, which represents what doctors are mostly trained about, to the most emotional, which has an extremely culturally-relevant component for these Latino elders. The next chapter will present four aspects of relationship and communication often persuading patients' patterns of receptivity to decision-

making. Table 4.1 summarizes the themes and categories pertinent to patients’ medical decision-making that emerged for both this chapter and the next.

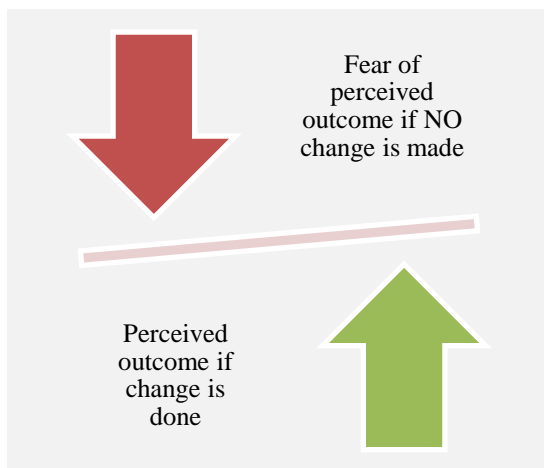
Table 4.1: Themes and Categories on Patients’ Engagement in Medical Decision-Making (Chapter 4: Aim 1) and Patients’ Family Involvement in Medical Decision-Making (Chapter 5: Aim 1.1)		
Overarching Domain: Patients and family members aimed to <i>have their needs met, but often only engaged the healthcare system as far as cultural norms, beliefs and values dictated it to be appropriate.</i>		
Themes	Categories	Sub-categories
Receptivity	Receptive	Listen to advice of others, willing, open
	Cautiously optimistic	Positive attitude, optimistic, not focus on problems
	Cautiously skeptical	Negative attitude, fear, takes time, thinks of social and family problems
	Non-receptive	Closed, unwilling, curt
Communication	Technical	Professional (Technical; services-oriented)
	Social	Non-technical information
	Emotional	Share emotions, emotional exchanges
Trust (Chapter 5)	Professional Relationships	Good doctor, person of trust, advocate
		Culturally valued characteristics associated with warm relationships (e.g., <i>amable, risueña, simpatía</i> , and the like)
		Going beyond the expected role
		Language concordance; listening; silence
	Hybrid/Intermediate	health professionals (cross-over); technical and emotional support, <i>confianza</i> (trust)
Personal Relationships	Family, center friends, acquaintances, instrumental/cultural support, emotional support, positive emotions, negative emotions	
Aim 1.1: Family Involvement (Chapter 5)		
Types of Decisions	Crisis	Life or death
	Preference	Non-urgent nature
Family Distance	Location/physical proximity	
Quality of Relationship	Positive	Supportive (instrumental, emotional)
		Listens to loved one’s preferences and acts
		Accompanies loved one
		Frequent positive communication
	Negative	No visit, no frequent, no extended family
	Sparingly visit and communication	

4.1 General Model of Medical Decision-Making

Balancing the perceived risks and benefits often drove the general pattern of medical decision-making. Patients either avoided medical decision-making associated with an action-oriented behavior and remained in their current health state or made a medical decision and hoped for an improved quality of life. Itemizing these risks and benefits often heightened perceived threats to their personal quality of life; patients often assessed priorities driven by personal values and belief systems.

Medical decisions associated with behavior change can often be an emotional, physical, spiritual, financial or social inconvenience. People often disliked being bothered or taken out of their comfortable routines. Medical decisions associated with action-oriented behaviors, such as changing practitioners, meant the perceived fear of the outcome without some kind of intervention was greater than remaining in their current state (Figure 4.1a). Patients making decisions requiring action often either felt threatened or susceptible to having health conditions worsen, and perceived themselves in danger unless they took some kind of control over the situation. On the opposite end, patients making a decision that did not include a behavior change component did not feel the need to make a medical decision or engage in a treatment, because they did not feel threatened that their condition would worsen or perceive themselves in immediate danger (Figure 4.1b).

(a) Medically-Related Decision: Behavior Change



(b) Medically-Related Decision: NO Behavior Change

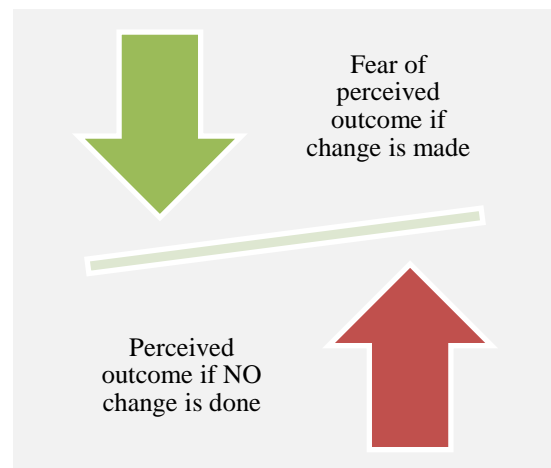


Figure 4.1: Decisional Balance in Action-Oriented Medically-Related Decisions

(a) Represents making a medical decision requiring an action-oriented component (e.g., changing clinicians, treatment decision, moving to another country due to health) (b) Represents either not making a medical decision with an associated behavior change or not making a medical decision altogether (e.g., refusing insulin treatment, non-compliance to recommended medical treatment).

Patients most often feared the perceived consequences of refraining from engaging in medical treatment when their current situation was in an undesired state (Figure 4.1a). Take a patient, for instance, who values independence and one of her most emotionally-charged fears is behavioral dependence. She fears that her condition will worsen and will lead her to become behaviorally dependent without medical intervention. Her fear of the perceived outcome without a medical intervention is strong enough for her to seek out alternative medical attention. Her hope is that the medical intervention will stop her fear from becoming a reality. Her hope in medicine is stronger than the fear associated with the side-effects of having the medical procedure. This excerpt showcases the synergistic relationship between fear and hope often seen in preference-based decision-making.

Excerpt 4.1a: Fear and Hope

The fear that [my disease] could progress to an insulin-dependent state and this [medicine] improves kidney function that is why I took them. I think hope that the pills would suit me well (Translated from Spanish).¹³

Importantly, medical decision-making is contextualized along a second, parallel continuum based upon perceived urgency that runs from preference-based on one side of the spectrum to crisis-based on the opposite end. In preference-based decision-making, the benefits of the treatment outweigh the risks and the probabilities of a positive outcome are high. In crisis-based decision-making, on the opposite end of the spectrum, decisions are often life-threatening (e.g., cancer diagnosis) with a perceived time pressure, given that the risks frequently outweigh the benefits and the likelihood of negative outcomes (e.g., death) increases. Along this continuum of decision-making, fear and hope work synergistically or antagonistically depending on the context of the decision. In preference-based decision-making, fear and hope appear to work synergistically with each other; as the fear increases so does the hope in this new medical intervention. The synergism between fear and hope, however, becomes more antagonistic and tension-filled as the situation becomes increasingly critical and crisis-mode decision-making takes place (e.g., end-of-life care). At this state, fear of the perceived outcome is heightened and hope for medical intervention decreases. However, among foreign-born Latino elders, even when the hope for medical intervention diminished, a lingering hope often remained in the supernatural ideas of God and miracles.

In sum, patients who were happy with their current health state were not likely to make decisions requiring behavior changes; however, if the perceived fear of the outcome without a medical intervention were heightened, patients were more likely to make a medical decision requiring active family/patient willingness and participation. An influential component to

¹³ “*el temor que me podía llegar a insulina y esa [medicina] le mejoran a uno los riñones por eso me las tome. Yo creo la esperanza. La esperanza que me cayeran bien.*” –am1t1

decision-making is the patients' experience of medical encounters. Below, four basic general patterns for engaging the medical encounter are presented.

4.2 Patterns of Receptivity

The way patients engage the medical system is dynamic and can alter over time depending on contextual life events, patients' preferences and family involvement. In this section, I describe four basic patterns of how patients engaged the medical encounter, primarily during doctor office visits. Briefly, they follow a continuum of receptivity to engaging in the medical encounter and making medical decisions with an observable behavioral component. The continuum follows a pattern of receptivity from openly receptive, cautiously optimistic, cautiously skeptical (i.e., cynical) and closed and unreceptive to engage and change (Table 4.2). Both the cautiously optimistic and cautiously skeptical have similar engagement characteristics/attributes. A key distinction between these two patterns is the patients' positive versus negative frame of mind, which was often influenced by their environment and/or previous personal and vicarious medical experiences.

Table 4.2: Four Patterns of Receptivity as it Pertains to Medical Decision-Making	
Receptive (+)*	Non-Receptive (-)**
Receptive	Cautiously Skeptical
Cautiously Optimistic	Unreceptive
<p>* The patients' fears of the perceived outcome if engage in medical decision with behavioral intervention is lower than the patients' fear of the perceived outcome if nothing is done. If a decision with no intervention is done the patients' fears of the perceived outcome increases.</p> <p>**The patients' fears of the perceived outcome if no intervention is done is NOT greater than doing nothing.</p>	

The dynamic nature of individuals and decision-making means people can move in and out of these patterns of engagement at any time. Decision-making is often context-dependent, considering that participants' state of vulnerability and their beliefs and values can shape foreign-born Latino elders' pattern of receptivity for engaging changes over time. There are nuances with these patterns that will be discussed in the subsequent chapter, which describes modifying factors.

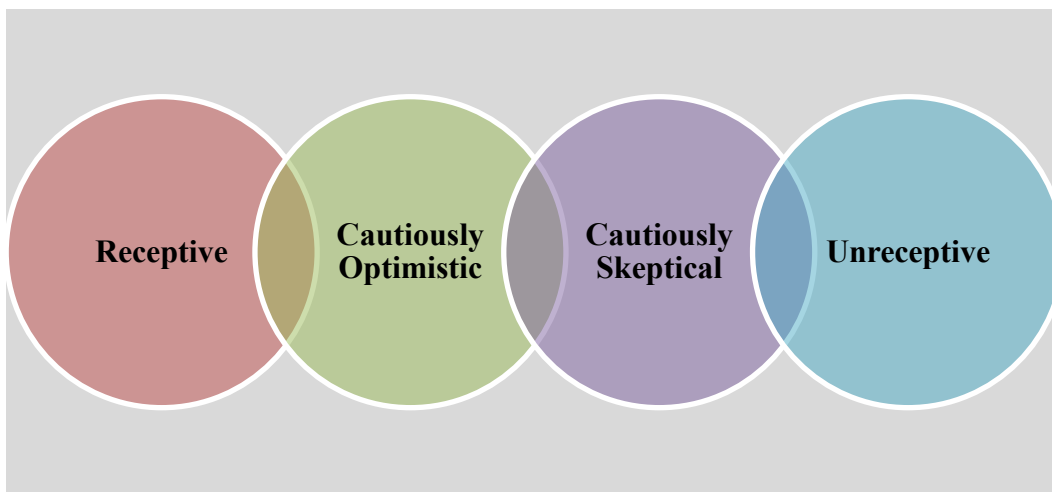


Figure 4.2: Four Basic Patterns of Receptivity

An illustration of the porous patterns of receptivity in engaging medical encounters ranging from openly receptive, cautiously optimistic, cautiously skeptical (i.e., cynical), and closed and unreceptive to engage and change.

4.2.1 Receptive

At our age, we all need medical attention...all of us...for a small cough we need attention. We do not know the consequences that that will bring. So it is better to be checking ourselves...It is better to prevent. You don't know what illness will come (Translated from Spanish).¹⁴

Patients who engaged the system receptively were open to listening to the advice of medical staff and others and willing to make medical decisions involving behavioral change. As

¹⁴ “A la edad de nosotras, todas necesitamos asistencia médica...Todos, todos...por un catarrito necesitamos la asistencia. No sabemos las consecuencias que eso va a traer. Así es que, es mejor estarse chequeando...Es mejor prevenir. No sabes qué enfermedad te llegue.” –am1t3

mentioned earlier, the boundaries between the observed structures are fluid. Hence, people gravitated towards one framework during certain periods of their lives and moved towards others depending on their circumstances. Most of the participants that fit within an open pattern of receptivity were in heightened states of vulnerability and required increased medical attention. Patients were responsive and amenable to making decisions that necessitated immediate change. Their level of readiness for change was in an elevated state. Patients and/or family members were unhappy with the patients' current health condition and feared their situation would deteriorate if a decision with an associated action were not made. The fear of the perceived outcome if the situation remained stagnant was greater than the fear of the perceived outcome if a decision involving a medical intervention was made (Figure 4.1a). They were hopeful that the medical decision involving change would meet their needs and preferences.

Example of Medical Decision: Changing Medical Systems

Changing clinicians is a difficult medical decision that older adults may make (Strombom, Buchmueller, & Feldstein, 2002). All respondents in this study were currently enrolled in a Program of All-inclusive Care for the Elderly (PACE),¹⁵ which is a managed care program that includes long-term care services but which participants have to transfer into after they become disabled (See Chapter 3: Methods). Many respondents made the decision to enroll in PACE both during extreme and non-extreme states of vulnerability. The health care system they were involved in prior to entering Grace Med's¹⁶ PACE program motivated them and/or their family to seek change. The circumstances around this decision provide a useful insight into

¹⁵ For further information, please see: <https://www.medicare.gov/your-medicare-costs/help-paying-costs/pace/pace.html>

¹⁶ A fictional health plan name is used for anonymity purposes.

decision-making on significant issues. The driving force for making the decision to change medical systems often resulted from a perceived threat (i.e., fear) to their current state of being and their quality of life.

Generally, in severe states of vulnerability, either elder-initiated or and/or family-initiated action sought out alternative care for themselves or on behalf of their loved one. When the patient made the decision, they were usually not in a medical crisis, but were more often managing negative life circumstances or events (e.g., loss of loved ones, divorce and the like) that made them dissatisfied. Francisco,¹⁷ as an example, had several of his key medication benefits cancelled. He feared his condition would eventually worsen and sought to get into a system that provided the care he needed:

Excerpt 4.2.1a: The Medical Plan Stopped Covering my Medication

I was with [a medical plan], but they were no longer caring for me well...I suffer from incontinence because I was operated [from my prostate]...They took away my medicine and I needed it (Translated from Spanish).¹⁸

He then talked to medical staff, allied health professionals, insurance companies and others willing to offer advice about other possible health plans. Francisco does not have family near-by, so he did not have family support during the decision-making process. However, other patients' circumstances were such that the patient initiated the decision and subsequently told their decision to family members, who usually supported it.

In another case, Maria¹⁹ became so dissatisfied with the lack of immediate care from her health plan that it increased her fear of what could happen if she did not switch to another health plan; therefore, she was open, willing and receptive to switch practitioners and enroll in PACE.

¹⁷ Pseudonyms have replaced respondents' actual names for anonymity purposes.

¹⁸ *"Yo estaba con [nombre del plan de cuidado de salud] pero ya no me estaban pues atendiendo muy bien...yo sufro de incontinencia porque me operaron... Me quitaron la medicina y pues yo la necesitaba."* -am4t1

One Sunday morning she was getting ready to go to church. Suddenly, her knee locked and she was no longer able to move. She became fearful about becoming behaviorally dependent and emotional due to the pain and the burden she felt she was to her children. On that day she was not thinking of changing medical systems, but rather thinking of getting the medical attention she needed to take care of the problem. The following day, she went to her clinic and was lucky enough to get a ticket number, which symbolized hope of being seen by a clinician. “It didn’t bother me having to wait all day because I knew that they would see me” (Translated from Spanish).²⁰ As the hours went by, however, it was clear that the clinic was up to capacity, and they would not be able to see all the people with ticket numbers. It was at this moment she decided it was time to seek alternative sources of care. A general theme for engaging the medical encounter was that *people engage the system as far as they needed to have their needs met*. Her medical plan was unable to provide her the comfort or hope she needed to appease her fears, hence the decision.

Excerpt 4.2.1b: As if Waiting to be Seen was Something I was Doing for Fun [Sarcastic Tone]²¹

In reality I felt like I was going [to the clinic] as if I liked it because I didn’t get to be seen. I don’t know what happened if a lot of help from Medi-Cal or something got suspended and all those people that Social Security paid the private doctors. All of a sudden everything changed and all those people arrived there, and the same with other clinics. So then it got too full. There were up to three blocks of people waiting to be seen day after day we would go and get a number. They would say it is going up to 270. I would reach that number, and I would spend the whole morning inside and all of a sudden they would say sorry but the doctor will only be able to see up to such number, and the ones after such number go home. So then I decided no more (Translated from Spanish).²²

²⁰ “No me importaba pasar allí todo el día porque sabía que me atendían.” –am11

²¹ “¡Yo sentía que iba por gusto! [Tono Sarcástico]” –am11

²² “en realidad yo sentía que iba [a la clínica] por gusto porque no alcanzaba porque no sé qué fue lo que paso como que suspendieron mucha ayuda del Medi-Cal y toda la gente que iba antes que no se el seguro le pagaba el médico particular. Y de repente las cosas [cambiaron] esa gente llego allí. Y así a otras clínicas. Entonces se llenaba demasiado. Eran hasta tres bloques de gente y día tras día íbamos le dan número. Va llegar hasta las 270.

Maria's motivation to change health plans was driven by the problems with her current care rather than an inducement for improved medical attention. Her usual source of care was no longer meeting her needs, which elevated her fears associated with becoming behaviorally dependent on others (e.g. immobility, feeling useless). Maria made the decision and then informed her family of her wishes to obtain their support. Her children were encouraging, but she was the driver in the process. These fears were the driving forces to decision-making. Maria was more emotionally disturbed by the thoughts of the outcome if she failed to take control by switching to a health plan more so than the inconvenience of change (Figure 4.1a). The fear of the outcome encouraged her to make the health plan change, despite her apprehension about the challenges of going through enrollment in a new health plan.

Although many decisions to change health plans were driven by the patients' health needs at the time of engaging the medical system, some decisions were not made when the patient was in a vulnerable state; some were made for the benefit of the greater good – their family members. Prior to entering GraciaMed, many patients had loved ones drive them to their medical appointments. Often, the task required a family member to sacrifice a day off work, which became a financial burden on the family. For example, the primary reason why Elena moved to GraciaMed was to meet a family need since GraciaMed provides transportation to their adult daycare site where most services are also available.

Excerpt 4.2.1c: Thinking of my Family Needs

Before, I used to go to a clinic close to GraciaMed PACE...my son would take me. That's why I tell you I moved...They treated me well...only that the truth is that they [PACE] come and take me because the other [clinic] it was difficult. My son works and now with his kids it's not the same, right? My son would go [into work] when they would schedule my appointments. [He had to take time away from his work]. And now I am fine

Ya alcanzaba número, pero al estar adentro pasaba la mañana y ya de repente nos decían lo sentimos, pero el doctor solo va poder atender hasta tal número. Y las demás vallan se. Entonces no ya no.” – am11

because right there...the doctor is right there where I go. There they care for me...it turns out if I need to go to get x-rays; they themselves take me (Translated from Spanish).²³

Patients in both patient and family-initiated kinds of interventions were under various states of vulnerability. Qualitatively speaking, however, family-initiated interventions more often resulted when loved ones were in severe states of crisis. Respondents often changed medical systems when patients' medical circumstances became so severe that their family sought to intervene. However, if the patient was comfortable, most of the time they did not see a need to change. Juan, for instance, states: "Why am going to move if I am comfortable there? Since I entered GraciaMed I have been at peace without having to deal with any doctor-related problems" (Translated from Spanish).²⁴ However, this was not a reality for other patients. Staying in the same circumstances meant contending with barriers and delays to care in their current health plan to the point where it became unacceptable to them and their family members. They would then initiate contact with fellow family members and engage various medical personnel for changing their health plan. The following are the kinds of incidents that led participants and their family members to consider making a medical decision to change their current practitioners and seek care elsewhere. Claudia, for example, is a highly independent patient who suffers from severe depression due to complicated grief. She had just suffered the loss of her youngest son. Prior to entering GraciaMed she was seeing a physician in a private practice.

²³ "antes iba a una clínica cerquitas de [nombre del plan de salud] ...me llevaba mi hijo. Por eso le digo me moví...Me trataban bien porque yo iba y me trataban muy bien...nada más que ahorita la verdad que vienen y me llevan porque la otra se me hacía muy difícil trabaja mi hijo y luego pues con los niños ya no es igual verdad. Entonces mi hijo entraba [a trabajar] ya cuando me daba las citas. [Tenía que quitarse el tiempo de su trabajo]. Y yo ahorita digo pues estoy bien porque ahí mismo me dan...ahí mismo está la doctora donde yo voy. Y allí me atienden o me...resulta que me van a llevar a rayos o a eso, allí mismo me llevan." – am13t1

²⁴ "¿Pero para que me voy a mover si yo estoy a gusto aquí? ¿eh? Yo desde que entre en [nombre del plan de salud] yo he estado tranquilo sin problemas de doctores"-am24t1

Excerpt 4.2.1d: Recurrent Hospitalizations Blamed on Over Medicating

Every once in a while, [the doctor] would hospitalize me. I was hospitalized five times, and when I would go to his clinic, he was never there and his assistant would only give me antidepressants. That is why I fell, like five times from the stairs in the other house; I even cut my head open. All the time he had me drugged up...Can you imagine [the doctor] would keep me drugged up? Until my daughter said ‘how is this possible? Let’s see what we will do. So then a person from her work told her about [GraciaMed]...So then she called with a person that works there that she knew and she enrolled me. Then they started to perform tests and everything (Translated from Spanish).²⁵

Claudia is a highly independent and direct woman, often informing her family about her decisions rather than asking for their recommendations. Her children often responded to their mother’s requests until her children realized that their mother was unable to direct her own health care. She was receiving poor medical attention and needed help. The daughter, who lives out of the country, initiated the conversation with her siblings in the United States who traveled to meet the needs of their mother.

In sum, the patient’s decision to change clinicians was made because of problems with their current source of care, which motivated them to look for alternatives. For some, the issues were access to quality care; for others, the problem was that the health care created a burden on another family member. But in almost all cases, the motivating factor was dissatisfaction with the current arrangement rather than an inducement to shift from a satisfactory arrangement to one that was more coordinated, comprehensive or offered more services.

²⁵ “cada poco [el doctor] me hospitalizaba. Estuve cinco veces en el hospital y cuando yo iba a su clínica nunca estaba y el asistente solo me daba a mi antidepresivos. Por eso yo me caí como cinco veces de las gradas en la otra casa. Hasta me abrí la cabeza. Porque todo el tiempo estaba drogada por ese doctor...Pues fíjese [el doctor] me mantenía drogada. **Hasta que mi hija dijo no dijo ¿no cómo va hacer? vamos a ver qué hacemos.** Entonces una persona allí del trabajo parece que le conto de eso de [GraciaMed]... Entonces **ella hablo con una persona que trabaja allí** que ella conocía y ella me ingreso. Luego ya me empezaron hacer análisis y todo eso.” – am10t1

Example of Medical Decision: Hysterectomy and Oophorectomy

In addition to making decisions around changing clinicians, others engaged treatment-based decisions receptively due to the level of comfort and trust established with their practitioners. Catarina and her husband, for instance, had a long-term relationship with their OB-GYN in their home country. Catarina suffered many miscarriages, and after her last pregnancy, the doctor expressed his sincere opinion that they discontinue having children due to these medical complications. Regardless of the difficulties, she and her husband managed to have six live births. All first five children were male. Being a personal family friend, their OB-GYN knew how much the couple longed to have a girl. When the last live birth was a female, the doctor made his opinion heard and strongly suggested they have no more children. During her last live birth post-partum period, she had some abnormal readings suggesting cancer, and he suggested she undergo a radical hysterectomy as a prophylactic measure.

Excerpt 4.2.1e: Prophylactic Surgery

I had suspicions of cancer after I had my daughter...during the time that one is attentive of the post-delivery tests, right? They found something rare so the doctor said, **‘I don’t want you to have more children’** because **he was good family friend with my husband**. With the number you are is enough! I have six...Then came that time that he said what do you want all this inside for? Take it out. Let’s take it out. And see he operated on me. My daughter is now XX years old. Since then I have no uterus or ovaries (Translated from Spanish).²⁶

Catarina reported little back and forth discussion between the couple and the physician on the radical hysterectomy. Catarina’s husband’s only concern was about having his wife become “cold” towards him, meaning she no longer would feel the need or desire to be intimate with him. The couple and the physician had a brief open conversation about sexually related

²⁶ “...Tuve como sospechas de cáncer después que tuve a mi hija...el tiempo que uno está pendiente de sus exámenes después del parto ¿verdad? Me encontraron algo allí raro entonces **dijo el doctor ya no quiero que tengan más hijos** porque era bien familia bien amigo con mi esposo. Ya con ustedes ya son suficientes. Tengo 6.... Ya llego ese momento que dice ya que quiere va querer todo esto aquí adentro. Saquemos. Saquémoslo. Y mire me opero. Ya mi hija tiene XX años. Y desde entonces. No tengo matriz ni ovarios.” –am2t1

repercussions, which influenced their decision. He was doing what a “good doctor” does, looking out for the well-being of his patient (See Chapter 5: Modifying Factors). There was trust on the part of the patient and her husband on her practitioner’s opinion and his recommendation was taken at face value. Trust seems to be a major component of a patients’ level of receptivity to recommended treatment options as we will shortly discuss in the next chapter.

In sum, many things in medicine are often uncontrollable; however, in an attempt to bring some kind of perceived order to an out-of-control health problem, patients and/or families engaged the medical encounter receptively around medically-related changes. Elders and families were more likely to coordinate efforts to make changes in medical care or to agree to medical procedures to avoid foreseeable deteriorating future problems, which motivated them to change or to agree to certain medical procedures. Many patients and/or families that engaged the encounter receptively had heightened perceived threat, fear, susceptibility and/or vulnerability to an unwelcomed outcome.

4.2.2 Cautiously Optimistic

Patients who engaged the system in a cautiously optimistic pattern were frequently amenable to listening and favored decision-making for change, but always with more caution than the receptive group. They usually entered with high hopes for treatment options that could potentially resolve their symptoms. They made decisions to follow the doctor’s recommendations because it sounds good in the doctor’s office, but the excitement was often short lived. Do what the doctors asks them to do but then get discouraged by the realities of their conditions and the behavior is not sustainable (e.g., txt is not as fruitful as expected, results are not quickly apparent or because the treatment was too cumbersome or for whatever other

reason). They often sought immediate results; if the treatment regimen or the condition gets difficult to manage they often sought other avenues of management (e.g., alternative treatments as discussed in the next chapter). They kept trying other treatments searching for the right treatment options.

Excerpt 4.2.2a: Growing Frustrated

I am taking my treatment regimen to the tee but we still don't know. [I: do you feel there is another treatment available that you have not tried yet?] Well yes yes (Translated from Spanish).²⁷

Participants who engaged the system in a cautiously optimistic pattern need extra help from the system to ensure sustainability of the behavior accompanied by the medical decision (e.g., continuing treatment regimen, dietary and nutritious compliance). These individuals have more willingness to change than the subsequent pattern described in the next section (cautiously skeptical), but need deeper understanding, deeper engagement including more engagement from the system.

Their circle of influence also plays a crucial role in managing their conditions. They can either serve to positively or negatively support the decision-making process to manage their conditions.

Example of a Medical Decision: Living Between Two Countries to Receive Medical Care

An example of a pattern of engagement can be made in making a decision to receive care from the U.S. health system. Often, some of the medical decisions made prior to entering the GraciaMed's PACE program involve family members. One couple, Carlos and Liliana, lived in Mexico, except when they would spend a couple of months of the year visiting their children in

²⁷ “tengo mi tratamiento así al pie de la letra, pero no sabemos todavía. [I: Siente que hay algún otro tratamiento disponible que todavía no haiga encontrado? C: Pues si pues...]” –am12/16t1

the United States. Carlos was diagnosed with diabetes and Liliana was managing heart problems. Having no source of regular care, their daughter made arrangements for them to get care in the United States. Before having their daughter do the paperwork arrangements, for months at a time they traveled back and forth never with the intention of living in the United States. However, once they decided they were going to treat their conditions, they made it a priority and remained in the United States for the past three to four years.

Excerpt 4.2.2b: I Came for a Visit and I Stayed!

We've been here [in the U.S.] for three years...going on four. We used to go and come and we were here, but now we are going on four years...can you believe it? We came for a visit and I stayed...well we would stay three/four months and that's how we were but right now we have stayed...we started to medically take care of ourselves and you know there are times when the doctor gives you the appointment up to three months, two months, one month apart...so that's how we have been going along and now it's been three years going on four (Translated from Spanish).²⁸

Although patients acknowledge that they need healthcare, they still have mixed feelings. Liliana feels that although she is getting care, her nutrition is deteriorating here. Her mindset was that this was only a visit not a permanent situation, and that they would get enough care to manage their conditions and travel back home, but they were unable to do so.

In sum, patients who engaged the system in a cautiously optimistic pattern were willing to participate in a medical decision requiring behavior change, but not necessarily with a high degree of certainty of the effectiveness of the chosen treatment (not both feet in). They were often quick to engage while never giving up the likelihood of another more favorable treatment option that could give them their desired outcome. They were often willing to initially try the proposed treatment; however, if the treatment failed to meet their expectations in what the

²⁸ “¡Vine de Visita y Me Quede!” “ya tenemos tres años...vamos para cuatro años [aquí en los E.U.] como íbamos nos veníamos y estábamos aquí pero ahorita si ya vamos para cuatro años...fijese que nosotros así [vine de visita y me quede] pues estábamos...nos quedábamos tres/cuatro meses así y así estábamos pero ahorita ya nos quedamos aquí nos quedamos...**nos empezamos a tratar** y ya ve que hay veces que le dan la cita al doctor hasta tres meses, dos meses, un mes y...y así la llevamos así la llevamos y ya tenemos tres años, ya vamos para cuatro años.” – am12t2

patients deem is an appropriate time frame they were open to getting involved in something else. They are not completely sold on the treatment decisions. They are often fickle yet most often agreeable. The questions for this group becomes an issue of maintenance and sustainability of therapy options.

4.2.3 Cautiously Skeptical/Reluctant/Apprehensive

Patients that fit this framework of medical engagement were often open to listening but not always willing to make a medical decision for change, always listening with an internal and/or influential circle of skepticism. The patients that fit within this category were often initiated by the system. The medical care establishment made attempts to engage the patient, often requiring patient response (e.g., phone call, letter, and the like). Patients in this structure were a bit reluctant and apprehensive. They entered the doctor's office with a negative attitude. They often listened to a practitioner, but were skeptical about the treatment for potentially several reasons. One reason is they did not highly trust members of the medical care system or the recommended treatment options was due to medical problems they or people they have heard about experienced. Claudia, for instance, is skeptical and finds it difficult to trust U.S. physicians to perform risky back surgery. She was told that if one of her nerves were to be mistakenly cut she could risk becoming paralyzed.

Excerpt 4.2.3a: I Do Not Trust U.S. Clinicians to Perform Complicated Surgery
I do not [U.S.] doctors. I am telling you the truth I do not trust [U.S.] doctors with surgeries. I went through a risky operation because I had two hernias and the nerves were intertwined between my vertebrae...A Cuban doctor in the United States detected the problem. He told me, 'Look I think you have this and that but I am not sure. I would have to examine you, but if you are thinking of going to Guatemala find yourself a specialist.' That is exactly what I did. They put me in the tube (MRI) and that is where they found the problem. Then they told me I needed an operation immediately. They broke bones to pull out my nerves to be able to walk. Everybody when I returned thought they would be seeing me in a wheelchair, but no blessed be God three days later the doctor had made me

walk. They are really good. He is a good doctor. These doctors travel to the United States to perform surgeries. Uh huh (Translated from Spanish).²⁹

Similarly to the respondents who engage cautiously optimistically, patients who engage cautiously skeptically may still follow some of the doctor's orders. The patients' general predisposition to issues of life, their experiences and the influence of their closest relationships play a crucial role in the way they engage their medical care and decision-making. They may decide to take the medications/treatments or not. The cares of life usually overwhelm their thoughts and supersede personal treatments ideas. One woman, for instance, called herself a *preocupona* (worrier). She explained that she worries about everything and everybody. They tend to focus on these issues rather than their own treatments (more on generalized anxiety disorder in the cultural concepts of illness chapter). The threat of the perceived outcome is not greater than remaining in their current state of affairs. The choice is either they do something and stay the same or get better or do nothing and stay the same and possibly get worse. If people are okay with getting worse, then they may decide doing nothing is a legitimate option, as Elena explains. She has repeatedly refused treatment options, but states she is ready for whatever God has in store for her.

Excerpt 4.2.3b: Ready to Meet my Maker

I: Are you afraid? R: of death, no. I only ask God to have me...that I be prepared when that hour comes. That God-willing, He grants me to go with Him (Translated from Spanish).³⁰

²⁹ “[Yo] No confié aquí [E.U.] en los médicos. La verdad le digo con operaciones no. [25:43]. Ya le digo no. La operación que me hicieron fue fuerte porque tenía dos hernias y los nervios metidos así entre la vértebra. Y me dijo el doctor si llega a cortarla llega presionar más [inaudible]. Entonces aquí me lo detecto un cubano el doctor. Mira me dijo mira me dijo yo pienso que tienes esto y esto, pero no estoy seguro. Tendría que hacerte examen, pero si vas a Guatemala busca un especialista. Y eso hice. Me metieron al tubo y allí me encontraron. Entonces me dijo hay que operarla inmediatamente. Me rompieron huesos para sacarme los nervios para poder caminar. Y todos cuando yo vine creían que venía en silla de ruedas. Y no gracias a Dios a los tres días me levanto el doctor allí. Son muy buenos. Es muy buen médico. Que viajan aquí a los Estados Unidos para operar. Uh huh.” -am10t1

³⁰ “I: ¿Le teme? C: A la muerte no. Nomás que Dios me tenga...que esté preparada para esa hora. Que Dios me de licencia de ir con él.” -am13t1

Example of Medical Decision: Knee Replacement Surgery

Elena has been managing high cholesterol, arthritis and high blood pressure. Her most prominent health problem was her body aches and pains from arthritis, which affected her mobility and her quality of life. Her chronic pain is observably agonizing, but she refuses surgery, cortisone injections or any strong painkillers. Her clinician has offered multiple therapies, but she has refused the most invasive, such as surgery and cortisone shots. She manages her pain with pain killers, physical therapy and acupuncture. The rationale for Elena's decision is based on cultural concepts of illness.

Excerpt 4.2.3c: No More Surgeries

[They asked me] if I wanted a knee operation...and no. They took x-rays or I don't know what it is...they put me in a tube and they told me I had my back broken. I don't have it broken. I have not fallen. If I had it broken I wouldn't be able to walk...recently my knee pain has started before they didn't hurt...The hip has always hurt and this knee but now the other knee hurts from the weight I carry, it is now shared. But no I tell you...I am here walking even it is...how they say, complaining but...I do not want an operation...when I was in Mexico I had many operations on my stomach- No more, I don't want more operations...I have acquaintances that have been operated on and they limp a lot and they are always in pain. I say no, not me. They don't get better. People complain that they are in pain or I see that they limp to one side...so this way its better...Yes it hurts but I take pills and that's it... I am able to walk even if it is slowly (Translated from Spanish).³¹

This is an example of how a person's prior personal and vicarious medical experience contributes to a decision making process of risks and benefits. She attributes her current hip and knee aches to the consequential factors of previous multiple falls. Another major factor she

³¹ “[Me preguntaron] que si quería operación en mis rodillas...y no. Le digo hace poco me tomaron unas radiografías o no sé qué será...que me metieron a un tubo y me dijeron que tenía la espalda quebrada. No la tengo [quebrada] porque yo no me he caído...si la tuviera quebrada no pudiera caminar hasta ahora pronto...mis dolencias de las rodillas no me dolían...La cadera siempre me ha dolido y esta rodilla y ahora ya me duele el otro lado del mismo peso que cargo en una, ya se compartió...Pero no, le digo...yo aquí estoy, caminando, aunque sea...como dicen, quejándome, pero... ya no quiero operación ... cuando yo estaba en México [tuve] muchas operaciones en el estómago—ya no, ya no quiero más operaciones. Tengo compañeras que ya las han operado y cojean mucho y siempre les duele. ¡Le digo hay no! ¡Le digo yo no! No quedan bien ya. Gente se quejan que les duele o veo que le cojean de un lado no pues así mejor así...Si me duele, pero pues yo me tomo pastillas y así...aquí camino, aunque sea al pacito.”-am13t1

includes in her decision-making is the influence of her environment and relationships with other people. She perceived the outcome will be equally as bad as she is currently in and to endure a recovery period, based on prior bad experiences, is not worth undergoing surgery.

Example of Medical Decision: Amniocentesis

Due to Beatriz's³² age during her last pregnancy, her Obstetrics and Gynecologist suggested she undergo amniocentesis testing. Her physician used various scare tactics to persuade her to have the testing done, such as telling her baby would be born with Down syndrome or other problems that could lead to complications and potentially result in losing the baby. Due to a bad experience of her cousin that she knew about, she adamantly refused. Her cousin in Orange County was 40 years old when she had an amniocentesis testing incorrectly performed on her. Her uterus became infected and the baby died inside. They then had to surgically remove her uterus, and she became infertile. She sued and won because the doctor was inexperienced, but she was the one who ended up losing. Because of such a horrific experience, Beatriz said "no way!" Another doctor later told her that scaring her during her pregnancy was bad because she could have lost her baby. She called her doctor stupid for scaring her. Later when the baby was born she took the baby and told him off.

As Beatriz experience illustrates, a patient's circle of influence has the power to persuade medical decision-making. She was skeptical because of the experiences of others within her circle of influence.

³² Am20t2 interview summary

Example of a Medical Decision: Pace Maker

In other instances, there are those patients who may be initially reluctant to accept a medical treatment, but with additional help and support from the healthcare system they decide to undergo a medical procedure. Juan, for instance, underwent open heart surgery and was reluctant to have a pacemaker installed due to his previous experiences with acquaintances who passed away due to cardiovascular conditions (e.g., heart attack, strokes, and the like).

Excerpt 4.2.3d: The Doctor Guaranteed 95 Percent Success

I was really scared to have that apparatus [pace maker]...I was afraid because there are some that do not last long and people die. They are battery-operated and batteries run out, eh? Also, I have had seen people die from that sort of thing. I was afraid to have that [pacemaker] installed in me. They said that in 2-3 years but what if it runs out before that time? Instead of helping me it's going to harm me. So no. I: What did the doctor tell you? P: She then told me that she guaranteed 'I guarantee 95 percent that with that [pacemaker] you will be better, and you will establish your time and your life more comfortably she said (Translated from Spanish).³³

After Juan's doctor provided a guarantee, he agreed to have it placed in him. His fear was informed by his experiences with other people, yet he was actively engaged by a doctor who guaranteed his quality of life would improve if he underwent the medical procedure to have the pacemaker installed.

In sum, patients who fell within the cautiously skeptical pattern of receptivity were less likely to engage in medical decision-making involving change. Patients were more likely to respond negatively, refusing treatment immediately upon the introduction of treatment recommendation. If a treatment option was being contemplated, the decision-making process was reported to be at a much slower pace than those who engaged medical encounters in a more

³³ "Yo **tenía miedo** realmente a tener este aparato. Yo tenía miedo porque hay unos que no duran muchos y digamos personas se mueren. Porque como son de batería se acaba la batería. ¿eh? También eso me ha tocado ver personas que se han muerto de eso por eso yo tenía miedo a que me instalaran ese aparato. Dijeron. Me dicen que 2-3 años, pero ¿que si antes de los dos tres años se acaba? En vez de ayudarme me va perjudicar. Pues no. I: ¿Y qué le dijo la doctora? P; Entonces ella me dijo no me garantizaba. "No yo te garantizo el 95 por ciento a que con eso vas a quedar mejor." Y vas a establecer tu tiempo tu vida más a gusto me dice" -am24t1

cautiously optimistic pattern. Patients who engaged in cautiously suspicious patterns were not quick to accept a treatment option. Patients' circle of influence and the medical system significantly impacted their medical decision-making process. Although a rare occurrence, some patients skeptically listened to practitioners' recommendations and immediately declined treatment options; however, with time and additional treatment-related information some patients ultimately agreed to engage in suggested treatment options.

4.2.4 Unreceptive / Closed / Unwilling to Interact

Respondents who fit this category of medical engagement appeared uninterested in engaging the system. They were unenthusiastic about their health and the possibility of interacting in any medical encounter, much less in a doctor's visit. They often resisted listening either to attempts initiated by the medical system or by others aiming to provide medical assistance (e.g., providing information).

During the interviewing period, the respondents were all active members of GraciaMed's PACE program. Therefore, most of the participants did not totally engage their health care without receptivity because they were in a medical context several times per week. However, how they describe participating with the medical system before entering the program is where this specific pattern of engagement is observed. Beatriz, for example, before joining the program was unreceptive to recommendations by the system or others and refused to participate in self-care. She had been diagnosed with clinical depression and given medication. She did not follow the prescribed therapy, and the depression progressed to a dire state of losing all interest in personal hygiene and sanitary living standards. She weighed over 300 pounds and had hypertension and hypercholesterimia. Due to her difficulties in breathing and walking she

suffered limited mobility. She had a sedentary lifestyle, where she sat and watched television all day. Because of her sedentary lifestyle, her depression, and her cardiovascular conditions, her health spiraled out of control. She experienced a series of life-threatening conditions (e.g., peritonitis, cancer, stroke), all before she was Medicare-eligible.

Other respondents spoke about loved ones' personal experiences with health care that resembled the unreceptive pattern of engagement.

Excerpt 4.2.4a: Patient Interest is Lacking!

Sometimes [medical care] depends on the person...the patient. I know a friend that has some ideas that I do not agree with. For example, she goes to the doctor only when she is gravely ill. She has a pacemaker and she says "God already healed me. God already cured me, I do not take medicine" and she stops taking it. And she does not tell anybody. I even tell her to go to [GraciaMed] and she says, "No, I don't need those things." I see that many times patients' interest is lacking due to the ideas that the patients have...She only goes when she truly needs it...When she hits rock bottom she needs to be hospitalized. And even while being hospitalized she says that all of her tests come out fine. "I am perfect" (Translated from Spanish).³⁴

Some of these issues are potentially confounded with mental health factors, personal beliefs and perceptions. People do not often perceive themselves as being at risk. The couple's fears, for instance, were brought on by the perceived consequences of receiving (free/low cost) medical care. Generally, to participate as a member of GraciaMed's PACE program, one must qualify as low-income and nursing home eligible. Almost all have both Medicare and Medi-Cal. Many rumors in the community exist such as the elderly married couple who describe worries of losing their home.

Excerpt 4.2.4b: Keeping Assets to Pass One

There are a couple of older adults. A marriage. They are of advanced age. I know that it is troubling for them to go to their medical appointments...and I tell them 'sister, you

³⁴ "¡Falta Interés del Paciente!" "A veces [el cuidado médico] depende de la persona...del paciente. Porque yo conozco una amiga, que ... tiene unas ideas que no me parecen. Por ejemplo, ella va al médico solo cuando verdaderamente esta grave. Tiene marcapaso, pero ella dice Dios ya me sano, Dios ya me curo, yo ya no tomo medicina y la suspende. Y no se lo dice a nadie...Aun le digo que vaya a [GraciaMed] y me dice que, 'no, yo no necesito esas cosas'. Y, yo veo que muchas veces **falta interés del paciente** o del, por las ideas que el paciente tiene...Ella no más va cuando deberás necesita...Cuando ya cae que la tienen que hospitalizar. Y aun estando hospitalizada dice que todos los análisis le han salido bien. 'Estoy perfecta'." – am1t3

guys need special attention. Go to an institution like [GraciaMed].’ ‘Oh, no! Because they are going to take away our home when we die’ (Translated from Spanish).³⁵

In sum, patients in the unreceptive patterns of engagement are almost entirely closed to the possibility of being involved in any aspect of medical decision-making. Active participation in their care is often non-existent.

The four patterns of patients’ receptivity provided insight into respondents’ interaction variability during medical encounters and decision-making. However, other factors, such as patients’ forms of interaction, modified the respondents’ willingness to engage health encounters and medical decision-making. The following section describes three types of engagement between patients and members of the healthcare organization and explains how these kinds of engagements often functioned to modify patients’ openness to medical decision-making.

4.3 Types of Engagement

Medical encounters are not exclusive to the patient-doctor interactions that occur primarily during the doctor’s office visit, but encompass a broader concept including all medically-related exchanges within the medical plan infrastructure of the Program for All-Inclusive Care for the Elderly (PACE). Patients and individuals within the medical system engage one another in a myriad of ways. Older immigrants’ experiences of the medical office visit before entering the GraciaMed³⁶ PACE program mirrors their current experiences. The unique difference among foreign-born Latino elders and other ethnic groups represented in Western society is in the types of engagement they have in the medical encounters, particularly during their office visits, via technical, social and or emotional engagements. Latino foreign-

³⁵ “*también hay una pareja de señores. Un matrimonio. Ya son de edad bien avanzada. Y, yo sé que les cuesta asistir a las citas médicas...y yo le digo ‘hermana, ustedes ya necesitan un cuidado más especial. Vayan a una institución como [GraciaMed]’. ‘Ay no! Porque nos van a quitar la casa cuando nos muramos’*” – am1t3

³⁶ A fictional health plan name is used for anonymity purposes.

born elders were more likely to engage the medical encounter using similar types of engagement, depending on the kinds of individuals with whom they were interacting. Generally, clinicians were more often involved in technically-related interactions, while allied health professionals and other health plan members engaged using socially, and emotionally related interactions. The unique program features of PACE, however, allowed for respondents to share experiences where patients and clinicians interacted with each other in emotionally and socially-relevant types of engagements (Table 4.3). Emotion engagement indicated emotionally associated interaction. Socially interacting meant the social spheres of the people crossed, not necessarily by entering their physical world, but by sharing non-technical information particularly during the medical office visit. Finally, engaging technically with healthcare personnel and other members of the health plan meant there was a sharing of disease-related factual information.

These types of engagements modify the overall patterns described earlier, which in turn have the power to influence the patient’s medical decision-making process. The three types of engagement are presented from the most technical, which represents what doctors are mostly trained about, to the most emotional, which has an extremely culturally-relevant component for these Latino elders.

Table 4.3: Medically-Related Engagement by Personnel within GraciaMed’s PACE Program

	Technical	Social	Emotional
Clinician Office Visit	yes	rare in United States	yes
Other Allied Health	sometimes	yes	yes
Fellow Health Plan Members	rare	yes	yes

4.3.1 Technical Engagement

Patients and individuals from the healthcare system that engaged in technical conversations shared an exchange of disease-specific and other patient-specific relevant

information. This kind of interaction was reported to occur more frequently during the medical office visit, where information-giving sessions pertinent to patients' conditions were frequent. With any of these engagements there is a perceived two-way process; however, for these older Latinos, active engagement meant the doctor was talking directly to them, allowing for both verbal and non-verbal responses from the patient. It did not need to include active questioning sessions. It simply meant the physician acknowledged the patient's presence and provided enough technically-related information for the patient to feel engaged. Eye contact or speaking in the direction of the person, rather than simply at the screen, was a significant behavioral aspect, which they reported made them feel engaged.

Patients that were technically engaged gained valuable information about their conditions and their associated treatment options. Patients and clinicians interacted, both verbally and non-verbally, to exchange technically-related information. Most often patients had knowledge about their condition(s) and the ways to manage it. For instance, Beatriz demonstrates a level of basic information about her ear.

Excerpt 4.3.1a: Exchanging Valuable Technical Information

I don't hear right without my apparatus (hearing aid). That is why I am using my right ear to hear...I have had [this problem] for many years. [My doctor at GraciaMed] sent me to a specialist who told me that I needed it because when I was a child I got that [refers to a specific disease] fever, and it popped my ears and they leaked liquid and it smelled bad. I was about eight or nine years old, they operated on my ears in Guadalajara Mexico. Mixing different curations that at time made me cry, but thankfully, my specialist says that because of that surgery I am not completely deaf. That is why I need the hearing aid. I also need it on the right side, but not as much as the left (Translated from Spanish).³⁷

³⁷ "No oigo bien sin el aparato. Por eso estoy usando mi lado derecho que puedo oír...Ya tengo muchos años [con el problema]. Es que, me dijo el especialista, que me dio cuando me examinó el doctor [mi doctor en GraciaMed] y me dijo que necesitaba porque cuando yo era niña me dio, como le dicen esa fiebre, y me reventó los oídos y me supuraban y oían muy feo. Y entonces tenía yo como ocho o nueve años, me operaron los oídos allá en Guadalajara en México. Y mezclar unas curaciones, que hasta el doctor me hacía llorar, pero gracias a eso me dice el doctor [el especialista] que por esa cirugía que me hicieron no quede completamente sorda. Por eso es que necesito el aparato. También en el derecho este necesito el aparato para oír, pero no tanto como el izquierdo." - am20t3

Beatriz and the specialist exchanged pertinent information about her auditory conditions. She provided historically-relevant accounts, while he assessed her current condition informed by these events and provided a treatment option. In fact, being technically engaged often influenced the patients' patterns of receptivity. For instance, Maria went from being cautiously skeptical about accepting insulin treatment to being receptive. She blamed insulin for temporarily losing her eyesight. Due to that scary event, she adamantly refused to get insulin treatment. However, her situation became dire, and her current doctor at GraciaMed technically engaged her and provided sufficient information to make her feel content with the decision to accept insulin treatment.

Excerpt 4.3.1b: Technically Engaging Physician Modifies Patient Receptivity

Look [my previous doctor] cared about health but many times he did not provide explanations. I remember on one occasion, I told the doctor...because he told me it was best to put me on insulin and I told him no... [on that same occasion] right there I do not know what they did to me...I do not know...but the thing was that they kept putting eye drops and after the doctor put like a tool to open my eye, and then the other eye I don't know but I was no longer able to move. Then I saw what looked like a plated tile, a thread of light, and the same with the other. From there I came out perfectly fine, but they suspended the insulin. Since then some tell me that maybe it was because I had a lot of blood cells covered in blood...In reality, I don't know what they did. [The doctor] didn't explain anything. They only did the procedure and that was it. So then that's why I felt fear toward insulin. But he would tell me, 'you don't want it, you don't want it. It's your decision.' But in comparison, [my doctor in GraciaMed] explained why I needed the insulin. So therefore, I thank her [starts to cry]. I understood that I needed it and I left it. Since then they have been able to control [my diabetes]. At the beginning they started with 12 units, when I had it at 460...when the impact of seeing the man. Slowly [its improved], now they only put six (Translated from Spanish).³⁸

³⁸ "Mire, el doctor H [previous doctor] si se preocupaba bastante por la salud y todo, pero muchas veces no me dio explicaciones. Porque yo me recuerdo que en una ocasión le dije al doctor...porque él me dijo que necesitaba mejor ponerme la insulina y yo le dije que no... [en esa misma ocasión] allí me hicieron no sé qué...ay no sé qué me hicieron...pero la cosa es que me echaban gotas a cada momento y después el doctor puso como una garetta [¿?] Y me abrió un ojo y ya el otro no sé como pero que no lo pudiera yo mover. Y vi que me entro una loseta bien plateado, un hilito de luz. Y después en otro. Y así salí perfectamente bien. Pero me suspendieron la insulina. Desde ese entonces algunos me dicen que quizá tenía muchos glóbulos cubierta de sangre ...No sé en realidad que me hicieron. [El doctor] no me explico nada. Solo me hicieron el procedimiento y ya. Entonces yo por eso le tenía temor a la insulina. Pero él me decía no quiere, no quiere. Es su voluntad. Pero [mi doctora en GraciaMed], la diferencia es que ella me explico por qué necesitaba la insulina. Así es que, le agradezco. [empieza a llorar] Yo comprendí que la necesitaba y me la dejé. Y ya desde ese entonces me la han ido controlando [la diabetes]. Porque

She also suffers from glaucoma and the treatment she was referring to was most likely eye laser surgery and was not even related to the insulin treatment. However, before succumbing to the surgery, she provided her previous doctor a rationale for refusing insulin treatment and explained her experience going blind. The clinician did not clarify misconceptions and the idea perpetuated for many years. Unlike her previous doctor, her current primary at GraciaMed was able to relay information about the treatment in such a way that made sense to her. Maria was able to overcome the negativity she associated with insulin, thereby bypassing her fear and accepting the treatment.

Unfortunately, although most respondents expressed the desire to be engaged, the reality is that most of them reported that they were not. During their medical consultations occurring in the United States, rarely did the participants feel that the clinicians engaged them with disease-specific factual information. Maria³⁹ explained that her previous physicians did not provide enough information, but that she likes her current doctor because she receives information about her condition and is able to talk to her. “She is not like other doctors where the consultation is quick. Five or ten minutes and that’s it! And **one wants to ask questions about other things but that’s it...**she does have that patience” (Translated from Spanish).⁴⁰ Most were instructed by their clinicians and other allied health personnel on what to do with little or no room for open conversations or negotiations. This is not to say that quick office visits with little or no information about the patients’ disease were an undesired phenomenon by all, but the lack of time to ask questions certainly felt unwelcoming for several patients.

al principio me ponían doce unidades. Cuando la tenía en 460...cuando el impacto de ver al señor. Y poco a poco [ha mejorado], ahora solo me pongo seis.” – am1t3

³⁹ Pseudonyms have replaced respondents’ actual names for anonymity purposes.

⁴⁰ “No es como otros médicos que la consulta es rápida. ¡Cinco o diez minutos y ya! Y uno le quiere preguntar otras cosas y ya no...ella sí tiene esa paciencia.” – am1t3

Since having a patient provided with sufficient disease-specific factual information by the system/clinician was a rare occurrence for this population, there were times when the patients demonstrated efforts to obtain additional information through questioning. The patients' repeated attempts became missed opportunities for a meaningful interaction. Unfortunately, the patients reported they felt their inquiries were dismissed and unwelcomed. "I tell [the doctor about a complaint] there **I am not going to be telling them anything anymore**; they don't even pay attention to me" (Translated from Spanish).⁴¹ Patients' often justified the clinician's actions as resulting from a systemic problem such as overbooked schedules rather than as the personal failings of the practitioner. "We should not blame the doctor; I don't complain about the doctors" (Translated from Spanish).⁴²

As a result of such a lack of engagement, one patient and her caregiver decided to leave the PACE program. The patient, Bertha,⁴³ only achieved a second grade education, yet prides herself in having taught herself how to read. She is socially outgoing and has no problems sharing about her conditions. During our first interview, she was battling body rashes, and these rashes went unmanaged for extended periods of time. By our second interview, the patient and her daughter, her primary caregiver and decision-maker, had grown frustrated and the patient left GraciaMed's PACE program, in part because Bertha felt that she was not receiving information that answered questions she had about her condition.

Excerpt 4.3.1c: Frustration Rises and Complaints Fall on Deaf Ears

I left [GraciaMed]...because the doctors don't pay too much attention...I was very comfortable there. I was happy and I had a lot of fun, but then I got really sick and the doctor...no...no— [So you still had the rashes and she wasn't paying too much attention?]

⁴¹ "Le digo [llevando la queja al doctor] hay ya no les voy andar diciendo nada **ni me hacen caso**." –am13t3

⁴² "No tiene uno por que echarle la culpa al médico" – am12t2; "Los médicos no me quejo de ninguno." –am1t1

⁴³ Pseudonyms have replaced respondents' actual names for anonymity purposes.

Well, no, she would only laugh...Look let me explain, I had a bad case of the flu, and I would tell her that I had bad body aches and all she would say was, ‘Look you are of age...you know you are going to feel a lot of things.’...That’s what she would tell us...that we were of age. Yes, that is true. So then I could not tolerate it anymore, and I stayed home a couple of days. Then my son took me to the hospital. In the hospital they put an injection in the vein...thirty minutes later I was out... I was well...Too bad. My daughter took me out because even she got frustrated...In that program you have to be well liked by the people or the doctor so you can be well taken care of... ‘*la que tiene más saliva, traga más pinole*’ [Spanish saying no direct translation, roughly it means smooth talkers are more likely to get their way] [chuckles] (Translated from Spanish).⁴⁴

Other times, patients showed interest in obtaining more information about their conditions, treatments and results but often the preference went unmet. Referral specialists avoided direct communication with patients and instead gave information to the primary physician. Several respondents complained that the primary care doctor quickly read testing results without engagement. Other respondents used a less direct way of stating preferences that went unmet. Elena, for instance, indirectly and jokingly states her desire for reducing the number of times blood was drawn and wanting to know the results of such draws.

Excerpt 4.3.1d: Indirectly and Jokingly Asking no More Blood Drawn, Please!
 They were drawing [blood] often up to seven tubes...they leave me dizzy, then you are going to leave me without blood and they laugh. I tell them ‘no, no **but you don’t even tell me what I have**. ‘You don’t have anything; if you did we would have told you already.’...They do analysis for I don’t know what...’But you only take out blood...no, a little bit only because you are going to leave me without any blood [chuckles].’ I tell them I think you are taking out so much blood to sell it [chuckles] and the young ladies laugh...I tell them I come without drinking anything, and you don’t even give me anything and you take out so much blood and they laugh (Translated from Spanish).⁴⁵

⁴⁴ “Me salí de ahí [GraciaMed] ...Porque las doctoras no hacen mucho caso con uno...Estaba muy agusto ahí, contenta, me divertía mucho, pero es que me puse malita y la doctora no...no— [Entonces todavía las tiene (comezónes) y no le estaba haciendo mucho caso la doctora?] Pues no, nomás se reía [la doctora]...Es que mire, me dio una “flu” bien fuerte y le decía yo—a mí me dolía mucho el cuerpo y eso y pues no, nomás lo único que le dice a uno...mire pues ya tiene la edad...usted sabe que va sentir muchas cosas...es lo que nos dice a todas...que ya estamos mayores. Eso sí es cierto. Entonces yo no aguante y me quede en mi casa dos días, no fui...y entonces mi hijo me llevo al hospital...En el hospital me pusieron una inyección en la vena...a la media hora yo ya estaba fuera...ya andaba yo bien...Pues ni modo. Me sacó mi hija de ahí porque por eso se desesperó ella también...Ahí tiene uno que caer uno bien a la persona o a la doctora o algo para que lo atiendan bien... la que tiene más saliva, traga más pinole [CHUCKLES]...” am6t2

⁴⁵ “seguido que me estaban sacando [sangre], sacaban hasta siete tubitos... me dejan toda borracha, luego me van a dejar hasta sin sangre y les daba risa. Le digo no, no...pero ni me dicen...díganme que es lo que tengo. ‘Ay no tienes nada, si tuviera algo ya te hubiéramos dicho.’... No que para hacerme análisis de **quien sabe de qué**... Pero

As will be discussed further in the next section, patients often used culturally specific methods of communication, such as the use of idioms, sayings and jokes to inform clinicians and allied health professionals about their preferences. This subtle method of communication was often ignored, misconstrued, or incorrectly interpreted as in the example just provided.

Other patients raised concerns such as the desire to avoid multiple medications. For instance, one elder made repeated attempts to voice her concern, and the clinician failed to provide her with a response until one day the clinician finally responded in a way that the patient felt was dismissive and meant to discourage her from further questioning.

Excerpt 4.3.1e: Shut Up!

Well, the doctor says, ‘If you want to cure yourself, take the medicine. If you don’t want to take care of yourself don’t take it (sarcastic tone).’...Sometimes they give a lot of medicine...There is no decision to be made...[these] are recommended by the doctor...but if you see that this pill is making you ill, well don’t take, right? (Translated from Spanish).⁴⁶

Practitioners’ perceptions of aging can influence the way they communicate technical information to their patients. If professionals hold ageist views and believe that the patients are unable, unwilling and uninterested in receiving facts about their conditions, they may be more likely to limit their medically-related communications with their patients and respond in a way that feels dismissive to the patient. Bertha, for instance, explains her encounters with her physician where she felt disrespected by her physician’s indifferent and almost rude responses to her complaints about her rashes, aches and pains.

pues nomas me sacaban y me sacaban...Le digo no poquito y me van a dejar hasta sin sangre [CHUCKLE] Le digo ... a mí se me hace que estas sacando nomas para venderla [CHUCKLES] y les da risa. Les da risa a las muchachas... le digo yo voy sin tomar nada y luego ni me dan nada y me sacan tanta sangre y les da risa.” –am13t1

⁴⁶ *“Pues dice el doctor si te quieres curar tomate la medicina si no te quieres cuidar no te la tomes ... Porque a veces dan demasiadas pastillas...No, no hay decisión. [Son] recomendadas de la doctora...pero si usted ve que aquella pastilla le está haciendo daño pues no hay que tomarla ¿verdad?” – am6t1*

Excerpt 4.3.1f: I Tell My Doctor, but She Says I am Aging

I have seen the doctor there only twice. Only twice. Only to ask how I am doing. I tell her but she says, “Look at your age, and as you age you are going to feel worse. Just take the medicine for your pains” (Translated from Spanish).⁴⁷

During medical visits in the United States, the clinicians did not always engage the patients with technical information, and while some patients sought to interact, others were relieved that they were not expected to participate in technically-related information exchanges. Not having to engage in a technical conversation was a welcomed phenomenon, especially for patients who felt they lacked the ability to understand. They preferred having the system deal with coordination of care services, medications and other technically-involved activities. To think that they needed to write something during an office visit or in seeing a referral specialist when they were unable to read or write made them uncomfortable. In addition, they justified the desire for not wanting to have any part in communicating by stating that the doctor just knows more than they do. Patients enjoyed having one less thing to worry about in dealing with coordination of care services.

Excerpt 4.3.1g: It is Okay because We Don't Know Anything! (Translated from Spanish)

The [specialists] communicate with the doctor. They do not give us a printed report about what we have. They communicate among themselves... They never give us a report. They communicate directly with each other... They fill out the paperwork, [and the results] are sent to them, never to us. The person that accompanies us is given an envelope [we aren't given any results] ...Nothing. If we wanted them, yes [they would give it to us]. But **since we don't know anything** [laugh], we prefer not to have any [printed reports] (Translated from Spanish).⁴⁸

⁴⁷ “*Dos veces nomas he visto a la doctora que está allí. Nomás dos veces. Nomás para preguntarme como estoy. Es todo. Y le dijo. Pero. Mire es la edad y entre más peor se va sentir. Nomás tómesela medicina para las dolencias.*” – am6t1

⁴⁸ “*Ellos [los especialistas] se comunican con la doctora. Porque no nos dan el papel de que tienen. No ellos se comunican... A nosotros nunca nos dan papel. Ellos directamente...Ellos llenan el papel todo [y los resultados] le mandan a ellos. A nosotros jamás. La que nos acompaña o el muchacho que nos acompaña le dan el sobre [a nosotros no nos dan ningunos resultados]...Nada. Si quisiéramos si [nos las dan]. Sí, pero **como uno no sabe pues** [laugh] prefiero no tener [papeles].*” –am12/16t1

They expressed liking the care their clinicians' and the medical system provided because it alleviated the stress of caring for all of their medical needs. However, feeling incapable of engaging in a technically-rich information exchange did not mean they were uninterested in being involved in decision-making. This is simply one piece to a patient's individual decision-making algorithm. Being members of PACE, they may not be exchanging facts with their clinicians; however, they are more likely to technically engage other members of the healthcare system, such as social workers, nurses, and even other patients; this helps patients make medical decisions. When trust is established between the patient and the allied health personnel a much more open communication was reported, and the increased likelihood that the patient involved these people during decision-making processes (e.g., moving out of state, starting alternative treatments) was more easily determined.

A typical practitioner office visit is a specific kind of interaction between an expert and usually a non-technically savvy patient. The power dynamics, as well as other factors often displayed in this interaction, modify how a patient engages, and communicates. The power often lies with the expert; thus, patients often do not perceive being engaged or engaging the clinician on an equal power footing. If patients needed to communicate something, they often resorted to seeking out other allied health professionals and social workers with whom they had already established a trusting relationship. Given the accessibility of social workers and other allied health professionals and staff, most often patients felt more comfortable talking to them. Power and respect are on a continuum. The more power a person holds, the more respect they are to receive, and the less likely a person is to divulge too much information. Patients felt physicians deserved respect because they worked hard to earn their degree studying. “[*El doctor*] *se quemó las pestañas estudiando*” (does not translate but another way of saying “the doctor burned the

midnight oil”). However, power does not equate trust. Trust serves to broker the relationship between power, respect and communication. Patients preferred to disclose openly to people with whom they felt had an equal level of respect towards them. It is no surprise that people are less likely to complain to people with power and respect (discussed further in Chapter 5, the “Meaning of Silence” Section).

Engagement based on technically-rich information can serve to modify patients’ level of receptivity, which can either be augmented or decreased, based on their willingness to listen to facts about their conditions. These facts about their diseases speak to the patients’ beliefs, values and perceived risks/threats to their conditions and will ultimately be an influential component to a patient’s medical decision-making process.

4.3.2 Social Engagement

Unlike engaging the medical encounters using technical medical exchanges, social engagements among foreign-born Latino elders and members of the health system involved sharing non-technical information about their lives, such as aspects of their social and cultural identities (e.g., home country of birth, motherhood, widowhood, hobbies, impact of medical conditions on life). Technical engagement within the healthcare system was often restrictive to the medical doctors’ consultation, putting the onus of the patients’ medical experience on the physician-patient interaction. However, social engagement rarely occurred within the consultation. Patients most often socially engaged members of the health system; each member contributing to a patient’s medical care experience, from the receptionist at the front desk, to the medical assistant, to the nurse, to fellow members of the healthcare plan sitting in the waiting area. Patients’ medically-related interactions and conversations with various people within the

health plan influenced their medical decision-making process. In fact, the sharing of this kind of information often developed into relationships.

Many times when socially-oriented information was shared with professionals, it developed into relationships beyond the traditionally professional roles. Patients reported developing friendships with their physicians within GraciaMed's PACE program; however, it was a rare occurrence. The friendship relationship with physicians was most often reported with physicians in the patients' home countries. "The doctor...was a good family friend and spoke to my husband like a friend" (Translated from Spanish).⁴⁹ However, patients reporting socially engaging the professionals within the GraciaMed system did so less during the office visit and more during other medical encounters with allied health professionals, center staff and other members of the health care team, such as "the social worker or with her nurse or the assistant (translated from Spanish).⁵⁰ It is important to note that few patients differentiated between the various professions within the medical system. Patients interchangeably used the term *trabajadora* (worker) to refer to social workers but also to the in-home support services (IHSS) workers and "nurses" to refer to anybody wearing medical scrubs aside from the clinician.

The social engagement with allied health professionals was in part influenced by the social infrastructure of the PACE model, but also the social orientation of many Latinos. The patients generally felt comfortable with others at the PACE site, who were typically Latino or culturally competent in Latino culture and knowledgeable in working with geriatric minority populations. Carlos,⁵¹ for example, did not report technically engaging his clinician due to his

⁴⁹ "el doctor...era bien familia bien amigo con mi esposo...le hablaba, así como amigo." -am2t1

⁵⁰ "con la trabajadora social o con su enfermera, o su asistente" -am12t1

⁵¹ Pseudonyms have replaced respondents' actual names for anonymity purposes.

perceived inability, but when he wanted a symptom resolved he sought help from the *simpatica* Latina social worker.

Excerpt 4.3.2a: Social Worker Brokers Patient-Doctor Relationship

I wasn't getting treated with needles (acupuncture). Until after I told the social worker, Miss Amy, 'I would like you to sign me up for [acupuncture] if at all possible because I cannot tolerate my back, waist and neck pains...if it were at all possible.' She said, 'we will sign you up.' And yes, blessed be God, the pain went away from the neck and the back, too (Translated from Spanish).⁵²

As in the case with Miss Amy, allied health professionals often served to broker the power imbalance between the physician and the patient. According to patients' reports, the social worker was unable to authorize patient requested treatments and activities (e.g. swimming, acupuncture, physical therapy, and the like) until the worker received approval from the patients' primary care provider. Often, the patients had a perception of a professional simply based on their title (e.g., doctor, social worker). Many patients blindly trusted their IHSS and social workers simply because of their expected role to assist the patient. "We trust the social worker/IHSS worker that is helping us" (abbreviated version from Spanish translation).⁵³ These contacts often developed into family-like relationships where the professionals often went out of their way to seek out the well-being of the patients. The allied health professionals were often entrusted with family-like roles. For instance, Juan has a distant relationship with his children and preferred to have the social worker take care of his final plans rather than rely on his children.

⁵² "no me estaba tratando por medio de las agujas. Hasta después **le dije yo** a la trabajadora social, le digo oiga señorita [primer nombre] yo quisiera que me apuntara para las agujas si es posible porque yo no aguanto los dolores de mi espalda, de mi cintura, de mi pescuezo...a ver si es posible. Dice sí, lo vamos a anotar. Y si, bendito sea Dios que, si se me quito lo del pescuezo, lo de la espalda igual." - am12t2

⁵³ "La trabajadora según uno pues tiene confianza con la trabajadora que le está ayudando a uno todo. Es como si fuera su casa de ella. Está haciendo todo y revisando todo arreglando. Entonces a ella le robo cosas, pero bastantes eh tuvieron que andar hasta en la corte." – am25t1

Excerpt 4.3.2b: Allied Health Professionals Replace Family

The same when I die. I do not want tubes or filter. I do not want anything. I have a letter because I want to be burned (cremated). I do not want to be buried. I want to be burned (cremated). I have life insurance that will take effect when I die. I: ‘Do you have an appointed person to take care of your preferences?’ P: ‘Oh, my social worker. She is the one that is attentive of anything.’ I: ‘You were telling me you have two sons, right?’ P: ‘Yes, but one is in [name of the country]. The other is in [name of a city]. But they are distant people...I mean they call me every 2 or 3 months. We do not frequent each other.’ I: ‘So in case of an emergency, you do not depend on your sons but rather the social worker’ P: ‘Yes, for everything. Her number is right here, and her daughter works there in GraciaMed...So they take care of anything. If it is to fill out paper, the daughter comes and fills them out and like that’ (Translated from Spanish).⁵⁴

Medical professionals who socially engage patients have a higher relational power to influence patients’ medical decision-making. However, medical encounters are not exclusive to medical professionals. Encounters include fellow members of GraciaMed. The social infrastructure of the PACE model encourages conversations among health plan members for their patients’ mental health benefits. Similar to the development of relationships with professionals within GraciaMed, fellow plan members develop relationships that at time mirror that of a family. GraciaMed hosts social-like and common interests’ events (e.g., dances, church services, knitting workshops, and the like) that encourage social interaction among its health plan members.

Excerpt 4.3.2c: We are Family

In [GraciaMed] How can I tell you? We are like family. Because I have...when I arrived I felt alone, right? I slowly began making friends. Today there are over 300 members and they are all my friends. [My] greatest pleasure [is] being with my friends over there in GraciaMed. It revives me because most of them are my friends...many girlfriends. Then

⁵⁴ “Y lo mismo también para morirme. Yo no quiero mangueras no quiero filtros no quiero nada...tengo una carta. Porque yo quiero ser quemado. No enterrado ni nada. Quiero ser quemado ¿eh? Tengo una aseguranza de vida que...actualmente para que el día que sea. I: ¿Y alguien tiene apuntado allí como persona que se encargue que vea que todas sus preferencias se han cómo? P; Oh este **mi trabajadora**. Ella es la que está al pendiente de cualquier cosa. I: Me estaba diciendo que tiene dos hijos, ¿no? P: Si, pero uno está en [sitio fuera del país]. Otro está allí en [nombre de ciudad]. Pero son personas que como si no estuvieran...Si ósea que allá una fregadera dos o tres meses duran para hablarme. ¿eh? Ósea que no nos vemos frecuentemente... I: Entonces en caso de emergencia, los hijos ¿casi no depende de ellos depende de la trabajadora? P: **Si para todo**. Allí está el número de ella. Y de la hija que trabaja allí en GraciaMed ...Entonces ellas se encargan de cualquier cosa. De llenar papeles viene la hija y me los llena todos así y ya se va.” –am25t1

they come get me, hug me, and give me a kiss on the cheek [laugh]...The truth is I am very happy. Really, I feel really happy where I am (Translated from Spanish).⁵⁵

Engagement based on social engagement can serve to modify patients' level of receptivity to listen to the social impacts that other people have experienced with similar health problems. Fellow patients' experiences, and the information provided by allied health professionals about their diseases, speak to the patients' beliefs, values and perceived risks/threats to their conditions and will ultimately be an influential component to a patient's medical decision-making process.

4.3.3 Emotional Engagement

Unlike engagement that is based on medically-related technical information where personnel within the medical system and the patient interact based on facts on the management of certain conditions, emotional engagement among foreign-born Latino elders and medical personnel, including clinicians, is heart to heart. Foreign-born Latino elders and personnel within the medical system emotionally engaged one another on a regular basis with physical touch (e.g., hug, slight touch), by tone of voice and by affectionate words of kindness.

During medical consultations with their clinicians, patients described genuinely feeling cared for as individuals, as if there was an emotional subtlety within the medical conversation, which often spoke to their heart.

⁵⁵ *“Es que allí [GraciaMed] se lleva uno como ¿Cómo le diré? como familia. Porque yo tengo. Cuando llegue me sentía yo pues solo ¿verdad? No y ya empecé así poco a poquito. Nombre ya ahorita son como 300 y tanto y todos son mis amigos. [mi] mayor placer [es] estar con mis amigos allá en GraciaMed. Me despierta porque ...la mayoría son mis amigos ... muchas amigas tengo. Y luego llegan y agarran y me abrazan y me dan beso en el cachete [laugh]...La verdad si me siento feliz. Deberás. Yo me siento muy feliz allí en donde estoy.” – am5t1*

Excerpt 4.3.3a: Caring Clinician

Oh it feels nice. One feels like we are worth something [chuckles]. I feel like she cares about me...that she cares about me. Like we do interest her enough to help us...even if I do not understand her...The doctor treats me well, thank God. She is very caring...very kind...she smiles and sometimes I feel like I can trust her...You feel even more trusting...you feel more trusting to explain things that are often inexplicable (Translated from Spanish).⁵⁶

The patient expressed that she feels the care of the physician despite the language barrier. She also implies that emotionally engaging is a good way to build trust (more on this in a later section).

Before becoming GraciaMed's PACE members, many participants did not emotionally engage their clinicians in the United States. However, once they arrived at GraciaMed's PACE, they felt that they were in a more culturally comfortable environment. During the medical consultations, not all, but several participants reported that they felt emotionally engaged with their clinicians, and more reported feeling this way with allied health professionals. The following respondent reported that she felt emotional support not only from allied health professionals and other PACE members, but more importantly from her primary care provider.

Excerpt 4.3.3b: Emotionally Supportive Medical System

They are all attentive. If they see us sad [crying] they start asking, 'what's wrong?' When that event happened that I felt useless [crying], I fell into depression. I was with the doctor and he cared for me, 'It will pass, wait for the therapy; it will help you.' And yes it helped me. They console us. They motivate us. They lift our spirits. That is what I liked (Translated from Spanish).⁵⁷

⁵⁶ "Ay se siente bien bonito. Se siente uno como que ay como que si vale uno algo [CHUCKLES]. Yo siento como que me tiene cariño...que me tiene cariño. Como que si le interesa a uno para ayudarlo...aunque yo no le entienda. ... La doctora si me trata muy bien gracias a Dios. Es muy cariñosa. Muy amable, muy risueña y a veces siento como que le siento confianza hacia ella. ...Se siente uno hasta con más confianza...se siente uno más confianza como explicar uno las cosas que a veces no puede uno explicarlas." - am13t2

⁵⁷ "todas están atentas. Si a uno lo ven triste [llorando] y andan '¿Qué le pasa?' Cuando me dio eso que me sentí inútil [llorando] hasta me dio depresión. Y yo andaba con el doctor. Y me atendía, 'ya le va pasar espérese la terapia le va ayudar'. Y si me ayudo. **Lo consuelen a uno. Le dan ánimo. Le levantan el ánimo. Eso me gusto.**" - am1t1

The physician's attempts to empathize with her patients were seen favorably. She was trying to make them feel better, and that carried a genuine level of care. It told the patient that the doctor truly cared for her person not only her disease. Similarly, other patients have expressed how their physicians demonstrate genuine care by sharing their personal stories to console them. The clinician focused all her attention, emotions and body language on the patient. Some patients mentioned that the clinician "looked worried" and showed emotional support.

Excerpt 4.3.3c: Empathetic – Emotionally Attentive

...**She cares for all of us with affection.** She looks very worried sometimes. I have cried in front of her because I cry a lot. I cry. That is normal in us. She understands because I am old already. **She compares me with her grandmother;** also, that she was like that also. **She is loving.** Almost all of the patients always talk and we are very happy with her because she cares for us (Translated from Spanish).⁵⁸

Similar to the previous lady, her physician not only shares personal stories but goes out of her way to make the members in the center feel cared for. She walks away from her consultation to talk to patients on the floor in a more social setting.

Excerpt 4.3.3d: Consoling Physician

We start to think of sad things. I have come to talk to her [physician]. I even have cried. She says 'No, no, no don't feel like that. These are the things of life. It's ok.' She consoles me and talks to me of her own personal things to try and help me gain control of myself (Translate from Spanish).⁵⁹

In addition to the physician, allied health professionals and staff develop emotional bonds with the patients. Many staff share a cultural identity that is concordant with patients; therefore, many of the cultural norms and nuances translate and increase the level of comfort and trust that the patients feel. Claudia, for instance, was grieving the loss of her son; she felt supported by the

⁵⁸ "...**nos atiende a todos nosotros con todo cariño.** Ella se le ve muy preocupada a veces, si eh llorado delante de ella, pero porque soy muy llorona. Yo lloro. Eso es normal en uno. Ya ella comprende porque yo soy viejita ya. **Ella me compara con su abuelita,** también, que así era. **Es un amor.** Casi toda la mayoría de pacientes siempre hablamos, y estamos contentas con lo que ella [la doctora] nos atiende." –am23t2t3

⁵⁹ "Uno se pone a pensar en todo melancólico. Si he llegado a hablar con ella [medico]. Hasta he llorado así ¿verdad? 'No, no, no se sienta así. Esas son cosas de la vida it's ok. Ella me consola y me platica de sus cosas para controlarme.'" – am2t1

people at the site. As a new member to GraciaMed, she was battling depression and did not want to be in GraciaMed but rather be home alone. She said that those at the provider site engaged her to the degree she was able to slowly recuperate.

Excerpt 4.3.3e: Emotionally Engaging Allied Health Professionals

There are girls [in GraciaMed] that are from Guatemala. So they would talk to me and tell me my son was in a better place. Sharing with them helped me a lot. The young ladies that work to help patients in [GraciaMed] are great. They like me a lot. I get there and they hug me and give me a kiss. I feel very well liked. I feel they all like me. Uh huh! (Translated from Spanish).⁶⁰

She was in such an emotionally vulnerable place in her life that required the medical system to be in tune with her mental health needs to avoid her falling into a deeper clinical level of depression. Strategically engaging patients emotionally meant the staff helped the patients feel safe, secure, and as though they were part of a family.

Excerpt 4.3.3f: Physician Compared to Family

A very friendly doctor, very loving with me...it's like if she was my daughter [chuckles]. The same here in GraciaMed also...she is very loving only that I do not understand her...that doctor is a white, blond lady. But I have had [consultation] with a dark-skinned short lady...you should see how...friendly they are (Translated from Spanish).⁶¹

In a typical office visit, patients were often in a vulnerable state of being, which puts them at a disadvantage. When physicians made it comfortable, it allowed the space and time for their patients to express their vulnerability. The infrastructure and this physician created an emotionally safe environment for their patients to cry. One of the highest forms of communication is that in which feelings and emotions are expressed and the respondents feel like

⁶⁰ “Hay unas muchachas allí que son de Guatemala. Entonces ellas me hablaban que mi hijo estaba en mejor lugar. Y todo eso pues me fue ayudando bastante porque pues convivimos y las muchachas todas las que ayudan allí son finas. A mí me quieren mucho. Y ella y me abrazan y me dan un beso. Si me siento querida. Me siento que me quieren todas. Uh huh.” – am10t1

⁶¹ “una doctora muy amable, muy cariñosa conmigo...como si fuera mi hija [chuckles]. Lo mismo aquí en “GraciaMed” también...es muy cariñosa nomas que no le entiendo a ella... esa doctora güera. Es güera, una doctora güera. Pero ya ahora ya me ha tocado veces que entro con una morenita muy chaparrita... viera que amables son” – am13t1

the other one knows them, which is why, when asked, many of the participants felt their clinician knew them as a person (more on communication factors discussed further in section 5.5 of this chapter). Clinicians expressed empathy and genuine care by sharing their personal stories (e.g., the passing of a grandmother). This tells the patients that they are being cared for in the same way that the clinicians would care for their own family, which builds trust and allows a clinician the potential privilege to penetrate inside the patients' thought process, getting to know the inner self of their patient, and hence their preferences and decision-making process.

Some members of the health care delivery system engaged Latino foreign-born elders in culturally appropriate and acceptable patterns. Many minority cultures, including Latino cultures, often value getting to know the medical provider and their "moral" qualities more than knowing the provider's technical skills. A similar concept is the idea of "genuine care" during medical encounters. Patients may be more interested in whether members of the health care delivery team genuinely care (i.e., emotionally) for the well-being of the patients rather than pass judgment on the clinicians' knowledge or skills. The doctor's office visit within the medical encounter is a unique and special interaction with a power disparity between patient and physician. The physician holds most of the "expert" power, having technical knowledge and access to resources that have the potential to reduce symptoms and save lives.

In closing, similar to the technically-based and social engagement, emotional engagement can serve to modify patients' level of receptivity, which can either be augmented or decreased. Social and emotional types of engagement are more prone to relationship development outside of the professional realm. The strength and quality of these relationships have the power to influence levels of receptivity for future medical encounter interactions that ultimately influence patients' overall medical decision-making process.

4.4 Chapter Summary

Foreign-born Latino elders repeatedly made decisions informed by deep-rooted fears and hope in medical interventions. This mental process, driven by personal beliefs and values, was the predominant theme in medical decision-making. The patient's apprehension of the seeming outcome and the hope in the intervention must be higher than the perceived outcome without any medical intervention before acting (Figure 4.1a). Foreign-born Latino elders engage the medical encounter using four basic patterns of receptivity: receptive, cautiously optimistic, cautiously skeptical and unreceptive. Patients tended to be mostly found in the receptive, and cautiously optimistic realm when accepting action-oriented medical decisions, and often unreceptive and cautiously skeptical when refusing medical treatment (e.g., refusing surgery). In this cohort of GraciaMed PACE members, it was unlikely we would typically be able to see people fitting the unreceptive pattern of engagement because that group would be unlikely to opt-in to this highly structured managed care program. And once in the system, programmatic features of the PACE model create unique situations that increase the patients' likelihood of establishing trusting relationships with their medical practitioners and other allied health professionals. By the simple act of being a member of the PACE program, the patients are potentially unknowingly agreeing to participate in regular doctor visits and engage in multiple medical encounters with allied health professionals several times per week.

These patterns of medical engagement and the general medical decision-making model have implications for any kind of decision-making. However, they have larger ramifications within the realm of medicine because of the value that people place on life and health.

CHAPTER 5.0: FINDINGS - MODIFYING FACTORS TO THE PATTERNS OF RECEPTIVITY

Older Latino immigrant patients engage in decision-making within the medical encounter using four typologies within a receptivity-to-engage continuum: one end being receptive and willing to engage and at the opposite end being unreceptive and unwilling. A myriad of factors, including culture, affect the four typologies found to be consistent with other Western societal research populations. Cultural values associated with communication and the development of relationship often functioned to modify patients' decision outcomes. Two relationship frameworks – the patient-clinician relationship where relationships develop with a health-related focus and communication surrounds a medical context, and the family relationship with more complex webs of communication frameworks and contexts – both function to modify patients' medical decision-making process.

In this section, I present two communication/ relationship structures by first discussing three hierarchical developmental levels of the patient-clinician relationship in the establishment of trust, and its persuasive impact on patients' decision-making. Secondly, I explain how culturally-relevant communication during the patient-clinician interaction such as language concordance, *dichos/refranes* (expressions/sayings/idioms) and the meaning of silence directly influenced patients' receptivity to medical decision-making. Lastly, I describe contexts around the family relationship such as the nature of decisions, quality of family relationships, family proximity and patients' autonomy that play a contributing part in family involvement, yet a more indirect role in patients' receptivity to engage in medical decision-making.

5.1 The Elder Latino-Clinician Relationship and Medical Decisions

The patient-clinician relationship is a complex and dynamic feature within medical encounters and in particular with medical decision-making. Latino elders place a high value on respecting those in professional positions, such as *licenciados* (college graduates) and *medicos* (medical doctors). The patient-doctor relationship is a key modifying factor to a patient's level of receptivity for medical decision-making. As the level of trust increases between the patient-doctor relationship, it also influences patient medical decision-making (excerpt 5.3.3a).

This section describes three hypothesized levels of relationship development of a Latino elder and a clinician relationship that go from a professional realm to a blurred personal relationship realm, not often seen with U.S. doctors but more so with doctors in patients' home countries. The three stages of relationship development build upon each other. The first level is the most superficial stage as it only focuses on the physicians' technical expertise. The concept of *el buen doctor* (a good doctor) is described in this phase. If the clinician passes this test they are labeled as *good doctor*. In the second tier, trust has been established, and it is only strengthened as the doctor continues to demonstrate trustworthy characteristics over time. At this point the doctor is identified as *una persona de confianza* (a person of trust) and these clinicians embody truth-telling, irrespective of the status quo. The last and the highest stage of the relationship embodies all that a *person of trust* is plus an additional advocacy dimension: doctors who look out for the well-being of the patient and are willing to provide their opinion, occasionally sticking their neck out for their patients.

5.1.1 The Concept of the Good Doctor “El Buen Doctor”

In aiming to identify what provider characteristics participants sought in a physician, a repeated concept was the idea of a good doctor. Although Latino elders value relationships over task, the notion of *el buen doctor* (a good doctor) describes one who can perform the task. The respondents typically expressed the idea that all doctors have the fundamental technical information and capability to do their job with minimal information. These were doctors who first and foremost did their job of prescribing the correct medications to take care of the problem. Lucia, for instance, spoke about still being in the process of evaluating her current clinician to see if he is considered a good doctor. She needed to wait and see if he was able to correctly diagnose and provide her with the right medication to eliminate her ailment. Irrespective of the amount of information the patient provides, a measure of a good doctor is one who is able to identify the problem. Alma, for instance, received a cancer diagnosis that went undetected by two physicians before a good doctor diagnosed her and started her on treatments.

Excerpt 5.1.1a: Good Doctor Finds the Disease

This doctor is the one who is treating me, but he was not able to diagnose me...until I went with doctor P. He did diagnose me and started me on treatment...**Good doctor**...The other two were not as good, as doctor P because they did not find the disease (Translated from Spanish).⁶²

A *good doctor* is one who is willing to look at all possibilities and run the necessary number of tests to identify the problem and find the solution. When Francisco was recuperating from prostate cancer surgery, he had bladder complications. His specialist was giving him medications, but his symptoms were unmanaged to the point of affecting his quality of life. He went to Mexico and consulted with a doctor to obtain a second opinion. This doctor in Mexico embodies how a *buen doctor* behaves.

⁶² “Él es el que me está tratando, pero él no me encontró la enfermedad...ni el otro doctor me encontró la enfermedad...hasta que fue con el doctor P, el si me la encontró y él es el que me puso en tratamiento... **Buen médico**...Y los otros dos no son iguales de buenos porque no encontraron.” –am22t3

Excerpt 5.1.1b: “*El Buen Doctor*” in Mexico Gave Me the Correct Treatment

I went to Mexico to see a doctor, and he told me **the truth** of what was happening with my bladder. He told me my bladder was fine; it just needed more time to recuperate. He said ‘I am going to prescribe this medicine and you take it for about 2-3 years. And don’t stop doing the exercises. That medicine that you have is the wrong medication because that is for a prostate and you no longer have a prostate.’ He then did an ultrasound and he told me ‘all that medicine you have instead of curing you is producing more liquid.’ (Translated from Spanish).⁶³

Francisco’s incontinence did not immediately disappear. As his doctor had explained, Francisco’s bladder needed time to heal. However, due to the fact that the Mexican physician had discovered the problem, Francisco’s symptoms greatly improved. The Mexican physician was deemed a *good doctor* because he had run the adequate number of tests needed to identify the problem, adequately explained the facts to Francisco and delivered a treatment regimen that greatly improved the patient’s symptoms, which meant Francisco was on the road to a speedier recovery. In addition, the doctor in Mexico looked out for Francisco’s future well-being by providing the patient with the required paperwork to take to his primary care provider to continue the treatment regimen he had started in Mexico.

A *good doctor* identifies the disease and tells you the truth; they also listen to your preferences and either refer you to another *good doctor* or gives recommendations. Claudia, for instance, previously spoke about not trusting U.S. doctors to perform complicated and risky procedures, such as back surgeries. She expressed her desire to seek care in her home country, and her doctor provided her with the tools to seek specific specialists needed for her back pain. Her story was previously told in Chapter 4 (Excerpt 4.2.3a).

⁶³ “*fui a ver [un médico] a México...él me dijo la verdad digamos de lo que estaba pasando con mi vejiga yeah él me dijo mira dice lo que pasa con tu vejiga dice que pues está bien lo que pasa que todavía necesita más tiempo. Dice necesitas hospicios anales dice y te voy a recetar esta medicina dice que es [vitamina] y que te la pones de un periodo de unos 2-3 años dice. Y no deje de hacer los ejercicios dice. Y esa medicina que tu traes dice te la estaban dando equivocada porque esa es para la próstata dice y tú ya no tienes ninguna próstata. Yeah. Y me hizo la como se llama el ultrasonido. ... toda esa medicina dice que en vez de curarme me estaba produciendo más líquido. Si me dice el doctor esta medicina dice en vez de que te alivie dice te está produciendo más líquido...*” –am5t3

5.1.2 The Concept of a Person of Trust “Una Persona de Confianza”

The patients spoke about how ideally they would want a doctor to be a *persona de confianza*. A provider who is deemed to be *una persona de confianza* (a person of trust) is a clinician who embodies truth-telling, irrespective of what mainstream America perceives as informed decision-making. The characteristics repeatedly used to describe trust-worthy individuals personified benevolent qualities (e.g., *amable, risueña, abierta, sincera* kind, always smiling, open and sincere). Another common phrase used to refer the concept of a person of trust is a *persona de corazón* (a person with heart). In this phase, the doctor’s heart is deemed to be in the right place, with the patient and not his pocket, therefore trust is placed in the doctor’s hands. A clinician who embodies the characteristics of a person of trust *habla con el corazón* (speaks from the heart), and thus sincere care is transmitted and felt by the patients.

Una persona de confianza (a person of trust) is willing to make their opinion clear to the patient with what they think is the best method or strategy. The provider has to go out on a limb stating their preferences, personal ideas and opinions about what they foresee to be the best treatment by clarifying the decision-making process.

Excerpt 5.1.2a: Tells me the Truth

A person of trust that could tell me the truth...for example, if there was a solution that they would tell me ‘Francisco’ it’s all right. Having that confidence to give us that encouragement, right? That they tell me, you know what is good...that they do not put in doubt, but if they do make you doubt that they say ‘think about it.’ I would still appreciate it, right? (Translated from Spanish).⁶⁴

A person of trust understands how these patients view truth-telling. Francisco wanted someone to tell him the truth, which meant providing a word of encouragement when the course

⁶⁴ “*una persona de confianza que me dijera exactamente la verdad...por ejemplo si usted hubiera una solución ahorita que me dijera no [nombre del participante] está muy bien ¿verdad? O sea, la confianza es como un ánimo que le dan a uno ¿verdad? Que me diga sabe que está muy bien...y si me pusiera en duda que dijera pues sabe que piénselo o X pues de todas maneras también se lo agradecería ¿verdad? Pues si” – am5t3*

of action was clear to the provider and not adding doubt to an already difficult decision.

However, if doubt was in order it meant making it clear that the course of action would need to be thought out by the patient.

Unfortunately, not many of the patients have ever experienced having a doctor in the United States as *a person of trust*. Most have described this kind of relationship with physicians they had long-standing relationships with in their home countries. They described those earlier relationships as involving all three types of engagement: technical, social and emotional. The relationships crossed over from a mere professional relationship filled with one-way technical information to a two-way process where there was a high level of trust.

Excerpt 5.1.2b: My Favorite Provider Someone Like Me

To have a favorite provider, it would have to be me...it's that I would need a person of trust...and well right now I don't have one (Translated from Spanish).⁶⁵

The concept of truth-telling is crucial because it has the power to build up a relationship or destroy what little if any trust was already established. If the doctor provides the patient with information, and that information turns out to be incorrect, the patient is often left feeling as if they have been lied to. Francisco, for example, was told by his physician that he would fully recuperate from the prostate surgery side-effects in seven years. He believed that timing, and seven years later he is still suffering from the side-effects and left feeling disheartened.

Excerpt 5.1.2c: Tell me the Truth

[The urine] is what has bothered me the most since I had surgery...They have already checked me, all of the specialists, and well they say I am fine. [But the urine comes] Yes and I am still leaking, right? Yeah, but it's already a lot of time. It was in 2007. So the doctors say that I should have already recuperated 100 percent (Translated from Spanish).⁶⁶

⁶⁵ *“para tener un proveedor favorito necesitaría ser yo mismo...es que necesitaría una persona digamos una persona de confianza.... Y pues ahorita no lo tengo.” – am5t3*

⁶⁶ *“[La orina] Es lo que más me ha molestado siempre desde que me hice la cirugía...Ya me han chequeado todos los especialistas y pues dice que está bien [Pero se le viene la orina] Si y todavía sigo “liquiando” ¿verdad? Yeah pero ya tiene bastante tiempo fue en el 2007. Entonces ya según los médicos ya tiene que haber recuperado al 100 por ciento. [loud sigh]” – am5t3*

Value and Perception of Truth-Telling

An important feature that builds a patients' trust is the concept of truth-telling. Foreign-born Latino elders do not equate truth telling as mainstream America views informed decision-making. Truth-telling is not "informed decision-making." Truth-telling is being able to appropriately tell the patient what they are to expect and to go out in a limb to share their personal opinions as to what treatment they feel will be the best for the patient. Truth telling is not informing patients of all available treatment options under the sun and describing the benefits and consequences of each. The expert's function is to provide clarity and is not expected to muddy a decision by introducing doubt.

Latino elders do not expect the doctor to share information that does not pertain specifically to the patients' circumstances. The "expert" who cares about his patients has to be willing to display what they deem are the good, bad and ugly things for patients to consider, which means only displaying those cards on the table that pertain to the patient's unique situation. Patients do not want the physician to lay out all of the cards on the table, particularly if they are not viewed as viable treatment options by the physician. The good doctor is supposed to know the trajectory and course of the patients' condition, have expected timelines, and know the patient's preferences as to what issues must be brought up to the patient and family and which ones can be left unspoken.

Patients do not expect clinicians to know everything, as if being God, but they do expect the doctor to be skilled and understand the basics of science which are informed from their schooling and from their personal experiences in working with other patients with similar conditions.

Excerpt 5.1.2d: Tell Me what I Should Do

A sincere person that tells me exactly what is best for me. Like when we are going to die and we say, ‘Doctor how many days do I have left?’ No, well I can’t tell you [laugh], right? What I want is that he puts the cards on the table. Seeing my health, my way of living and all of that, that he tells me exactly what I can do. That he explains it to me (Translated from Spanish).⁶⁷

Respondents respect clinicians who are able to provide information benefitting the patients’ well-being. Latino elders would have the physician answer, “Please put yourself in my shoes and tell me what you would do if you were in my position?” Then explain why you think this is the best treatment option for me. Bertha sums it all, “that the [doctor] talk to me, that they tell me the truth” (Translated from Spanish).⁶⁸

5.1.3 The Advocate

The advocate embodies all of the features of *a person of trust* and more. Similarly, to the *person of trust*, an advocate goes out on a limb to state their opinion and support the patient’s positive health and well-being. Based on the clinicians’ expertise and knowledge of the patient, the clinician actively aims to prevent undesired health consequences (e.g., side-effects from radiation, cancer diagnosis). Unlike a person of trust who speaks honestly and broaches situations as they arise, an advocate sees a potential problem likely to happen and takes action to prevent it from occurring. The advocate can play a persuasive role in the patient’s decision-making process. Usually at this level of the relationship, the patient and physician share values and belief systems. This gentleman, for instance, has a provider that shares many cultural

⁶⁷ “Una persona sincera que me diga exactamente que está mejor para mí. Como cuando uno se va morir que le diga “doctor, ¿cuantos días me quedan?” no pues no te lo puedo decir [laugh] ¿verdad? Y lo que yo quiero digamos es que me diga que me ponga como dice **el dicho “las cartas sobre la mesa”** viendo en mi salud y en mi modo de vivir y todo eso que me diga exactamente qué es lo que puedo yo hacer. Que me explique bien digamos. Por ejemplo, que me haga saber digamos lo que es mejor para mí. Si es mejor que me quede aquí por los beneficios por muchas cosas que puede ver bueno para mí aquí ¿verdad?, el ambiente, el modo de vivir que tiene uno aquí, el modo de gozarse con otras personas ¿verdad? de platicar con alguien más y todo eso.” – am5t3

⁶⁸ “Pues que me platique. Me diga la verdad.” –am6t1

perspectives. They both share the value of limited use of drugs and increased use of natural medications.

Excerpt 5.1.3a: Discouraged me from Taking Tests

He [My doctor] prevented me from going to take a cardiology test. He told me, 'Francisco don't go! Don't go to the cardiologist!' They were going to do a nuclear test where they give you a lot of liquids. They had already done it one time. He told me 'don't go, look they give you a lot of liquids. See, your heart is fine so you don't need it. The only thing is that your heart is a little big, that's it. Look' he said, 'it seems to me that it being a little big could be due to inflammation.' He said, 'it gets a little large when one suffers a stroke or when one is really stressed, but I recommend you do not do the exam.' I didn't go! (Translated from Spanish).⁶⁹

At this level of the relationship, there is a significant degree of trust that has been established between the patient and the provider. The patients' confidence in their physicians' recommendations weighs heavily on the patients' medical decisions. Putting your trust in something means you are relinquishing some of your control over the situation (e.g., stop getting information and go forward based on what the physician has said). The physician has established a great influential power.

Some of the patient-clinician relationships reported within GraciaMed PACE evolved from a professional realm, where the value of *respeto* (respect) for those in positions of power was reported to a relationship within the realm of friendship and family-like. This transition manifested in the way the participants spoke about their medical practitioners. In the Spanish language there are two forms of speech, a formal and an informal. Cultural norms and rules

⁶⁹ “*El me evito que fuera yo a un estudio con la cardióloga él me dijo [primer nombre del participante] no vaya dice. No vaya con la cardióloga porque me iban hacer un estudio nuclear. Donde le ponen a uno muchos líquidos. ¿Verdad? Ya me lo habían hecho una vez. Y me dijo no vaya dice mire allí te ponen muchos líquidos digo ya me lo hicieron una vez. Mire su corazón está bien dice no lo necesita. Dice lo único que tiene tu corazón es que esta un poquitito grandecito. Eso es lo único dice. Yo creo que era. Mira dice para mí eso de grandecito es como inflamación dice. Que se inflama dice por cuando uno sufre un infarto cuando uno sufre un 'stroke' cuando uno está muy estresado cuando dice es lo que pasa dice, pero yo te recomiendo que no hagas el estudio. Y no fui.*” – am5t1

guide the usage of these forms of speech in addressing others, especially those who are deemed to be respected such as those in positions of power (e.g., elders, physicians).

In the first level of relationship development of *el buen doctor* (the good doctor), the patient often speaks about the physician in a formal sense. As the patient acquired a higher level of trust, and the perception that the clinician opened the opportunity for more emotional and social types of engagement, the dynamics between the two people were leveled, and the forms of speech intermixed between formal “*usted*” and informal “*tu*” both meaning (you) in English. The formality remained because a physician is someone to be respected, but the number of times less respectful forms of speech were included increased. A more familiar way of addressing each other (e.g., first person) were reported in patients who had established relationships with the medical practitioner in the realm of a *persona de confianza* (person of trust) or an advocate.

In sum, the patient-doctor relationship is a key modifying factor to a patient’s level of receptivity for medical decision-making. As the quality and intensity of the patient-doctor relationship graduates to that of a *persona of confianza* and beyond, it has the power to influence medical decisions-making (excerpt 5.1.3a).

5.2 Culturally-Relevant Communication Factors in the Elder Latino-Clinician Relationship

Communication involves a major cultural component that plays a key role in all medical encounters, particularly in the patient-doctor interaction. Cross-cultural miscommunication has been reported in the health literature for many years (Kagawa-Singer & Kassim-Lakha, 2003). However, when culture is not serving as a barrier, it can function as a catalyst for the positive development of the patient-clinician relationship. This type of interaction has the potential to serve as building blocks to establishing a good quality relationship, which in turn has the power

to positively influence decision-making. Trust and shared values are also involved in effective communication as will be described in greater detail below.

Aside from the obvious issue of a common language, there are unique aspects of communication among the Latino culture that can aid in the establishment of trust and in the development of a patient-clinician relationship. In this section, I will discuss the use of the Spanish language, factors that precipitate relationship development and, lastly, describe styles of culturally-appropriate communication styles, such as the use of *dichos y refranes* (sayings and idioms) and *chistes* (jokes) as potential means to open communication channels between patients and clinicians.

5.2.1 Patient and Clinicians' Cultural and Language Concordance

The language used during the medical encounter often modifies how a foreign-born Latino elder whose language preference is Spanish engage in the encounter. Language and cultural background concordance are often appreciated by the participants, as they add a comfort level and make it easier for them to interact and engage in deeper and richer points of communication, rather than the one-sided conversations that involve simple rendering of facts. This allowed for a respectful two-way exchange of ideas and emotions. Having a Latino doctor was good, but even better is engaging with a *paisano/a* (fellow countryman).

Excerpt 5.2.1a: Paisanos

Paisana...that means we are from the same place. When it comes to talking and everything we understand each other better because sometimes the nuances of the language come out. Like you the Mexican comes out and for us the Chapin⁷⁰ comes out. We are “catrines” (no direct translation - high-value people). So then if there is another

⁷⁰ Chapin is a common name used to identify people from El Salvador.

person we don't understand, she already knows all of the words and we mutually understand each other (Translated from Spanish).⁷¹

When people from the same regions of the country speak, there are unspoken similarities that enhance effective communication. A non-native speaking the language is appreciated, having a Latino doctor is preferred, and even better for communication is having a *paisano/a*. An immediate level of trust is established with effective communication, as can often occur with Latino doctors.

Excerpt 5.2.1b: Language Helps Gain Trust

He speaks Spanish very well. Well I don't know, but he gained my trust. Much of my trust I gave to the doctor (Translated from Spanish).⁷²

Speaking the same language helps put the patient at ease knowing that direct communication is being accomplished. Plus, language concordance allows the patient the comfort level to express themselves freely in their preferred language. They often feel more comfortable and at ease discussing their medical problems. Those that identified their relationship with their physicians using positive terminology did so in their preferred language.

Excerpt 5.2.1c: Trust and Speaking the Same Language

I do not know how to speak in English...it is like one feels more trust [with a doctor that speaks Spanish]. Lately, it's been twice that my regular doctor has not been available to see me...there is another one and she speaks Spanish and it's like one feels more trust to say things. Like to express oneself because I always say [to the translator] 'I think you are not even saying what I say.' Well maybe yes, but I don't know (Translated from Spanish).⁷³

⁷¹ "Paisana... que es de mi país... Ósea que somos de la misma tierra. Ya, ósea que nos entendemos mejor a la hora de hablar y todo porque a uno a veces se le sale lo digamos así ustedes lo mexicano y a nosotros los Chapín que nosotros somos bien catrines. Entonces si es otra persona no se entiende o no entendemos a otros entonces, ella, ya sabe todas las palabras, ya pues ya se le entiende, nos entendemos, pues, mutuamente." -am10t3

⁷² "Habla muy bien el español. Y pues no sé le agarre mucha confianza. Muchísima confianza le agarre al doctor." -am5t1

⁷³ "No sé hablar inglés... como que se siente uno con más confianza [con una doctora que hable español]. Y ahora últimamente dos veces que no hay la que me atiende mi doctora...hay otra y **ella si habla español y como que se siente uno con más confianza para decir las cosas**. Como para expresarse que...ósea porque siempre le digo 'ay yo creo que yo lo que le digo le dice a él' ...Pues a lo mejor si se da, pero yo si no se." - am13t1

Some patients, in an attempt to minimize miscommunication and maintain the integrity of the information being exchanged, make an effort to speak English with their physicians, even though they are aware of available translation services and their preferred language is Spanish. A respondent⁷⁴ spoke about making an effort to learn English not only to become a U.S. citizen, but also because she thought it to be a necessity in a country where English was widely spoken. Speaking English could help diminish the possibility of miscommunication in areas such as healthcare.

Others do use translation services, but there is always a lingering issue with patients' level of trust in the accuracy of the translation. If the physician is not a Spanish speaker and translation services are sought out, the communication may be a bit hindered. It is not necessarily that the patients do not trust the physician or the translator, but the nature of the job may give concern over the accuracy over what is getting translated (excerpt 5.2.1c).

Excerpt 5.2.1d: Accuracy of Translation Questioned

And like [the doctor] speaks English, who knows...for me a nurse is always present as an interpreter. She is the one who tells her everything. That she [the interpreter] actually tells her what I tell her, **who knows if she does** [chuckles] (Translated from Spanish).⁷⁵

More valuable to Latino elders is when a non-native speaking doctor makes the effort to learn and speak Spanish. The action shows a level of “genuine care,” which is valued.

5.2.2 Indirect Verbiage, Idioms, Sayings, and Jokes

Older Latinos are great story-tellers and have an indirect way of communicating their wishes and preferences to others, especially to authority figures such as physicians (Garcia,

⁷⁴ No direct quotes. Participant declined to be audio-taped –am20t1

⁷⁵ “Y como habla inglés [la doctora] pues quien sabe...a mí siempre esta una de las enfermeras [como intérprete] que es la que le dice a uno...que le diga lo que uno le dice **quién sabe si le dice** [CHUCKLES]. [I: Siempre tiene un poco de desconfianza porque no sabe exactamente lo que le van a decir]. Si exacto. Yo eso es lo que pienso.” - am13t2

2007). For example, being direct and to the point is often perceived as rude; it is considered to be an aggressive form of communication. Many patients did not directly express their medical preferences. However, when they perceived they were being engaged by the clinician, the patients were more likely to divulge medical preferences. Due to how patients often indirectly expressed their preferences, it often remained hidden in the language and potentially difficult for clinicians to grasp. Therefore, even after patients shared their preferences, some left the consultation feeling unheard, “well I told her but she didn’t say anything” (Translated from Spanish).⁷⁶

Culturally appropriate manners of communicating to collect information begin by actively listening to the use of *indirectas* (indirect verbiage), *dichos* (sayings), *refranes* (idioms), and *chistes* (jokes), which carry meaning. These are at times subtle comments that could easily get dismissed. These could be potentially missed opportunities for anybody aiming to understand their patient preferences and desires for medical care. It requires practitioners to engage in active listening.

Excerpt 5.2.2a: “*¡Más Sano que un Gusano!*”

I also tell the doctor, he says, ‘how do you feel today?’ I say, ‘No, I feel healthier than a worm.’ [laugh] He says, ‘good, good we can tell (translation for Spanish, but joke does not translate).’⁷⁷

The patient was updating his physician on his physical health. However, the clinician was not only able to capture the patients’ physical health status, but his mental health as well.

Francisco,⁷⁸ for instance, had been suffering from clinical depression, and his joking behavior and professional appearance signaled to the provider that his mental health was improving. If a

⁷⁶ “*pues si le dije, pero no me dijo nada.*” -am12, otras conversaciones personales

⁷⁷ “*Yo también le digo al doctor. Dice [el doctor], “¿cómo te sientes ahora?” y le digo “¡No! ¡Yo me siento más sano que un gusano!” [laugh]. Dice “¡Qué bueno! ¡Qué bueno! Se te nota.*” -am5t2

⁷⁸ No direct quotes

clinician does not understand and does not react appropriately there is wasted energy, time, and money on behalf of the clinician and the patient. If the patient leaves feeling unheard after an attempt by the patient was made, the patient's medical care experience is sacrificed, and the patient is less likely to want to engage again. The physician could potentially lose valuable information that could serve in building a trusting relationship with the patient and understanding patients' preferences regarding truth-telling.

5.2.3 The Meaning of Silence

Within the realm of the patient-physician relationship, the issue of communication style arises. It is often assumed that verbal and non-verbal communication in a relationship is a two-way street, where people engage one another. This cohort of foreign-born Latino elders varies in their modes of communication. Many patients report not "actively" and "verbally" engaging their physicians in the way mainstream Americans would perceive as engagement. As mentioned earlier, the participants felt engaged when the clinician acknowledged the patient (e.g., a slight touch, eye contact while providing technical information, talking directly to them, rather than at the input screen of an electronic medical record).

Many foreign-born Latino elders do not "actively" engage their clinicians, a person of power, and choose silence rather than questioning. Minimizing conversations or choosing to be quiet in situations of power imbalances is often a culturally acceptable behavior due to the embedded values that inform these practices. Although verbally expressed forms of communication may not be engaged during interactions with the physician, the likelihood that Latino elders engage the medical system using non-verbal emotional and social ways of communicating with other members of the healthcare team increases to ensure their needs are

being met (e.g., social worker, fellow health plan members, auxiliary health staff, and the like). The likelihood of patients engaging in emotional and social communication highlights the influential power other members of the health team have on patients' medical care experiences and medical decision-making.

There are obvious issues related to health literacy, which confound the meaning of silence even further; however, power imbalances transcend health literacy. Claudia is an outlier and often speaks out, but talks about others who often choose to remain silent about poor quality dental care.

Excerpt 5.2.3a: Do not Complain!

There are a lot of people who have all their teeth bad and falling out, and I tell them **'Why don't you say anything?'** They keep going to the same dentist, right? So when I saw that my bridge broke, I told the ladies in charge 'look the bridge broke and the [dentist] has not taken out the teeth. I no longer want to go with her. Can you change me? [The dentist's work] has a lot to say for itself because a lot of people complain, but **they don't say anything to the clinic.** Well then keep going. There was a man who said, 'one day I waited 55 minutes just to have her tell me that she was not going to do anything.' So I tell them, **'why don't you complain,' right?** I complain. Uh huh because otherwise, am I going to stay like that? (Translated from Spanish).⁷⁹

Few of the older respondents choose to speak up. In contrast to mainstream America's value system that often encourages being direct and demanding, in many Latino cultures "submissive- appearing" behaviors such as *el no molestar* (not being a bother), *el no ser pediche*⁸⁰ (not being a beggar) and lastly not being confrontational are informed by key values

⁷⁹ "allí hay muchas personas que están con los dientes malos que se les caen. Y les digo '**¿por qué no dicen?** Y van con la misma dentista. ¿verdad? Entonces cuando yo vi que se me quebró el puente. Entonces le dije a unas de las encargadas miré le dije se me quebró el puente y la doctora no me ha sacado los dientes. Yo ya no quiero ir con ella ¿me puede cambiar? [El trabajo de la dentista]... tenía mucho que decir porque había mucha gente que se quejaba porque hablaban allí **pero no decían nada** los demás pues sigan yendo. Había un señor que dijo un día estuve 55 minutos esperándola a ella para que me dijera que no me iba hacer nada. Entonces le digo **¿por qué no se queja?** ¿verdad? Yo si me quejo. ¡Uh, ha! Porque si no ¿cómo voy a estar así?'" – am10t1

⁸⁰ "No ser pediche /pendiche, no molestar, la vergüenza." The direct translation of the Spanish verb "pedir" is to ask. "Pediche" is a colloquial Mexican term often used to indicate a person who lives off others, such as a scrounger or deadbeat.

related to respecting authority such as doctors. All of these values fall within a higher-level concept of being grateful for what you have and not complaining because it is like complaining against God, who has graciously provided all and is in control of all (see Faith Chapter). Hence, if a foreign-born Latino elder sees or experiences an injustice or poor medical care, it is much harder for a Latino to decide to speak up. Vanessa, for instance, overheard questionable comments about the quality of work the dentist was performing on her. The dentist assumed Vanessa was a monolingual Spanish speaker, and therefore unable to understand the conversation between the dentist and his assistant when she overheard the following:

Excerpt 5.2.3b: “You Get What You Pay for!”

[the dentist with] this tooth, I don’t know what he was doing wrong. His assistant told him something...I didn’t hear but he responded “You get what you pay for” and his assistant then told him “she understands English.” He was doing something wrong. I never said anything. Too bad. They give you this dental plan so **maybe there’s a connection**. I don’t know what he did here [points to her tooth] because there is a bad smell...maybe food is going in. I have to be cleaning and cleaning it...before it wasn’t like this. I didn’t feel it like this. But now I think my suspicion was right... I now say I should have said something. I later thought about it and said to myself if he did that with me he is going to do it with other people that do not understand. I did understand what he said. His assistant told him something and he responded with “you get what you pay for” (Translated from Spanish).⁸¹

She chose to remain silent about the situation as she questioned her suspicion. Now she regrets not having told anybody about what occurred because the dental work that was performed was obviously of lower quality since she is now suffering complications in the area. She realizes that if it happened to her they must have done it to other people. Unfortunately, reports of poor medical care where patients feel dismissed, disrespected or ignored help to encourage/perpetuate

⁸¹ “[el dentista con] este diente no sé qué me estaba haciendo mal. Su ayudante le dijo...yo no olli y él dijo “You get what you pay for” y le dijo su ayudante “She understands English” Pero algo estaba haciendo mal ..Y yo nunca dije nada. Ni modo. Te dan este plan de dientes quizá que está conectado esto. No sé qué hizo aquí [apunta a un diente en la boca] porque tiene un olor que yo no sé se está metiendo cosas. Se está metiendo cosas allí. Tengo que estar limpie y limpie y limpie...anteriormente no estaba así. No lo sentía yo así. Pero ahora siento que era verdad porque se mete [la comida] ...Yo digo yo debería de haber dicho. Yo pensé después porque digo si hizo eso conmigo lo va hacer con otras personas que no entienden. Yo si le entendí. Algo le dijo ella que eso no lo ollí. Pero el si dijo “you get what you pay for.”-am15t1

patient's silence. "I tell [the doctor about a complaint] there **I am not going to be telling them anything anymore** they don't even pay attention to me" (Translated from Spanish).⁸²

As mentioned earlier, many Latino cultures have "submissive-looking" value-driven behaviors that are informed by the beliefs in an omnipotent and omnipresent God, which also supports the idea of not being confrontational as a key value related to respecting authority. Elena, for example, commented during our second interview she had forgotten the context of the project and started questioning her participation in the project. She had forgotten receiving the information sheet or having been interviewed in her home. After a brief conversation about her rights, she agreed. Although, not totally convinced due to her perception of possibly losing her services she agreed and justified it by saying only God knows why God is providing these services.

Excerpt 5.2.3c: Do not complain; it's in God's control!

I: Once again I ask, may I have your permission to record our conversation? R: Well it's okay if it is not something that will ill affect one you know...I only asked. It is in these occasions that I am in...I mean that if they do not take away my services well only God knows why [chuckles] (Translated from Spanish).⁸³

These concepts continually push the idea that silence is better than confrontation, especially with authorities. Participants are not to ask for more than what they need, and they do not want to overly bother. These ideas have a cultural component, but also a generational one, with older adults, especially those raised in Mexico, being the most deferent. For instance, Elena has debilitating chronic pain but refuses to ask for more medication because she does not want to be a *pediche*. She is embarrassed to have to bother her physician and keep asking.

⁸² "Le digo [llevando la queja al doctor] hay ya no les voy andar diciendo nada **ni me hacen caso.**" –am13t3

⁸³ "I: Ok entonces otra vez le voy a preguntar, ¿si me da permiso de grabar la conversación? C: Pues está bien. Si no es cosa que le afecte a uno usted sabe...yo nomas le preguntaba. Son ocasiones de esas que ando...ósea que si no se me quitan las cosas pues solo Dios sabe por qué [chuckles]" –am13t1

Excerpt 5.2.3d: Embarrassment

They give us the medication there in GraciaMed. [The doctor] told me ‘Oh you do not have any medicine.’ No ma’am I do not like...I don’t know, **I am embarrassed to be asking everyday asking and asking** (Translated from Spanish).⁸⁴

Embarrassment is another aspect of maintaining silent. Alma, similar to Claudia, talks about how fellow members perceive her as knowing how to engage the system more effectively given her time as a patient. She knows the system well enough to understand that patients must be a bit proactive. She tends to intervene on behalf of her fellow peers to squash the detrimental effects of silence, and nip the idea of leaving things to be done later, and left to *la decidia*.

Excerpt 5.2.3e: Seeking Help from GraciaMed Friends

“They get behind with the medicine and with a lot of other things and **the people come and complain to me**. Oh Alma you have many years being here (GraciaMed). You know how this place works. Yes, but I am not a nurse here. I am a patient. It is not the same being a patient and a nurse. You have to talk with the nurses and if they do not listen to you, then go with other ones. I send them to the pharmacy. I take them inside and I talk about them and their medicines. I go with them. No, men only talk and they don’t act [chuckles]...to do things...**they leave it for another time**. I tell them no, the medicines that are given to you are to be taken daily. It doesn’t matter if it’s night or day...and talk to the staff to not be left alone so they do not forget about you, I tell them (Translated from Spanish).⁸⁵

Cultural values are often the driving force for choosing to remain silent during medical encounters, particularly during the medical office visit. Awareness of these values provides an understanding to foreign-born Latino elders’ use of silence. These values indirectly affect how individuals engage people of power and how involved these people of power are in the

⁸⁴ “*nos da la medicina ahí en el GraciaMed. Me dijo [la doctora] ay usted no tiene nada de medicina. No S a mí no me gusta...no sé, como que me da pena estar pidiendo todos los días pide y pide...lo único que pido es pomada de miel...*” –am13t1

⁸⁵ “*Se atrasan con la medicina, se atrasan con muchas cosas y la gente conmigo se queja. Hay Alma usted tiene muchos años de estar acá (GraciaMed), usted sabe mejor el movimiento de acá. Si, le dije, pero yo no soy enfermera de acá le dije, yo soy paciente. No es igual ser paciente a ser enfermera, ustedes tienen que hablar con las enfermeras y hablar y si no les hacen caso ellas entonces vayan con otras. Yo las mando, las llevo y las mando a la farmacia, las llevo para dentro y voy a hablar sobre de ellos de la medicina. Yo los acompaño. No, los varones...nomas hablan y no hacen [CHUCKLES]...de hacer las cosas...lo dejan para otro tiempo y le digo no. La medicina que les dan tiene que ser día a día les digo. Sea en la noche o sea en la mañana...con la medicina y hablar para que no lo dejen solo si no se acuerdan de ustedes les digo.*” –am22t2t3

individuals' medical decision-making process. These values will be further described in the discussion chapter as they play a larger and more dynamic role in people's everyday lives.

5.3 The Role of the Family in Medical Decision-Making

Family involvement usually plays a modifying role in foreign-born Latino elders' medical decision-making process. Family can influence a patient's level of receptivity to engage medical decision-making with a behavioral change component. At the extreme end of the receptivity continuum, family involvement has little impact on patients' medical decisions. However, for patients who are cautiously optimistic and or skeptical, family involvement can have a stronger influence in the patient's decision-making process by either serving to encourage or dissuade a patient's level of receptivity to medical decisions with actionable components. Understanding the role of decision-making within Latino families is particularly challenging given the cultural, generational and familial obligation dimensions involved in the medical decision-making process, issues that I will only tangentially discuss as they have emerged in my analysis.

In this section I will present data that suggests that family involvement in a patient's medical decision-making process depends on the nature of the decision, including the patient's state of vulnerability, the relational components with family/loved ones and the physical proximity that family has to the patient. In addition, I will describe how GraciaMed influences family involvement and patient autonomy, which impacts patients' levels of receptivity to engage in medical decision-making. Lastly, I will end the discussion describing the limitations specific to this family-related analysis.

5.3.1 Nature of Decisions

The nature of decision-making plays a decisive role in family involvement. Similar to the process described earlier with the patterns of engagement, patients made decisions on whether to include others in a similar fashion. For some patients and families, the nature of the decision and the situation had to be dire enough to justify *molestar* (bothering) others and including them in the process. If the decision to be made was of the preference-based rather than crisis-based territory, then it was typically deemed unnecessary to include family in the decision (see Chapter 4). Maria, for instance, was in a stable phase of her health, where she was adequately managing all of her conditions with medication, exercise and diet.

Excerpt 5.3.1a: Family Communication with Doctor Not Necessary
Sometimes they call, and I see family members entering to talk with the doctor about the patient's health. In my case it hasn't been necessary...I don't think it's necessary (Translated from Spanish).⁸⁶

Family involvement often meant the situation was in the crisis-based territory, and an immediate life-threatening incident that could potentially spiral to death had taken place, or in a situation where immediate death was expected without intervention (see Chapter 4). Patients who fiercely valued their independence, and feared behavioral dependency, waited until the health decision was particularly consequential/complex/uncertain before involving family. The more independent seniors were used to getting things when they wanted, and how they wanted it. For instance, Claudia⁸⁷ is a goal-driven individual with a history of making solo decisions based on what she wants to accomplish. Prior to her declining health status, she had been financially independent owning and running a successful business. She left her husband and moved to

⁸⁶ “A veces llaman así yo veo que entran familiares a hablar con la doctora sobre algo de la salud del paciente, pero en mi caso **no ha habido necesidad...No lo creo necesario.**” – am1t2

⁸⁷ Pseudonyms have replaced respondents' actual names for anonymity purposes.

another country to pursue different dreams. There is no doubt in her mind that if her primary care provider needed to talk to her family because of a serious medical situation or because she requested it, that it would be done. However, she justifies not including her family at this point because it has not been necessary.

Excerpt 5.3.1b: No Need

No he [my primary care doctor] doesn't involve my family...If I say I want them involved he will do it, but there hasn't been any need (Translated from Spanish).⁸⁸

While some had a preference for family involvement solely based on the nature of the decision and severity of the situation, others had a preference for family involvement independent of the nature and severity of the decision. Some were accustomed to having family accompany them to consultations and, either on behalf of the patient or with the patient, engage with clinicians in conversations leading to decisions. However, that preference was not often well received or embraced by the system. Although there may not have been any policies prohibiting family involvement, the medical encounters, the organizational design of the PACE program, made family participation in medical encounters difficult. One typical respondent indicated that prior to entering GraciaMed her daughter accompanied her, and she liked that compared to how it works now.

Excerpt 5.3.1c: I Want My Daughter with Me

Well, my daughter has never gone to the doctors there in GraciaMed... In this one here [previous doctor's office] my daughter would go with me. It was doctor [last name]. She would go with me...my daughter would take me. And I liked that...because she would go inside the doctor's office with me and talk... and there [in GraciaMed] only the people that work there know what's wrong with me (Translated from Spanish).⁸⁹

⁸⁸ “E: ¿Hasta qué grado siente que su doctor, el chinito, está disponible para involucrar a su familia? P: ¿A mi familia? No él no involucra a mi familia. E: ¿Aunque usted lo requiera? P: No yo digo cuando lo requiera **lo va hacer** [50:23] pero ahorita no ha habido necesidad.” – am10t1

⁸⁹ “Pues mi hija nunca ha ido con los doctores de aquí del [GraciaMed]...En la de aquí [oficina medica que asistía anteriormente] si iba mi hija conmigo. Era la doctora [apellido de la doctora]. Ella iba conmigo... mi hija me llevaba. Y me gusta más así. ¿eh?...porque se mete al consultorio y con ella habla. ...Y allí [en GraciaMed] solo las que trabajan allí son las que se dan cuenta lo que uno tiene.” – am6t1

She wanted to have her daughter continue to be involved in her care, the same way she had been previously to her arrival at GraciaMed. “Well I do want my daughter to talk to the doctor” (Translated from Spanish).⁹⁰

5.3.2 Family Relationships

Although the nature of the decision may not fully determine preference for family involvement, it does determine who the people are to be involved in the process, which is often contingent on the quality of the relationships. Latino families tend to be inclusive as to who are considered “family members” well beyond the nuclear family unit, often including extended family members (e.g., cousins, nieces) and others (e.g., *compadres* [baptizing Godparents], *vecinos* [neighbors], *amiguitas/os* [good friends]). This whole range of family and extended family are usually included when discussing the “family” involved in medical decisions. Relationships develop for many reasons, but the closeness of relationships is often determined by issues of estrangement with children and the trust that the patient felt in sharing personal information, including about their medical conditions. In discussing who the older adults talk with about health issues, they would often make comments like, “*confianza con mi cuñada*” (trust in my sister-in-law).⁹¹

The family members involved in decisions, therefore, may not only include blood-related individuals but others as well. Juan, for example, is more likely to seek advice and talk about his conditions with his siblings, neighbors, friends, fellow GraciaMed patients and even his IHSS worker than with his blood-related sons. Some nuclear families are more united than others, and

⁹⁰ “*Pues si quiero que mi hija platique con la doctora.*” – *am6t1*

⁹¹ *Am23t1*

some may opt to include many extended family members, a few or none in talking about their conditions. Francisco says his relationship with his siblings is not close, so they are not involved when it comes to medical decision-making.

Excerpt 5.3.2a: No Family Unity

Well, you see I have poor communication with my siblings, right? We aren't very close. I only call them when in the hospital and they go and visit, but for them to come and visit me at home or to invite me to go out and eat, no (Translated from Spanish).⁹²

Francisco is also estranged from his blood children in Mexico and is more likely to communicate and share about his medical care with his stepdaughter and her husband than with anyone else.

Excerpt 5.3.2b: Non-Blood Related Family

The only person I have grown close to is this boy that is right here [points to a picture frame with a couple and a young boy]. That young lady that is there was my stepdaughter. I was her mother's partner. Yeah. They are the only ones that I've grown closer to. The little boy sees me like his grandfather. Yeah! (Translated from Spanish).⁹³

Some circumstances can push the boundaries of usual consultation patterns. When Francisco learned that he had prostate cancer, he traveled to Mexico and visited his estranged children, whom he thought he might never again have the opportunity to speak to if the treatment outcome were not positive. So he went and told them of his situation.

Excerpt 5.3.2c: Family Discussion

Did they know what was happening with you? P: No. No. I: Did you get to talk to them about it? P: When I arrived with them, yes (Translated from Spanish).⁹⁴

This suggests that in crisis decision-making the network of family involved in health discussions can change. Talking about medical conditions with others automatically opens the possibility for

⁹² "P: Si mire ósea que pues tengo un vehículo pues muy leve con mis hermanos ¿verdad? No estamos muy unidos pues ¿eh? Yo solamente cuando va uno al hospital y van y lo van a ver a uno, pero así que me visita y vengan o hermano que. O te invito a comer, no." – am5t1

⁹³ "La única persona que se me acercado un poco más es ese niño que está allí [apunta a un cuadro con fotografía de una pareja con un niño]. Esa muchacha que está allí era mi hijastra. Yo fui su pareja de su mama. Yeah. Y son los únicos que se me han acercado un poco más. Porque el niño me ve como su abuelito. Yeah." – am5t1

⁹⁴ "I: ¿Y ellas si sabían lo que estaba ocurriendo con usted? P: No. No. I: ¿Si llego a platicarles? P: Cuando llegue con ellos sí." – am5t2

suggestions/recommendations from them. In reaching out to share the news of his condition, Francisco received advice in return.

Excerpt 5.3.2d: Come on Down

I contacted various people like my brother-in-law that lives in Mexico. He is married to my sister and he said ‘no brother-in-law’ he says ‘here they do this and they do that. Come down! (Translated from Spanish).⁹⁵

Another key aspect to inclusion in decision-making is living arrangements. Although living with family did not automatically provide social support because of the family presence, it did tend to increase the likelihood that communications about medical conditions are shared and, therefore, family decision-making involvement increased. Most participants of this study either lived alone or as members of a multigenerational family, or were living with extended family members. The quality of the relationship determined whether or not information was shared. For instance, one respondent lives with her brother and sister-in-law. Although she would prefer to live with her daughter, she is more likely to share everyday medical situations with her sister-in-law than with her daughter. She says,

Excerpt 5.3.2e: Conversations about our Conditions

We always talk about treating our illnesses. She tells me her problems and **sometimes I** tell her mine...she is the one I talk to a little bit more (Translated from Spanish).⁹⁶

In summary, the quality of family relationships determined the degree a person included them in their routine decision-making process. In times of crisis the network of contacts often expanded. If the decision was preference-based, only those members of the family that were closest to the patient were usually involved, compared to including most/all family when the situation and decisions turned grave. Sometimes the closest family was other GraciaMed patients

⁹⁵ “Contacte a varias personas como mi cuñado que vive en México él está casado con mi hermana me dijo, ‘no cuñado’ me dice ‘aquí te hacen esto te hacen el otro.’ ¡vengase!” – am5t2

⁹⁶ “Siempre hablamos de tratarnos las enfermedades. Ella me cuenta sus problemas y **a veces** yo las mías...con ella es la que hablo un poquito más.” – am23t1

and staff, including the case of a gentleman who is estranged from his son and so chose to put specific GraciaMed employees as his health care proxies (excerpt 5.1.2b).

5.3.3 Family Proximity

Another key element of family involvement during medical decision-making is the aspect of family member's physical proximity. The likelihood of a patient involving family for preference-based decision making often decreased with distance. Living with loved ones increased the possibility that interpersonal interaction occurred more frequently than with the distanced family member. Therefore, communication about medical conditions was often shared with people they lived, thereby increasing the level of involvement in decision-making.

However, proximity alone is not enough to dictate family involvement. A better indicator is the strength and quality of a relationship between a family member and a patient. Distance is not a deterrent from participation with people with strong relational bonds. Involvement, however, requires additional effort, focused energy and deliberate action to ensure the patient and potentially the patient's clinician are regularly engaged. As Maria noted, "Yes, my daughter is attentive to how I am doing. She frequently calls me and asks" (translated from Spanish).⁹⁷

Many patients had children in their home countries or out of state that they spoke to regularly. However, a similar pattern to that described earlier regarding the nature of decisions emerges. The decision must be severe enough to justify alarming other family members, particularly those in other countries (Table 5.1). Although the daughter *está al pendiente* (she is attentively looking out for her), that family member is often not included in preference-based

⁹⁷ "Si. Ella [mi hija] está pendiente de como estoy. Este seguido me habla y me pregunta." -am1t1

decision-making. Only when it is deemed a *cosa grande* (big thing) are they more likely to involve far away family.

Excerpt 5.3.3a: Something Big

I: So you have considered your son. Is there another person? R: Here are my son’s wife and my daughter also, but she is in El Salvador. She is attentive to my well-being. She frequently calls me to ask. I: And when they have to change your medicine, do you mention that? R: No, only when it is something big (Translated from Spanish).⁹⁸

Family members living far away run the risk of not being included in preference-based decision-making and are more likely to only be included during a crisis situation. It can also depend on whether or not they have the ability to travel to the United States. Most families outside of the United States do not have easy access to the visas needed to visit. Therefore, loved ones in the United States aim to alleviate the burden and potential anxiety by only sharing information when in a crisis.

Table 5.1: Family Involvement Patterns and Medical Decision-Making (MDM)			
		Nature of Decision	
		Preference-based MDM	Crisis-based MDM
Quality of Family Relationship & Physical Proximity	Close family (Close relationship and/or close proximity)	Sometimes	Yes
	Distant Family (estranged relationship and/or far proximity)	No	Sometimes/Yes

In closing, the findings suggest that family involvement influences patients’ medical decision-making process and potentially modifies a patient’s level of receptivity to engaging medical decisions. Family involvement, however, is influenced by many factors, such as the

⁹⁸ “I: Entonces ha considerado a su hijo. ¿Hay alguna otra persona? R: Aquí la esposa de él [su hijo con quien vive] y también mi hija, pero está en el Salvador. Ella está pendiente de como estoy. Este seguido me habla y me pregunta. I: y cuando le tienen que cambiar medicina, ¿eso les comenta también? R: **No nomas cuando es cosa grande.**” –*amItI*

nature of the decision, the patient's state of vulnerability, the relational components with family/loved ones and the physical proximity that family has to the patient – distance being a factor for potentially including or excluding loved ones.

5.3.4 Family Involvement and Patient Autonomy

Before becoming GraciaMed's PACE members, participants frequently had family accompany them to their geriatric consultations. Family involvement was essential to the patients' healthcare experiences. Although GraciaMed's PACE program does not have existing organizational policies excluding family, their operations were void of family participation, particularly during office visits. GraciaMed's PACE all-inclusive features replaced some patients' need for family involvement (e.g., issue of transportation). Current experiences in the doctor's office are reported to mirror those before attending GraciaMed's PACE. However, GraciaMed's PACE program compensates for the lack of family involvement during the office visits by the accommodation of cultural elements.

Culturally-appropriate behaviors and norms were not always discussed directly with the doctor, but were typical while engaging allied health professionals, center staff, and in the delivery of auxiliary services (e.g., acupuncture, therapy, religious activities, dancing, culturally appropriate arts and crafts and other socially-relatable activities). Having these cultural-appropriate basics in place helped the system build trust with their members. Trust is the bridge that helped the system replace familial obligation, and hence involvement. If prior to entering GraciaMed's PACE program family involvement was minimal, then the system superseded family, however, if before entering GraciaMed's PACE family involvement was 100 percent

then it was minimized rather than obliterated. Nonetheless, GraciaMed's PACE transfer of responsibilities takes on previous familial obligations.

Because the doctor office visits within GraciaMed PACE were reported to mirror those in community-based ambulatory care, the participants' had to ascertain a certain level of independence, without the assistance of family, during the office visit. Possessing a degree of independence was an essential element to reap medical benefits and maintain interdependent autonomous features with programmatic support. Latinos valued autonomy in a way not perceived by mainstream America. The American health care system upholds an individualistic value system, where the person is valued over the collective. Unlike a collectivist society where the group is valued over the individual, America upholds ethical principles of autonomy and individuality. Although some argue that autonomy is an individualistically-driven value that is not relevant to Latinos given their collectivist nature (Montemayor, Adams, & Gullotta, 2000), my findings suggest otherwise. My findings agree with researchers who argue that people depend on each other during their lifetime, albeit to various degrees, which implies that autonomy can only be delivered through interdependence (Tronto, 1993). Many foreign-born Latino elders with multiple chronic conditions in my cohort practiced interdependent autonomy with the assistance of friends and family. Some individuals before entering GraciaMed PACE fully relied on family for medical decision-making. If a patient was used to having caregiver do everything, the patient was not likely to benefit from a PACE program like GraciaMed without involving a family component. To ensure patient "success" a higher level independence without family assistance was required. Bertha, for instance, did not change her consultation behavior and was "not successful" in maintaining her stay there. Her daughter, before entering GraciaMed's PACE program, accompanied her to all her medical appointments, spoke to her

clinicians and made all the medical decisions. Once she registered into GraciaMed's PACE program, she was expected to engage the doctor office visit with some degree of independence when she had never done that before. She was very sociable and loved the cultural features of the program. However, her office visits were compromised due to the cultural miscommunication and expectations between Bertha's mode of engagement and her clinician's expectations. The situation with Bertha and her daughter was a rare occurrence among the respondents, yet an insightful observation of a person no longer participating in PACE. Most of the time, patients were able to get what they wanted with the assistance of the system. The system took on the roles and responsibilities of family members who previously served as patient's support system (e.g., transportation, accompany to doctor visits and the like). The system was not likely to adapt to patients needing full family support, but rather new patients needed to adjust to the system's culture of individuality. Therefore, incoming patients must have a certain level of visually recognizable autonomy during the doctor's office visits if they are to be "successful."

The findings reported here are atypical and represent the best case scenario for delivery of care to foreign-born geriatric Latino patients. This cohort represents the best possible medical attention and highlights the potential of what could be the ideal care for vulnerable geriatric populations.

5.3.5 Limitation of Family-Related Analysis

Note, a caveat is warranted with the issue of family involvement and medical decision-making with this unique sample of patients from GraciaMed's PACE program. This group does not represent the general population of community-dwelling foreign-born Latino elders receiving non-integrated and non-comprehensive medical care in private practice or community-based

clinics and hospitals. As members of GraciaMed's PACE program, they must have a certain level of independence that needs to be actively displayed if they are to be successful members of this health plan. If members are too dependent on family for decision-making they may struggle voicing concerns and engaging medical staff in a meaningful and helpful way and, therefore, will not benefit from all the program has to offer. Therefore, family involvement may not be accurately represented as it is often characterized in the "real world." There is probably more family involvement in the "real world" than what is represented in GraciaMed. However, participants were able to relay retrospective information that allowed for the analysis of family involvement with the current definition of medical encounter expanding to engagement, delivery of services and follow-up, irrespective of the type of medical plan.

5.4 Chapter Summary

Multiple factors, including cultural beliefs and values, were often the driving forces altering the levels of patients' receptivity to engage in medical decision-making. In this chapter, a description of how Latino elders reported engaging medical encounters within the healthcare system was provided. The discussion continued with an explanation of aspects contributing to family involvement, which can positively or negatively impact a patient's medical decision-making process. Lastly, a major modifying factor in any kind of medical encounter and ultimately decision-making was the patient-professional relationships. The patients' values and beliefs were explained around issues of trust, communication and silence.

A key issue observed across all the modifying factors is the issue of relationship with others. Foreign-born Latino elders interacted with people within the healthcare system using technical, social and emotional methods of engaging. These three types of engagement modified

the overall patterns of patients' receptivity and influenced the patients' medical decision-making process. Foreign-born Latino elders were more likely to engage others in social and emotional modes of communication and were more prone to relationship development outside of the professional realm. The strength and quality of these relationships had the power to influence levels of receptivity for future medical encounter interactions that ultimately influenced patients' overall medical decision-making process.

On a similar note, the values of family and family involvement are key modifying factors to patients' decision-making. The quality and intensity of family relationships were often the drivers in their involvement with patients' medical decisions. The influence was more likely felt when the patients were within the realm of the cautiously skeptical and cautiously optimistic compared to those who fell within the extreme end of receptivity.

Lastly is the development process of the patient-clinician relationship, which has the utmost influential power to modify patients' levels of receptivity. Medical encounters house dynamic components of the patient-professional interaction, such as issues of power dynamics, communication, types of engagement and typical decision-making. Table 5.2 serves to organize the reported qualitative associations between the concepts presented in the chapter. As the patient and provider move down the table their level of relationship strengthens.

Table 5.2: Dynamic Components of Patients' Medical Encounters					
Power Directionality	Communication	Type of Engagement	Decision-Making	Pt-Provider Relationship Level	Primary Practicing Locale
Clinician	Superficial	Technical predominates	Physician	<i>El buen doctor</i>	United States
Clinician/Allied Health Professionals > Patient	Fact	Technical predominates	Physician	<i>El buen doctor</i>	United States
50-50	Thought	Social/Emotional	Both	<i>Persona de Confianza</i>	Home country
Patient > Physician/Allied Health Professionals	Genuine communication	Social/Emotional	Mostly pt	Advocate	Home country
*usual not always, in GraciaMed saw all four					

The levels of communication mirror those of the types of engagement (Table 5.2). At the superficial level, people engage each other to discuss facts, similar to the technical engagement. A slightly higher level of communication is when people talk about what they think about the facts, similar to the social engagement. Lastly, a slightly more intimate/deeper level of communication is when people talk about how they feel about the facts, similar to emotional engagement. The levels of communication parallel the types of engagement. As the levels of communication grow deeper and more intimate, the power dynamics described between the professionals and patients are balanced. In sum, relationship, communication and trust are key factors for foreign-born Latino elders to experience positive medical care that influences medical decision-making.

CHAPTER 6.0: FINDINGS - CULTURAL CONCEPTS OF ILLNESS AND MEDICAL DECISION-MAKING

The majority of patients held to traditional views of health, as often cited in the Latino health literature. Foreign-born Latino elders believed in traditional culturally-related concepts associated with the idea of balance, such as *impresiones* (fright-like emotions within negative contexts), hot-cold therapies often referred to in *remedios caseros* (home remedies) and astrology-related concepts of moon shapes as associated with pain. However, the decisions for treating such conditions were not exclusively traditional folk remedies. Immigrant elders held on to traditional non-biomedical ideas and yet still believed in biomedical solutions. Although there were nuances of these cultural ideas presented, all of them fit an overarching theme of maintaining the human body in a state of balance and harmony, which was not in direct opposition to biomedicine. Biomedicine and traditional remedies often functioned to complement each other (Table 6.1).

In this chapter, I demonstrate how foreign-born Latino elders cultural concepts of illness influence medical decision-making by describing disease causation agents as depicted by the patients, the introduction of new treatment ideas, and ending with a description of the interface between cultural concepts of illness and the use of biomedical health services, including the treatments of disease by a suggested order of intervention importance: *remedios caseros* (home remedies), biomedicine, and alternative treatments.

Table 6.1: Themes and Categories about the Relationship between Patients’ Cultural Concepts and Perceptions of Illness and Medical Decision-Making (Chapter 6: Aim 2)

Overarching Domain: The belief that human body is in existence in a state of balance and harmony with the cosmos. A negative impact “shock” to the body places the body in a state of vulnerability and increases the probability of disease development. Therefore, a vulnerable state (e.g., intense shock – emotional or physical) requires recuperation time to normalize and return the body to a state of harmony and balance.

Themes	Categories	Sub-categories
Body in a state of balance and harmony	Body in natural state	Natural treatments (medical preference to limit biomedical intervention); Positive feelings associated with management of chronic conditions without use of medications
		Biomedical treatment intrusive, but for momentarily use only
		Wear and tear of human body natural cycle of life
	Body in state of balance	Adaptation to life stressors
		Hot-cold treatment
		Treatment sought to normalize unbalance body
Self in Relation to Universe: Body is holistic entity (mind/body interconnected) with self and environment	Cosmos affect the individual (emotion and physiology)	Negative emotions resulting from moon (e.g., anger during a full moon)
		Extreme weather affecting human health and pain (e.g., pain exacerbated)
		Moon influencing pain levels
		Faith produces hope
	Strong emotions affect physiology	Anger disrupts human system fears elevates and changes things
		Positive emotions produce healing effects (e.g. hope);
		Combination of stress-related emotions from an event such as lack of sleep, anger, injustices, sudden shocks and negative impressions (<i>las malas impresiones</i> especially for diabetes)
	Social ills have negative and cumulative effect on human being	Negative impact on body causes ill-health (e.g., depression, anxiety)

A caveat of such findings has to be mentioned. The findings include “cultural beliefs” that can often be viewed as an oversimplification. Latinos are not monolithic and represent a heterogeneous mix of subgroups with a rich heritage originating from diverse regions of Mexico, Puerto Rico, Cuba and Central America. Variability in beliefs exists among members of the same culture (see Baer, 2003 for a cross-cultural study on a cultural concept); therefore, it is misleading to condense such variability into commonly expressed ideas and deem it a “cultural norm.” Such logic, in fact, perpetuates stereotypes and inequalities in the delivery of healthcare and policy-making. Using such ideas misrepresents the culture as “backwards” and can provide ammunition to people with decisional power (e.g., politicians, physicians) by putting the onus of the problem on the patient⁹⁹ for their inability to “accurately” identify the biomedical view of their health problem and apply the recommended biomedical treatments; rather, people with decisional power may consider looking at societal problems as created by members of society and their sociological systems. Thus, while I will explain several commonly held culturally-related concepts of illnesses as described by my immigrant respondents, the findings are not to be generalized to other foreign-born Latino elders.

6.1 Cultural Culprits of Disease

In this section, I will describe the most commonly described cultural concepts of illness within my sample, “*la impresión*” (fright-like emotion) as a cause of diabetes; extreme weather, moon shapes as associated with joint-related conditions and pain; “*descuidos*” (neglect) for

⁹⁹ The DSM-5 acknowledges cultural concepts of distress and outlines various ways of coping, but fails to put the onus on the broken systems. In the DSM-5, several codes such as “acculturation difficulty” code V62.4 (Z60.3) are listed under “other problems related to social environment.” Similarly, other codes under housing and economic problems, such as homelessness code v60.0 (Z59.0), extreme poverty code v60.2 (Z59.5), and low income code v60.2 (Z59.6).

multiple chronic conditions; and “*nervios*” (nerves) a much more complicated culturally-informed condition often associated with anxiety and depression.

6.1.1 “*La impresión*” Fright-like Emotion

In the psychiatric literature *susto* is defined as a “culture bound syndrome” whose literal translation is “fright.” Latino groups and individuals from Mexico, Central America and South America have described *susto* as a sudden and “frightful” event causing “soul loss,” such loss resulting in physiological symptoms’, and vulnerability to physical and mental illnesses, and in extreme cases, death (APA, 2000; Poss & Jezewski, 2002; Weller et al., 2002; Cabassa, 2007).

All of the participants who developed diabetes and complications described a sudden and negatively impactful event as the initial cause of disease. All participants, with the exception of one, did not utter the word *susto* but rather used fright-like terminology to describe the impact of a sudden unexpected unwelcomed event that was negatively perceived. The original works/literature on *susto* has “soul loss” as a key element that incorporates a spiritual realm. *Impresiones* (fright-like emotions) share concepts associated with fright components in that people were scared around a sudden an impactful event; however, the spiritual component of losing one’s soul, thereby increasing the probability of death and seeking out spiritual intervention, is void in these descriptions. There is a conceptual distinction between “*el estar asustada/o*”¹⁰⁰ (being in a state of fear) and having a “negative impression.” They are overlapping concepts but the treatment requirements, although nuanced, differ. *El estar asustado* is what most of the traditional literature around *susto* is often referring to when outside spiritual intervention is needed. However, the patients used fright-like terminology that is being referred

¹⁰⁰ It is like the difference between “being startled” versus “being scared to death as in a traumatic event.” Scared to death hits deep in your soul needing outside mental health and spiritual intervention (e.g., therapist, church fellowship, and the like) and being startled you just need a few minutes to recuperate.

here as *impresiones negativas* (fright-like emotion) occurring within a sudden and negatively impactful event to showcase that diabetes and other medical conditions can have lay theories of disease causation, which indirectly influence medical decision-making.

All respondents in my sample managing diabetes described *impresiones negativas* (fright-like emotions) as the culprit of diabetes development. *Una impresion* (an impression) was a sudden, unexpected, unwelcomed and shocking event that was negatively perceived and was either emotionally or physically taxing on the body. All of the people who had diabetes called it *azucar* (sugar), and they all attributed some form of *impresion* as initiating the development of the disease. *La impresion* was identified at a specific point in time where they recalled in meticulous detail how they felt their body reacting as a result of the frightening event. All described it as a “sudden” negative impact to their being. They emphasized the impact of such an event in their lives by their retelling the impactful historical events that shaped their current state of being. During our first interview, Maria recounted the time she was diagnosed with diabetes due to a frightful car wreck.

6.1.1a: Car Accident Fright Led to Diabetes

One time we were heading to the airport to pick up a person. The man that did me the favor took us in his car... I remember he only said hold on...suddenly he crashed with another car on the freeway. Because he suddenly reduced his speed, he was unable to stop...the thing was that since that moment I felt neck and back pain....they took me to a general hospital...I remember that is where they told me I had diabetes... I think *susto* caused [diabetes] and family history, right? (Translated from Spanish).¹⁰¹

By our second interview, a negative impression/frightful event caused Maria’s diabetes to go out of control. She was having a hard time managing her sugar levels. It had been just a couple of months earlier that her health was in superb condition. She was only taking diabetic

¹⁰¹ “Mire...una vez íbamos... al aeropuerto a recoger a una persona y resulta que el señor que me hizo el favor de llevarnos en su carro...me acuerdo que solo dijo agárrense...y **de repente** choco con un carro en el freeway. Él dice que como que disminuyo de repente la velocidad y ya no se pudo detener...la cosa es que de ahí yo sentía dolor en la nuca, en la espalda...y me llevaron al hospital general...y me acuerdo que ahí me dijeron que si tenía diabetes...**susto** me causo pienso yo [la diabetes] y la herencia de la familia, ¿verdad?” -am1t1

pills but was not on insulin. When asked what caused such uncontrollable situation she tells of a story of an older gentleman she only knew by sight that attended the same medical center. He was also a diabetic. She often saw him wearing sandals, dancing and having a good time. This one time, she saw him but he was sitting in a wheelchair with his leg amputated. Maria immediately felt sick and her sugar numbers started to climb. She was taken to the doctor's office who then explained to her that she would need to start taking insulin to manage her sugar levels because her pancreas was no longer functioning. Against her preference to not take insulin treatment, she agreed (6.1.1b).

Excerpt 6.1.1b: Negative Impression Causes Uncontrollable Diabetic Complications
Listen I think...I don't know very well...there was a man in the center that had his leg amputated due to diabetes. It negatively impressed me seeing him suddenly like that...I was heading [to the center] perfectly well. A short time after seeing him I placed my head on the table then an assistant from there asked me what was wrong with me, did I feel bad and I told her yes I feel bad. She took my blood pressure and it was at 470, and the sugar was at 460. Then they took me to the clinic and they checked my pressure and everything again. Since then I am like this...that is when they started to give me insulin. That is why the doctor told me that the pancreas was no longer working; it does not produce insulin...they are injecting me. With that I have been slowly improving. Insulin is helping me (Translated from Spanish).¹⁰²

In another example, Francisco explains he developed diabetes the moment he was told of his prostate cancer diagnosis. "That impression provoked my blood sugar to rise!" (Translated from Spanish).¹⁰³ He took it as a death sentence and was overcome with fear. During the course of the three interviews, he retells the same story every single time, and in all three interviews, he

¹⁰² "Pues fíjese que yo pienso... no sé muy bien... había un señor ahí en el centro que le habían amputado la pierna por la diabetes. Entonces **me impresiono verlo de repente así**...yo iba [al centro] perfectamente bien. Y al poco tiempo de verlo me agache sobre la mesa entonces llego a la clínica y ya me preguntan que qué me pasaba, que si me sentía mal y yo le dije si me siento mal. Y me tomo la presión y la tenía en 470. Y el azúcar en 460. Entonces me llevaron a la clínica y ya me chequearon otra vez la presión y todo. **Desde entonces estoy así...es cuando me empezaron a poner la insulina.** Por eso la doctora me dijo que el páncreas no me funciona ya, ya no me produce insulina...ya me están inyectando. Ya con eso poco a poco me he ido mejorando. La insulina me está ayudando." -am1t2

¹⁰³ "¡Esa impresión fue que me provoco la subida de la azúcar!" – am4

reported that the fear of having received such sudden news was the reason for him developing diabetes along with many other chronic conditions (e.g., high blood pressure, stroke, heart attack and the like).

Excerpt 6.1.1c: Bad Impression Sweetened my Blood

It was a bad impression for me, and from that my blood sugar sweetened. I developed diabetes because I was told I had cancer and immediately I felt like a bucket of cold water had been poured over me. From that moment onward I developed diabetes. My body was unable to withstand such sudden bad news like that (Translated from Spanish).¹⁰⁴

All of these people attributed developing diabetes to a sudden, unexpected and often unwelcomed event that created a negative impression on their body.

La impresión (fright-like emotion) as the culprit to developing diabetes was not only experienced during the medical encounter as illustrated in the previous examples. Carlos, for instance, lived under a highly stressful situation for many years until he felt that one frightful incident, outside of the medical encounter, was the one that led him to develop diabetes. However, he did not receive immediate confirmation of his suspicions as the previous patients had during their medial encounters.

Excerpt 6.1.1d: Innocently Thrown in Jail

There came a time when she called the police on me because I had allegedly done I don't know what ill thing that was not even true, I was innocent. They arrested me. They took me up to the administrative offices/head district to book me that is where I felt (Translated from Spanish).¹⁰⁵

The event from where this excerpt was taken will be presented below.

Thus far, *la impresión* has been described by the patients as an event in time (e.g., car crash, cancer diagnosis, innocently held in jail), which was often perceived to lead to health

¹⁰⁴ “Se me desarrollo diabetes porque me dieron las noticias del cáncer y luego luegoito sentí como si me hubieran echado una cubeta de agua fría encima. **Y de allí para acá** empecé con la diabetes. Mi cuerpo no pudo soportar digamos a **una mala noticia así tan de repente**, pues.” –am4t2

¹⁰⁵ “llego el momento que **me hecho la judicial** porque según yo le había hecho no sé qué travesuras o cosas que ni siquiera, yo inocente. Óigalo bien que me agarro la judicial y me detuvo. Me llevo hasta la cabecera del distrito y **ahí sentí yo.**” – am12t2

problems. However, in the following examples I will present how *la impresion* can often be the “culminating event” of a long string of acute, chronic, and cumulative stresses. The benefit of having conducted longitudinal interviews was they allowed me to gain a deeper understanding of the most impactful stories of an individual’s life (usually compounded with crisis-based decisions). I, repeatedly learned nuances of the story by asking follow-up questions and, therefore, gained a clearer picture. By asking background information about the event, I was able to determine the context of the circumstances and identify concurrently developing events and surrounding issues around the event that caused *la impresion* (the impression) that led many participants to sugar-up their blood. “That [event] was when my blood turned sweet” (Translated from Spanish).¹⁰⁶ The patients described the “event,” but always in combination with other stressful events of their life with which they were coping (e.g., death of loved ones, migrating to the United States, work-related abuses and mistreatments). They reported being in altered states of high-stress from a series of negative life stressors. From my perspective, it seemed that the event was often a culminating point in the body from all of their anxieties and stresses—their bodies’ breaking point. Their body was already in a heightened state, and this “event” was the one thing that broke the camel’s back and when they felt that a physiological response had occurred in their bodies (e.g., one felt like a bucket of cold water had been poured on him, the other felt as if the blood rushed to the bottom of her feet).

Most of the patients understood that psychological distress and other physical stressors can negatively affect the human body. They all spoke about how these life events impacted their health. Their health was influenced by their emotions, their knowledge, lived experiences and surroundings. The effects of life experiences became even more sensitive and harder to control when managing complicated conditions such as diabetes. Francisco, a gentleman managing

¹⁰⁶ “*Ese fue cuando se me endulzo la sangre*” –am4

diabetes, referenced the idea of the body functioning as a system where organs impact one another, “When one is diabetic, with any little thing that anybody tells us, our whole system becomes uncontrolled” (translated from Spanish).¹⁰⁷ During his first interview, Francisco explained that his stressful work experiences sent him to the hospital. He claimed that his employer’s mistreatment and abuse was to blame for his ill-health. The gentleman was already under a lot of stress, and his employer did not allow him to properly recuperate from his operation; in fact, he did the opposite and added physical pressure while sprinkling in verbal abuse. In a later interview, Francisco recounted the same story with more details.

Excerpt 6.2b: *La impresión* a Culminating Event

Once the [new supervisor] entered, No [emphasis]...everyday he would say, ‘where are those fifteen years you have working here if you don’t know anything.’...Everything about me he disliked [I felt attacked]. I developed diabetes because I was given the news of cancer, and immediately I felt as if they had poured a bucket of cold water on me. From that point forward I started with diabetes...it was all during that same time period. When I had surgery, I was already diabetic...Yeah....And then to f*[bleep] finish it off... my father had just passed away. I was really stressed, very depressed and the manager didn’t care because he told me, ‘I do not care if you are sick or that you end up dying here I still have to order you around.’ Yeah. And then soon after in 2011 my mother passed, right? More to handle, right? I was very depressed until in 2011 [the manager] almost wanted to hit me and my sugar levels, cholesterol, and blood pressure started rising and he sent me to the hospital. Yeah. Well I lost my job in 2011 December...I told the doctor I was unable to work because I also suffered an accident and I didn’t report it. My shoulder tendon ripped and I didn’t report it. And then I developed a hernia on my neck, right? I couldn’t handle it (Translated from Spanish).¹⁰⁸

¹⁰⁷ “cuando uno está diabético con cualquier cosa que le digan a uno se le descontrola a uno **totilito el sistema.**” am4t1

¹⁰⁸ “Desde que entro él para acá. No [énfasis]... todos los días diario “donde están los quince años que tienes trabajando aquí si no sabes hacer nada...Cualquier cosita le caía mal de mí. [Me sentí atacado]. Se me desarrollo diabetes porque me dieron las noticias del cáncer y luego luegoito sentí como si me hubieran echado una cubeta de agua fría encima. Y de allí para acá empecé con la diabetes...en ese mismo tiempo fue. Ya cuando fui a la cirugía ya estaba yo diabético. Yeah....Y luego para acabarla de...se acababa de morir mi papa también. **Andaba yo muy estresado, muy deprimido** y pues el manager no le interesaba porque él me dijo “a mí no me importa que estés enfermo dice o que te mueras aquí yo de todas maneras yo tengo que mandarte. Yeah. Y luego después enseguida en el 2011 murió mi mama ¿verdad? Y más todavía. Y **andaba yo bien deprimido** hasta que en el 2011 ya casi él me quería pegar y me empezó a subir la azúcar, y el colesterol, y la presión y al hospital me mando. Yeah....Si pues perdí mi trabajo en el 2011 ya para Diciembre. Yeah. Ya para Diciembre deje yo el trabajo. Ya porque le dije al doctor. Pues yo no podía trabajar porque yo sufrí un accidente y no lo reporte. Se me rompió un tendón del hombro y este no lo reporte. Y luego me salió una hernia en mi cuello ¿verdad? **Y ya no aguantaba yo.**” – am4t2

When Francisco retold the entire story, one is able to see that he was coping with multiple negative events, and he had no buffering positive support (e.g., family, friends, relationships, church and the like). The implication is that he was succumbing to the ill-treatment that, in addition to the other events in his life, had a culminating impact on his body that pushed his limits until one day the manager's treatment landed him in the hospital.

There was this idea that a stressor(s) had the potential to be stored in the body and begin to accumulate until the one event causing a large impactful shock to their bodies (*la impresión*) made their bodies "break." Similar to Francisco, Carlos discussed how the physical environment he lived in affected his physical, mental and emotional states of being, but understood that the social environment has the power to impact a person's health. Carlos talked about how a highly stressful situation affected his health. He talked about noise pollution, injustice (power struggle with authorities being behind this event), sleep deprivation, and his uphill battle of over 20 years that resulted in an accumulation of stress culminating in the event of being innocently thrown into jail. This event was *la impresión* (the fright-like impression) that caused him to develop diabetes.

Excerpt 6.2b: Physical Environment Affects Well-Being

Close to where we live there is a cabaret with loud noises that did not ever let us sleep. I would call the head of regulation, and he would go...only for that brief period that he was there the sounds would be lowered, and as soon as he left the volume would increase. It was like that all the time. There was never an authority to stop the problem, and we were close. We shared a wall. And so much reporting that lady, one time she called the police on me because I had allegedly done I don't know what ill thing that was not even true, I was innocent. They arrested me. They took me up to the administrative offices/head district to book me that is where I felt...like I have never in my life have been involved in that kind of trouble, and they threw me in jail. Because some people came to my aid, they released me after a while for lack of merit, but I always felt that was when my health problems started...that was the beginning where I felt I had finished myself, almost 20 years tolerating that situation (Translated from Spanish).¹⁰⁹

¹⁰⁹ "Mire, yo ahí...yo lo que creo que de ahí me empezó porque ahí cerquitas de donde ahí nosotros vivimos hay un cabaret que un sonidazo **que no dejaba dormir** a uno para nada...habíamos unos...le hablaba yo por teléfono al

La Impresión and Diabetic Treatments

The patients came into the doctor's office with the idea that an external "culminating" event had taken place, and for symptomatic individuals, it was now impacting how their bodies functioned. Although the cause and culprit were external to self (e.g., spiritual, social ill, etc.), the solution to normalize the body was now biomedical. In certain conditions, like cancer, the clinician is able to explain a condition using a biomedical ideology that agrees with the patients' existing cultural paradigm of removing a foreign agent (e.g., bug, oncogenes, rotten flesh and the like) acting to oppose the normalization of the body. However, with *la impresion*, clinicians are unable to explain the cause of diabetes in a way that would not contradict patients' explanatory model. Biomedicine does not have a treatment option for removing *la impresion*, since there is no physical agent to get rid of. However, the biomedical treatment regimen for the consequences of *la impresion* concurred with patients' cultural paradigm. Patients were often willing to follow treatment regimens as prescribed by their clinicians. The newly emerging idea that the impact of the external source caused the body to react by overproducing, under producing or stop working altogether agreed with the physical consequences thought to occur with an *una impresion*, which caused patients' sugar to sweeten. Biomedicine introduced the idea of "sweet blood." Patients' often felt a physiological response, which suggested a physiological change. However, to attribute such a response to the idea that their blood was being sweetened would not emerge had

jefe de reglamento e iba...nomas en lo que estaba ahí se le bajaba y ya nomás se iba él y otra vez...bueno, así todo el tiempo. Nunca hubo una autoridad que pararan ese problema y ahí cerquititas. Cerquitas ahí rallábamos las cercas ahí pegaditas. Y de ahí de ahí y tanto denunciar a esa señora de que no le bajaba y que eso...bueno, llego el momento que me hecho la judicial porque según yo le había hecho no sé qué travesuras o cosas que ni siquiera, yo inocente. Óigalo bien que me agarro la judicial y me detuvo. Me llevo hasta la cabecera del distrito y ahí sentí yo de que...como yo nunca en mi vida pues he andado en eso y no me metieron a la cárcel porque hubo personas que fueron luego luego y me tuvieron detenido ahí un rato y ya me dejaron libre por falta de medito, pero siempre yo sentí de que ahí empezó lo mío, el problema...Eso fue el principio donde ya sentí yo donde me acabe yo casi en eso...Veinte años tolerando esa situación.”-am12t2

somebody not introduced the idea. Patients reported being informed by their clinicians as having elevated sugar in their blood, a biomedically accurate description that agrees with the patients' paradigm for treatment. Treatment had to make sense with the patients' current paradigm; otherwise, it was likely to be rejected.

6.1.2 *Extreme Weather and Moon Shapes*

The ideas associated with weather and moon shapes goes back to the notion of balance and harmony. For a human body to be healthy, it needs to be balanced between a hot and cold state. There are ideas that the weather, in its coldest and hottest forms, affects a person's well-being. The body's equilibrium is disturbed and illness can result. In the coldest weather, the body can develop arthritis, osteoporosis and other joint-related conditions that are exacerbated with pain (6.1.2b). As Bertha indicates, "Body aches and pain are felt the strongest during cold weather" (translated from Spanish).¹¹⁰ During any extreme weather pattern, the body can enter into a cold or hot state and treatment options are chosen aimed to reestablish the body's balance and harmony. The best climate for a person to live in is in moderate temperatures.

Similar to the idea of balance as it applies to weather are the beliefs of moon shapes. There are beliefs that the moon's shape influences individuals' behaviors and is associated with joint-related and bone pains. The ideal moon shape is a crescent one because it represents balance. Neither a full moon, nor one that is barely showing *tiernita* (tender) are favorable shapes for the effects it has on the body. A full moon is believed to negatively affect a person's emotions, while a tender moon is associated with stronger joint pains.

¹¹⁰ "el tiempo de fríos es cuando le viene a uno [los dolores]"-am6t2

Excerpt 6.1.2a: With the cold, when it rains, and when the moon is tender
When it rains! Do you know when it hurts one? The body hurts when the moon is tender
and when the moon is small. The new moon is when the body and the joints hurt. Once
that passes the aches are less, eh? (Translated from Spanish).¹¹¹

Frida makes similar claims as Bertha in terms of the weather. She says, “The weather did
not sit well with me” (Translated from Spanish).¹¹² Her daughter lives in Missouri, and prior to
receiving care at GraciaMed, she tried to relocate to be with her. However, Frida had to make a
decision to relocate to warmer settings for her well-being.

Excerpt 6.1.2b: My Body Disliked the Weather

I had never been sick. When I came here to the center it was because I got sick with
osteoporosis, arthritis, and a lot of cold [from being in Missouri]. The climate did not sit
well with me because I was always sick. My brother then told me, ‘why you don’t come
to Los Angeles the climate here is like the one in our home country.’ I am from
Ecuador...we always have warm weather (Translated from Spanish).¹¹³

Frida describes her body not being used to the cold temperatures she experienced in the Midwest,
and therefore her body reacted against it. In her attempts to normalize her body she decided to
move as a way to *descongelar* (defrost), a way to normalize her body back to a state of balance.

Beatriz adds to the perceived association between the moon and emotion

Excerpt 6.1.2c: They are Carrying the Moon

They say that the moon has a lot to do with the person. Don’t you see that when a person
is mad they tell them ‘you have the moon’ right? They are carrying the moon because
they are angry, right? (Translated from Spanish).¹¹⁴

¹¹¹ “¡Cuando llueve! ¿Sabe cuándo le duele a uno? Cuando esta la luna tiernita es cuando le duele a uno el cuerpo. Cuando esta la luna recién. La chiquita. La que se ve así chiquita. La luna nueva es cuando le duele a uno el cuerpo...las coyunturas...Y ya pasa eso y ya son menos las dolencias ¿eh?” –am6t1

¹¹² “No me sentó el clima” -” –am23t2/3p2

¹¹³ “En Missouri... yo nunca he sido enferma. Entonces cuando vine aquí al centro fue que [en Missouri] me enfermé con osteoporosis, artritis, mucho frío. **No me sentó el clima porque siempre estaba enferma.** Entonces mi hermano fue que me dijo porque no te vienes acá a Los Ángeles. Es más, porque él dice que el clima es como el de nuestro país. Yo soy de Ecuador...nosotros siempre hemos tenido clima cálido” –am23t2/3p2

¹¹⁴ “¡Ya trae la luna!” “Dicen que tiene que ver la luna con la persona. No ve que cuando uno anda enojado le dicen ‘ya trae la luna’ ¿verdad? Ya trae la luna porque anda enojada ¿verdad?” – am6t1

6.1.3 “Descuidos” (Neglects)

Negligence is the voluntary omission to the tasks involved in taking care of the human body. Carlos best describes negligence as “the consequences that come about when one not taking care of ourselves the way it should be” (translated from Spanish).¹¹⁵ The patients who mentioned issues of disease developing due to negligence are taking personal responsibility for their carelessness in not taking care of the tasks that would ensure their human bodies do not develop illness.

Catarina mentions that she does not know why she developed cataracts. She rationalizes the development of her disease originating from a potential *descuido* (neglect), something she failed to do for her eyes. She somehow misused her eyes either by overworking, not protecting them or some other way unknown to her.

Excerpt 6.1.3a: Disease Develops Due to Neglect

Cataracts began like a cloud something that is growing like that. I don’t know why it happens; it must be due to some kind of neglect. When the [doctors] detect it, they are seeing that it is growing and they are trying to avoid a more serious problem later, right? (Translated from Spanish).¹¹⁶

Similar to the idea of maintaining the body in balance and equilibrium, a body is meant to work but not overwork. It is meant to rest but not overly rest. However, if the body fails to obtain the proper respite or receive the proper medication meant to normalize the body and return it to a state of balance and harmony, the body can rebel. Carlos continues to speak about the consequences of negligence in taking prescribed medications.

¹¹⁵ “Las consecuencias de que uno no se atiende como debe ser” -am12t2

¹¹⁶ “Empecé las cataratas como una nube una cosa que se le va creciendo así. No sé porque **sea por algún descuido**, pero ya cuando la detectan los médicos ya van viendo que va creciendo y que va para evitar el evitar el problema más serio después ¿verdad?” – am2t1

Excerpt 6.1.3b: Sheer Neglect

Yes, those are the consequences from one not taking care of oneself the way it should be. I mean that one is taking care of oneself and the medicine you do not take due neglect. The doctors do give...they have enough medicine it's not an issue that they didn't give us medicine today, that we needed, that...no nothing. All the time we have enough medicine. If one does not take it is because we have obviously/blatantly neglected ourselves but the medicine has always been available.... all the time (Translated from Spanish).¹¹⁷

Carlos places the blame for not ensuring his body is being cared for the way it should be on his medication-taking compliance. However, sometimes what was construed as negligence by others could have been due to the way people perceived their illnesses. For instance, Maria, an asymptomatic patient who was unaware of her condition would not seek care, irrespective of doctors' recommendations (excerpt 6.2.2.2 a) due to her perception that there was nothing wrong with her. Similarly, Beatriz did not perceive her depression as a problem resulting from chemical imbalances in her brain and refused to comply and take prescribed medications. Elena did not perceive her chronic pain as a medical condition that could be healed but rather as part of the normal aging process.

6.1.4 “Ataque de Nervios” (Attack of Nerves)

Ataque de nervios has been discussed in mental health and anthropology literatures for over 50 years (Guarnaccia, 1993). Similar to *la impresión*, there are nuanced culturally-related conceptualizations of *nervios* that inform how people make decisions on how to treat it. Studies have described it as a “culturally sanctioned response to acute stressful experiences... characterized by a number of symptoms, including trembling, heart palpitations, a sense of heat

¹¹⁷ “Si, esas son las consecuencias de que uno no se atiende como debe ser. Ósea que se esté uno atendiendo y la medicina **no se la tome usted por un descuido**. Porque los médicos también dan...nos tienen la medicina suficiente no es cosa de que o no me dieron la medicina hoy, que me faltó, que...no, nada. Todo el tiempo tenemos medicina suficiente. Si uno no se la toma es porque de plano se ha uno descuidado, pero si la medicina no nos falta a nosotros...todo el tiempo.”-am12t2

in the chest rising into the head, faintness, and seizure-like episodes” (Guarnaccia, 1993, p. 158). The attack has a similar presentation to that of a panic attack, but is arguably a distinctive diagnosis according to the DSM-IV.

The patients often spoke about those life events that had been historically significant and impactful in their lives. Frida, when asked how she was managing her conditions, responded by telling me of a story of a recent medical experience when she was referred to a heart specialist. She was referred to a heart specialist because her heart rate was too low, but she did not know what the specialist was going to do, and she was nervous and scared. She describes a severe physiological response that she referred to as *ataque de nervios* that was interfering with the medical procedure. Stories such as these are hard to come by in a cross-sectional interview because they are often forgotten as unimportant since the outcome was a positive one. In her story, I was able to capture an event where an attack *nervios* occurred immediately before undergoing a medical procedure.

Excerpt 6.1.4a: The nerves! The nerves are attacking me! (Translated from Spanish).¹¹⁸ *Nervios* is such a common condition that many individuals and family members tend to self-diagnose. For instance, Bertha self-diagnosed herself with *nervios*, and was taking medication that was purchased out of the country. She attributed her condition from the stressors of living with a husband who liked to drink alcohol.

Excerpt 6.1.4b: Social Ill Causes Nerves
[For] the nerves...I used to take this [medicine] that is sold in Mexicali...[laugh]. It was the nerves because I had a husband who drank a lot. How was I not going to be nervous? (Translated from Spanish).¹¹⁹

¹¹⁸ “¡Los nervios ya me atacaron los nervios!” -am23t2t3p2

¹¹⁹ “[Para] los nervios...tomaba de esta [medicina] que venden en Mexicali... [laugh] Era el nervio porque tenía el esposo bien tomador como no iba a estar nerviosa.” -am6t1

Nervios is not often a topic broached by Latino men; it is more commonly expressed by women. However, the topic was briefly addressed by some men under other contexts. Juan, for instance, was fighting depression. His psychologist ordered him to exercise, but not too strenuously as he suffers from severe heart-related conditions. He talks about his strategy for exercising and in turn expresses an incident that scared him and affected his nerves.

Excerpt 6.1.4c: Heart Explodes and My Nerves Are Triggered

They instructed me to stop [exercising] when I start to sweat because [it's a sign] my heart is struggling to get oxygen to my brain. I have kept that control like that. The psychologist ordered me to 'take it easy like! [Do what] I am telling you and you will see we are going to be at peace', she says 'because you have taken some crazy uncontrollable situations.' I tell her, 'not me.' Only that I got more scared of a man. I never thought that the heart thundered when it explodes. Let me tell you about a gentleman from [name of city], [his heart] exploded inside. His body turned completely purple from the [internal] bloodshed. [The heart] exploded! He had too much pressure. The blood pressure was too high and it exploded. I say that this is when **I had the nerves** (Translated from Spanish).¹²⁰

6.2 *The Interface between Cultural Concepts of Illness and Biomedicine*

Cultural concepts of illness and biomedical concepts are based on different value systems. Cultural concepts of illness often value subjective, anecdotal and personal experience, while biomedicine values scientific objectivity and gains traction from empirical evidence. Given such opposing value systems, one may logically perceive that treatment options provided by either camp would contradict one another. However, my participants often described how they supplemented the biomedical regimen prescribed by their practitioners with *remedios caseros* (homeopathic and/or home remedies) and other forms of alternative medicine. Armed with

¹²⁰ “me encargaron que cuando empiece a sudar... Que pare. Porque el corazón se está forzando de más para agarrar oxígeno al cerebro ... Y he llevado ese control así. Es lo que me ha encargado la psicóloga “llévase, así como le digo y vera vamos a estar tranquilos” dice. Porque veces se me ha dado unas descontroladas tremendas. “Yo no” le digo “Únicamente que este. **Me asuste más yo de un señor** yo nunca creía que el corazón tronada reventaba. Y fíjese a un señor de aquí de [nombre de ciudad] le exploto por dentro. Y se le puso todo el cuerpo morado completamente. Toda la sangre se le rego. ¡Le exploto! Tenía mucha presión todo así. Eso ¿eh? La presión muy alta y le exploto. **Y digo allí donde traía los nervios.**” – am24t1

information from their practitioners, the participants worked towards normalizing the body to a state of balance and harmony.

In this section, I describe the shared boundaries between cultural concepts of illness and the use of biomedical health services and explain how these beliefs rely on the idea of maintaining the body in a state of balance. I do this by first introducing the patients' competing beliefs between the power of science to cure and the cultural belief of maintaining the human body in its natural form, away from external manipulations and the perceptions of disease. The discussion continues with an explanation of how these competing beliefs influence participants' medical decisions for using home remedies, biomedical and alternative therapies for managing multiple asymptomatic and symptomatic chronic conditions, attempting to return the body to a state of balance.

6.2.1 *Competing Beliefs*

A pendulum seems to be swinging between two values: the belief in the power of modern science to cure and the importance of maintaining the human body in its most natural form. The latter results from the belief that the human body never fully recovers to its natural state once it has succumbed to invasive medical interventions (e.g., surgery) and aging beliefs.

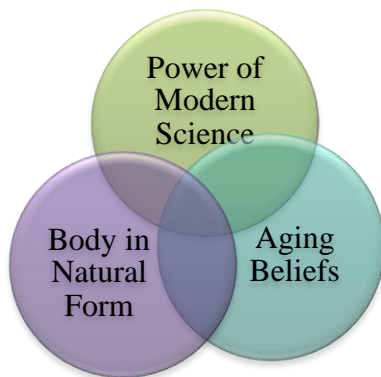


Figure 6.1: Treatment Competing Beliefs

Power of Modern Science: Patients had a strong faith in medical science. The rationale for not rejecting biomedical treatments was the idea that biomedicine is faster, stronger and more effective at curing illness than home remedies because “science is more powerful” (translated from Spanish)¹²¹ than homeopathic treatments.

Excerpt 6.2.1a: Science is more Powerful!

One trusts in scientific medicine...there are things that science cannot do, where can we go? Well what can we do? To my way of thinking I think [science is more powerful]. Look, there are things that science cannot do nothing for, Tell me! What can we do? (Translated from Spanish).¹²²

Carlos’ faith in science was associated with his prior social and economic experiences. In general, more affluent people have more resources and opportunities to experience higher quality services and care. Less affluent people do not often have the same level of choices for services and medical care. The idea that the same resource being purchased by the affluent is of higher quality than what the poor often have available sometimes influenced the patients’ decision to follow recommended medical treatments that in their home country would have been for the rich only. In the United States, the fact that they are receiving expensive medical care was valued and much appreciated.

Growing up, patients may have favored natural remedies since those were the only medical treatment options available to them. Carlos, like others, has less than a 6th-grade education, and his great faith in science was informed by his experience with natural remedies on a ranch in Mexico, and financial issues.

Excerpt 6.2.1b: The Rich Use Western Medicine

¹²¹ “la ciencia es más poderosa” -am12t3

¹²² *¡La Ciencia es más Poderosa! “se confía uno de la medicina de la ciencia pues... hay cosas que si la ciencia no puede hacer nada ¿adónde se puede ir uno? ¿Pues qué se puede uno hacer? ...A mi modo de entender yo creo que [la ciencia es más poderosa]. Oiga porque hay cosas que si la ciencia no puede hacer nada ¡dígame! ¿Qué se puede hacer?” – am12t3*

You know before, we would cure ourselves with home remedies and that sort of stuff and well yes we had faith in them. Like there weren't any specialties, or maybe there was but only for rich people that had the means, but a poor person, with what? We would die...look, before people would die from a scorpion bite. We didn't have the means to buy scorpion anti-serum, it's the truth, right? Or that one got a snake bite in the mountains and they would die from the snake bite because there wasn't any means, it's the truth, right? But now you see what science does. There is medication for all those animal bites. Yes, look, the [science is more advanced] (Translated from Spanish).¹²³

Body in Natural Form: Patients commonly believed that the human body in its natural and God-given form is a preferred state compared to one that had succumbed to an invasive medical intervention. The human body, once it has had a medical intervention, is no longer “pure” or “natural.” Once any kind of medical manipulation has occurred, the body is less likely to fully recover to its original state of being. The “operated eyes” will never regain their full function (6.3.1c). “Dentures will never be as good as your natural set of teeth” (translated from Spanish).¹²⁴

Excerpt 6.2.1c: Body Never Fully Recuperates

Look, they did surgery on both of my eyes because I had cataracts...one does not recuperate 100 percent...one does not return to the same state, right...one does not return to a state like having your natural eyes (Translated from Spanish).¹²⁵

Related to the importance of maintaining the human body in its most natural form is the value towards the use of natural medications (e.g., herbs, vitamins and the like). The assumption with the use of “natural” remedies is that they will not harm the human body and, therefore,

¹²³ “Antes ya ve que se curaba uno con remedios de casa y todo eso y pues si les tenía fe. Como no había especialidades, o si había, pero **nomas para la gente rica** pues que tenía manera, pero uno pobre ¿con que? Se moría uno... antes fíjese se moría la gente de piquete de alacrán. Pues **no había por lo menos para comprar** el suero de alacrán... ¿verdad? O que le pico una víbora en el monte y se moría del piquete de víbora porque no había manera ¿verdad? Pero ahorita ya ve lo que hace la ciencia. Ya hay medicamento para eso para los piquetes de animales. Si fíjese que [la ciencia está más avanzada].” – am12t3

¹²⁴ Los dientes postizos no van estar tan buenos como los de uno.

¹²⁵ “Mire me operaron de mis dos ojos porque tenía yo cataratas...No, no queda uno en el cien por ciento...ya no queda uno bien pues. Ya no queda uno igual verdad...**ya no queda uno igual pues como sus ojos naturales** ¿verdad?”-am12t2

negatively manipulate the human body. Participants holding such beliefs were likely to find stronger value in home and alternative treatments, compared to biomedicine. Biomedicine was used to cure/rid the body from malignancies, but more natural forms of treatments (e.g., home/alternative remedies) were favored for stabilizing/normalizing/restoring the body back to an original state of “health.”

Excerpt 6.2.1d Natural Remedies do not have Consequences

I know that all medicine has drugs, eh? And bad are the ones that we buy; the Tylenol that we buy for muscular pain. Creams no. But pills yes. Everything that is a pill has its consequence, and the natural does not have consequence (Translated from Spanish).¹²⁶

Excerpt 6.2.1e: Drugs have side-effects

The truth is that the [medicine] for the pain, I only take it when the pain hits...I take the pill and the pain subsides for a while...I sometimes endure, I say, ‘No I am going to endure until I really cannot stand the pain any more’ because if [the pain pill] cures us from one thing it will affect something else (Translated from Spanish).¹²⁷

Normal Aspects of Aging: Many patients attributed certain conditions and ailments as being part of the normal aging process. They believe that it is normal for pain to be experienced in an aging body due to the human body slowing down. People at more advanced ages are more likely to experience more symptoms. This notion, coupled with the cumulative aspects that social, emotional and physical stressors have on the body, is believed to normally manifest in old age. Elena feels most of her ailments are due to how one cares for our bodies when we are younger. She fell a lot when she was younger, and she believes that falling has affected her as she gets older. Also, she had 18 children, so she feels that also contributes to her aches and pains. She

¹²⁶: *La Natural No Tiene Consecuencia* “Yo sé que... toda la medicina tiene droga, ¿eh? Y mal los estos los que compra uno el Tylenol. Que compra uno cosas para el dolor muscular. Las cremas no. Pero las pastillas. Todo lo que sea pastilla todo tiene su consecuencia. Y **la natural no tiene consecuencia.**” – am4t1

¹²⁷ “la [medicina] del dolor la verdad nomas me la tomo solo cuando me llega el dolor...me tomo la pastilla y se me calma un rato. ... yo a veces aguanto digo ‘no, yo voy a aguantar hasta que dé a tiro ya no puedo. Porque pues si [la pastilla del dolor] cura una cosa le va afectar otra” – am13t1

believes that the body holds on to physical impacts and then the results are manifested in old age. Elena says, “[The doctors] say I have three or four broken disks. It must have happened during one of those many times I fell as a young woman, and now at my age these are the results; it’s the truth, right? (translated from Spanish).¹²⁸ Elena continues,

Excerpt 6.2.1f: Pain Comes with Old Age

...well, I think the more, more---the older I get, the more it hurts...at my age well there...I give thanks for God that he has let me live so much... well we are here...as long as God has us here we move forward, but we are not going to be well anymore (Translated from Spanish).¹²⁹

Since pain is seen as a normal part of aging, biomedical efforts to appease pain were often viewed as futile and even harmful to the human body because they would never completely take away the pain. Therefore, most people found the greatest way to cope with pain was to resist taking medications for as long as possible. Plus, resisting pain medication naturally kept the human body from building a tolerance to the pain medications.

6.2.2 Treatments of Disease: A Balancing Game

Many patients described cultural concepts of illness as their lay theories of disease causation; however, they did not exclusively identify culturally relevant treatments of care. The process towards reaching the goal of normalizing the body to a state of harmony usually followed an order of intervention importance. For minor symptomatic conditions, the first line of defense was home and natural cures, followed by biomedical, and if biomedicine failed to cure and/or resolve the problem, then most often there was a return to some other form of alternative

¹²⁸ “*dicen que la espalda tengo tres o cuatro discos quebrados ha de ver sido una de las veces que me caí—una vez cuando yo estaba de muchacha yo me caí muchas veces. Y ahora ya a mi edad estos son los resultados ¿verdad?*” – am13t1

¹²⁹ “...*pues yo creo que entre más más—entre más viejita estoy más me duele...ya a mis años pues ya... le doy gracias a Dios que ya me ha dejado vivir tanto...pues aquí estamos...mientras Dios nos tenga aquí adelante pues no vamos a estar bien ya*” – am13t1

treatment. For conditions that often develop asymptotically, such as diabetes, some cancers and cardio-vascular conditions, the cycle often started in the biomedical realm once disease progressed to major symptomatic stage and then branched out.



Figure 6.2: Diagram of the Most Reported Order for Treatment of Disease

Participants did not often report to the doctor problems that they thought could be solved/ameliorated using home remedies.

6.2.2.1 Homeopathic (Home Remedies)

The homeopathic component of this continuum was usually the first line of defense for self-diagnosable symptomatic conditions. Patients did not often report to the doctor problems that they thought could be solved/ameliorated using home remedies (e.g., rashes, cough, allergy and other perceived minor conditions) (Figure 6.2). Although the respondents were part of a PACE program and had exposure/access to allied medical personnel on a weekly basis, they reported using home treatments, such as *pomadas* (ointments) and teas, before even considering consulting their physicians. The decision to seek out professional care was based on their perceptions of the condition and its potential treatment requirements. Like a participant indicated, “home remedies for simple things only...like a cough or a cold...sometimes that cures it easily” (translated from Spanish).¹³⁰ For self-diagnosable and recognizable symptoms from skin, digestive, upper respiratory, joint and muscle-related conditions, most respondents turned to the use of a combination of culturally-appropriate and over-the-counter (OTC) treatments that

¹³⁰ “*los remedios de casa solamente para cosas sencillitas...como la tos o la gripe...hay veces que se la cura uno fácil.*” – am12t3

were informed by either prior personal experiences or suggested by fellow health care members for ameliorating symptoms. The treatments often included the use of *pomadas* (ointments), teas and massages by a *sobador/a* (cultural masseuse healer), and these were often used either in isolation or in combination with one another. For instance, one could take tea, before or after seeing a *sobador*, who is likely to apply ointments with or without the use of prayer.¹³¹ The use of home remedies may not necessarily be that uncommon, especially among the oldest old; however, the types of remedies are often culturally specific (e.g., *arnica* (arnica), *savila* (aloe vera), *té de anís* (anise tea), *pomada de abeja* (bee ointment), *veneno de culebra* (snake venom) and many more).

Ointments: Ointments were often used for various kinds of conditions. Patients applied ointments for skin, joint and muscle-related conditions. Patients often applied different forms of ointments and treatments, including OTC, until finding they found one that alleviated the symptom. Bertha, for instance, had been suffering from incontinence-related rashes, and during our first interview had yet to speak with her doctor about it even though she had been in the program a little over a year and had seen her doctor several times. She was using a combination of ointments and OTC remedies in attempt to find one that best fit her needs.

Excerpt 6.2.2.1a: Heal, Heal Bell's Little Butt

I do not know what is happening to me, maybe the soap or the medicine but I itch all over my body, and over here [points to her butt] like I use pamper because I pee on myself, I get red rashes, and I put alcohol here where my rashes are and it helps with the itchiness...I also use "*la crema de la campana*" (ointment)...they say heal heal bells little butt. I have a lot of faith in that ointment and Vicks VapoRub ...sometimes I cannot

¹³¹ The use of prayer is not discussed in this chapter. See chapter 5 for a description of how faith influences medical decision-making.

even sleep from the itchiness. I get up and I put the ointment on...I am also putting an ointment that is called Sarna (translated from Spanish).¹³²

Teas and Coke: Teas were used to improve *malestares* (general malaise/discomforts) including constipation, body aches, appeasing coughs and preventing colds. Bertha talks about using an OTC ointment, vapor rub in a tea format, to heal a bad episode of constipation. Both Alma and Beatriz talk about using *árnica* (arnica), which can be used both as an ointment and as a drinkable solution.

Excerpt 6.2.2.1b: Constipation

VapoRub once cured me from a bad case of constipation. Do you know what it is to be constipated? When it's so bad that you carry the smell in your nose. With that I got cured (Translated from Spanish).¹³³

Excerpt 6.2.2.1c: Arnica

I also use arnica...let me tell you that arnica functions as a drinkable solution. It works to drink and it helps for the aches of bones also...it comes in an ointment form for the muscles...I get a lot of cramps when I walk a lot or when I do a lot of exercise...cramps bother me a lot because the doctor says I have poor circulation (Translated from Spanish).¹³⁴

Home remedies are often used as a prophylactic mechanism to prevent colds. As mentioned earlier, a combination of home remedies were often used simultaneously. In this case,

¹³² “Sana Sana Colita de la Campana” “Y no sé qué me está pasando, será el jabón o la medicina tengo comezón por todo el cuerpo. Y acá [apuntando a la sentadera] como uso pamper porque me orino, me roso y aquí me pongo hasta **alcohol** aquí donde me roso y me ayuda para las comezónes....También la **crema de la campana**...Dicen sana sana colita de la campana. Yo le tengo mucha fe a la campana y al **Vicks VapoRub**...a veces ni puedo dormir de la comezón. Me levanto y me pongo pomada...me estoy poniendo una pomada que se llama **Sarna**.” – am6t1

¹³³ “A mí el vaporub me alivio una constipación ¿usted sabe lo que es constipado? Que hasta le huele mal la nariz. Con eso me alivie.” – am6t1

¹³⁴ “También uso la **árnica**...le cuento que la **árnica** sirve para tomar. Sirve para tomar y sirve para ... los dolores de los huesos también...y viene en pomada [para]...los músculos... me da mucho calambre cuando camino mucho o cuando hago mucho ejercicio ... me **molesta** mucho con los calambres porque dice el doctor que tengo mala circulación.” – am22t2t3

Beatriz used a tea-like cocktail and OTC VapoRub ointment on her chest area to prevent the onset of colds.

Excerpt 6.2.2.1d: VaporRub

To this day I hardly get any colds because as soon as I feel bad I run to grab water and I squeeze lemon and I drink it, and then I rub VaporRub (Translated from Spanish).¹³⁵

Excerpt 6.2.2.1e: Interestingly, Alma was not Mexican

I have a lot of medicine that I buy for me and that same medicine. I mix with arnica ointment or other ointments I bring from Mexico...with those I wake up, with the medicines from Mexico...one is called [name of ointment]; it is really good...it helps heal aches. This one has camphor, eucalyptus and menthol...those are ointments for body aches (Translated from Spanish).¹³⁶

Influencing Power of Others: Cultural concepts of illness and treatment are often shared with patients' circles of influence. As mentioned earlier, the approach was to use the home remedies, which were informed by personal prior experiences and/or suggested by fellow health care members for ameliorating symptoms. The PACE program is based on the use of adult day-care, which brings patients into contact with each other multiple times each week and therefore has a significant social aspect. Patients often established friendships and made acquaintances there and they often exchanged information and experiences, influencing the types of home treatments they used. Members of this health center are people with various explanatory models of disease causation that influence/inform their treatment options, but also influence the potential treatment options of their fellow center clients. Alma, for instance, is self-identified as a *sobadora*, a person who provides culturally-appropriate "massages." A person who provides such services

¹³⁵ "*Hasta la fecha casi no me dan gripas, pero yo nomas me siento mal así agarro un agua le exprimo un limón y me la tomo. Para prevenir y luego me pongo el vaporub.*" – am6t1

¹³⁶ "*Tengo un montón de medicina que yo compro para mí y esa misma medicina les hecho pomada de arnica o pomadas que traigo de México...con eso me levanto, con las medicinas de México... una que se llama [INAUDIBLE] es buenisima...ayuda a aliviar los dolores. Esa tiene alcanfor, eucalipto y mentol... esas son pomadas para los dolores del cuerpo.*" -am22t2t3

not only massages, but does so in combination with other cultural concepts of treatments (e.g., applying ointments, and prayer, which is out of the scope of this chapter). Her goal was always to try and help those around her and massaging with the ointments she purchases while praying was a way of providing relief.

Excerpt 6.2.2.1f: Cultural Massage Therapist

My family, my friends, my hospital friends, my friends from my house, my friends that I have surrounding me...if I can help, if I can support, if I can help them in alleviating a pain, in something 'look I have these things [ointments]. I take it to them, I go to give them healing massages, I pray for them' (Translated from Spanish).¹³⁷

Alma often provides these massages out of her own home, or in other people's homes. She only offers these services when she sees a friend or family member in need, or when a person in the community specifically asks her to. She does not do this for money, but rather out of the kindness of her heart. In exchange, she often receives gifts to continue to provide her services to others. Bertha describes how she learned about a specific ointment from a fellow health center participant.

Excerpt 6.2.2.1g: Bee Venom Ointment

I put an ointment here on the knee that was recommended by another member there in GraciaMed; it's called bee venom, and that helped me a lot also (Translated from Spanish).¹³⁸

Similarly, Vanessa uses coke to balance her body back to normal. Whenever she feels a little off, she drinks half a can of coke to bring her back to feeling normal. Some of her girlfriends from GraciaMed health center shared their experiences using coke as a treatment for general *malestares*. She tried it and it worked, so now she uses it more frequently.

¹³⁷ "Mi familia, mis amigas, mis amigos del hospital, mis amigos de mi casa, mis amigos que tengo alrededor...si los puedo ayudar, si los puedo respaldar, si los puedo ayudar en un dolor que tienen, en algo que [INAUDIBLE] ay mira ahí traigo esas cosas [pomadas], ahí se las traigo, **las voy a sobar le digo**, voy a orar por usted...si [yo les sobo]." -am22t2t3

¹³⁸ "Me pongo pomada aquí en la rodilla que **me receto una señora ahí del GraciaMed**, se llama veneno de abeja y ese me ayudó mucho también." - am6t2

Excerpt 6.2.2.1h: Coke to Balance the Body back to Normal

I have medication for cholesterol, hypertension, and I have for the allergies and for the pain... And I have my own machine. If I wake up a little bad I take my pressure and sometimes it is not even the blood pressure... evils that come in... I drink half a can of coca cola. I don't drink it all the time... [only when I feel bad]... some friends of mine told me, and I tried it and it works. It works so... (Translated from Spanish).¹³⁹

6.2.2.2 Biomedical

Unlike the symptomatic conditions listed in the homeopathic section above, conditions such as diabetes, cardiovascular diseases and cancer often start asymptotically until the disease progresses to an advanced stage of illness. For such asymptomatic conditions, participants did not generally report their symptoms, if any, to their practitioner as their first response. If the participants had symptoms, many played the waiting game to see if the condition persisted, worsened or quietly disappeared. If the symptom worsened to disrupt activities of daily living, then it was often reported to their practitioners where a biomedical diagnosis and treatment would begin. For instance, Maria, after the car wreck *la impresión* (fright-like emotion), was taken to the hospital where she was diagnosed with diabetes. They gave her a follow-up appointment but because she felt fine, she did not return until the disease was in a more advance stage.

Excerpt 6.2.2.2a: Asymptomatic Diabetes

They gave me an appointment for February... I did not go. I did not go because I felt fine. But it was there where they found diabetes (translated from Spanish).¹⁴⁰

Maria, who like the others holds to the idea of balance and harmony as an ideal state of being, believes that a blow to the body can cause organs to be thrown out of balance, and they

¹³⁹ “*tengo medicina para el colesterol, hipertensión, y tengo para las alergias [y] para los dolores... Y yo tengo mi propia maquina. Si me levanto poco muy mal me tomo mi presión y a veces ni siquiera la presión... males que le entra a uno... me tomo una mitad de una coca cola. No me la tomo todo el tiempo [solo cuando me siento mal] ...unas amigas me dijeron y lo probé y trabaja [14:24]. Trabaja así es que.*” -am14t1

¹⁴⁰ “*me dejaron una cita para en Febrero...y yo no fui, no fui a esa cita porque me sentía bien. Pero ahí fue donde me descubrieron la diabetes.*” – am1t2

take time to normalize. However, the way in which treatment options are described to the patient and the patients' symptoms have the power to influence treatment decisions. Initially, when she was diagnosed with diabetes, she was given insulin against her will. She went temporarily blind until they stopped giving insulin. Her idea that strong medicine can cause more damage was confirmed by her experience. Medical decisions are impacted by prior experiences, and personal beliefs and values inform cultural paradigms.

Excerpt 6.2.2.2b: I Said No Insulin

[The doctor] told me he needed to put me on insulin, but I told him no. I told him I feared insulin because when the doctors in [name of hospital] I was in first, diagnosed me with diabetes they injected insulin and eight days later I started to lose my vision (Translated from Spanish).¹⁴¹

Twenty or so years later, her pancreas stops working, and she is now again facing a decision to take insulin. Her current physician at GraciaMed was able to provide information in a way that made sense to her, and she agreed. However, decision-making does not occur overnight. It takes time for a new idea to be assimilated with culturally-informed paradigms. Some people need time to mentally prepare themselves for upcoming analysis or treatments. Maria later had to undergo cataract surgery and, due to her usually anxious nature, she mentally and physically prepared. Although she had an anxious nature, she was ready for surgery because she had mentally prepared herself. Unlike Maria, Frida who had a tendency for being *nerviosa* (nervous) was given little time and information to assimilate the idea of the test, and as a result she had a nervous breakdown. Knowledge is often the key to reducing decisional conflict (Bergeron, Friedman, Messias, Spencer, & Miller, 2016; Bergeron, Friedman, Spencer, et al., 2016).

¹⁴¹ “él me dijo que necesitaba mejor ponerme la insulina y yo le dije que no. Que yo le tenía temor a la insulina que cuando me descubrieron la diabetes aquí en el hospital general, este a los ocho días de ponerme la insulina...este empecé a perder la visión.” –am13

Other conditions that initiated in the biomedical phase were annoying symptoms that were bothersome but were not perceived to put the individual at risk for a deadly condition or to the degree as to disrupt daily living. Francisco, for instance, was battling with a *ruidito* (buzzing sound) in his head during the entire length of participation in the study. During our first interview, he indicated the sound truly bothered him. He would cope by putting competing sounds from the radio or television to allow him to tune out the sound resonating in his head. Finally, it bothered him enough to report it to his doctor. The participant was confused because he did not know what could be causing it. He speculated that it was due to a potential infection from a mosquito bite from his travels to Arizona or Mexico. By the second interview, the noise in his head was one of the first things he provided an update on. He had taken action. He had reported it to his doctor, who then sent him to a specialist. The specialist did an MRI and everything looked normal. Finding no resolution with biomedicine, and no idea of what homeopathic or alternative treatment to use, he decided to ignore and cope with it. If it gets too much of a bother, then he planned to retell his doctor, hoping to find a solution. By our third interview, he even forgot to mention it. He had forgotten the issue not because he had found resolution but because he chose to ignore the problem in hopes that it would quietly disappear. He had decided that ignoring it was the course of action. Ignoring the problem helped him place all his energy in positive things, and he learned to cope with it to the point that he no longer heard it.

Excerpt 6.2.2.2c: Buzzing but Doctor Says Everything was Perfect

The little buzzing noise I had in my head I do even pay attention to it. [It is still there], but they already did an MRI, and they didn't find anything. I told him about the noise and he sent me with a specialist, right? To do the MRI but he told me that I didn't have anything...Maybe further down the line I may ask the doctor again about the noise that

has not gone away and it could be he sends me again to see what is happening (Translated into Spanish).¹⁴²

6.2.2.3 *Alternative Medicine*

Alternative medicine was used for managing both chronic asymptomatic and symptomatic conditions. Given the two competing beliefs — the power of science to cure and the importance of maintaining the human body in its most natural and pure states — most of the participants described using alternative treatments in conjunction with biomedicine, not in lieu of biomedicine. However, there were some cases where alternative medicine was used exclusively. If a respondent did not like the idea of the biomedical regimen being recommended (e.g., starting dialysis, cholesterol medication, pain management therapy), they often either decided to try some kind of alternative treatment first in lieu of the biomedical regimen prescribed in order to test its efficacy in alleviating the problem, or they decided to forgo medical intervention all together.

Examples of in Lieu of Biomedicine: The other reason provided in the use of alternative treatments were used instead of biomedical regimen (often without the knowledge/consent of their practitioner). For example, Maria was about to go on dialysis; however, given her previous experience with insulin, she did not want to and sought other forms of treatments to see if they would take care of the problem. She started taking “natural” pills (perceived to be vitamins) prescribed by her son who is a physician in her home country. The pills were supposed to improve her kidney function.

¹⁴² “me mando hacer un MRI...pero el doctor dice que no salía nada. Que no salió absolutamente nada que estaba perfecto.” am4t3 “El ruidito que trailla en la cabeza **ya ni le hago caso**. [Todavía anda] pero ya me hicieron una MRI y no me encontraron nada...le dije yo [lo] del ruido y él me mando con el especialista ¿verdad? Hacerme la MRI pero me dijo que no tenía yo nada. ...Hay más adelante a lo mejor le voy a decir al doctor que ese ruido todavía no se me ha quitado y puede que sea que mande otra vez a ver qué es lo que está pasando.” – am4t2

Excerpt 6.2.2.3a: No need for Dialysis

I have improved because, look when I used to go the [previous clinic] the doctor wanted me to go to his clinic...so that they could start me on dialysis...My son however, he is a medical doctor but he lives in my country, said to take some capsules called...KBU(4Life)...for the kidneys...and the doctor says that I have improved greatly (Translated from Spanish).¹⁴³

She was never really able to articulate the reason why she refused the treatments recommended by her physician in the United States, but she also always refused invasive medical intervention to try to control her pain. She refused cortisone shots “*¡No! Cortisona no he querido.*”¹⁴⁴ (No cortisone I have not wanted). Rather she has opted to use more natural and alternative treatments such as *pomadas de abeja*, acupuncture, exercise and physical therapy.

Excerpt 6.2.2.3b: Acupuncture

I have had the...twice that I put those injections that one receives on the body...what is it called?...Needles that are placed ...What is it called? [Acupuncture]. Yes. Twice they have put them on my hip and knee because the hip from sitting I cannot even stand up...but they tell me I have to do a lot of exercise and walk—I can’t. A little while and oh no I cannot withstand [the pain] in my legs (Translated from Spanish).¹⁴⁵

Patients also described two reasons for the use of alternative treatments. One reason was if the biomedical treatment was not working as perceived by the participant then something more was sought out to alleviate a symptom, or used as a way to normalize the body at a much quicker rate.

¹⁴³ “He mejorado porque fijese que cuando yo iba [clínica anterior] el doctor quería que fuera a su clínica...para que [me] empezaran a poner diálisis entonces... mi hijo me dijo. Él es médico, pero vive en mi país. Le dijo toma una capsulas que se llaman...KBU (4Life)] ...para los riñones. ...Y el doctor me dice que he mejorado bastante.” - am1t1

¹⁴⁴ am13t1

¹⁴⁵ “Y me he puesto la...ya dos veces que me pongo la inyección esa que recibe una del cuerpo... ¿cómo se llama?...Agujas que le ponen a uno... ¿cómo se llama? [Acupuntura]. Si. Dos veces me la han puesto en la cadera y en mi rodilla. Porque de la cadera a veces de estar sentada no puedo ni levantarme...pero me dicen que tengo que hacer mucho ejercicio y caminar—no puedo. En un ratito y ay no aguanto, no aguanto [el dolor en] mis piernas.” - am13t1

Examples of Complementary Treatment: Francisco received surgery and afterwards he took *uña de gato* (cat claws) hoping it would remove all the cancer the oncologist was unable to remove during surgery.

Excerpt 6.2.2.3c: Cat Claws Removed Prostate Cancer

When the doctor did surgery he left about a point and a half because I had the cancer at an advanced stage...like between 1 and 10 mine was an 8...and he told me he did everything possible to take away all the cancer but a little still remained...when the oncologist released me from the hospital, I had a big bottle of cat's claw. I took all of it and as I was taking it the cancer was disappearing. The doctor would tell me because she would draw blood to see how my cancer was developing. She would say [name of patient] your cancer is decreasing/reducing. You had one and half point and now you only have a point. And like that I continued. When I finished the jar, it had 300 pills and I would drink one every day, and before you knew it the doctor said your cancer disappeared. She asked me, 'are you talking something?' I told her no [laugh] (Translated from Spanish).¹⁴⁶

Another gentleman also started with biomedical after his diabetes diagnosis and has found no resolution with the numbness and pain in his legs. Carlos says, "I am taking my treatment as prescribed but I don't feel anything" (translated from Spanish).¹⁴⁷ As a result, he has decided to use the *agüjas* "needles" (lay term used for acupuncture).

Excerpt 6.2.2.3d: Biomedical Treatment Not Working – Let's Try Acupuncture

I am receiving treatment through needles because I cannot stand my back, waist, and neck pain...blessed be God that the neck pain and back pain went away...it went away. Right now we are seeking to see if it could fix the feet...I am hopeful that the [numbness in my legs] will slowly go away (Translated from Spanish).¹⁴⁸

¹⁴⁶ "cuando el doctor me opero me dejo como un punto y medio más o menos. Porque tenía el cáncer ya casi bastante ya avanzado como del uno al diez como un ocho más o menos...Y me dijo hice todo lo posible dice te quite todo el cáncer pero todavía te quedo poquito de cáncer.....cuando él [oncólogo] me dio de alta del hospital yo tenía un bote grande de una de gato. Y me la tome toda y conforme me la iba tomando iba desapareciendo iba desapareciendo. La doctora me decía. Porque siempre me sacaba sangre para ver lo del cáncer para ver como estaba. Y me decía [nombre del paciente] dice tu cáncer va bajando. Traías un punto y medio y ahorita ya tienes un punto nada más. Y así y así. Ya cuando me la termine el bote ese tenía 300 pastillas tomaba una todos los días una todos los días. Y ya cuando menos vine a ver me dijo la doctora sabes que tu cáncer desapareció. Y me dijo. Me pregunto ¿estás tomando algo? Y le dije que no [risa]." – am4t1

¹⁴⁷ "Me los estoy tomando al pie de la letra y pues no siento nada." – am12

¹⁴⁸ "me [estoy] tratando por medio de las agujas...porque yo no aguanto los dolores de mi espalda, de mi cintura, de mi pescuezo...bendito sea Dios que, si se me quito lo del pescuezo, lo de la espalda igual...Si se me quito. Ahorita vamos por los pies a ver si es posible...tengo esperanzas de que se me vaya ir poco a poco quitando." – am12t2

Excerpt 6.2.2.3e: Biomedicine is Not Working

The leg numbness does not go away for anything. Look here I am following the doctors' treatment for muscular pain, and I am taking it with meticulous care but I don't feel anything. The same. Well I just convinced myself that it's the thing with my diabetes then (Translated from Spanish).¹⁴⁹

6.2.2.4 Idea of Balance

Even when participants were functioning within the biomedical paradigm, there was this constant idea of balance. Not too much drugging, not too much restriction, not too much monitoring—all within a balance is the healthiest way of managing chronic conditions.

Medications: Given the complexity of managing diabetes, all the participants followed doctors' orders for a medication treatment regimen. They did not deviate from the recommendations, fearing that their diabetes would be uncontrolled, and their condition would quickly escalate to a critical situation of life and death (6.3.1a). The benefits of taking the pills greatly outweighed any potential side-effects.

Excerpt 6.2.2.4a: Fearing the Consequences of Diabetic Complications

What I fear the most of having diabetes is that all of a sudden my sugar escalates and I get a heart attack. Yeah. I mean that it will go out of control from one minute to the next. That is the only thing I fear (Translated from Spanish).¹⁵⁰

Excerpt 6.2.2.4b: Medications

I only have the medicine that the doctor gives me to control the diabetes, cholesterol and blood pressure. [But only when is a little high]. I take it anyways. In other words, I take it to keep it controlled. Because for example if I do not take it and then I eat, for instance I

¹⁴⁹ “Eso si lo entumido de los pies eso si no se me quita ni por nada. Fijese que tengo yo el tratamiento de la doctora para dolores musculares y me los estoy tomando al pie de la letra y pues no siento nada. Y lo mismo. Pues ya me convencí que es cosa de mi diabetes pues.” – am12t3

¹⁵⁰ “De la diabetes lo que más le temo que yo **de repente me suba la azúcar y me vaya dar un infarto**. Yeah. Ósea que se me vaya descontrolar de un minuto a otro. Es lo único que temo [28:41] De eso.” –am4t2

love chocolate, right? But if stop eating chocolate and I take the medicine the sugar comes out at 140, 130. Yeah (Translated from Spanish).¹⁵¹

There were some individuals that, although they took medications as prescribed, for those medications that were on an “as needed” basis, they avoided taking them by using other forms of home remedies first. Medications were often taken with perceived moderation as to not disrupt the notion of balance.

Monitoring Blood Sugar: The participants had an understanding that taking regular blood sugar readings with their meals was an important task; however, as with the other components of the diabetic treatment regimen, all within balance. There was an order of importance or sequence: Eat right, take medications as prescribed, and take sugar reading levels once in a while. The idea driving the sequence was that if the patient is compliant to doctors’ orders as prescribed, then there is no need to be constantly checking blood sugar levels. Checking blood sugar levels too often is seen as causing additional and unnecessary emotional and physical distress, especially if the patient is not following dietary recommendations.

Excerpt 6.2.2.4c: Checking Blood Sugar Levels in Moderation

Yes, look, here my daughter was checking it—I am checking it but like, when I don’t feel problems, I am checking it every 8 days. Each Saturday or Wednesdays like that every 8 days I am checking it and I am fine. I see that many are checking it before breakfast on an empty stomach, after breakfast and like that all the time and whatever they have it is super high...don’t take care of the nutrition...that is primordial, the nutrition...what good is it to be checking it so often and the nutrition is not adequate, right? [Only to serve as reminders]. I just finished eating this taco let me check my sugar [chuckles] (Translated from Spanish).¹⁵²

¹⁵¹ “Tengo la pura medicina nomas que me da el doctor digamos para la diabetes para controlar la diabetes el colesterol y la presión. [Pero eso solo cuando está un poquito alta]. Yo me la tomo de todas maneras. Ósea que yo me la tomo para seguir controlándola. Es que por ejemplo si no me la tomo y luego como, por ejemplo, me encanta el chocolate ¿verdad?, pero si dejo de comer el chocolate y me tomo la medicina el azúcar me está saliendo a 140, 130. Yeah.” – am4t2

¹⁵² “Si mire, yo aquí mi hija me la está checando—yo me la estoy checando como no siento problemas yo me la estoy **checando cada ocho días**, cada sábado a veces o miércoles así cada ocho días me la estoy checando y pues estoy bien. Y veo que muchos se la están checando antes de desayunar en ayunas, después de desayunar y así

Even with biomedical treatment options, the idea was not to overdo anything but keep everything balanced.

6.3 Chapter Summary

Cultural concepts of illness are important theories of disease causation among Latinos, reflecting their context in a way that influences how illness is perceived and experienced. The cultural concepts presented in this chapter are engulfed within the overarching theme of the patients' idea that the body must be in a state of balance (Table 6.1). A sudden, unexpected, unwelcomed event that is negatively perceived and is emotionally and or physically taxing on the body, especially when the individual is living within a stressful situation, is perceived as vulnerable to illness. The body requires enough time to recuperate and normalize from the “shock” to decrease the likelihood of illness development.

Identification of such models of disease causation helps practitioners understand how a patient expresses and perceives such culturally-related illnesses, which give light to potential supplemental treatment options that are deemed appropriate by the patient (e.g., prayers and home remedies for *la impresión*, stress-reducing relaxation techniques for *nervios*, and the like).

Although foreign-born Latino elders believed in traditional cultural views, the decisions for treating such conditions were not exclusively related to traditional folk remedies. Immigrant elders held on to traditional non-biomedical ideas and yet still believed in biomedical solutions. In fact, there was an interface between cultural concepts of illness and the use of biomedical health care services, which included treatments by a suggested order of intervention importance:

todo el tiempo y como quiera la tienen altísima pues. ... no se cuida uno la alimentación...es lo primordial, la alimentación... de que sirve que se la esté checando a cada ratito y la alimentación la tenga no adecuadas ¿verdad? [Nomás se están recordando]. Me acabo de echar ese taco déjeme chequeo la azúcar [CHUCKLES]” – am12t2

remedios caseros (home remedies), biomedicine and alternative treatments. The order of importance was motivated by the participants' competing beliefs systems that emerged from both cultural concepts and biomedicine. Patients overwhelmingly valued maintaining the human body in a state of harmony and balance. However, competing beliefs about the power of science to cure, maintaining the human body in its natural form, the perceptions of disease arising as a normal part of aging and biomedicine often interacted with one another depending on the context and condition.

CHAPTER 7.0: FINDINGS - FAITH AND MEDICAL-DECISION MAKING

Faith in God among foreign-born Latino elders plays an inherent role in medical decision-making. Faith had a direct and determining role in mental health- related decisions, which were not often perceived by participants to be in the realm of medicine. In addition, faith played an important indirect role in medical decision- making, where patients used faith to make sense of the recommended medical treatments and used it as an alternative form of coping mechanisms. The way in which faith plays out or is manifested in everybody’s life varies. However, all of the foreign-born Latino elders who participated in this study had a belief in God and held a Catholic/Christian-based worldview. Two major inter-related themes emerged: a belief in God who supernaturally controls all aspects of life and death; communicating with God through prayer and, as a result of life’s circumstances, God communicating with people (Table 7.1).

Table 7.1: Themes and Categories on the Role that Faith Plays in Medical Decision-Making (Chapter 7: Aim 3)		
Overarching Domain: God is omnipotent and omniscient (is everywhere and <i>controls</i> things in this world and the next)		
Themes	Categories	Sub-categories
Communication with God	Prayer	Coping with physical pain
		Coping emotionally
		Miracles
		Provides hope; positive emotions
		Dynamic; mixed emotions
	Circumstances	Creates meaning (e.g., death, pain, practitioners are part of God’s plan)
Communication with others	Identification of preferences	<i>Indirectas</i> (indirect speech)
		Embedded in technical & non-technical conversations
	State of grace	Traditional use of God-related statements

Communication between God and the patient was a crucial component of faith during medical decision-making. Prayer was a consistent means that patients used to communicate with God, and life's circumstances were perceived as God's way of communicating with people (Figure 7.1).

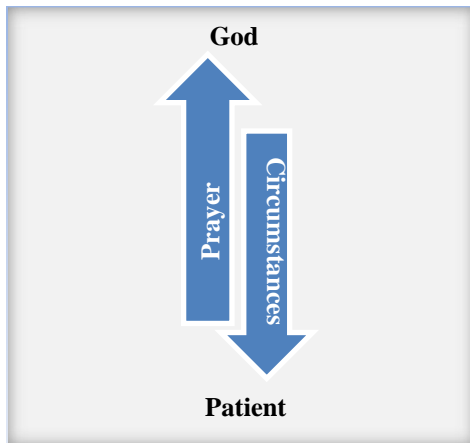


Figure 7.1: Communication Between God and a Person Foreign-born Latino elders initiated communication with God through the use of prayer, while interpreting life's circumstances as God's attempts to communicate with them.

In this chapter, three patients illustrate how faith directly determined medical decision-making with psychologically-related issues, a powerful but relatively rare situation. Additional examples highlight the use of faith as a coping mechanism for dealing with physical pain. Frequently encountered situations where faith played an indirect and shaping role in crisis-based decision-making demonstrate how participants attached meaning to challenging circumstances and relied on a belief that interpreted medical practitioners' actions as part of God's larger divine plan. With the indirect and shaping roles in crisis-based medical decisions, faith may provide unique opportunities for clinicians to identify patients' medical care preferences, an essential element in the delivery of patient-centered care. In this chapter, I describe how faith can serve as a communication tool during the medical encounter, where many decision-making processes are initiated and treatment options modified. Finally, the chapter concludes with an example that illustrates the dynamic nature of faith, and a primary reason it behooves clinicians to routinely assess patients' self-identified faith.

7.1 Faith's Direct Interaction with Medical Decision-Making

The impact of faith on medical decision-making falls within a continuum. Faith, when involved, often had a determining role in mental health-related decision-making. At the extreme end of the spectrum, patients opted to forego medical treatment and increased their engagement in spiritually-related care; however, that was an uncommon situation.

In this section, patients describe the variability of faith interactions in mental health-related medical decision-making. Maria, for example, is a practicing Evangelical/Protestant Christian who refuses secular counseling and opts for biblically-based counseling with her church elders. She perceives counseling as not directly related to medical treatment, but rather to issues of the heart—things of God.

Excerpt 7.1a: Christian vs. Secular Counseling Services

My doctor wanted me to go to a psychologist, but I go to a Christian church and we have a group of elders that helps us...when we have a problem we tell it to them. They pray and motivate us. There are more difficult cases...ask God they say. He listens. They encourage (Translated from Spanish).¹⁵³

Maria's church served as a social support system.

Alternatively to a social support system, faith often included prayer. For instance, Catarina used prayer, rather than anti-anxiety medications, as part of her medical treatment. In contrast to Maria who refused secular counseling, Catarina accepted secular counseling both in her home country, as well as in the United States. However, Catarina mentioned how God was ultimately the one who helped her. She viewed God as her personal psychologist, "Oh, Lord! You are my psychologist" (translated from Spanish)¹⁵⁴, expressing the idea that secular

¹⁵³ "Si quería que pasara con un psicólogo, pero como yo voy a la iglesia cristiana allí hay un grupo de ancianos y ellos lo ayudan a uno...cuando uno tiene cualquier problema se lo cuenta a ellas. Ellas hacen oración y también lo animan. No si hay casos más difíciles... ¡Pidale a Dios! El la escucha. Así. Le dan uno aliento." – am1t1

¹⁵⁴ "¡Hay Señor tu eres mi psicólogo!" -am2t1

counseling was unneeded when God himself could do the job. Catarina experienced her husband's death at the age of 40 in El Salvador. She suffered severe psychological distress and she saw a psychologist in El Salvador. She reported disagreeing with his judgmental comments about how she should not even think about separating herself from her children and migrate to the United States. There were some cultural gender roles at play, but even though she went to see the therapist, she always relied on her faith in God as her primary "psychologist." Ultimately, she viewed Christ as her doctor and relied on him to make final decisions. After three years, she was no longer able to provide for her family and decided to come to the United States and leave her children behind until she was financially stable and able to send for them.

Excerpt 7.1b: Speaking Directly to God

I came to the United States first, and later my family joined me. It happened after trying to financially make it for three or four years. Financially things worsened, and I lost control, right? [mentally]. [The doctor] would tell me not to move without my children because they would get tired and I was going to lose them too. They would not be interested in the money order I would be sending every month. He would say that, right? There's nothing like living together and seeing to all of your children's necessities. Well, he gave me a good therapy, but Oh Lord, you are my psychologist (Translated from Spanish).¹⁵⁵

She thanks God. *Gracias a Dios*. She says without God's help it would have been impossible to endure all of the hardships she encountered when she first arrived in Los Angeles. She gives God credit for opening doors of opportunity here in the United States. "He has strengthened me. He has protected me. He has helped me in this country. He has divinely opened the doors"

¹⁵⁵ "No. primero yo [me vine]. familiares que después [low voice] me paso ya después de tratar allá por tres o cuatro años no podía ...el colon [low voice] me puse un poco mal y [29:49] ...perdí el control ¿verdad? Me decía [el médico] que no hiciera nada de moverme sin mis hijos porque se iban a cansar y yo los iba perder también sin interesar el "money order" que mandara cada mes. Él decía el ¿verdad? No es como convivir diariamente con sus hijos viendo sus necesidades bueno me dio una buena terapia, pero "hay señor tu eres mi psicólogo [low voice]." – am2t1

(translated from Spanish).¹⁵⁶ During all of her decisions and turmoil she relied on her prayer to God to pull her through.

Similarly, Frida also relies on prayer to manage her mental health. She has a strong faith in Christ and is a devoted Catholic. She lives with her brother, who is in poor- health. She is saddened by his illness. Her emotional health came up in all three interviews because she is saddened by the people who have passed. Her “husband” [never formally married but remained a couple for 10 years] had died two years prior to our interview, plus other brothers had died. She uses prayer as a way to calm her anxiety, and she speaks to God on a regularly basis even during a health event.

Excerpt 7.1c: Praying to God

What I do is pray for their eternal rest and that God forgives all of their sins, all they committed during their lifetime and that’s it. I pray for them. And I then stay calm, sleep well...then I do not think of anything...we are all going to leave. Nobody stays. God says, ‘come to heaven’ and that’s it, and with God’s will...we don’t know when or where only God knows. I am very Catholic (Translated from Spanish).¹⁵⁷

My sister-in-law likes to go to the casino...I don’t like to play but I do accompany her...I was sitting waiting for her to play...just then I started to see my vision darken...I didn’t see anything. I was praying...Lord, what is happening to me? And after it passed...it passes...nothing happened to me (Translated from Spanish).¹⁵⁸

Although rarely seen these days, the women demonstrated a continued reliance on their faith for mental health issues. Maria, Catalina and Frida engaged in mental health-related decision- making, demonstrating how prayer, as a means of communicating with God, is often

¹⁵⁶ “Él me ha fortalecido. Me ha protegido. Me ha ayudado en este país también. Me ha abierto las puertas divinamente.” -am2t1

¹⁵⁷ “Entonces lo que hago es rezar mucho por el descanso de ellos y que Dios pues perdone todos sus pecados, todo lo que ha cometido durante su vida y nada más y **les rezo. Y yo quedo tranquila, duermo bien...ya no pienso en nada...** todos nos vamos a ir. Nadie nos quedamos. Dios dice hasta aquí nomas y con la voluntad de Dios...no sabemos ni donde ni cuando solo Dios sabe. **Yo soy muy católica.**” -am23t2/t3part1

¹⁵⁸ “Mi cuñada le gusta ir al casino...a mí no me gusta jugar, pero si la acompaño...estaba sentada esperando que juegue ella y...en eso yo veía oscuro, oscuro, oscuro...y no veía nada. **Y yo rezando... Señor ¿qué me pasa Dios mío? Y después se me paso...se me paso...no me paso nada...**” - am23t2/t3part1

initiated by the participants and used to directly determine their treatment rather than accept psychologically-related treatments. In the next section, prayer is also used as a coping mechanism to deal with physical pain.

7.1.1 Faith in Coping with Physical Pain

An area where faith was often important for this group of patients was in coping with pain. Campbell et al. (2009) described theoretical approaches in coping with pain among Latinos, a subject with limited literature available. They discussed two broad categories of pain coping: problem-focused and emotion-focused. Problem-focused involved the efforts to control or change the source of pain by taking analgesics to relieve pain or change activity patterns. Emotion-focused coping could entail efforts to seek out socially supportive others who could help reduce the anxiety that occurs in response to a pain flare, including "looking for meaning associated with the pain experience, and seeking emotional support from others" (Campbell et al., 2009, p.1013).

Patients' often used faith as both a problem-focused and emotion-focused coping mechanism that allowed them to minimize the use of pain medications. In some cases, if patients decided to medically treat the pain, they ultimately decided only to take what they perceived was needed to make the pain more bearable, which often resulted in taking smaller dosages than prescribed or recommended. Most patients disliked the idea of taking an excessive amount of pain medications and aimed to decrease their intake, a potential insight into the belief of balance and keeping the body in its most natural state (discussed in the Explanatory Model chapter). The two examples below, Catarina and Lucia, demonstrate how patients used faith to cope with their pain. Catarina, for instance, used faith to manipulate her thoughts and endure the pain. She was

often in pain, but tried to defeat the pain herself before she resorted to taking painkillers. She told herself that if Christ endured so much pain, why was she complaining of this little pain.

Excerpt 7.1.1a: Faith Helps Endure Physical Pain

...to take a pill for the pain that they give me...I take half a pill every twelve hours. If it hurts **me here, deeply, I take it. If not, then I don't. It is not necessary**....Because sometimes that [the pain] in various places [of my body], and that is when I try **not** to take so many pills, so much that **I win over the disease. I can endure and I remember Christ's suffering, of how he suffered from his nails in his hands Lord...To endure, this is nothing** (Translated from Spanish).¹⁵⁹

In a similar case Lucia, a breast cancer survivor from Guatemala uses faith to make the pain totally go away. She credits God for her cancer recovery. She received treatment, but only the first dosage of chemotherapy was provided. She prayed that she would not need to undergo radiation and the subsequent chemo dosages. She avidly communicates and shares her medical preferences with the Lord. She is currently managing chronic back pain that started after her breast cancer, knee pain and carpal tunnel in her hands. She has requested all of her medication be suspended because they provoked anxiety-type reactions. She uses prayer as a continual communication with God to manage her pain. She first prays to God, telling him what she wants and with faith believes it will be granted (a trust-based prayer). She believes God's medicine is the best, and that He is the doctor of all doctors. He is the one who provides the doctors with wisdom.

Excerpt 7.1.1b: God Makes the Pain Disappear

Only your [referring to God] medicine is the best...how can I tell you something that [pause] to ask of God that...in your hands I commend myself and that **He makes the pain disappear**. I pray to the Lord and...**the pain disappears** (Translated from Spanish).¹⁶⁰

¹⁵⁹ "... tomar pastillita para el dolor que me dan... tomo media pastillita cada doce horas. Si me duele **aquí profundamente la tomo si no no. No es necesario**. ... Porque a veces que así me han dado partecitas y todo, pero allí trato de no tomar me tanta pastilla tanto así **me venzo yo la enfermedad. Puedo soportar y me acuerdo del sufrimiento de Cristo de como sufrió el, sus clavos en sus manos Señor...No soportar eso no es nada.**"-am2t1

¹⁶⁰ "Solamente tu [refiriéndose a Dios] medicina es la mejor...como le puedo decir algo que [pausa] pedir a Dios que...en tus manos me encomiendo y que haga **El dolor desaparecer**. Hago oración al Señor en si...**El dolor desaparece.**"- am25t1

In a similar process as Lucia, Maria used her faith-related beliefs to shape her thoughts and endure the pain. She used prayer; a means of communicating with God that is often initiated by the participant, to communicate her desire to eliminate the pain.

Excerpt 7.1.1c: Enduring Pain

I haven't really suffered from despairing pains that lead me to complain...**everything has been tolerable...I can endure them...** I simply ask God to allow me to tolerate, bear them (Translated from Spanish).¹⁶¹

The Value of Enduring Physical Pain and Fear of Taking Painkillers

In this section, I discuss issues related to physical pain such as the value of enduring pain and fear of taking painkillers because these issues are associated with faith and its role in medical decision-making.

The foreign-born Latino elders in my sample often avoided the use of invasive pain-related medication or treatments [in the form of pills/steroid shots/surgery] and opted for other forms of home remedies of managing pain (e.g., teas, OTC medicated creams such as “Arnica,” Hot/Cold, Vicks and the like). Respondents provided two explanations for avoiding pain medications that included a faith component, neither of them mutually independent of each other: the potential value of enduring physical pain and a fear of taking painkillers due to the value of a natural state of being (non-medical intervention).

The Value of Enduring Physical Pain

The cases presented above illustrate how some foreign-born Latino elders used faith as a coping mechanism to “endure pain.” I hypothesize an associated value to enduring physical pain.

¹⁶¹ “Fijese que no he padecido dolores que en realidad me desesperen y que yo reniegue...**todo ha sido aguantable...los puedo resistir...**nomas le pido a Dios que los pueda soportar.” – am1t2

The literature talks about stoicism,¹⁶² defined as “the quality or behavior of a person who accepts what happens without complaining or showing emotion” (something I did not find in my sample because they were not selected for their faith-related characteristics); however, that does not mean stoicism is not observed in foreign-born Latino elders. Stoicism originates from the idea that God controls all aspects of life and death. As Francisco succinctly stated, “God provides everything” (translated from Spanish).¹⁶³ In other words, God has allowed the circumstances to be what they are, including the existence of all kinds of pain. As a result, complaining would be complaining against God himself. However, stoicism also serves other values/benefits for family members (Campbell et al., 2009; Juarez, Ferrell, & Borneman, 1998; Kagawa Singer, 2012). Given my experiences in serving in bereavement ministry and serving in the hospice-like feature of the program, before conducting the interviews, I expected to gather findings of diverse meanings that people attach to pain. During my pastoral home visits, before I started this study, I found some of the oldest devout Catholics giving meaning to pain as a sanctification process before going home to see the Lord. The pain was the mechanism the Lord was using to purify their spirit (Judisch, 2009, personal conversations). These ideas likely originated from the concept of purgatory (Dumsday, 2014), particularly for Catholics. I did not have any findings other than those mentioned above about people attaching some kind of meaning to their pain; however, the kind of interviews I conducted did not lend themselves to in-depth questioning exclusively on faith-related issues. Despite this, phrases associated with Divine control of living when it came to ideas of old age were seen almost like a gift from God.

¹⁶² As a faith-related chapter, "stoicism" referred in this chapter is not the ancient Greek school of philosophy founded in Athens by Zeno of Citium. The school taught that virtue, the highest good, is based on knowledge, and that the wise live in harmony with the divine Reason that governs nature, and are indifferent to the vicissitudes of fortune, pleasure, and pain.

¹⁶³ “*Dios provee todo*” -*am4t2*

For instance, Elena was only age 76 but perceived herself as a *viejita* (old lady) not due to her chronological age but due to her aching body. She was managing high cholesterol, arthritis and high blood pressure. Her biggest health problem was her body aches and pains from arthritis, which observably affected her mobility and her quality of life. Her chronic pain is noticeably agonizing but she refuses surgery, cortisone injections or any strong painkillers. She was never quite able to articulate the reason for such endurance other than *hasta que Dios quiera* (until God decides [to take me]) because every day lived was a gift from God. Again, she appears to value non-medical interventions whenever she sees as optional treatment.

Excerpt 7.1.1d: God Controls My Lived Days

We are here until God decides. In the meantime, let's move forward (Translated from Spanish).¹⁶⁴

Similar to the idea of people attaching meaning to life's circumstances is this idea that people attach to pain. Elena does not know the meaning of her particular pain, but she believes it is from God, and she has chosen to endure it.

Excerpt 7.1.1e: God, if you don't take it away, at least help me endure.

Well, sometimes I ask God please take away my pain...why don't you want to take it away? Or do I not deserve it? Well, it's the only thing I say, and that He may cure me. That He give me strength...Well, I say that if I have [pain], it's for a reason, right? [chuckles]. But only God knows (Translated from Spanish).¹⁶⁵

Fear of Addiction

My respondents harbored a dislike for unnecessary medical intervention, particularly pain medications. Patients' often made comments on avoiding unnecessary drug use and other "unnecessary" medical interventions with statement, such as "God made me like this and I am

¹⁶⁴ "pues aquí estamos...*mientras Dios nos tenga aquí adelante.*"- am13t1

¹⁶⁵ "Pues a veces yo le pido ay Dios mío quítame mi dolor... ¿por qué no me lo quieres quitar? o no lo merezco? Pues es lo único que yo digo y que me alivie es lo que le digo. Que me de fuerzas...Pues yo digo que si lo tengo [el dolor] es por algo ¿verdad? [chuckles]. Pero solo Dios sabe."-am13t2

leaving [to heaven] like this,” “Why do I want more medicine?” (Translated from Spanish).¹⁶⁶

Many talked about the fear of becoming addicted to prescribed medications and referred to reducing or stopping particular pain medication to not allow the body to get used to it.

Excerpt 7.1.1f: Changed Medication

He changed my medication so that I would not become addicted to it (Translated from Spanish).¹⁶⁷

Foreign-born Latino elders in my sample deeply value natural remedies and the idea of being in “natural” states of being. The common dislike was to allow the body to get used to the effects of the drugs.

7.2 Where Faith Indirectly Shapes, But Does Not Determine, Medical Decisions

There are other ways that faith fits into medical decisions, such as giving meaning to the challenging circumstances they are facing (for an additional example, see the Dynamic Aspects of Faith section), and doctor’s actions incorporated as part of God’s larger divine plan.

7.2.1 Meaning to Challenging Circumstances

Unexpected and highly stressful situations often happen to people: how a person responds varies. People often face challenging circumstance such as a potentially life-threatening diagnosis. Still, many people cope by giving such circumstances meaning, what other researchers in the realm of oncology have termed “positive reframing” [carrion]. Most people in this cohort resorted to some form of prayer as part of their medical decision-making process. Prayer, as with other aspects of faith, is not in competition with medicine. It is often used to intensify or assist in treatments.

¹⁶⁶ “*Así me hizo Dios y así me voy a ir!*” “*Para que quiero más medicina?*”

¹⁶⁷ “*Me cambio de medicamento para que no me hiciera yo adicto al otro tratamiento*” -am12t2

The first case provides Bertha's example of experiencing a high-stress medically-related diagnosis and opting to pray first before going to get medical help. She was able to avoid the need for medical intervention. An 83-year-old Mexican, Bertha narrates her story of a time when a doctor diagnosed her with an orange-sized tumor in her uterus. Before her scheduled appointment for surgery, she stopped by a church to pray to God for healing.

---The case for miracles---

Excerpt 7.2.1a: God Saved Me

In those years, they did Papanicolau testing in the schools...I went with a doctor and he told me I had a tumor the size of an orange in my uterus. I said, Oh my Lord! I went home crying to my husband. He said, 'What's wrong?' I responded, Well, they told me this. So they sent me to the hospital to have surgery, and I went to the hospital with my suitcase, and I stayed all day in the hospital...Then a lot of doctors checked me, a lot of students. Then the last one who checked me was the main one. He said, 'Ma'am what are we operating on you for? What do you mean? You don't know of what I am being operated for? Well, supposedly I am having surgery because I have a tumor in my uterus. He said, 'You don't have anything.' But before heading there I had stopped by the Placita Catholic Church in Downtown Los Angeles to ask God that I would not have anything. I went to the Placita to ask God. So then when he told me I didn't have anything and asked unless you want us to remove your uterus. I said, 'Oh no! I don't want that... Well, I was overjoyed, very happy. That was what happened... Yes, God healed me because later I was examined again and they didn't find anything. Up to this day they have done Paps and I don't have anything. [I prayed]...I asked God that I would not have it. I prayed. I cried there in the church. There I cried to God that I would not need an operation. God heard me...I [did it] with a lot of faith. When I pray I do it with a lot of faith...Even a neighbor saw me crying and I got embarrassed. She didn't ask anything. But I cried. Now I understand why the ones that go pray to church cry because in Christian churches people cry when they are praying to God. Now I understand why they cry, because of their faith (Translated from Spanish).¹⁶⁸

¹⁶⁸ "Antes chequeaban a las mujeres en las escuelas. Le hacían a uno el Papanicolaou en las escuelas en aquellos años. Y resulta la que me mando con un doctor. Y fui con el doctor y **me dijo el doctor que tenía un tumor en la matriz del tamaño de una naranja [26:15]**. Hay dije Dios mío. Llegue llorando a la casa dice mi esposo ¿Que traes? Pues me dijeron esto. Como dice y en eso íbamos ir a México con mis hijos. Entonces me mandaron al hospital a que me operaran y me fui al hospital con mi veliz y todo me estuve todo el santo día en el hospital...Entonces ya de allí **me revisaron muchos doctores**. Muchos estudiantes. Entonces el último que me examino fue el mero jefe. Me dice ¿De que la van a operar señora? ¿Cómo que de qué? ¿No sabe usted de que me van a operar? Porque disque me van a operar que tengo un tumor en la matriz. Me dice 'usted no tiene nada.' Dice, **pero para esto llegue a la placita a pedirle a Dios que no fuera a tener nada [27:16] yo antes de ir al hospital. Me fui a la placita a pedirle a Dios**. Entonces ya que me dijo el no usted no tiene solamente que usted quiera que le quitemos la matriz. Le dije oh no le dije yo no quiero porque el doctor que me había visto que no fuera a salir embarazada porque si salía embarazada cuando tuviera a mi hija se me iban a salir los intestinos. Y para eso íbamos a ir a México. Y fuimos y todavía le dije a mi esposo llevaba con un doctor aquí que me dice el doctor de aquí. Y ya le platicué al doctor señora es que en Estados Unidos dice le gusta mucho capar a las mujeres dice. Les

She attributed the lack of a tumor to a miracle from God. While this did not influence a medical decision per se, it does illustrate how faith intertwines with the process of receiving medical care, serving as the basis for interpreting medical events.

The subsequent cases illustrate additional ordinary behavior where people used prayer in conjunction with medicine; it was not an either or option. Many people associated meaning based on the number of severe conditions they had to endure and overcome. The common and intuitive belief was that God was in control; therefore, anything that happened was associated with a purpose. Even if Bertha did not understand God's rationale, the belief that it was God's intention was present. This lady, for instance, had five major health events that brought her face-to-face with death. However, she thanked God because He was the one who pulled her out of death and into life. She claimed to be a living testament to God's power to heal. For her, every one of these health events had a purpose to increase her faith in Him, which made her feel like she was being born again.

Excerpt 7.2.1b: God has a Purpose

I do [have a lot of faith] because God has given me more than five opportunities with all of those things that I spoke to you about my illnesses. I am a living testament of all of the opportunities God has given me to be cured and to continue living and improving my health...It was like being born again. With the cancer, what happened to me with the embolism, the operation on my head, when I had peritonitis, when I had gallbladder surgery, and the hernia. Everything they [doctors] gave me, the blood transfusion because I had severe anemia. All of that...all of those times that I have been face to face with

gusta mucho meteré cuchillo decía él. Pues ya yo bien encantada bien contenta. Pero para eso primero llegue a la placita para pedirle a Dios. Y ya me salí ya más contenta. Eso es lo que me paso [28:13]. Tenía apenas el tercer niño cuando me paso eso. Pero ya tuve a los demás.... Si [Diosito me sano] porque ya después me volví a examinar y no me encontraron nada. Y hasta la fecha aquí ya me han hecho Papanicolaou y no tengo nada. [Hice oración]...le pedí a Dios que no fuera a tener. Una oración. A llorar allí en la igle. Allí llore en la iglesia. Allí le llore a Diosito que no tenga nada que no me vayan a operar decía yo. Y Dios me escucho...Si [lo hice] con mucha fe. Yo cuando le pido a Dios lo hago con fe. Hasta me vio una vecina dice me vio llorando allí hasta pena. Ya ni me pregunto nada. Pero yo llore en la iglesia. Ahora comprendo porque las que van a orar a la iglesia lloran porque en las iglesias cristianas lloran cuando están pidiéndole a Dios lloran. Ahora comprendo porque lloran. De la fe.”- am6t1

death, God has given me life to continue because God does not need me yet. It is not my time (Translated from Spanish).¹⁶⁹

She claims God used these events to increase her faith in Him:

Look, each time I have fallen ill and I have recuperated, it is with **a purpose that God** has to give me another opportunity for life and health to continue...remain strong in my faith, and in what I believe and what I have been taught...I feel like a new person, like I was born again. Each time that I have faced death with all of those illnesses, I feel that each time I have a new birth and am a better person...a better human being. To see life...in a more positive light and believe more in God. That God does exist. He exists (Translated from Spanish).¹⁷⁰

Her belief in God is not strengthened by what she perceives is God's purpose for her life, but by experiences that she associates with miracles. While this did not influence a medical decision per se, it illustrates how faith did not interfere in receiving medical care, but rather was part of Divine control.

Similarly, other people believe that they have also endured hardships to draw them closer to God. Francisco went through a lot of health problems which, he believes, God put him through because it was the pathway to happiness to be able to get up and be strong. "God put me in that pathway" (Translated from Spanish).

Of course God provides for everything...I feel very happy and full of energy. That is the change that I feel in me...closer to God...with my medical situation...God put me

¹⁶⁹ "Yo sí [tengo mucha fe]. Porque si Dios a mí me ha dado más de cinco oportunidades con todas las veces que le platique que me he enfermado, soy un testigo viviente de todas las oportunidades que Dios me ha dado a mí para aliviarme y seguir viva y estar mejor de salud...Fíjese que sí [era como volver a nacer]. Yo con lo del cáncer, con lo que me paso con la embolia, la operación de mi cabeza, cuando me dio el peritonitis, cuando me operaron de la vesícula, la de la hernia. Todo, señorita, que me pusieron a transfusión de sangre por lo que tan mala tenía mi anemia. Todo eso...todas esas veces que **yo he estado frente a frente a la muerte, Dios me ha dado vida y salud para seguir adelante. Porque, es que, todavía Dios no me necesita. No es mi tiempo.**" -am20t3

¹⁷⁰ "Mire, cada vez que yo me he enfermado y que me aliviado, es con un propósito que Dios tiene de darme este ... otra oportunidad de darme vida y salud para seguir adelante y yo ... **mantenerme firme en mi fe.** En lo que yo creo y lo que a mí me enseñaron. Me siento como una persona nueva. **Como que volví a nacer.** Siempre, siempre que enfrentado yo la muerte con todas las enfermedades que me han pasado yo **me siento que cada vez vuelvo a nacer y ser una mejor persona...un mejor ser humano. Ver la vida ... más positiva y creer más en Dios. De que Dios existe, si existe.**" - am20t3

through the correct path where I needed to go. He placed me exactly where I needed to go through in order to lift me up again (Translated from Spanish).¹⁷¹

Not everybody found the meaning of their circumstances through their faith. The question was not related to God's involvement in the action, but rather why is God doing this? What does it mean? Why does God show me this? Juan, for example, suffers from heart conditions and has deep fears surrounding this topic. He described at least three graphic stories of people around him (acquaintances and friends) dying suddenly from a heart condition (stroke or heart attack). These stories highlighted his fear of dying from a sudden heart attack. In the first event, one of his good friends, *a huesero* (bone-setter) from back home in Guadalajara, Mexico, fell and died. In the second event, he described how he often attended a public park situated across from his home where older gentlemen gathered during the day to pass the time and talk. While standing and talking with several gentlemen, out of the blue one of the men fell down and died. In the third event, he was sitting next to a 28-year-old in a park gymnasium as they waited for a free lunch. The young man leaned towards him and plopped his head on the table instantly dying from a heart attack. Juan wonders why God has allowed him to see all of these things. He wonders if he will be dying that kind of death. His fears of dying a similar death have led him to be more active and engaging during medical encounters. He was one of the few people interviewed who was able to instantly describe stories and events with practitioners, specialists and all involved on a first and last name basis. Although he believes in Divine control, he was not passive about his medical care and his involvement in medical decision-making.

Patients found meaning in almost every medical-related phenomenon, which in turn fed back into their medical decision-making process. As mentioned earlier, they believed it was the

¹⁷¹ “**Claro que Dios provee todo...Y pues me siento bien contento lleno de energía. Ese es el cambio que yo noto en mi...Mas unido a Dios... con [mi] caso medico...El [Dios] me puso en el camino correcto donde tenía que ir. Si. Él me puso exactamente donde yo tenía que ir para levantarme de nuevo.**” –am4t3

way God often tried to get the patients' attention, tried to communicate something either through the use of miracles, or like Juan who speculated that being in these places at the exact times of death was God's way of communicating something to him, potentially about his own future mode of death. All of these circumstances fed into his fears and often resulted in his making proactive medical-decisions that supported the management of his heart-related conditions (see Chapters 4 and 5).

7.2.2 Doctors Actions: Part of God's Larger Divine Plan

Foreign-born Latino elders at the time of the study believed in an all-powerful and mighty God who controls all aspects of the human experience and beyond. However, this belief did not oppose practitioners' treatment recommendations, but rather often increased participants' trust in physicians. An inherent order of importance seems to be present when it comes to faith in medicine. "God is first and then the doctors. That is the base. God is first and then the medical doctor and then medicine" (Translated from Spanish).¹⁷² Faith was often used in conjunction with medical treatments not as a replacement. "We believe in God. Yes! We believe in medicines, too" (Translated from Spanish).¹⁷³ All of the foreign-born Latino elders in this sample believed in Divine control, which indirectly influenced the way patients made medical decisions.

Most foreign-born Latino elders also believed that God works through people to accomplish His will, which included the clinician. The clinician was often viewed as being God's instrument of curing/healing (irrespective of whether the clinician agrees or not).

¹⁷² "Dios primero y después el médico. Esa es la base. Dios esta primero y después está el médico y después esta la medicina." -am22

¹⁷³ "Cree uno en Dios. ¡Sí! Cree uno en las medicinas también." -am16t2

Therefore, rarely did a contradiction of values impede recommended treatments unless the treatment was seen as being in direct opposition to God’s commands or as something not from God such as secular versus biblically-based counseling (see Faith’s Direct Interaction with Medical Decision-making section) or simply not perceived as a health issue (e.g., mental health). This is not to say that tensions around value systems between foreign-born Latino elders and the medical system do not exist. Unfortunately, tensions do exist particularly as we move to decision-making in critical situations, when emotions are heightened such as the case of end-of-life care (more on this subject below).

The patients’ placed their faith in God, whom they felt was capable of performing miracles. There are two methods in which the miracle is believed to be performed. Earlier, a respondent explained how she saw God perform a miracle directly by eliminating a tumor. Second, God can use the physicians’ hands as his instruments, a second potential avenue for hope that I explain with the following example.

Excerpt 7.2.2a: Doctors are God’s Instruments

God works...through people...Works through medical doctors as well because the people who took care of me...like the doctors who took care of me, they are instruments that God uses so that they can give me the medicine, to make the correct diagnosis and so that they could help me feel better and to improve my health...They are instruments of God...because if God did not give them the intelligence, the knowledge how would they be able to take care of us? (Translated from Spanish)¹⁷⁴

When we talk about resiliency in the Latino population, we may simply be seeing an increased level of hope—a double measure of hope if it could be quantifiable. Since they believe the doctors are the working hands of God, the only thing left to do is *encomendarse al Señor* (entrust

¹⁷⁴ “Dios trabaja...atreves de las personas...Trabaja atreves de los médicos también porque, [Dios] a las personas que a mí me cuidan que me...como los doctores que me atienden y todo esos, son instrumentos que [Dios] usa para que ellos me den la medicina, que hagan los diagnósticos correctos y me puedan para que yo me sienta mejor y este mejor de salud...Son instrumentos que Dios...porque si Dios no les diera las...la inteligencia, el saber todo eso, como lo iban a cuidar a uno.” – am20t3

yourself to God), a popular Catholic Spanish phrase. This is a final form of surrender to a higher power.

Excerpt 7.2.2b: Surrendering to God's Will

I entrust myself to the Virgin Mary and to God the Father...if they are going to do something to me...like a treatment, I always entrust myself to them. Because, as I said, I am not scared that I could get hit or that I could die in that moment. I don't get nervous. I only entrust myself to them and that's it (Translated from Spanish).¹⁷⁵

Many try to surrender to God's plan and to accept the outcome. However, this is often easier said than done, as will be explained further in the next section.

Excerpt 7.2.2c: We Must Endure the Good and the Bad

I know that for everything we must consult with God, and let His will be and then we do what is convenient. One asks God with hope and faith that He will help us but also sometimes God says wait...be patient or...it is your hour. Endure that, like also enduring the good that happens...we must also endure the bad. So then I am content (Translated from Spanish).¹⁷⁶

Patients also attached meaning to circumstances created by the physicians' actions, believed to be part of God's divine plan. Although, most prayers associated with medical decision-making were individually-based and self-initiated by the patient, some were initiated by the physician. When a prayer request was initiated by the physician, the patients created meaning. The context and the physician's role matter because the physician holds much power and responsibility. In the following scenario, the physician has just given Francisco a prostate cancer diagnosis and referred him to an oncologist, which he perceived as a death sentence. The physician then suggested that they pray. The doctor's actions confirmed his idea that she had just handed him a death sentence. He told himself that she, the expert, was seeking help from a

¹⁷⁵ "siempre cuando salgo me encomiendo a la Virgen de Guadalupe y mi padre Dios...si me van hacer algo...una curación o algo así, siempre me encomiendo yo a ellos. Así porque como luego se dice yo no soy así que **me asusto** porque se me va pegar o me puedo morir en ese momento. No me agarran los nervios. Yo no más me encomiendo a ellos y eso es todo." –am24t2

¹⁷⁶ "yo sé que para todo debemos consultar a Dios. Y dejar a la voluntad de él y hacemos lo conveniente. Porque uno pues **le pide a Dios con la esperanza y la fe de que él nos va a ayudar**, pero también hay veces de que Dios dice espérate... tener paciencia o...ya es tu hora. Soportar, así como soportar lo bueno que te pasa...también soportar lo malo. **Entonces me conformo.**" – am1t2

Higher Power (through prayer), and if she, being the expert, was seeking additional help it meant that the situation was dire. His doctor's actions told him he was dying; it was like giving him a *despedida* (farewell).

Excerpt 7.2.2d: Physician-Initiated Prayer

The doctor motivated me. She said don't worry there are a lot of good doctors that can help you with surgery. She then asked **do you want to pray with me**. I said 'ok,' We prayed, right? We also prayed before I went into surgery...its strange but I felt like I was going to die. Well, because **to pray like that is like saying farewell to the world** [laugh]. Yes, those were my thoughts. Yes, she was motivating me but I felt like something bad was going to happen...[she was giving me mixed messages] (Translated from Spanish).¹⁷⁷

The clinician's actions implied to the participant that the situation was more serious than words revealed, so when he went to see the oncologists, *he chose* the most invasive treatment option available. He was given other options, but he went into the oncologist office with a decision already made, prompted by his physician. The perceived degree of seriousness did not even let him consider learning about the other potential treatment options. This was a crisis-based decision, and he feared for the worst if he failed to pursue the most drastic medical treatment available, surgery.

The primary care physician initiated prayer twice: once when he received his cancer news, which he equated as a death sentence, and right before going into surgery, which he interpreted as a way of asking God to work through the surgeon's hands.

In these cases, faith has the potential to directly or indirectly influence decision-making.

Faith is often used as a coping mechanism and as a way for participants to make sense of the recommended medical treatment. As we will see in the sections that follow, faith and medicine

¹⁷⁷ "La doctora me animo me dijo no te preocupes ya hay muy buenos médicos que te pueden hacer una cirugía que te pueden este ayudar. **Ya agarro y me dijo quieres hacer una oración conmigo**. Le digo "ok." Hicimos una oración ¿verdad? También hicimos una oración cuando iba yo ir a la cirugía ¿eh? Es raro. Pero yo sentía como que ya me iba yo a morir. Pues si porque **hacer así una oración es como para despedir a uno del mundo**. [risa]. Si esos [son los] pensamientos. Si...me estaba animando, pero sentía yo digamos que algo me iba pasar pues... [me estaba dando mensajes mixtos]...exacto."-am4t32

work synergistically together, both providing hope in medical treatment, and in God. Whether or not these two function to have a cumulative effect or work to provide the same goal mutually exclusive from one another is left to be discovered in future research endeavors. Nonetheless, what is known is that one does not compete with the other.

7.3 Dynamic Aspects of Faith

Faith is a dynamic and multidimensional concept with the potential to penetrate and be included at all levels of an individual's life. The more aspects of an individual that faith touches, the stronger the influence it has on a person's medical decision-making process and deliberation. Faith is not necessarily a constant feature of a person's life but rather represents a potentially dynamic journey in the relationship between God and the person. Claudia's story puts into perspective how God at times may be perceived as speaking directly to the person through circumstances, and how those circumstances can lead to an ebb and flow of faith. These experiences directly feed into a person's decision-making, including medically related decisions (e.g., seeking care in the United States versus home country).

A 69-year-old married female from Guatemala was taking medication for high blood pressure, depression and anxiety. She was experiencing a streak of misfortunes. Her home had been recently foreclosed, and she was unhappily living in a studio apartment with her husband. She was coping with the loss of her mother, and most recently her youngest son had passed away from kidney cancer. She had been hospitalized five times due to her previous doctor overmedicating her. During this interview, she utters God's name a few times, all in an abstract form of thanking God. A large focus of the first interview was the constant comparison of quality of care, costs, and quality of doctors in the United States and her home country.

By the time our second interview, she was actively grieving the sudden and unexpected loss of her husband. The whole interview was embedded with tangible God-related phrases.

When she was directly asked about her faith, she explained how her losses challenged her faith:

Excerpt 7.3a: Faith is a Journey

Well...at the beginning I am going to be honest...when my son died **I lost faith** in God...I complained. But slowly I started regaining my faith and the belief that God exists...there is a reason He took him and...I would pray the rosary every day and there was a time when I stopped...sometime later I started seeing a psychiatrist, then I started to pray again and now I pray every day. I pray for myself...people who have passed, my family's well-being, my living children...and like that, thank God I have recovered my faith... I didn't believe in God. I blamed him. I was mad at him. (Translated from Spanish).¹⁷⁸

She felt that God's actions had spoken to her. She created meaning by the events that had occurred. Claudia perceived her husband's sudden death as a blessing from God. Had events not unfolded with her husband's death the way they had, she would have been serving in a caregiving role, something she did not desire.

I tell you it was so sudden that I didn't think of anything in that moment. And what I say is that **God knows why he did it like that, so that I would not suffer. Well that made a lot of sense to me...**because had it been that something would have happened to him, I would have suffered. How would I be now? [I would have had to take care of him] (Translated from Spanish).¹⁷⁹

By the third interview, she was hopeful and proactively seeking avenues for financial stability. Although she possessed a grade-school level of education, she was a successful

¹⁷⁸ “Bueno...al principio le voy hacer franca...cuando murió mi hijo **yo perdí la fe** en Dios pues...renegaba. Pero poco a poco la fui a agarrando otra vez y ya la agarre otra vez la fe que sí existe Dios y que...**por algo se lo llevo** y...pues yo rezaba el rosario todos los días y llegue un tiempo que ya no lo hice pero de ahí...al poco tiempo pues cuando seguí viendo el psiquiatra pues ya empecé otra vez a rezarlo y hasta ahora pues lo rezo todos los días ya le pido por mi...gente que esta fallecida, por mis familia que está bien, mis hijos que están vivos pues...y así pues gracias a Dios pues he recuperado la fe. Porque si la había perdido...no creía en Dios ... No creía. Le echaba la culpa...Estaba enojada.” – am10t2

¹⁷⁹ “Si. Pero digo yo pues...no sé cómo le digo una cosa tan repentina que yo no pensé en nada en ese momento. Y lo que digo pues **Dios sabe porque lo hizo así. Y para que yo no sufriera. Me dio mucho sentido pues...**porque si, si hubiera sido que viera que yo sufriera pues le hubiera pasado algo a él y yo sabe cómo me hubiera quedado.” – am10t2

businesswoman and owned properties in her home country. She had become hopeful with a positive outlook, and she was optimistic of her future.

When unexpected, highly stressful and negative situations happen to people, they may question their faith. Being angry at God is a natural human response to misfortunes. Therefore, it is necessary for the health system or the practitioners to constantly assess a patient's faith, as much as they assess other aspects of a person's life that may impact their health. Not simply because one asks about a person's "religion" and checks a box does this reflect patients' personal values and beliefs as ascribed by an organized religion. People's faith may ebb and flow in the same way as do many other dynamic and relational aspects of human beings.

7.4 Faith, Fear, and Hope in Medical Decision-Making

Faith's role in medical decision-making among foreign-born Latino elders may appear tangential since it does not seem to interfere with medical care treatments. However, this observation was made when analyzing preference-based medical decisions. Medical decision-making is contextualized along a continuum of perceived outcomes, ranging from preference-based on one end of the spectrum to crisis-based on the opposite end of the spectrum. The severity of the perceived outcome gives faith a different level of importance that creates unique dynamics with varying degrees of tension between hope, fear, and faith. Following the same conceptualization as briefly discussed in Chapter 4, for preference-based decision-making fear, hope, and faith work synergistically, while crisis-based decision-making can have fear, hope, and faith work antagonistically with each other.

7.4.1 Preference-Based Decisions

Although there was a general understanding among the participants that their medical conditions were chronic and incurable, many clung to the hope for a miracle from God. They felt they should never relinquish hope regardless of the circumstances. (This can be problematic in critical decision-making, as we will see).

Excerpt 7.4.1a: Almost Incurable

Treatments controlling only a little because to cure is difficult...you know that diabetes is almost...is incurable, well, it's controllable only...well, look I have the hope that maybe God will want to perform a miracle, and I will regain my health (Translated from Spanish).¹⁸⁰

Although there is an understanding that chronic conditions are incurable, there is a lingering hope that lies in the supernatural, in God and in miracles. They are hopeful that in asking through petition and prayer a cure could happen. They pray and hope for the best, while at the same time they wait and accept their situation. They never relinquish hope because they feel that a miracle could happen at any time. The waiting process is where emotions and choices are made. If their prayers go unanswered within their expected time frame, then they either surrender (excerpt 7.2.2c) or feel despair (excerpt 7.4a), but never relinquish total hope.

7.4.2 Crisis-Based Decisions

On the opposite end of the medical decision-making spectrum are situations like those often encountered in end-of-life (EOL) care decision-making. In this situation, tensions between personal values of hope, belief in miracles and Western medicine appear to be heightened.

During our general health decision-making discussions, foreign-born Latino elders often shared their preferences for end-of-life care. We would start by talking about the people they involved

¹⁸⁰ “*uno por medio de tratamiento va uno controlándose nomas tantito porque para sanar pues es difícil...ya ve que la diabetes esa casi...es incurable pues se controla únicamente...Pues miré yo con la esperanza que quizá Dios quiere un milagro ya quedé bien yo pues ...*” – am12t2

during their decision-making process and about faith and the meaning of dignity, which brought up discussions around EOL care. Most patients sternly voiced their opposition to strenuous measures such as maintaining the body alive with a ventilator and being attached to tubes. That was often viewed as artificial living and was rejected by many participants. “I do not want anything artificial” (translated from Spanish).¹⁸¹ The value of living as naturally as possible, as described in Chapter 6, is seen here. Also, their decreased hope in medicine and a surrendering to the will of God is described in these circumstances.

Excerpt 7.4.2a: No Tubes

I have said if for any reason I end up landing in the hospital and I am full of tubes, I do not want tubes placed, nothing. Whatever God wants and period (Translated from Spanish).¹⁸²

Excerpt 7.4.2b: No Machine

When I am in a serious situation, dying, if they ask if I accept that they hook me up to a machine, I will say no. I do not want the machine. Even if the doctor argues nonstop, no way. Even if they have me there dead except for the machine, I don't want it (Translated from Spanish).¹⁸³

As discussed earlier, the doctor holds a lot of power. They have the power to influence decision-making because they are not only seen as the instrument of God's hands, but they are also expected to know what is going to happen, as was explained in Chapter 5 in the discussion of “*el buen doctor*.” Doctors hold the influencing power to say there is nothing more medicine can do, and to provide no alternatives.

¹⁸¹ “*no quiero nada artificial.*” -am1t2

¹⁸² “*yo también he dicho que, si por alguna causa llego caer en el hospital y estoy lleno de tubos, yo no quiere tubos puestos, nada. Lo que Dios quiera y punto.*” – am24t2

¹⁸³ “*Que si cuando ya esté muy grave ya muriéndome que si yo acepto que me pongan la máquina. Yo digo que no. Yo no quiero la máquina. Que el doctor diga hasta aquí ya ya no. Pero que me tengan allí muerta con maquina eso si no quiero.*” – am6t1

All members of GraciaMed's PACE program are required them to fill-out advance directives. Most discussed their process when thinking through the questions in the document. Most included family members' names, but had yet to talk to loved ones about the issue.

Excerpt 7.4.2c: Advance Directive

I have a document I signed, for example, it says that in case I need to be intubated or was in a coma, if I would accept to be there the necessary time...many medical questions like that...in case I needed to receive tube feeding...like that...so then I have everything ready there...whatever happens, that document they have to take it to the doctor or the hospital. Because my decision for everything is that I do not want anything artificial...the one who is to decide is my son. But I do not want anything artificial (Translated from Spanish).¹⁸⁴

Although the participants voiced their preferences to the system, and family members, given my personal experience, I foresee problems. There is a tension between faith and medicine. Once the patient has been placed on “artificial” life support, it is difficult for family to decide when to relinquish control. The family may very well insist doctors do everything possible to stave off death, even in the face of incurable disease and great pain. If patients believe in the power of God and miracles, then by stopping treatment it is often like saying they do not trust God to perform a miracle.

¹⁸⁴ “Tengo un documento que firme...por ejemplo, ahí dice que si en caso de que yo necesite estar entubada o estar en...como digamos que este en coma...que aceptaría estar ahí el tiempo necesario...también muchas preguntas así medicas si en caso yo necesitara comer por sonda...y así...entonces tengo eso ahí listo...que cualquier cosa que me pasa, eso se lo tienen que llevar al médico, al hospital. Porque ya mi decisión por todo es que **no acepto nada artificial**...el que debería de tomar decisiones era también mi hijo. Pero mi deseo era no quiero nada artificial.” – am1t2

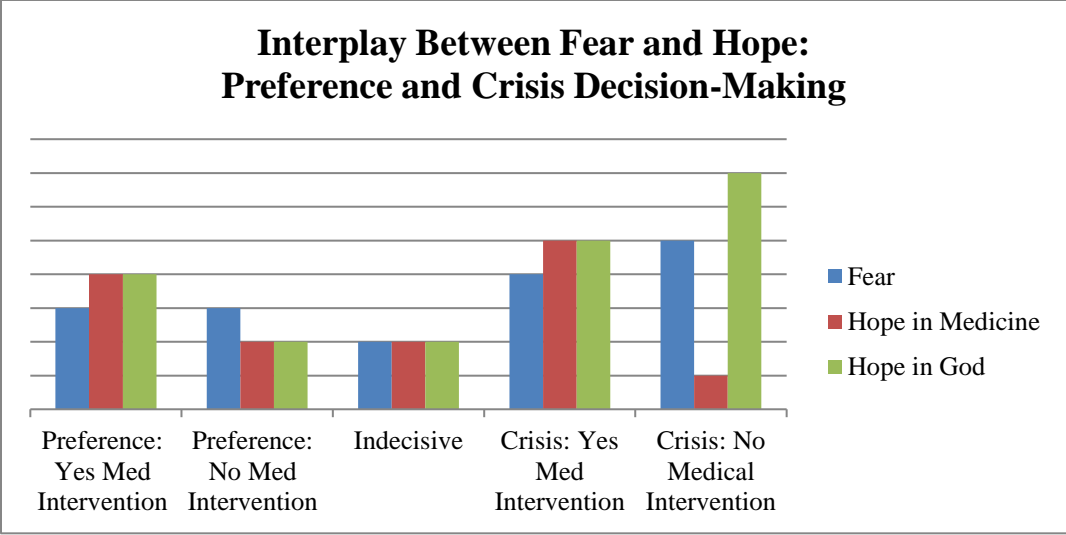


Figure 7.2: Medical Decision Making Along the Continuum
(a) Preference - Yes: The hope in medicine and God outweigh any fear, and a decision for medical intervention is reached. **(b) Preference - No:** Fear is greater than hope in medicine or God, **(c) Indecisive:** No decision is reached. Fear and Hope levels are the same. **(d) Crisis - Yes:** The hope in medicine and God outweigh any fear and a decision for medical intervention is reached. **(e) Crisis - No:** The hope in medicine is low, and the hope in God outweighs fear.

In summary (Figure 7.2), along the decision-making continuum, an acceptance of a preference-based medical intervention basically means the fear of the perceived outcome is smaller than the hope in medicine and hope in God; whether the hope has a cumulative effect will need to be analyzed empirically later. Refusing preference-based medical intervention essentially means the perceived fear of the medical intervention is greater than the hope in medicine or hope in God. Being indecisive about a medical decision means the dynamic features of fear, hope and faith are cancelling each other out. A medical intervention acceptance in a crisis-based situation plays out in a similar pattern to that described in preference-based medical intervention acceptance: the hope in medicine and God are greater than the fear. A decline in a medical intervention during a crisis-based situation means that hope in medicine has decreased to a lower degree than fear; however, the only hope remaining is a hope in God, which is heightened at this stage. Faith is brought to the forefront during critical periods while in

preference-based it usually moves to the background. In crisis-based decision making all of these values are heightened.

7.5 Faith and Active Listening

Active listening for faith-related comments can be used as a strategy to identify foreign-born Latino elders' medical preferences, which can aid practitioners to facilitate the patient's medical care decision-making process. The majority of my interviews had expressions of God linked with the patients' desired health state. Many nuanced forms of "thanks to God"¹⁸⁵ statements were coupled with a patient's medical preferences from avoiding radiation treatments, to disliking the idea of becoming dependent on others, to the undesired state of having their diabetes condition progress to an insulin-dependent state.

By listening to people call out to God, the practitioner may get an indirect indication of what the patient sees as a valuable health state. Calling out to God also highlights another value that these patients have on the importance of being in a state of constant gratefulness. An expected cultural norm is to be grateful for what is currently given and to ensure nothing is taken for granted—another value correlated to the idea that God is in control. Here is a list of quotes taken directly from the interviews to better illustrate the point:

- *"no tengo necesidad de walker, ni de bastón gracias a Dios hasta ahorita."* – am10t1 (Until now I have no need of a walker or a cane, thanks to God.)
- *"Y luego problemas de cataratas [01:43] y ya con este casi llego poco y ya no bendito sea Dios allí en GraciaMed me operaron los dos ojos."* –am1216t1 (and then problems with cataracts, and then with this one I got close but blessed be God, at GraciaMed they operated on both of my eyes.)
- *I: ¿No está tomando insulina? P12: No. Bendito sea Dios que no.* (I: Are you taking insulin? P12: No, blessed be God, no.)

¹⁸⁵ *Por la gracia de Dios* (for God's grace). *Bendito sea mi Padre Dios* (blessed be my Heavenly Father)

- “*Gracias a Dios que nunca he caído al hospital.*” (Thanks to God I have never landed in a hospital.)

It would seem that these kinds of comments and remarks embedded within everyday conversations are potential goldmines for medical practitioners who are seriously interested in knowing about patients’ medical care preferences.

This cohort of older foreign-born Latinos range in communication styles¹⁸⁶ but overwhelmingly fit into the traditional views of the Latino culture, as cited previously (Alejandro, Elliot, etc.). Thus, people may not be good at expressing their medical preferences but when a doctor engages in patient—centered interviewing and seeks to actively listen they are more likely to passively and indirectly capture a patient’s true desires—a culturally appropriate manner to collect information (see Chapter 6).

7.6 Chapter Summary

I see [the Lord] when I am in a dire sick state. Yes, I talk with them [the Virgin Mary and my Heavenly Father]. I don’t last long in such a grave state. I start to notice that I begin to come out of my discomfort (Translated from Spanish).¹⁸⁷

Faith is an important aspect of medical decision-making for the older immigrant Latinos I interviewed repeatedly. The belief in an all-powerful and mighty God, who controls all aspects of life and death, led patients to use faith as a coping mechanism through prayer and to associate meaning to circumstances, behaviors, life events and experiences. Generally, faith was not in direct opposition to medical care treatments, with the exception of secular counseling for mental health. Given faith’s underlying notion that God is in control, faith indirectly influenced

¹⁸⁶ Described in the medical encounter chapter.

¹⁸⁷ “*Lo miro [al Señor] cuando me miro muy enfermo. Si les...hablo con ellos [la Virgen de Guadalupe y mi padre Dios]. Y no duro mucho grave, pero empiezo a notar que voy saliendo de mi malestar, así.*” – am24t2

decision- making; however, faith was particularly magnified in times of crisis where critical decisions were contemplated.

CHAPTER 8.0: MEDICAL DECISION-MAKING DISCUSSION AND CONCLUSION

Managing multiple chronic health conditions is an ever-increasing reality for a majority of foreign-born Latino elders living in Southern California. As a result, they are at increased risk for mortality and poorer day-to-day functioning. Management of multimorbidities necessitates ongoing attention, requiring numerous medical encounters and medical decision-making.

This study aimed to identify the factors that foreign-born Latino elders with multiple chronic conditions residing in Southern Californian used to make medical decisions. Through a series of longitudinal interviews, patients' experiences during medical encounters, cultural beliefs and values involved during medical decision-making were identified, such as cultural concepts of illness, treatment regimens and the role faith plays in medicine.

Decision-making is a dynamic and enigmatic process, but add a medical context and a culture dimension and it compounds the layers of complexity. Latino culture, faith, patterns of engagement and communication are all intertwined. Various behaviors that Latinos manifest often originate from deeply embedded values that have been passed down through generations. These core ideals are so intrinsic to the individual that participants are often blind to how their actions are telling. Foreign-born Latino elders' decision-making processes are made within a cultural context and unique to each person. Decisions follow a pattern described by a proposed model that involves balancing a fear of perceived results with or without medical intervention and hope both in medicine and God (Figures 4.1 and 7.2). Personal and vicarious experiences, knowledge, available resources and, most importantly, cultural beliefs, values and norms inform the pseudo cost-benefit analysis of perceived risk and benefits. All of these factors are dynamic and moving pieces of the decision-making puzzle. Therefore, regardless of type of medical

decision these moving parts may hold more influence than others at any one time, yet are included in the decision deliberation process.

8.1 A General Medical Decision-Making Model

A general medical decision-making model was developed based on fears of perceived outcomes and hopes in medical interventions and God. Economic ideas of cost and benefits analysis and the image of Lady Justice influenced this framework. Rather than a traditional rational actor type of cost-benefit, however, this model is manipulated by patients' context-based experiences, knowledge, resources, cultural beliefs, values, and norms. The framework presented in chapter four highlights patients' fears as a decision-making driver—a negative perspective. The decision-making structure presented within the faith section explains the same process but from a hope rather than a fear perspective, which emphasizes patients' hope in medicine, and hope in God—an encouraging viewpoint. The model is described using the positive (hope) and negative (fear) viewpoints; two concepts simultaneously operating within the model.

Medical decision-making is contextualized along a continuum that runs from preference-based to crisis-based. Along the continuum of decision-making, fear of perceived results and hope work synergistically or antagonistically depending on the context of the decision. In preference-based decision-making, fear of the perceived outcomes and hope work synergistically with each other; as the fear of the perceived consequences increases so does the hope in a medical intervention and hope in God's works. An acceptance of preference-based medical intervention basically means the perceived fear of the results is smaller than the hope in medicine and hope in God, whether the hope has a cumulative effect will need to be analyzed empirically later. Rejecting preference-based medical intervention essentially means the fear of the perceived results of the medical intervention is greater than the hope in medicine or hope in God. However,

the synergy between fear and hope becomes more antagonistic and tension-filled as the situation becomes increasingly critical and crisis-mode decision-making takes place (e.g., end-of-life care). At this state, fear of the perceived results is heightened and hope for medical intervention decreases. However, among foreign-born Latino elders, even when the hope for medical intervention is diminished, a lingering hope usually lies in the supernatural ideas of God and miracles. Faith is brought to the forefront during critical periods while in preference-based decision it is typically in the backdrop. In crisis-based decision making all of these values are heightened (Figure 7.2).

8.2 The Influence of Cultural Beliefs and Values on Medical Decision-Making

Faith and culture are intertwined and ever-present, even if subtly, during medical decision-making. They inform foreign-born Latino elders with multiple chronic conditions on how to engage during the medical encounter, how to interact with authority, how to build relationships with respected professionals in positions of power, how to think about their conditions and treatment regimens, and how to make sense and manage all their conditions. This section and Table 8.1 provide a review of the research question and the summary of findings.

Table 8.1: Summary of Findings of Foreign-born Latino Elders with Multimorbidities and Medical Decision-Making

Overarching Research Question		
<p>How do foreign-born Latino elders with multiple chronic conditions make medical decisions?</p> <ul style="list-style-type: none"> By using a decision-making model based on balancing the fear of perceived outcomes with or without medical intervention and hope both in medicine and God (see figures 4.1 and 7.2). This pseudo cost-benefit analysis uses perceived risk and benefits, which are informed by personal and vicarious experiences, knowledge, available resources, and most importantly cultural beliefs, values and norms. 		
Specific aims and Sub-aims	Findings	Highlighted Beliefs, Values or Cultural Norms
Specific Aim 1:		
<p>What are the <u>patterns of engagement</u> in medical decision-making? (Chapters 4 and 5)</p>	<ul style="list-style-type: none"> Four patterns based on receptivity level (receptive/open, cautiously optimistic, cautiously skeptical, and unreceptive/closed) were identified. Three types of engaging medical encounters[#] (technical, social, emotional) were identified. Participants were most likely to engage in medical encounters in social and emotional ways. Trust increases with level of patient-doctor relationship (<i>good doctor, person of trust, advocate</i>), as trust increases so does patients pattern of receptivity. 	<p>Values in Engagement and Relationship Development:</p> <ul style="list-style-type: none"> Value emotion Value relationship Value family Value “truth-telling”^{**} Value personable/ honorable/ benevolent characteristics (e.g., integrity, friendly, inspires trust).^{**} <p>Beliefs in Communication:</p> <ul style="list-style-type: none"> Context-based belief in being grateful (undertone – God is in control, therefore do not complain especially to people in positions of power) <ul style="list-style-type: none"> <i>no begging, no bothering, embarrassment</i>^{&} Indirect communication
<p>Sub-Aim 1.1: Under what circumstances are older adults choosing to include or exclude family in the decision-making process? (Chapter 5)</p>	<ul style="list-style-type: none"> Family involvement varied based on severity of context, type of decision and family relationship. The more severe the circumstance, the more likely family was to be involved. 	
Specific Aim 2:		
<p>How do patients’ <u>cultural concepts of illness</u> influence medical decision-making? (Chapter 6)</p>	<ul style="list-style-type: none"> <i>La impresión</i> (fright-like emotion), negligence, <i>ataque de nervios</i> (nerve attacks), moon shapes and weather were identified as causes of disease. Cultural causes of illness (e.g., <i>la impresión</i>) and associated treatment regimens are not in direct opposition to medical care treatments. Biomedical treatment regimens were supplemented with home remedies and other forms of alternative medicine— anything that helped to normalize the human body to a natural state of balance and harmony. 	<p>Beliefs and Values in Human Body:</p> <ul style="list-style-type: none"> Human body in most natural form, unharmed by strong medicine/treatments, is the most desirable state. Human body in a state of harmony and balance <ul style="list-style-type: none"> Hot/cold Value natural treatments Belief in power of biomedicine Once the human body has been afflicted it never fully recuperates
<p>Sub-Aim 2.1: How do patients’ perceptions of their medical conditions influence medical decision-making? (Chapter 6)</p>	<ul style="list-style-type: none"> The perception of certain health conditions is not equivalent to Western medicine or mainstream American philosophies/views (e.g., depression, anxiety-disorders, diabetes, chronic pain). The participants often attributed such health conditions, particularly 	<p>Beliefs and Values in Health:</p> <ul style="list-style-type: none"> Social conditions and life stresses have a negative cumulative effect on human body. Belief that declining function of the human body is a normal

	<p>mental health, to social ills; therefore, biomedical treatments conditions may go ignored, or are treated with a combination of homeopathic, biomedical, and/or alternative treatments.</p> <ul style="list-style-type: none"> • The perception of disease causation often arose from the culminating impact of social ills on the physical human body. 	<p>part of aging. The rapidity of aging is due to life stresses endured earlier during their lifetime.</p>
Specific Aim 3:		
<p>What role does <u>faith</u> play in medical decision-making? (Chapter 7)</p>	<ul style="list-style-type: none"> • Faith serves as coping mechanisms most often manifested through prayer. • Faith helps to create meaning to life's circumstances (e.g., death, miracles). • Similar to medicine, faith provides hope. 	<p>Beliefs and Values in Faith:</p> <ul style="list-style-type: none"> • From a Christian/Catholic perspective, belief in the existence of an omnipotent and omniscience God. • People communicate to God through prayer, and God communicates to people through actions (including through clinicians, i.e. God's will may be done through the efforts of medical personnel).
<p>Sub-Aim 3.1: How does a patient's faith shape medical decision-making? (Chapter 7)</p>	<ul style="list-style-type: none"> • Generally, faith is not in direct opposition to medical care treatments, with the exception of mental health disorders due to perception of illness.⁺ 	
<p>Sub-Aim 3.2: Under what circumstances is faith most likely to be included? (Chapter 7)</p>	<ul style="list-style-type: none"> • Given faith's underlying tone in the belief that God is in control, faith indirectly influenced decision-making, however, faith was particularly magnified in times of crisis where critical decisions were contemplated (Figure 7.1). 	
#	<p>Medical encounters are broader than the clinical office visit and inclusive of all the experiences that the patients have had with various personnel within the health care system.</p>	
*	<p>Truth-telling is perceived different than the ethical principle of informed-decision as presented in mainstream America (see Chapter 5, Sub-Section of 5.3.2 "Value and Perception of Truth-Telling").</p>	
**	<p>Patients value when a person in a leadership position inspires trust (see Chapter 5).</p>	
+	<p>Caveat: Faith took a more determining role in mental health conditions. Often times when biomedical treatments declined, faith-related activities increased.</p>	
&	<p>See Chapter 5, Section 5.4.3 "The Meaning of Silence"</p>	

In sum, patients' placement within the four levels of the receptivity continuum influenced patients' medical decisions: receptive/open, cautiously optimistic, cautiously skeptical and unreceptive/closed (Chapter 4, Aim 1). These levels are not rigid but porous, allowing for free movement between the levels. Many factors potentially assist people in moving through the levels of receptivity to engaging medical decision-making. However, with respect to the data, cultural beliefs and values played a major role in such movement. Three types of engagement (technical, social, emotional) were described as occurring within medical encounters (Chapter 5,

Aim 1). Relationships are valued in the Latino community, and emotional and social types of engagements were better at developing relationships than technical-engagement. Relationships with various people within the healthcare system were key to assisting patients' movement throughout the levels of receptivity to medical encounters and medical decision-making. Positive experiences resulted from effective communication and trust or vice versa, while negative experiences worsened with ineffective communication devoid of trust. Similar to the valuing of relationships, Latinos also typically value family. However, family involvement was dependent on the nature of the decision, dynamics around the family relationship and family proximity (Chapter 5, Aim 1).

A recurrent theme is that cultural beliefs inform Latinos medical decision-making. Although Latinos' may hold to cultural concepts of disease causation, treatment decisions are not typically in opposition with biomedicine (Chapter 6, Aim 2). Preferred treatment options are those that fit within the patients' overall theme of maintaining the body in a state of balance. In situations where the body is diseased and this is seen as upsetting the body's balance, medical treatments meant to assist in normalizing the body are likely to be adopted. A new idea about treatment was not often incorporated exactly the way it was introduced, especially if the treatment did not exactly fit with the existing cultural paradigm of either maintaining the body in a state of balance or normalizing an ill one. The result was often to use a combination of home remedies, biomedicine and alternative treatments, in whatever order they thought best to meet their needs. In sum, decisions about health can take time, especially when treatment ideas are new, and the way clinicians explain effects of disease on the body and treatment regimens must make sense to each patient to increase patients' likelihood of adherence.

Another cultural key value involved in decision-making is faith (Chapter 7, Aim 3). All participants held faith-related beliefs that were often informed by Catholic/Protestant teachings. Similar to cultural concepts of illness, faith is not often in direct opposition to medicine. Patients' believed an all-powerful and all-knowing God controlled all aspects of the physical and spiritual realm. Patients reported coping and gaining strength by talking to God (prayer). Patients created meaning out of situations by believing God speaks to people through actions (circumstances), including through the actions and skills of medical practitioners (Figure 7.1). Therefore, biomedical treatment options were not often opposed due to a faith-related reason. Patients opposed treatment in those situations where the perception of disease was in dissonance with biomedical explanations of disease causation (e.g., depression resulting from social ills and/or life's realities' and not associated with biomedicine).

8.2.1 Patient-Clinician Relationship

All respondents in this study are from an integrated health system. GraciaMed's Program of All-Inclusive Care for the Elderly (PACE)¹⁸⁸ is a Medicare and Medicaid managed-care program for adults over the age of 55. The program uses an interdisciplinary team approach to provide patients' medical, social, nutritional and rehabilitative services. The patient-clinician relationships reported within GraciaMed's PACE program evolved from a professional realm, where the value of *respeto* (respect) for those in positions of power was reported to a relationship within the realm of friendship and family-like. This transition manifested itself in the way the participants spoke about their medical encounters with the healthcare system professionals (e.g., practitioners, allied health personnel, social workers and the like).

¹⁸⁸ For more information on PACE, please go to <https://www.medicare.gov/your-medicare-costs/help-paying-costs/pace/pace.html>

During the dissertation, the participants' high value and opinion of foreign-born Latino doctors was briefly mentioned. Such preferences for foreign-born Latino doctors were often attributed to their competence in valued skills in comparison to that of U.S. doctors. The United States was reported to have money and technology, but foreign-born Latino doctors had the heart and skill to improve patients' health. Additional research on this topic is needed to further understand the dynamics observed within professional-patient relationship development and patients' perception of clinicians true intentions for practicing medicine (e.g., prestige, money, personal mission to help). A good summary of this perspective is provided by a quote from an editorial piece titled "*ser un buen medico*" (being a good doctor), delivered to graduating medical students and surgeons in December of 2008 in Colombia that embodies what a future practicing physician in Latin America aspires regarding their relationship with their patients. This quote represents aspects of the patient-physician relationship found in this study:

To those who patients call 'good doctor: ' one of those aspects and maybe the most important one is trust, by which is built from scientific competence, truthfulness, integrity, respect and good relations with patient and colleagues (Translated from Spanish, Gomez, 2009, p. 10).¹⁸⁹

The foundation to any effective patient-clinician relationship falls upon trust (Friedenberg, 2003; Ommen et al., 2008; Thom et al., 2004). Plus, trust has been shown to contribute to improvements in health outcomes, such as among diabetic patients (Lee & Lin, 2011). All other characteristics, such as respect, integrity, and good relations, are value-driven characteristics with unspoken culturally-relevant dynamics most likely to be met by a person with an emic perspective. The quote embodies aspects of the findings regarding relationship development. I hypothesize that what participants may be identifying as skill-set may simply be the

¹⁸⁹ "*a quien los pacientes llaman 'buen doctor': uno de esos aspectos y tal vez el más importante es la confianza la cual se construye a partir de la competencia científica, la honestidad, integridad, el respeto y las buenas relaciones con pacientes y colegas*" (Gómez, 2009, p. 10).

manifestation of the different paradigm and values between medical practitioners in the United States and those in Latin America. However, additional research to identify what specifically is driving the idea needs further investigation.

8.2.2 Cultural Paradigms of Disease Causation and Treatment

The centrality of cultural values, beliefs and norms driving patients' medical decision-making were at times subtle, especially with this cohort of patients who were hyper-exposed to a biomedical culture due to their PACE membership and participation. Nonetheless, cultural ideas and beliefs about the development of illness were described as developing due to an issue of imbalance. Disease causation and therefore treatment decisions were often driven by the holistic idea that emotional, physical, social and spiritual stressors have the potential to impact a human body negatively. The negative social, emotional or physical impact to a vulnerable body increases its susceptibility to further damage. If the body fails to normalize and return to a state of balance (with or without biomedical treatment) it is at higher risk of developing an illness.

Cultural paradigms, like the one briefly described above, are often manifested in clinicians and patients' behaviors. The literature has often talked about patient adherence to biomedical treatments when they should probably be talking about cultural paradigm concordance between healthcare professionals and patients/family. As previously discussed, cultures are dynamic and are embedded within society. They are situationally and contextually responsive. A clinician practices medicine within a biomedical culture, while juggling their personal cultural paradigm and aiming to communicate with a patient/family holding their own. The patients in this study used pluralistic approaches in deciding what treatment options to follow for various illnesses. Although Latino families used traditional healers and treatments

(e.g., *sobador*, *curandero*, *huesero*), they still preferred biomedicine for specific ailments.

Medical pluralism, a healing system available in society that is made up of multiple traditional and conventional therapies stemming from ethnic, cultural, religious and scientific, has been widely documented and was found to exist within the Latino foreign-born elders within this sample. Similarly to other studies, patients used a combination of treatments (both biomedical, alternative and other culturally-informed) to bring their bodies in a state of balance and harmony (Leslie, 1980; Poss & Jezewski, 2002).

The literature shows that there is contention between traditional and biomedicine, and one system tends to dominate (Cant & Sharma, 1999; Kiesser, McFadden, & Belliard, 2006). Researchers working with predominantly Mexican-American families in Southern California, for instance, observed first-hand the tensions between the two healing practices. Families "sought to use an integrative, pluralistic approach to health care decisions." In turn, they experienced "the antagonism of the biomedical system toward "traditional, "complementary" or "alternative medicine" and structural barriers in access, language, and provider-patient relationships often forced these families into either/or health care decisions" (Kiesser et al., 2006, p. 224). Patients pick up on such contention, especially when felt obligated to make a decision between modalities. Patients' perceptions of the legitimacy of self-treatment then greatly influence their willingness to disclose prior self-treatment (Stevenson, Britten, Barry, Bradley, & Barber, 2003). Although the patients interviewed presented strong preferences for biomedicine, as supported in the literature (Applewhite, 1995; Jezewski & Poss, 2002), I can only suspect that in my population, there is more pluralistic behavior occurring that went unshared due to a combination of social desirability bias and perceived legitimacy of the self-treatment. However, irrespective of the potential social desirability bias or the inadequately perceived legitimacy for self-

treatments, the fact that dominant cultural concepts strongly emerged hint to the prevalent use of pluralisms, more so than described in Chapter 6. My findings point towards the pluralistic nature of patients to seek out treatment options, a finding mirroring empirical evidence discussed by Kleinman over 30 years ago (Arthur Kleinman, 1980). Historical debates on the conceptual distinction between the triad — disease, illness and sickness — in treatment decisions (Yew & Noor, 2014 for review) are very much alive. Knowing patients’ perceptions of illness are important to understand the type of treatment option sought. Biomedical treatments, for instance, must align with patients’ perception of disease causation. The treatment must make sense and exist within the patients’ existing cultural paradigm (i.e., my hypothesized idea of the rapid uptake of the concept of *azucar en la sangre* (blood sugar) in the Latino population) if treatment is to continue. If treatment is not in alignment with patients’ ideas for disease causation, then patients may not necessarily comply, and then conversations around patient adherence emerge, making it appear as if the problem is due to the patients’ lack of knowledge, lack of understanding or, lack of accurate perspective. Health care systems must be studied as a cultural whole that includes non-dominant belief systems as contributing factors to patients healing processes.

8.2.3 Centrality of God in Active Pain Coping Behavior - Faith as Coping Mechanism

*Of God I ask
If I die may it be of love
If I fall in love may it be of you
Of your voice may this heart be
Of God I ask everyday¹⁹⁰*

¹⁹⁰ *A Dios le pido
Y que si me muero sea de amor
Y si me enamoro sea de vos
Y que de tu voz sea este corazón
Todos los días a Dios le pido*

The idea of God is ubiquitous within Latino cultures. The centrality of God coupled with the belief of maintaining the human body in a natural state of balance and harmony were repeated themes identified in the analysis. The notion of Divine control is very much existent in Latino cultures (Leyva et al., 2014). Latinos manifest their belief in God through their beliefs of disease causation (Chapter 6) including beliefs around life's circumstances (Chapter 7), their use of language (Chapter 7), and beliefs around coping (Chapter 6 and 7) among many others. Although there are various points of discussion, the ideas around pain managements stemming out of views around God controlling all aspects of life and death and maintaining the body in a natural state will be discussed.

Latinos beliefs and values inform their treatment decisions for pain management. Juarez et al., (1998) conducted interviews with older adults in home health and hospice agencies and found that Latinos patients were often taught not to complain because "one has to be subject to what the Lord says for your life, you have to...whatever it is. If you're suffering, however much you're suffering, the Lord wants it that way" (Juarez et al., 1998, p.265). Plus, the literature also supports the idea that older Latinos contemplate coming to an old age as a gift from God (Beyene, Becker, & Mayen, 2002), a topic that briefly emerged but was not a saturated concept in my study. Patients in my study thought pain was associated with the normal part of aging and very much part of old age (Chapter 6). Although patients were in pain, they were not eager to take pain medications (Chapter 6).

Not complaining, coupled with the idea that natural is better, complicates treatment decisions for pain management. Patients' in my study used faith, not necessarily to forgo treatment, but rather to create meaning and to cope with their conditions. Other studies, similarly

A Dios Le Pido (Of God I Ask) by Juanes on Album *Un Día Normal* (A Normal Day). This is a brief verse of the lyrics of a popular culture love song, that also functions as an indirect prayer to God regarding his love preferences.

report high levels of faith-related coping strategies among Latino elders (Ana F. Abraído-Lanza, Vásquez, & Echeverría, 2004; Hollingshead, Ashburn-Nardo, Stewart, & Hirsh, 2016). Patients in my study used faith as both a problem-focused and emotional-focused coping mechanism that allowed them to forgo or reduce the use of pain medications. In some cases, if the patient decided to treat the pain medically, they took what they perceived as sufficient medication to make their pain bearable, which often resulted in taking smaller dosages than prescribed or recommended. The idea was to take enough medication to make the pain tolerable, not necessarily to eliminate it (speaks to the idea of balance, as well as to obedience to the idea of God giving the pain – Chapter 6). A literature review by Campbell et al., (2009) notes Latinos conservative use of pain medication compared to Whites or African-Americans. Latinos are significantly more likely to believe that medicine should only be administered when pain is severe. Other studies with a younger group (41-65 years of age) of Latinos with diabetes in Santa Ana (CA) found that only 20 percent of their sample was taking pain management medications, despite suffering from enormous amounts of physical pain (Zettel-Watson et al., 2011).

Given the literature on Latino behavior around pain management and the findings of my study, I theorize the following mechanism for decision-making process associated with treatment for pain management on Latino immigrant elders with multiple chronic conditions. The hypothesized scenario takes into account an interplay of cultural beliefs where God-related ideas are braided throughout the process.

Older Latinos believe that old age is a gift from God (Beyene et al., 2002), however, with old age the body is believed to begin to deteriorate and pain follows. Patients rationalized pain as associated with the normal part of aging (Chapter 6). Although older Latino immigrants were in

pain, they were not eager to take pain medications (Juarez et al., 1998; Rutledge, Cantero, & Ruiz, 2013, Chapter 6). They believed in keeping their body in a state of balance and in as natural state as possible; therefore, they engaged in various active forms of coping (e.g., prayer, change behavior, some medication and the like) (Ana F. Abraído-Lanza et al., 2004, Chapter 7). At the end of the day, older Latino elders complained because they are human, but aimed to keep complaints at a balance not to show ingratitude to God who is controlling all aspects of life and death, including their pain. If God still has the older adult alive, it is a gift from God, and only God knows why (Juarez et al., 1998, Chapter 7).

My proposed hypothesis falls back on the notion of Divine control and the belief and value of maintaining the human body in its most natural state. However, these ideas raise questions associated with *fatalism*, which will be discussed below.

Fatalism

My findings found an increased reason for older Latinos to trust the doctor — they are instruments/the hands of God (Leyva et al., 2014). My findings around the issues of faith and medical decision-making give light to what otherwise would be cast off in the literature as fatalism.

Fatalism is a term often used to reference the general idea of Divine control and issues of fate — that life events cannot be changed and are often beyond one's control. The fatalism concept is associated with negative beliefs and attitudes about health-seeking behavior and illness (Ana F Abraído-Lanza et al., 2007; Chavez, Hubbell, Mishra, & Valdez, 1997; Davison, Frankel, & Smith, 1992). Religious fatalism is linked to ideas of God and spirituality — the belief that God controls positive and negative outcomes of life. People who believe this philosophy are perceived to be fatalistic (Franklin et al., 2007). There is an associated danger

with this concept, as has been noted by others (Leyva et al., 2014). Outside researchers have often taken Latinos faith as a category and placed people's comments out of context or have lacked the nuanced understanding of Latino's beliefs associated with God.

My findings suggest that Latinos faith does not replace agency, which echo findings from another qualitative study of eight focus groups of Latino Catholics in Massachusetts (Leyva et al., 2014). Latinos have the free-will to engage in medical decision-making while retaining ideas of Divine control. A person is not devoid of decision-making power because they hold on to faith-related ideas as has been suggested. A study on the influence of religious traditions on health beliefs among Catholic Latinos in the United States found that Latinos stated their religious beliefs promoted positive health behavior and health care utilization, including cancer screening services (Allen et al., 2014).

My study findings identified faith is dynamic with patients at times drawing closer or farther from God depending on their life's circumstances. Belief in God provided the motivation for pursuing medical treatments by grounding the doctors' knowledge and skill in divine guidance. Moreover, as such, faith in God provided hope in situations where there was little otherwise. This does not mean that respondents declined or reduced treatments due to their faith (e.g. in pain control since suffering can be meaningful), although even if they had declined, it was still an active decision that does not disqualify a person's agency.

8.3 Study Strengths and Limitations

The study had two major strengths. First, medical encounters and engagements were broadly defined and analyzed to gain a hyperopic view of patients' medical experiences informing medical decision-making. Although there is no standard definition of engagement within a medical context, most sources consider issues of engagement as a single type of

relationship between patients and medical practitioners, either placing the onus of the active role on either the patient¹⁹¹ or the physician¹⁹² (Holmes Rovner et al., 2010). However, my study was designed to look at the variety of patterns of engagement as it actually occurs. Secondly, another major strength of this project is in the longitudinal aspect. Rarely does an opportunity emerge when researchers can follow people across time and explore decision-making processes as deliberation is taking place. Had these interviews been cross-sectional, some findings would not have been identified (e.g., patient-physician relationship development, *la impresión* as part of a culminating event; dynamic nature of faith; identification of potentially stigmatized mental health conditions; patient's perception of medical-decision making, and the time requirement for decision-making). Having conducted longitudinal interviews allowed me to gain a deeper understanding of patient's life situations in context; repeatedly learning nuances of patient stories.

Nonetheless, the study was not without its limitations. There were issues with patient recruitment, recall bias, sample size and lack of perspectives from other parties influencing decision-making processes, such as the physicians, caregivers, and/or system-level personnel. First, the methods used by the health center to gauge the patients' interest in the project participation are unknown. UCLA project researchers are unsure if the participants were "cherry" picked or randomly recruited. Interviewers observed that the participants were predominantly members of welcoming or patient advocacy committees. Later, UCLA researchers learned that participation into these types of activities was a form of therapy used by

¹⁹¹ According to the center for advancing health denotes it as "actions individuals must take to obtain the greatest benefit from the health care services available to them," putting the burden on the patient (see Holmes 2010, p.2).

¹⁹² According to the Journal of AHIMA denotes it as, "enabling people to work with healthcare professionals in full participation of maintaining their own healthcare and making informed health care decisions," placing the onus on the clinician. Retrieved from <http://bok.ahima.org/doc?oid=300227#.VzQWQ4OrK00>

the health center to improve mental health and encourage social support, suggesting that these may be common types of participants but probably not representative of the full variety of participants. Second, the data collection limitations likely impacted the analysis. Participants were asked about previous medical care decisions they had engaged in. There was a definite recall bias, and the memories of unpleasant experiences were not always “veridical” (Kahneman et al., 1993). Thirdly, the study’s sample size was inadequate to saturate culturally-related ideas and perceptions of illness. Usually an appropriate sample size for a qualitative study is one that allows the researcher to saturate concepts — that is repeated concepts emerge during the interview process to identify the uniqueness of the group. Given the within Latino diversity and the lack of male representation, further exploration is needed to clarify emerging concepts apparently related to established ideas in the literature. Lastly, the project did not capture the perceptions, observations or responses from other people involved in the decision-making process of an older adult, such as the medical practitioners, caregiver and/or family members.

This project, however, is unique in that it arguably displays features that can be deemed both a study strength and a limitation (Table 8.2). One, the cultural lens used to analyze the data can be viewed either positively or negatively. The researcher is Mexican-American and therefore has a personal view of Mexican beliefs and values much more precisely than Central-American values. Key Central American perspectives may have been missed. Secondly, the uniqueness of the sample is more a strength than a limitation (see Section 8.4.1). The way the participants made decisions while in PACE might not be a representation of what they would have done under a different system of care.

Table 8.2: Study Strengths, Limitations and Both		
Strengths	Limitations	Both Strengths and Limitations
Longitudinal	Patient recruitment	Unique sample
Definition of engagement	Recall bias	Mexican-American cultural lens
Interviews and coding in Spanish	Sample size	
	Lack other perspectives	

However, the uniqueness of this sample allowed the researcher to see various features of the patient-doctor relationship that would not be possible in other settings. The researcher was able to see how the participant perceived a system of care that was able to inspire trust and take on familial obligations, while still allowing the patient to demonstrate their interdependent autonomous being.

This researcher is cognizant that this project was unable to untangle all there was to know about decision analysis for older adults with multiple chronic conditions.

8.3.1 Study Population

The medical encounters reported by the participants while receiving care at GraciaMed’s Program of All-inclusive Care for the Elderly (PACE) program are arguably not representative of the medical experiences of all community-dwelling foreign-born Latino elders managing multimorbidities in non-integrated health systems, such as those with providers in private practice. The programmatic features of GraciaMed’s PACE model incorporate a social work and adult day healthcare center (ADHC) component along with integrative medical care, which makes for unique medical experiences of a type not often reported by patients before entering GraciaMed’s PACE. Taking care of everything for their patients alleviated their burdens and created an environment for increasing receptive engagement and encouraging culturally-relevant types of engagement, while understanding and at times embracing cultural concepts of illness

and treatment regimens along with faith. The uniqueness of this sample allowed the researcher to see various features of the patient-doctor relationship that would not be possible in other situations. The researcher was able to see how the participant perceived a system of care that was able to inspire trust and take on familial obligations, while still allowing the patient to demonstrate their interdependent autonomous being. Allied health professions built trust, which helped to broker power imbalances, often experienced within the medical system. This is why patient navigators, community health workers and *promotores de salud* have been found to be particularly powerful agents in evidence-based behavior change intervention studies in hard to reach vulnerable populations (e.g., Latinos). This dissertation only briefly addresses the importance of such agents, since they play a dynamic role in medical care delivery and the medical care experience, including for geriatric populations. However, the conversation about *promotores* is out of the scope of this work.

Given the programmatic characteristics of GraciaMed's PACE model, the researcher was able to study unique aspects of the medical encounters, including facets of the patient-doctor relationship not always observed in community-dwelling foreign-born Latino elders managing multimorbidities. Although the participants' current experiences are arguably different from community-dwelling older adults due to their hyper-exposure to biomedicine, current GraciaMed patients' were once also community-dwelling foreign-born Latino elders in non-integrative systems of care whose reported experiences are assumed to mirror those of other community-dwelling foreign-born Latinos elders. It is likely that the experiences reported by the participants prior to their integration into GraciaMed are similar to those not in a PACE program. The current findings, if not representative, approximate this populations' "reality." The question becomes an

issue of veracity and recall bias of those historical accounts of medical experiences prior to entering the program. Nevertheless, experiences are as truthful as perceived by the participant.

8.4 Theoretical Implications

Cultural systems are all-encompassing and persuasively impact all aspects of human life, including medical decision-making. The dissertation findings contribute to the theoretical conversations around immigrant Latino elders' medical decision-making processes, but its most significant contribution comes in aiming to give light to a potential mechanism to understand the paradox between Latinos mortality advantage despite the existence of epidemiologically identified risk factors for poor health outcomes. In this section, a hypothesis is presented on how Latino values associated with positive relationship development may play a compensatory role in the mortality advantage often spoken about within the Latino paradox. First, culture is defined within a social-ecological model. Secondly, the Latino paradox is briefly described. Thirdly, the suggested hypothesis aiming to explain the paradox will be discussed. Lastly, an explanation is provided on how the study findings partially buttress the hypothesis stating that cultural values play a positive psychosocial support in Latino patients' health outcomes.

A dialogue around the idea of culture is an important one to have, especially in light of the population used to describe the impact of cultural factors on medical decision-making. Controversies exists over the non-standardization of culturally-related terminology often used to identify cultural/ethnic groups exists (e.g., culture, ethnicity, race). Culture is complicated because, although dynamic, it is not random. Various definitions have been presented all pointing towards the use of repetitive patterns that are responsive to environmental contexts (Health & Services, 2000; Kreuter & McClure, 2004; Pasick et al., 2009). Culture is “the multilevel, multidimensional, dynamic, biopsychosocial, and ecological system in which a

population exists...[culture] develop[s] dynamically in response to geographic, social, and political circumstances” (Kagawa-Singer et al., 2010, p.17). Cultures are embedded within social structures of dynamic interactions, where individuals impact and in turn are themselves impacted by culture. Cultures are embedded within larger social-ecological environments, where cultures evolve.

Historically, various social ecological models have evolved providing definitional clarity and specificity by either adding or deleting layers influencing decision-making, but all discuss the associations between individuals and their environment and recognize the influence of the physical and social environments on health behavior (Sallis, Owen, & Fisher, 2008). The social ecological model allows the researcher to study the hypothesized environmental impact associated with individuals’ risk factors for health outcomes. Given the epidemiological literature on the risk factors associated with negative health outcomes, it would be expected that negative social conditions (e.g., poverty, crime-filled neighborhoods and the like) are likely to negatively impact the health status of Latino communities and individuals, yet epidemiological studies on the health status of Latinos have found that Latinos have good health despite their exposures to those conditions (Markides & Coreil, 1986). Studies about this contradiction have labeled this as the epidemiological paradox, Hispanic paradox and the Latino paradox, but all are describing the same conundrum.

According to the National Center for Health Statistics, Latinos are living longer compared to non-Hispanic Whites and have a mortality advantage despite having a worse risk factor profile (Arias, 2016; Horvath et al., 2016; Markides & Coreil, 1986; Ruiz, Steffen, & Smith, 2013). Several suggested hypotheses have been proposed to explain the paradox, such as the “salmon bias,” or the “healthy migrant effect” (Abraido-Lanza, Dohrenwend, Ng-Mak, &

Turner, 1999). The debates have often centered on the potential methodological flaws in calculating death rates. The numerator may be low because some Latinos return to their countries of origin before death (the "salmon bias hypotheses"), or the denominator may not be representative due to the healthiest Hispanics migrating to the United States — "healthy migrant hypothesis" (Ruiz et al., 2013).

One of the earliest explanations of the paradox was that Latino cultural values associated with family protected individual Latinos against stress and buffered the risks in their environment (Markides, 1986). They suggest cultural values such as *simpatía* (importance of displaying kindness and maintaining interpersonal harmony), *familismo* (importance of keeping warm family relationships) and *personalismo* (valuing and building warm relationships) help build stronger social support, which is linked to better health and lower mortality risk (Markides, 1986).

The current study's findings complement the idea that Latino cultural values about relationships play a role in patients' receptiveness to "actively" engage medical decision-making (Table 8.1), which is associated with positive health outcomes (Hibbard & Greene, 2013). Findings suggest that Latino values central to the *development of positive relationships* influence medical decision-making. Latinos valued warm and harmonious relationships, even beyond familial ties. Positive relationship development helped support aspects of patient's medical decision-making.

My findings also suggest that if the context upon which Latino elders are making decisions fosters a cultural-friendly environment and functions within patients' existing cultural paradigm, then the patient's engagement in medical decision-making increases. I suspect Latino patients' engagement increases due to a culturally-friendly and accepting environment, which

fosters positive relationship development and enhances the likelihood that patient's showcase sincere expressions of inner thoughts, emotions, and preferences. These relational values influence how patients engage medical encounters and influence a patients' receptiveness to participate in medical decisions and potentially adopt certain biomedical treatments. Positive relationships within medical encounters and finding common ground to share information within patients' existing cultural paradigm influences adoption (e.g., how *azucar en la sangre* or blood sugar was diffused into the population).

Other research with Latinos has suggested that such values as *familismo*, *simpatia*, and *personalismo* have positive mental health benefits. A study with pregnant Latinas found that familialism was positively correlated with social support and negatively correlated with stress and pregnancy anxiety (Campos et al., 2008). In addition, research on child welfare cases has found that values of *personalismo* stress the importance of good relationship development with the social worker (Ayón & Aisenberg, 2010). Would we not expect the same Latino values demonstrating psychosocial benefits for one sub-Latino group to be playing a similar mechanism in other Latino sub-groups, such as elder immigrants with multiple chronic conditions?

In sum, my findings complement discussions aiming to understand the Latino paradox, just one of the few paradoxes still lingering within the Latino population. Although Latinos may be living longer they are doing so with more disabilities which researchers have attributed to resiliency. The question becomes what issues of resiliency are we overlooking and in need of clarification? Additional research to empirically identify the association between Latino values and its positive health outcomes is still needed.

8.5 Public Health Practice and Policy Implications

The number of foreign-born Latino elders experiencing multiple chronic conditions is expected to grow substantially and is projected to increase and the healthcare costs associated with the management of multimorbidities is generally higher for people with multimorbidities compared to the general population. Multiple chronic conditions pose many challenges, one being how to provide patient-centered care in the context of competitive health care priorities and increasing complexity. My findings about medical decision-making in foreign-born Latino elders contribute to practice-based conversations, particularly around the implementation of patient-centered care in specialized populations.

First, it gives the medical decision science literature descriptive information on how a hard-to-reach vulnerable population makes medical decisions. The normative decision-making endeavor focuses on how humans “ought to make decisions” that are deemed effective, “good,” and correct. The prescriptive decision-making endeavor focuses on developing tools to facilitate “good” decision-making (Bell et al., 1988). My research findings support the descriptive endeavor which aims to describe “how” decisions are made in the real world. It gives a practical context of the realities/complexities of individual human behavior and decision-making. Decision-making at times may appear illogical and irrational, especially when emotion is involved. My study describes how foreign-born Latino elders with multimorbidities in Southern California, a hard-to-reach vulnerable population, routinely make medical decisions.

Secondly, study outcomes support research priorities from the National Institute on Aging aiming to improve communication strategies in patients with multiple chronic conditions. The byproducts of the study findings on issues of patient engagement, communication and patient-provider relationship indirectly satisfy recommended research priorities (Ritchie &

Zulman, 2013). The results support conversations around how best to improve communication strategies with patients with multiple chronic conditions, particularly underrepresented hard-to-reach vulnerable geriatric populations.

Thirdly, study conclusions can inform the development of special models of care for particularly hard-to-reach vulnerable geriatric populations, such as foreign-born Latino elders. The uniqueness of this sample brings to light the effects of combining/merging two leading models of care, the PACE model at an organizational level, and patient-centered care at an individual level, while ensuring to mix in meaningful culturally-relevant care where appropriate. The uniqueness of the sample made it an ideal situation to learn about the context of medical care experiences and decision-making. The unique and potentially unintentional hybrid models of health care delivery in this study sample capitalized on a powerful value in Latino culture, family. Briefly, the family usually helps elder Latinos with interdependent autonomous decision-making. The unique structure of healthcare delivery in the PACE model allowed for patients to entrust some medical system providers within some typical familial obligations and responsibilities, such as serving as healthcare proxies. The results could serve as a lesson for other health care systems wishing to serve underrepresented vulnerable populations. Other medical systems could use these findings to develop strategies and include sensible culturally-relevant features to their existing systems of care to improve the delivery of care to the unique vulnerable populations they serve. The integrated and patient-centered culturally-responsive medical experiences reported showcase what the ideal for our nation's healthcare system could be for geriatric populations.

Fourth, the results can inform health care policies aimed at delivering person-centered models of care, as well as assessing model components such as patients' health care preferences,

relationship development and communication styles. For any framework aiming to ensure patient-centeredness with older Latino immigrants, relationship development is key for establishing trust. Building a relationship requires that the individual's actual cultural belief system, values, and norms to be recognized and understood by the physician rather than by stereotyped group norms. Lastly, the study outcomes can facilitate discussion around the development, tailoring and implementation of geriatric decision-making tools to assist medical systems, practitioners, and patients during the decision-making process, and ultimately benefit geriatric medical care experiences.

Fifth, my findings can help inform conversations on how best to apply evidence-based methodologies to systematically assess the identification of patients' needs, preference, beliefs and values—all central tenets of patient-centered care. Healthcare settings hold a significant amount of interest in patient-centered care implementation, which encourages incorporating patients' needs, preferences and values.¹⁹³ Implicit to these patient-centered tenets are the systematic assessments for the identification of patients/families' personal beliefs and value systems. However, evidence-based methodologies to systematically assess and incorporate strategies are not clearly delineated.

Lastly, it provides the foundational work to advance the science of medical decision-making in foreign-born Latino elders with multimorbidities. A basic decision-making model with the potential to be used in other non-medical contexts was introduced. The study also identified cultural barriers and facilitations to effective communication, relationships and thus decision-making. The study outcomes identified preliminary theoretical and potentially foundational conceptualizations of a general model of decision-making with the potential to be used in a range

¹⁹³ According to the Institute of Medicine (2001), patient-centered is "care that is respectful of and responsive to individual patient preferences, needs, and values and ensuring that patient values guide all clinical decisions" (Institute of Medicine, 2001, p. 6)

of other conditions and contexts. However, the importance of identifying cultural values, norms and beliefs are important to address since they are often the driving forces behind the decision-making algorithm.

In sum, components of the study findings can function to inform multiple conversations that must occur prior to the development and implementation of geriatric-friendly models of care and policies. Guidelines that ensure hard-to-reach vulnerable geriatric populations, such as foreign-born Latino elders, are adequately receiving care while using cost-effective strategies of healthcare utilization. One would hope that by engaging in such developments geriatric medical care experiences and medical decision-making processes would be greatly improved.

8.6 Future Research

Various research avenues could be pursued, depending on the area of interest, to expand the study of medical decision-making in hard-to-reach vulnerable populations. The outcomes of this descriptive research project can serve as building blocks to larger hypothesis-testing investigations of older adults and decision-making. In this section, I discuss the need for empirical evidence to evaluate the general proposed model of medical decision-making in multiple populations across different decision-making contexts. Second, I discuss the need for additional research on the characterization of fear and hope, two prominent concepts feeding the proposed medical decision-making model. Third, I advocate for the need for additional research aimed at untangling the influence of generational, cultural, and political effects on identified minority health concepts as found to influence decision-making. Fourth, additional research should aim to determine the relationship between engagement type and patient adherence as ways to influence medical decision-making. Finally, additional research should aim to identify

the impact concordance of belief systems between patient and provider in medical decision-making.

First, the widely used medical-decision making model that assumes decisions are driven by patients' perceived risks and benefits needs testing with other vulnerable populations in non-PACE settings across various decision-making contexts. Such testing would help determine the models robustness. Individuals' belief system and values inform perceptions of risks and benefits, which implicates the possibility of the model used in other realms of decision-making.

Second, a future area of research is related to the rational-actor type of cost-benefit model whose perceived risk-benefit analysis is driven by the patients' context-based experiences, knowledge, resources, cultural beliefs, values and norms is the characterization of fear and hope. This study found that fear and hope are two dimensions that appear to work either synergistically or antagonistically in patients perceived risks and benefits during the medical decision-making process. Additional research needs to be conducted to identify the mechanisms qualitatively described here on how these two concepts work together across the decision-making continuum. In the preference-based decision-making, I discussed how hope in faith and hope in medicine appear to work synergistically, while in crisis-based decision-making the two dimensions seem to function in an antagonistic way. However, additional discussion and research must continue to study how best to measure hope and fear and quantify it to determine if these two concepts have a cumulative effect on each other or if these ideas are mutually exclusive (Figure 7.2).

Third, the study findings on the cultural concepts of illness and other cultural concepts do not add to the theoretical conversation for the minority health literature. However, my findings add depth and nuance to previously described concepts, such as resilience, *familismo*, *personalismo*, *simpatia*, *respeto*, health perceptions and disease causation in the Latino health

literature (Elder, Ayala, Parra-Medina, & Talavera, 2009; Kiesser et al., 2006; Tortolero-Luna et al., 2006). The study findings incorporate qualitative descriptions of Latino elders' beliefs and value systems that often drive decision-making behaviors, which qualitatively add depth and understanding to existing minority health concepts. However future studies should aim to disentangle the influence of generational, cultural, and political effects on such concepts which are ultimately associated with medical decision-making behaviors and, therefore, avoid the temptation to clump multiple generations of Latinos into one.

Fourth, the study found older immigrant Latinos have three different styles of interacting with the medical system (engagement based on technical information, social engagement and emotional engagement). Additional research needs to be aimed at determining the association between engagement type and patient adherence to determine if one influences the other. Intervention studies have often assumed that increasing patients' knowledge of health literacy could increase adherence levels, assuming that the problems were due to issues of understanding. However, my study findings point to engagement preferences that are culturally informed. Although increasing health literacy and knowledge could prove beneficial, increase engagement based on technical information alone is insufficient to change behavior. If emotional and social forms of engagement establish higher levels of trust, we would expect an association between those types of engagement and higher adherence levels as well. If we establish a culturally appropriate level and social types of engagement during the medical encounters, we should be able to trust.

Finally, my study found the quality of the relationship between medical practitioners and patients' was particularly strengthened when there was a concordance between patient and practitioners' cultural beliefs and value systems. Future studies would need to be developed to

identify what impact a concordance of belief systems between patient and provider under a specific model of care have on communication patterns and the patients' medical decision making.

In summary, many questions remain unanswered and in need of further exploration. The findings from this study could help bolster future areas of study.

8.7 Conclusion

Multiple chronic conditions affect the health and well-being of older adults, and are more prevalent in communities of color. The enactment of the Affordable Care Act has propelled efforts to implement patient-centered care in Americas' healthcare system. Patient-centered care is based upon the fundamental focus of the clinician creating a dialogue with patients to assess their preferences. However, passing of the Affordable Care Act alone will not ensure the patient is engaging in the decision-making process as is often assumed.

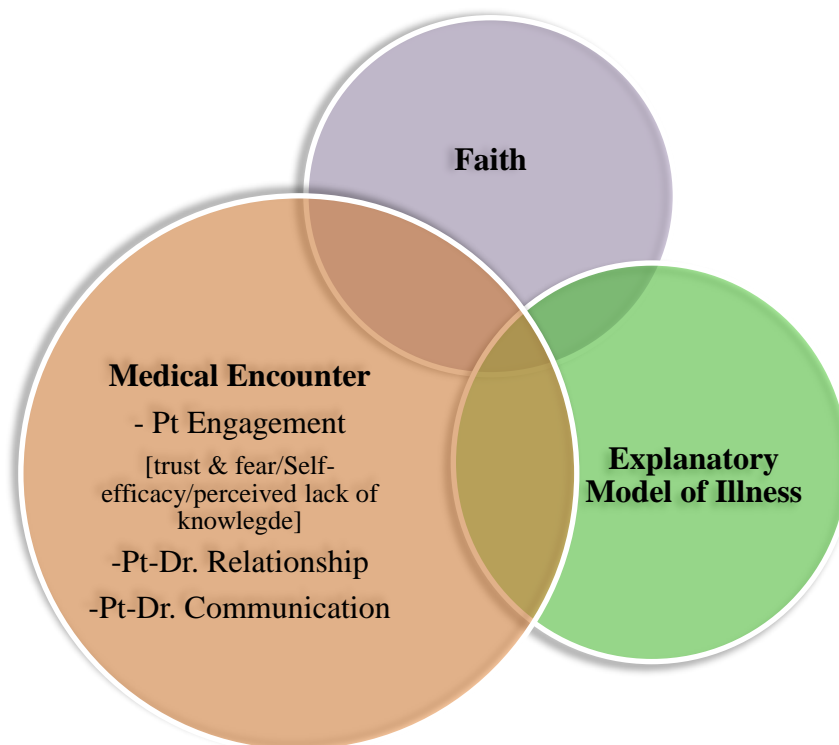
My study identified factors that foreign-born Latino elders with multiple chronic conditions residing in Southern Californian use to make medical decisions. Data highlighted how patients' experiences during medical encounters, cultural beliefs and values, perceptions of illness, treatment regimens, and faith influenced medical decision-making.

Although the healthcare delivery industry has a significant interest in patient-centered care implementation, experts acknowledge that a one size model is inappropriate. Geriatric experts understand that geriatric-friendlier models of care are required to meet the unique needs that older patients with multiple chronic conditions encounter, particularly the needs of vulnerable hard-to-reach populations. My findings are able to contribute to the practical, theoretical and political efforts to improve the medical care experiences of immigrant Latino elder populations.

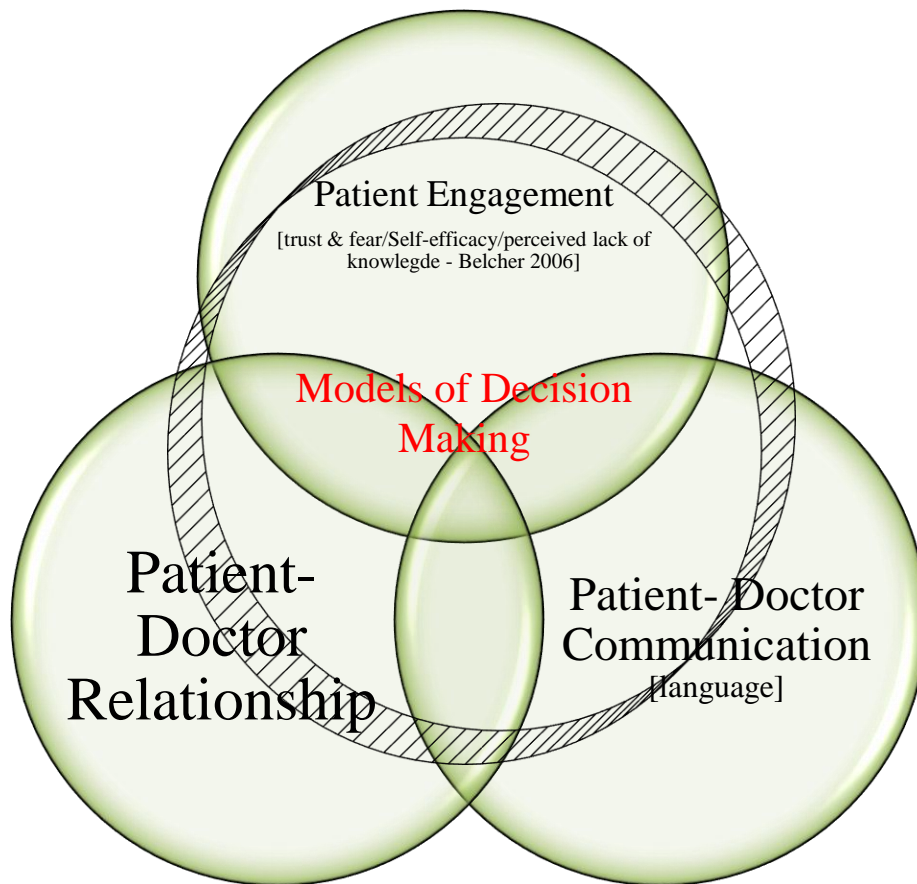
Appendix A

Conceptual Frameworks

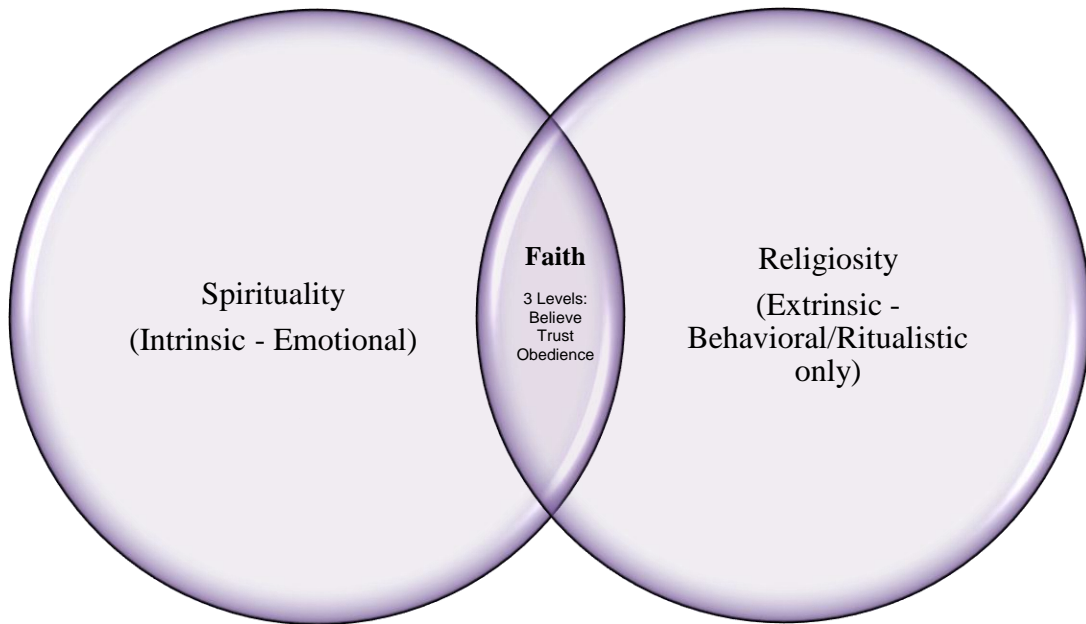
Overall Conceptual Framework (3-D)



Medical Encounter Construct (3-D)



Faith Construct



Appendix B

Interview Guide

UCLA Center for Health Policy Research
The Dignity Project

BASELINE QUALITATIVE INTERVIEW v8.0

Thank you for being willing to talk with us about your experiences with health care providers and the medical care system. As discussed, we would like to learn more about what makes patients happy with the ways their health care providers talk and listen to them when making important decisions about their care. Over the next several months, we would like to talk with you a total of three times to see how you are doing and to discuss your health care experiences. We are especially interested in hearing about decisions you have made about your health care and about any changes you may have experienced.

Before we get started, I would like to ask your permission to tape record our interview so that I am sure to accurately capture what you say. Would that be alright with you? You can tell me to turn the recorder off at any time during the interview, and if you change your mind at any point you can ask me to erase the recording.

A. CURRENT HEALTH CONDITIONS

[For T1 interviews only]:

Because of health care privacy laws, your medical provider has not told us anything about your health situation, so we would like to start by asking a few questions about your health status.

1. *[For T1 interviews only]:* **Would you tell me how you first came to get care at [participating health care organization]?** *[Probes: What was going on with your health at that time? How did you find out about [participating health care organization]? Were you referred by a healthcare professional? Did you hear about it from a family member or friend? What options for care did you have? What options did you consider?]*

2. *[For T1 and T3 interviews only]:* **Would you say that overall your health is excellent, very good, good, fair, or poor?**
Excellent₅ Very Good₄ Good₃ Fair₂ Poor₁
 - a. **Why do you say your health is [INTERVIEWER REPEAT PATIENTS RESPONSE]?**

3. *[For T1 interviews only]:* **Can you tell me more about the health condition(s) that you discuss most with your doctor?**

4. *[For T1 interviews only]:* **Aside from the health problems we just talked about, are there any others that worry or bother you?** *[Probe: arthritis, eye problems like glaucoma, anything else?]*

5. *[For T2 and T3 interviews only:]* **I would like to start by asking you to tell me a little bit about how you have been since we last spoke, in [Month]?**

6. [For T2 and T3 interviews only:] Since we last spoke in [Month], how have you been managing your health conditions? [Probes: What major decisions have you made? What have the conversations with your doctor(s) been like?] Interviewer Note: If respondent made any major decisions since last interview, proceed to Section B and ask follow up questions.

[THE FOLLOWING GRID IS FOR CODING PURPOSES ONLY]

Interviewer: DO NOT ask the participant if they have any of the following conditions. The grid is for coding purposes only. Please mark any the diseases that respondent mentions during the course of the interview.

COPD (Chronic Obstructive Pulmonary Disease, or problems with your lungs)	<input type="checkbox"/> Yes	<input type="checkbox"/> No
Chronic Bronchitis Only	<input type="checkbox"/> Yes	<input type="checkbox"/> No
Emphysema Only	<input type="checkbox"/> Yes	<input type="checkbox"/> No
Lower Respiratory Infections (or problems with your lungs)	<input type="checkbox"/> Yes	<input type="checkbox"/> No
	Bronchitis	<input type="checkbox"/> Yes <input type="checkbox"/> No
	Pneumonia	<input type="checkbox"/> Yes <input type="checkbox"/> No
Heart Disease (or problems with your heart)	<input type="checkbox"/> Yes	<input type="checkbox"/> No
	Congestive Heart Failure	<input type="checkbox"/> Yes <input type="checkbox"/> No
	Ischemic Heart Failure	<input type="checkbox"/> Yes <input type="checkbox"/> No
Cancer(s)	<input type="checkbox"/> Yes	<input type="checkbox"/> No
What type(s)? _____	Stage _____	
What type(s)? _____	Stage _____	
What type(s)? _____	Stage _____	
Cerebrovascular Disease (or Stroke)	<input type="checkbox"/> Yes	<input type="checkbox"/> No
Diabetes	<input type="checkbox"/> Yes	<input type="checkbox"/> No
Depression	<input type="checkbox"/> Yes	<input type="checkbox"/> No
Other Illness(es) Please specify _____	<input type="checkbox"/> Yes	<input type="checkbox"/> No

Kleinman's Explanatory Model of Illness (T2)

Interviewer: Thus far, we have talked about some of your health conditions. For the following set of questions, can we focus on the condition that concerns you the most?

1. How severe would you say your primary health concern is extremely severe, severe, somewhat severe or not severe at all? [Probes: How so? Will it have a short or a long course?]
 - a. Why would you say your [STATE ILLNESS] is [INTERVIEWER REPEAT PARTICIPANTS RESPONSE]?

Kleinmans [Probes]

2. What do you think has caused your [STATE ILLNESS]? [Probes: Society, lifestyle, fate, etc.??]
3. Why do you think it started when it did?

4. What do you think having [STATE ILLNESS] does to you? How does it work?
5. What kind of treatment do you think you should receive for the [STATE ILLNESS]?
6. What are the most important results you hope to receive from this treatment?
7. What are the chief problems your sickness has caused for you?
8. What do you fear most about your sickness? Could you please elaborate on that?

B. MEDICAL DECISION-MAKING

[For T1 and T3 if respondent made any important medical decisions since last interview]:

1. Now I would like you to take a moment to think about the last time you had to make an important decision about your medical care. Can you walk me through, step-by-step, and tell me what it took for you to make that decision? [Probe: Who was involved in making this decision? Your primary healthcare provider? Other specialist? Nurse? Social worker? Family members or friends? How did you learn about your treatment or care options? What did you do with the information that you were given? Did you look to anyone for advice? Did anyone help you reach a decision? If so, what did they do?]

- a. **How did it feel to make that decision?** [Probes: How comfortable were you with making that decision about your medical care? How did you feel about the choices you made? Did you feel that you had enough information?]
- b. **If you could change something about this experience, what would it be?**
- c. **What happened as a result of making that decision?**
- d. **What did making that decision mean to you?**

[For T2 interviews only]:

2. Now I would like to ask about your experience making decisions with your [healthcare provider]. This next set of questions requires either a “yes” or a “no” response. (AHRQ CAHPS Adult Supplemental, 2012)

1. In the last 12 months, did you and your healthcare provider talk about starting or stopping a prescription medicine? Yes No
[If Yes, proceed to Qs 2-4; If No, skip to Q5]
2. Did you and this provider talk about the reasons you might want to take a medicine? Yes No
3. Did you and this provider talk about the reasons you might **not** want to take a medicine? Yes No
4. When you and this provider talked about starting or stopping a prescription medicine, did this provider ask what you thought was best for you? Yes No
5. In the last 12 months, did you and this provider talk about having surgery or any type of procedure? Yes No

[If Yes, proceed to Qs 6-8; If No, skip to Q9]

6. Did you and this provider talk about the reasons you might want to have the surgery or procedure? Yes No
7. Did you and this provider talk about the reasons you might **not** want to have the surgery or procedure? Yes No
8. When you and this provider talked about having surgery or a procedure, did this provider ask what you thought was best for you? Yes No
-
9. Did you and this provider talk about including family or friends in making health decisions? Yes No
10. Did you and this provider talk about how much of your personal health information you wanted to share with family or friends? Yes No
11. Did this provider respect your wishes about sharing personal health information with family or friends? Yes No
12. Did you bring a family member or friend with you to talk with this provider? Yes No

Faith-Related Questions (T1, T2 &/or T3)

1. How would you describe your faith? [*Probes: Do you consider yourself religious or spiritual? Do hold a specific worldview/perspective? Do you have faith in a higher power? Is this related to a specific religion? How strong are your beliefs? Would you consider yourself faithful/devout?*]
2. Tell me how your beliefs or values are involved in making decisions about your medical care and treatment(s)? [*Probes: is there spiritual meaning for pain? Is there a spiritual meaning for fear?*]

Now I'd like to ask what you do when you are experiencing pain because of your health condition[s].

3. How does your faith [or beliefs and values] come into play when you are experiencing pain? [*Probes: How do you manage your pain? How do you understand it? Does it have a particular meaning?*]

Meaning of Dignity (T2 or T3, if not asked at T2)

1. What does dignity mean to you? What does it represent?
 - a. What does it mean for you to get treated with “dignity” during your medical care? [*Probe: Can you give me an example of when you felt you were being treated this way (with dignity)?*]

C. RELATIONSHIPS WITH PROVIDERS [*For T1 and T3 interviews only*]

Next I would like to ask you some questions about the people who are involved with your health care.

[THE FOLLOWING GRID IS FOR CODING PURPOSES ONLY]

Interviewer: DO NOT ask the participant directly about who is involved in their care. The following grid is for coding purposes only. Please indicate all individuals that the participant mentions during the course of the interview as being currently involved in their medical care.

Primary Care Physician	<input type="checkbox"/>	Clergy	<input type="checkbox"/>
Specialist (e.g. oncologist)	<input type="checkbox"/>	Home Care Worker	<input type="checkbox"/>
Nurse	<input type="checkbox"/>	Family	<input type="checkbox"/>
Social Worker	<input type="checkbox"/>	Friends	<input type="checkbox"/>
Other _____			

[MORE DETAIL OF THE INTERACTION WITH PROVIDER]

1. **Who is your favorite health care provider? What makes them different from others who are involved in your care?** [*Probes: What characteristics do they have that make them different from other providers? How is it that they treat you with dignity? Could you describe a time when they or another provider did not to treat you with dignity during your medical care?*]
2. **Who has been most helpful in making decisions about your health care? Why? How so?** [*Probes: Does anybody specific stand out as being especially helpful? A Social worker? Nurse? Family member? Friend? What qualities do they have that make them important? What about them made you want to get their help?*]
3. **Who else has been helpful in making decisions about your care? Why? How so?**
 - a. What about them made you want to get their help?
4. **In what ways does [name of individual OR healthcare provider] know your preferences for health care decisions?** [*Probes: How well does s/he know your wishes? How well does s/he know your preferences?*]
5. **In what ways does [name of individual OR healthcare provider] understand your specific health concerns/worries?**
 - a. Can you give me an example of how they respond well to your care needs?

b. How about an example of how they could do better?

[Interviewer: Only ask questions 5-9 if the answer to Q1 is a healthcare professional.]

6. **Describe the way your [healthcare provider] speaks to/communicates with you** *[Probes: How is their bedside manner? Can you give an example?]*
7. **Now, describe the way your [healthcare provider] gives you information and/or instructions?** *[Probes: What works well? What could s/he do better? Can you give an example of something that worked especially well?]*
8. **How do you respond when you don't understand your [healthcare provider] as much as you would like?** *[Probes: How do you let your [healthcare provider] know what you want? Does someone else help you understand or remember what they are saying?]*
9. **How does it feel when you ask your [healthcare provider] questions? What is an example of when you are comfortable doing so? ...not comfortable doing so?** *[Probes: What is your experience getting information from your provider? ...understanding your options? ...understanding their recommendations?]*
10. **In an ideal world, how would you like your [healthcare provider] to talk with you?** *[Probes: How would you like your provider to discuss information about your healthcare needs? How would you like your provider to talk to you about trying a new medication? Recommending a surgery or procedure?]*

[Interviewer: Ask Q10 of all participants]

11. **How does your [healthcare provider] involve your family or close friends in discussions about your care?** *[Probe: Does your provider involve them too much/ not enough? Does your provider ask you if you want your family or friends involved, what types of information you want them to share? Do you feel like your family/friends are welcome/can be involved as much as you want them to be?]*

D. LIFE DECISION-MAKING *[For T2 interviews only]*

I would like to shift the focus a bit, to ask you about major decisions you have made in your life that are not related to your current medical conditions.

1. **Now I would like you to take a moment to think about the last time you made an important life decision. For example, it might have been a decision about a job, or a relationship, or a place to live. Can you walk me through, step-by-step, and tell me what it took for you to make that decision?** *[Probe: Who was involved in making this decision? What were your options? What information did you have to help you make that decision? Did anyone help you reach a decision? If so, what did they do?]*
 - a. **How did it feel to make that decision?** *[Probe: How comfortable were you with making that decision? How did you feel about the choices you made? Did you feel that you had enough information?]*

- b. **If you could change something about this experience, what would it be?**
- c. **What happened as a result of making that decision?**
- d. **What did making that decision mean to you?**

E. HEALTH CARE PREFERENCES *[For T3 interviews only]*

Next I'd like to understand more about your preferences for health care or treatment.

1. **When you think about the health care that you currently receive, what matters the most? Why is that important to you? Can you tell me more?**
 - a. **In an ideal world, how do you want to be cared for?** *[Probes: What's most important to you? Can you give me an example of things your [healthcare provider] does that you like? Why? What about an example of things that you don't like so much? What needs to be in place for you to get good health care?]*
 - b. **What do you hope to get from the health care/treatment you are currently receiving?** *[Probes: What do you expect will happen as a result of the care you are currently getting? Where do you think it will take you, 6 or 8 weeks from now? What do you think your [healthcare provider] expects 6 or 8 weeks from now?]*
2. **If you could change anything at all about the health care that you currently receive, what would it be?** *[Probe for reasons why]*

F. QUALITY OF LIFE *[For T1 and T3 interviews only]*

We would like to know more about the things that affect your sense of well-being these days.

1. **What are the greatest challenges you face?**
2. **What would you like to do but can't because of your health condition(s)?**
3. **What worries you the most these days?**
4. **What gives you the greatest pleasure these days?**

[T1 and T2 only]

Thank you for taking the time to share your experience with us today. We would like to call you after a few months to talk with you some more. We will have some more questions that we would like to explore with you at that time. Is it OK if I call you at that time?

If we can't reach you, is there someone else we could call or email who is likely to know where you are? [e.g. if you are in the hospital; we won't bother you there, but will want to know when a good time to contact you would be] (get name, relationship, contact information)

[T3 only]

We are at the end of the interview questions. Is there anything else that you would like to share with us? Is there something that we have not talked about that you think is important for us to know?

Thank you once again for taking the time to share your experiences with us today. This was our last interview. However, we might conduct another study like this one in the future. If we do, is it okay if we contact you again?

[If respondent agrees to be contacted again, take the opportunity to reconfirm their contact information and to also ask for a secondary contact person, in the event that we are unable to reach them.]

Guide dated 5/14/14

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