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“It Made Me Question If I Was in The Right Hands”: Exploring Cancer Prognostic Conversations Between Providers and Latinx Patients

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“IT MADE ME QUESTION IF I WAS IN THE RIGHT HANDS”: EXPLORING CANCER PROGNOSTIC CONVERSATIONS BETWEEN PROVIDERS AND LATINX PATIENTS

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by

Yesenia Anabel Carrillo

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by

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ABSTRACT

“IT MADE ME QUESTION IF I WAS IN THE RIGHT HANDS”: EXPLORING CANCER PROGNOSTIC CONVERSATIONS BETWEEN PROVIDERS AND LATINX PATIENTS

by Yesenia Anabel Carrillo

People of color are often confronted by barriers within the health-care system that white people are not likely to encounter. Latinx patients are among those who experience racial health disparities, typically due to the lack of health literacy support and limited resource access. Drawing on previous work that focuses on exploring patient, provider, and caregiver preferences for cancer prognostic conversations; this study explores perceptions of cancer prognostic conversations between providers and Latinx patients to better understand the degree of cultural competence among providers and opportunities for enhancing interpersonal communication with Latinx patients. Interviews with seven patients and five providers were conducted and thematically analyzed. Results identified notable similarities and differences in the preferences for and experiences with Latinx patient care in the context of cancer prognostic conversations. Findings point to opportunities for providing better patient care through improved, provider and Latinx patient communication practices and the need for a new care model that promotes culturally-focused care.

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Introduction

Cancer is widely known as one of the most challenging and life-threatening illnesses due to its unpredictability and invasiveness, affecting the human body both physically and mentally. On a biological level, cancer is a constant and uncontrolled division of abnormal cells in the body (National Cancer Institute [NCI], 2021). Many cancers form solid malignant tumors with the potential to spread, eventually invading nearby tissues. Cancer can occur almost anywhere in the human body, requiring distinct and specific treatment depending on the type of cancer. In its different forms, cancer is reported to be a global health issue that accounts for almost 13% of deaths worldwide (López-Gómez et al., 2013). Due to its complicated and possible life threatening make-up, cancer is a challenging illness that requires detailed communication from healthcare providers to ensure the best possible approach to manage care. Prognostic conversations can be as intricate as the illness itself and difficult to navigate by both patients and providers (Hagerty et al., 2005).

There are various reasons why patients often express concerns related to prognostic conversations. Patients often feel overwhelmed by the news of their cancer diagnosis, which can lead to emotional distress (Sloan & Knowles, 2017). When patients receive a cancer diagnosis, they often express the need for realistic information, the ability to ask questions, and a desire for confident and supportive care from providers (Cartwright et al., 2014). Some patients want honest and straightforward information regarding their diagnosis, while others do not want to know the diagnosis at all (Sisk & Mack, 2018). Mori et al. (2019) found that some patients prefer prognostic conversations to include hope/prepare statements such as “hope for the best and prepare for the worst” (e944). Preferences for the delivery of prognostic information is often complicated by related concerns such as the cost of treatment and the potential for financial burden on family members (Haverfield et al., 2020). Medical professionals acknowledge similar difficulty with communicating a cancer prognosis. Mack et al. (2006) found that some physicians believe communicating a prognosis to be so challenging that they would rather not discuss prognostic information with patients at all to avoid further patient distress. Other physicians may limit the amount of information they disclose or give vague updates to avoid overly optimistic information (Gordon & Daugherty, 2003). Research conducted by Prouty et al. (2014) suggests that physicians may misunderstand patients' health beliefs, wishes about the delivery of a diagnosis, and prognostic information. With the understanding that delivering a cancer prognosis is difficult, the added layers of ethnic identity respective of an individual's culture can add to prognostic conversation complexity.

Various terms are used to classify an individual. Among minoritized groups, frequent terms include race, culture, and ethnicity. A socially constructed term, Dien (2006) defines race as the social group a person belongs to on account of a mix of physical characteristics. Culture represents shared values, beliefs and ideologies that an individual identifies with as part of a larger group whereas ethnicity refers to the social group a person belongs to base on a shared culture (Dien, 2006). Racial and ethnic inequalities are well documented throughout history (Bailey et al., 2017), highlighting the existence of structural racism. Structural racism refers to the ways in which society encourages or furthers racial discrimination through reinforcing systems such as housing, education, healthcare, the criminal justice system, and media representation. For many, structural racism represents inequity in the lack of available resources, which can have numerous implications (Bailey et al., 2017). One example of inequity is in the context of the health care system, described as health inequity. Health inequity refers to a difference in the distribution or allocation of resources between groups (Klein & Huang, 2022), such as health insurance access and health literacy education. Consequently, these disparities also include differences in social, economic, and environmental healthcare resources. The macro level systems, institutions, ideologies, and processes that interact with one another largely work to reinforce inequities among racial and ethnic groups.

Elements of one's culture or ethnic identity such as language, values, and religion, may impact navigation of a prognostic conversation and ultimately efforts to manage care (Muntinga et al., 2016). For example, a Latinx non-native English speaker may struggle to convey preferences for treatment or have difficulty understanding medical terminology. Studies have shown that ethnic minority cancer patients encounter less patient-centered communication when compared to white-patients (Costas-Muniz et al., 2013). Patient centered care is the ability to provide care that is respectful of and responsive to patient preferences while ensuring that patient values guide all clinical decisions (Patlak et al., 2011). Patient-centered care typically relies on the broader health care system to ensure patient health is managed effectively. However, given the longstanding institutional challenges within the health care system, most notably the history of systemic racism in medicine, it calls into question whether patient-centered care equally supports minority patient populations (Cole, 2020). The interpersonal features of patient-centered care, the interactions between patients and providers, are linked to more active patients in consultations and greater patient self-efficacy in taking control of their health (Patlak et al., 2011). Therefore, providers' understanding of patient preferences for prognostic conversations that also include consideration of a patient's culture and ethnic identity, may help to ensure more successful interpersonal interactions that promote patient-centered care and reflect greater equity in the care provided. Unfortunately, amidst efforts to provide equitable care, research suggests that providers are still ill prepared for interpersonal interactions with patients of marginalized populations, including Latinx patients.

Positionality Statement

My own identity and experiences have influenced the need to focus on the Latinx patient. As a Chicana, personal interactions with the healthcare systems in various settings have pushed me to advocate for my community. I became particularly sensitive to countless stories told by community members experiencing oppressive systemic barriers when seeking care; in addition to witnessing many Latinx individuals dying from cancer, largely due to a lack of proper medical attention and resource support. Bringing forward the direct needs, thoughts, and experiences of Latinx patients can help guide healthcare institutions in a more culturally inclusive direction, potentially improving Latinx patient care.

This research explores preferences for and experiences with cancer prognostic conversations between providers and Latinx patients to better understand the degree of cultural competence among providers and opportunities for enhancing interpersonal care with Latinx patients. The framework that will guide this exploration of provider and Latinx patient perceptions of care in the context of prognostic conversations is the Cultural Competence Model. The Cultural Competence Model considers the ability of healthcare providers and staff to effectively deliver care that meets the cultural and linguistic needs of their patients' furthering ethnic minority engagement, patient-centered care, and health equity (Harrison et al., 2019). It also highlights the micro-level interpersonal features of communication; tailored according to patients' social, cultural, and linguistic needs (Health Research & Educational Trust, 2013). While efforts to enhance provider, cultural competence are increasing through various continuing medical education programming, it is unclear how these training efforts are being implemented in practice and whether patients are receptive to these efforts. The following sections review previous research on healthcare experiences among minority patients, including Latinx patients, and then unpacks evidence on racism in medicine to contextualize the relevance of the Cultural Competence Model in exploring provider and Latinx patient preferences and experiences with prognostic conversations.

Literature Review

According to the National Cancer Institute, approximately 1.8 million people will be diagnosed with cancer in the United States annually, with the most common forms of cancer being breast, lung, prostate, and colon cancer (NCI, 2020c). In 2018, there were 9.5 million cancer-related deaths worldwide. Cancer is a disease that does not discriminate based on gender, age, or race. Cancer treatments vary depending on the stage, location, and potential treatments for the cancer (NCI, 2021). Therefore, it is a complex disease that requires the utmost care when delivering a prognosis and communicating with patients regarding the course of treatment(s) and other important life decisions. For minority patients, cultural beliefs and ethnic identity can compound the complexities of navigating an illness like cancer, presenting numerous challenges to delivering, understanding, and receiving care.

Healthcare Experiences for Minority Patients

Studies have documented that those with lower assimilation, often culturally diverse minority populations who have migrated to the United States, receive inequitable care relative to White Americans (Martinez et al., 2013). For example, studies indicate that patients of color, who are largely representative of culturally diverse minority populations, are less willing to return to subsequent visits for an existing medical problem due to lack of trust when compared to English-speaking or White patients in the primary care setting (Fernandez et al., 2004).

Research conducted by Jonnalagadda et al. (2012) looks at racial and ethnic differences in beliefs about lung cancer care. Patient perceptions about their lung cancer and treatment can influence clinical services utilization, potentially contributing to the racial and ethnic disparities observed. The ability for providers to understand these differences and effectively navigate them is important in providing culturally focused care that enables equal access to possible resources. Since ethnic identity can influence a patients' perception or understanding about information delivered to them or may even impact the course of treatment they decide (Perloff et al., 2006), providers should be sure to consider the cultural background of a patient in an effort to provide high-quality and equitable care.

To gauge the ways that culturally diverse patients understand their health, many institutions look at the patient's health literacy. Low health literacy is prevalent among immigrant minority populations (Becerra et al., 2016). The Health Resources and Services Administration (HRSA, 2019) defines health literacy as the ability for patients to retain, understand, and process basic health information to make appropriate health decisions. Furthermore, the HRSA (2019) lists some of the health literacy issues to be educational gaps, inability to fully understand medical terminology, and cultural barriers to healthcare. Taken together, the limited health literacy reported by minority patients can compromise prognostic conversations and management of care.

Characteristics of Latinx Patients

Though there has been an increase in research regarding oncology communication, few studies have considered best practices related specifically to prognostic conversations with Latinx communities where cultural differences may impede clinical care (Magaña, 2020). To better understand how patient ethnic identity, particularly among Latinx patients, may factor into prognostic conversations, the following section provides an overview of the characteristics among the Latinx community that likely contribute to the healthcare experience.

One should not assume homogeneity within the Latinx culture. It is composed of different ethnicities with diverse belief systems and is composed of different dialects. Though there are many differences within the Latinx community, there are some dominant similarities. Research by Floríndez et al. (2020) identifies some of the common cultural norms of U.S Latinx communities to be familismo, respeto, and confianza. These translate to familism, respect, trust, and sympathy. These cultural norms point to the particularly high value in fostering a patient-provider relationship with Latinx patients in order to understand patient preferences and enhance patient care experiences. Familism relates to the need for an immediate and extended family network. For example, familism is evident in the way that Latinx patients consider treatment decision making and caregiver support (Marín & Marín, 1991). Curanderismo is the practice of traditional healing rituals centered on spirituality, commonly adopted by members of the Latinx community (Trotter et al., 1997). Religion and spirituality play a significant role in the Latinx culture and within ethnic identity. Risser and Mazur (1995) concluded that cultural health beliefs were widely maintained in the Latinx population. For example, many Latinx caregivers take their children to curanderos (traditional healers) for treatment of folk illnesses. Acknowledgement from providers about these traditions are important for better care.

Another example of traditional Latinx approaches to health is the use of cultural narratives or metaphors to describe emotions or situations related to an illness. Semino et al. (2016) look at the usage of medical metaphors, which are reported to be particularly common in the context of prognostic conversations. Identifying the cultural metaphors used to discuss an illness may help providers understand how patients interpret their disease. Magaña (2020) examined language and metaphors and how they impact the ways the Latinx community conceptualize their disease. Patients compared cancer to combat and more generally violence, with examples such as “my battle against cancer” or “my fight against cancer”. Magaña (2020) provides revelations about the cultural and linguistic aspects of how Latina patients conceptualize their disease through metaphor. Through further examination of patient metaphors, it was discovered that some Latinx community members understand the causes of illness as a temperature imbalance in the body. These cultural nuances can be easily overlooked yet play a significant role in the patient's understanding of the illness as well as perceptions of managing care.

Relatedly, language is a factor that impacts Latinx patient’s ability to navigate the healthcare system. Language is the means by which people communicate beliefs, values, and customs, which can foster feelings of group identity and solidarity (Hassen, 2016). Costas-Muniz et al. (2013) found that patients who need linguistic interpretations are more likely to have information deficits about their stage and progression of their cancer. As a result, patients who reported needing or using interpretation services for their health care visits were more likely to be unaware of their cancer stage and were less likely to request further information about their cancer diagnosis or treatment. Fernandez et al. (2004) found that limited English-proficient Latinx patients are less satisfied with their care even with an interpreter present, largely due to the linguistic disconnect between patients and providers.

The language barrier impacts patients' perceptions regarding their care such that they believe their provider is less concerned about them (Fernandez et al., 2004). Taken together, language discordance between providers and the Latinx community is likely to perpetuate health inequity, adding to patient feelings of frustration, anger, and sadness, potentially making prognostic conversations and disease management even more challenging to navigate (NCI, 2020a; Sisk & Mack, 2018).

Other environmental factors are important to consider in the context of Latinx health. Velasco-Mondragon et al. (2016) identifies Hispanics as disproportionately affected by poor conditions of daily life, directly caused by an array of social determinants of health; some of these being income, education, and geographical region. This not only affects their access to fully functioning and supportive medical attention, but it further complicates proper care due to chronic stress and other behavioral risk factors (Velasco-Mondragon et al., 2016).

Velasco-Mondragon et al. (2016) state that Hispanics are twice as likely to live below the poverty line, which makes access to medical insurance extremely difficult. Research conducted by Terriquez and Joseph (2016) confirms that Latinx adults exhibit lower rates of medical insurance coverage and demonstrate higher rates of uninsured community members. This research also indicates that Latinx young adults are disproportionately coming from lower socioeconomic backgrounds, impacting both educational opportunities and income potential, that could lead to future problems purchasing private medical insurance and present challenges with health literacy. Moreover, Juckett (2005) notes that among Latinx patients, immigration status and mistrust of medical institutions may keep many Latinx from ever engaging with the healthcare system. López-Cevallos and Harvey (2016) found that access to healthcare services is particularly low among Latinx who live in rural communities. Many of these individuals are foreign born Latinx, who are also more likely to face discrimination with the healthcare institution when compared to first and second-generation Latinx patients. Latinx in rural areas often find themselves socially isolated, lacking community resources, and community support for culturally competent health care. Collectively, evidence suggests the need to consider and incorporate the ethnic identity of Latinx patients into clinical care.

Racism in Medicine

To better understand why prognostic conversations among minority patients, specifically Latinx patients, are subjected to institutional inequities, the following section expands on systemic racism in society, systemic racism in health care, the implications of systemic racism in health care, and the levels in which systemic racism in health care can be explored.

Systemic Racism

The United States has enabled marginalization of minority groups for centuries. Race, a term established in the early 1800s, places people into groups based on their physical appearance (i.e., skin color). The adoption of this classification led to the myth that race is a biological trait, rather than a socially constructed ideology (Huber et al., 2008). The continued focus on race in society promotes a hierarchy that justifies the superiority of one race over others (Bonilla-Silva, 2001). This propels the normalization of white values, beliefs, and experiences (Huber et al., 2008). Institutional racism or systemic racism focuses on racism that is embedded as normal practice within society or an organization; it is reflected in our history, culture, and interconnected within our institutions (Krieger, 2014).

There are centuries of historical examples of systemic racism including genocide, slavery, legal segregation, and white elitism all playing central roles in maintaining institutions as forms that further these oppressive cycles (Feagin & Bennefield, 2014).

Within the last decade, research focusing on racial discrimination and cultural inequalities is increasing. Feagin and Bennefield (2014) suggest that white resources and the continuous discrimination minorities face, restrict Americans of color from accessing better jobs, quality education, quality health care, political advancement, and social capital. One clear example of systemic racism in society is that people of color and the 'poor' are more likely to live in, work, and play in America's most polluted environments, resulting in communities of color to be disproportionately exposed to harmful living conditions (Bullard, 1993). Further, Yearby (2018) found that minorities generally have higher poverty rates than whites, contributing to the lack of resources that are associated with a low socio-economic status. Differences in health-care treatment and outcomes among minorities persist even after adjusting for socioeconomic factors (Nair & Adetayo, 2019). Research identified the lack of health insurance as one of the leading causes of health disparities among minority groups (Magaña, 2020). Taken together, systemic racism is designed to reproduce and reinforce disparities, which is present in many different sectors including housing, education, and healthcare (Rose & Rosen, 2017).

Systemic Racism and Healthcare

Most decision makers in health care, such as public health researchers, policy makers, medical educators and officials, hospital administrators, important medical personnel, and pharmaceutical executives are predominantly white (Feagin & Bennefield, 2014). The people who create the systems that are implemented to care for all people are generally led by white folks who are often unable to directly understand or relate with the hardships of minorities in the United States. Disparities in healthcare are defined by the NCI (2020b) as; differences in the rate, prevalence, and encumbrance of diseases and health conditions that exist for specific populations in the United States. These disparities reflect the many ways marginalized groups face systemic racism within the healthcare setting.

The Coin Model of Privilege is a framework that helps to uncover different systemic disadvantages experienced by minority groups, including within the industrial medical complex. Providers are situated within the medical industrial complex, a system with inherent discrimination, that influences providers' ability to help marginalized patients, thereby perpetuating imbalances in patient care (Nixon, 2019). The Coin Model of Privilege looks at norms, patterns, behaviors, and systems that privilege some social groups over others including sexism, ableism, classism, and racism (Nixon, 2019). The Coin Model of Privilege is a key tenant for discovering systems of inequity. The disadvantaged side of the coin is termed, "bottom side of the coin;" and refers to, 'oppression'. Those at the bottom of the coin can be connected to marginalized groups, vulnerable communities, and high-risk groups. The coin analogy provides insight into two important sectors of information. One side of the coin is described as the privileged population and one side the minoritized groups. The privileged populations are more likely to receive access to resources compared to systematically excluded groups. Nixon (2019) states, "Coins do not reflect the individual behavior of good or bad people. Rather, they are society-level norms or structures that give advantage or disadvantage regardless of whether individuals want it or are even aware of it" (p. 3). This framework points to the advantage that some patients have when they can communicate, understand, and advocate for themselves. Further, this framework draws attention to features of systemic racism evidenced by an ethnocentric approach to care. As Juckett (2005) states, “Ethnocentrism, the conviction that one’s own culture is superior, can hinder effective cross culture care” (p. 2267). The current healthcare system frequently demonstrates systemic racism in that it largely advantages one group and disadvantages others, hence promoting an ethnocentric ideology and health inequity.

There are numerous examples of systemic racism in healthcare. One example is medical education, which has a long history of systemic racism that works to promote health inequity. For instance, racial bias is present in pain screening assessments and treatments. Research conducted by Hoffman et al. (2016) found that Black Americans are systemically undertreated for pain compared to white Americans. Their study found that providers often rely on false instruction about biological differences between Blacks and whites to inform medical judgments contributing to racial disparities in pain assessments. Another demonstration of failed medical education training is van Ryn et al. (2006) study, which found that cardiologists perceive Black patients as less intelligent, less likeable, more prone to risky behavior, and non-compliant compared to white patients, negatively impacting the care that Black patients receive (van Ryn et al., 2006). Relatedly, Blair et al. (2013) assessed biases against Latinos and Blacks among primary care providers in terms of response time and the use of positive versus negative words. Out of the 210 clinicians who participated in the study, approximately 43% had implicit bias toward Black patients and 51% of bias toward Latino patients. These biases and perceptions can manifest in distrust between patient and provider, which inhibits the ability to mindfully and competently communicate.

Cultural Competence Model

Based on the evidence above, there are important considerations surrounding the communication between providers and Latinx patients, particularly in the context of prognostic conversations. Further exploration as to how medical professionals are trained to manage care of patients with different ethnic backgrounds may give insight on how to improve cultural education training curriculum. The need for providers to be capable of functioning in cross-cultural contexts is exceedingly important. The Cultural Competence Model may be a helpful guide for determining competence inefficiencies and best practices among providers.

The Cultural Competence Model was first introduced by Campinha-Bacote in 1999. The concept of cultural competence was developed to address the effects of cultural and linguistic barriers within interpersonal encounters between healthcare practitioners and patients. The model considers cultural competence as a process that looks at healthcare providers, and in some cases institutions', ability to deliver effective services to racially, ethnically, and culturally diverse patient populations (Fernandez et al., 2004). Some of these components may include awareness of one’s own cultural worldview, knowledge of the different cultural practices and worldviews that exist, cross-cultural skills, and attitudes toward cultural differences. Cultural Competence is considered critical to realizing the patient-centered care agenda for ethnic minority patients (Harrison et al., 2019). Research by Saha et al. (2008) describes the evolution of cultural competence and how early researchers of the cultural competence movement recognized the disparities in healthcare resulting from culture and other barriers between patients, providers, communities, and health systems. With these realizations, a deeper focus on cultural competence began. Cultural competence has become a widely used model to address the multiple interwoven equity gaps in healthcare. In 2008, the U.S National Quality Forum defined the Cultural Competence Model as a way for organizations and professions to provide culturally diverse client populations quality care that is equitable, safe, and centered on the client and family. Though these are the intentions of the Cultural Competence Model evidence in previous literature suggests that the Cultural Competence Model does not properly deliver culturally appropriate care.

The concept of cultural competence varies in definitions and explanations. Surbone (2004) stated "cultural competence in medicine is a complex multilayered accomplishment. It requires knowledge, skills, and attitudes whose acquisition is needed for effective cross cultural negotiation in clinical settings" (p. 698). Harrison et al. (2019) suggests cultural competence is, "the ability of healthcare providers to effectively deliver healthcare that meets the social, cultural, and linguistic needs of their patients'… central in enhancing engagement of ethnic minority consumers" (p. 2). Similarly, Nair and Adetayo (2019) describe cultural competence as, "the ability to collaborate effectively with individuals from different cultures…such competence can help improve health care experiences and outcomes" (p. 2). These distinct descriptions have a commonality; cultural competence is a requirement consistently identified within positive cultural communication practices in healthcare. Cultural competence is considered an ever-evolving model that works to decrease health disparities within interpersonal communication practices.

In recent years, cultural competence has become an important part of medical training (Govere & Govere, 2016). Research shows that there are different training mechanisms set in place for healthcare professionals to learn cultural competence. The U.S Department of Health and Human Services iterates in their research that the implementation of culturally competent health care is training that teaches physicians how to practice it. At the organizational level, it also minimizes the potential for liability, penalty, loss of accreditation, or legal action if someone felt that any of their cultural concerns were not adequately addressed (Govere & Govere, 2016). As such, cultural competence has become a core curriculum requirement in medical school education to help address patient health disparities.

Unfortunately, amidst existing efforts, health disparities persist. Minority groups continue to experience health inequity related to cultural assumptions and bias in interpersonal interactions with providers. These cultural inequities in healthcare call for a better understanding of how culturally competent care is practiced and how it can be improved, particularly between providers and Latinx patients in the context of prognostic conversations, where effective communication is paramount to patient care. Ensuring a patient gets thoughtful, thorough, and honest care allows patients to have the information needed to make informed decisions about their course of treatment. Notably, approximately less than 5% of U.S. providers identify as Latinx, which means that few Latinx patients are interacting with a Latinx provider (Association of American Medical Colleges, 2022). The lack of Latinx representation in health care providers suggests the potential for greater language and cultural barriers when navigating the health system, that may result in ineffective and un-equitable healthcare (Meuter et al., 2015). Meuter et al. (2015) also suggest that these discrepancies may add to increased psychosocial stress and anxiety further adding to medical communication errors. By applying the cultural competence model, this study seeks to explore prognostic conversation preferences and experiences among providers and Latinx patients, to better understand the interpersonal cultural competence of providers in the context of prognostic conversations and potential opportunities for improvement. Thus, the following research question is proposed:

RQ1: What features of cultural competence are recognized in the preferences and experiences with cancer prognostic conversations among providers and Latinx patients?

Methods

The corpus of this study consists of interviews to explore preferences for and experiences with cancer prognostic conversations among providers and Latinx patients. Virtual interviews were conducted between January and March 2021. Interview questions gathered demographic information, inquired about participant perceptions of culturally competent communication demonstrated during prognostic conversations, and general experiences and preferences for delivering or receiving a prognosis (see Appendix A and B for Patient and Provider Interview Guides). To be eligible to participate, all participants had to be 18 years of age or older. Patients had to have received a cancer diagnosis within the last 15 years and identify as Latinx. Patients were not excluded based on the cancer type and location of treatment. Provider eligibility criteria required that they work with Latinx patients throughout the oncology care experience. Providers did not have to identify as Latinx. To examine cultural competence with Latinx patients, recruitment of providers that identify as White/Caucasian was prioritized in order to understand their perspective about working with this community. The study received Institutional Review Board approval prior to participant recruitment.

Sample

A total of 7 patients and 6 providers participated in the study (N=13). The original intent for this research study was to interview 10 patients and 10 providers for a total of 20 interviews however, after conducting a handful of interviews with each participant group, common themes across participants emerged, pointing to saturation.

Among patient participants 100% identified as Latinx. Patient participants resided in California, Chicago, and New Jersey. Most patients (57%) reported the highest level of education as a bachelor's degree, 14% completed some college, and remaining participants (29%) identified as having a high school diploma. Most patients (86%) reported a household income between $30-65,000, with 14% of patients having an income over $100,000. The modalities of prognostic communication reported by patients varied between in-person news of prognosis (86%), while remaining participants had an over-the-phone confirmation of their prognosis (14%). Relatedly, the medical team delivering the prognosis varied. All but one participant reported that an oncology specialist delivered the prognosis. The outlier response reported that administrative personnel delivered the prognosis.

Among provider participants 50% identified as Latinx and 50% identified as white or non-Latinx (see Table 1). Providers resided in California and Chicago, with one provider located in Canada. This participant was maintained in the data to explore whether and how preferences and experiences differ from that of U.S. employed providers. The healthcare providers that participated in this research study consisted of two Clinical Social Workers, two Nurses, and one Pediatric Oncologist.

Table 1
Provider Ethnicity

Providers	**Latinx**	**Non-Latinx**
Provider 1	✓	
Provider 2	✓	
Provider 3		✓
Provider 4	✓	
Provider 5		✓
Provider 6		✓

Procedures

Patient and provider participants were recruited through various social media platforms (i.e., Facebook, Instagram), using a video post that explained the purpose of the study, how to contact the primary researcher, and what qualifications were needed in order to participate. The main source of participant collection was accomplished through snowball sampling. Other recruitment efforts included circulation of flyers at oncology clinics, through oncology listservs, and through listservs that were directly geared towards members of the Latinx community.

Individuals that expressed interest in participating were asked a series of questions to confirm eligibility (see Appendix C). Upon confirming eligibility, all participants were sent a digital consent form via DocuSign, both a Spanish and English version were made available. Oncology patient participants also received a one-page resource for counseling and support services (see Appendix D). Once consent forms were received, interviews were scheduled on a day and time that worked best for the participant. During the course of recruitment, 15 patients expressed interest with only 7 participating. Reasons for not participating include no response following completion of the consent form, backing out due to limited technical abilities, and deciding not to participate for fear of personal information being shared to the public. Among the six potential provider participants that expressed interest all 6 participated.

As noted, interviews were conducted virtually, using Zoom. To protect patient and provider identity, all video features were disabled. Zoom was also used to record interviews. Depending on patient preferences, interviews were conducted in either Spanish or English.

None of the participating providers expressed a need to conduct the interview in Spanish. Once the Zoom interviews were completed and downloaded, digital transcripts were created using the Canvas Studio tool. To use Canvas Studio, audio recordings are uploaded, and caption generation is selected. Once captions are generated, they can be downloaded as transcripts. Audio recordings were replayed while reviewing the digital transcription to confirm accuracy of the transcript. Interviews conducted in Spanish were manually transcribed in Spanish and translated to English by the primary researcher.

Data Analysis

A thematic analysis of the data was conducted to allow for identification of overlapping themes across patients, across providers, and across participant groups. This was specifically focused on preferences and experiences related to cultural competence and prognostic conversations between providers and Latinx patients. Thematic analysis is used to emphasize interpretive patterns within qualitative research (Clarke & Braun, 2016). To conduct the thematic analysis, the transcribed interviews were coded by the primary researcher along with a trained graduate student as a second coder. A second coder aided in confirming the presence of themes and limited potential coding bias.

To thematically code the data, an open and axial coding approach was used. Open coding refers to the first step in the coding process and allows the researcher to look at the entirety of the interview (Charmaz, 2008). Axial coding entails a more focused look at segments of a text (or interview) and developing more focused codes (Charmaz, 2008). For the open coding process, the primary researcher reviewed all transcripts to generate an initial codebook of themes and to remove any possible identifiable information from transcripts. At that point, the second coder independently reviewed all transcripts and added any needed modifications to the codebook, while confirming already identified themes. The following step consists of combining and collapsing topics and data to create overarching categories used as the main codes or themes. Then the primary researcher and second coder met with the study faculty advisor to confirm the codes identified including descriptions of the codes. After discussion and consensus, the primary researcher produced a finalized codebook. Due to the two distinct groups interviewed, two separate codebooks were developed and reviewed using the steps described. Both coders then independently reviewed one transcript from each participant group, following the axial coding process, to identify specific participant responses that exemplified identified themes. Using Cohen's ƙ as a reliability estimate, coders demonstrated high reliability in coded themes (ƙ = .89). Following confirmation of coding reliability, remaining transcripts were coded. The patient and provider codebooks resulted in a total of four themes: Communication Practices, Latinx Culture, Improvements, and Barriers.

Results

Following the thematic analysis, four themes were identified across patient and provider interviews. Each theme is described in detail below and supported with excerpts from both patient and provider interviews. The first theme identified is communication practices, both positive and negative, related to perceptions of interactions with the medical care team. The second theme is Latinx Culture, that includes sub-themes of bi-cultural identity, cultural beliefs, and family over self. The third theme, Improvements, considers opportunities for providers and the broader institution to enhance cultural competence to better serve the Latinx patient community. The fourth theme, Barriers, focuses on challenges to proper care, hospital navigation, and resource support.

Communication Practices

Patients

From the patient perspective, the communication practices theme refers to patient interactions with medical professional's during prognostic conversations and the emotions, thoughts, and feelings that patients experienced as a result. Two sub-themes were captured including positive and negative communication. Positive communication refers to patient acknowledgement of a good interaction. Characteristics of these interactions included patience, empathy, and honest diagnosis communication. The below example is a demonstration of Patient 4's perception of the prognostic conversation, noting the importance of direct and solution-oriented messaging:

> *I think my doctor was very, like, straight to the point…it didn't make me feel uncomfortable. But it also, wasn't like a touchy feely type of conversation and very much like, you know, I have some…not so, great news. Here they are. Here's*

> *our plan. So, it was very…straight to the point but also, like, respectful and like eased into it…*

Similarly, Patient 1 describes their experience with their doctor after seeking different medical care due to a lack of support from their initial diagnosis experience. The clear and honest communication was perceived positively:

> *I think my doctor was very, like, straight to the point…it didn't make me feel uncomfortable.*

The negative communication sub-theme captured communication practices that were considered too blunt or emotionless, unhelpful, and abrupt/rushed. The below quote is an example from Patient 1 that expresses their negative experience with the communication practices during their initial diagnosis delivery, specifically the abrupt introduction to the cancer:

> *So, when I received confirmation of it [cancer], I was standing up getting a mammogram done and the tech gasped and she said you have cancer I see it here…I wasn't able to leave the room. Then they automatically pull me over to do a biopsy on the spot. I felt…. it felt surreal.*

Feeling cared for, understood, and validated fosters a better connection between providers and patients. Communication that conveyed empathy appeared to be lacking among Latinx patient experiences. Notably, Patient 3 mentioned the desire for greater consideration of cultural difference in the delivery of a prognosis:

> *Doctors maybe too professional, I would say…they don't seem to loosen up or sometimes, like, when they give you the news, like, it's pretty, like straightforward. And sometimes it can seem a little harsh. So, I feel like that kind of like, makes a bit of a difference of like, how our culture and sometimes their culture, it might be a little different.*

Similarly, Patient 2 reiterates the need for more emotion during the prognostic conversation as they mention: *"Let's say more affection could have been given."*

These examples demonstrate the distinct preferences in prognostic delivery. Although one patient was content with straight to the point information the other described an out of body experience when receiving the news directly. Patient 1 describes that they were not given a diagnosis from a medical professional during their first prognostic conversation experience. There were no conversations about the exact cancer or a confirmation of the cancer. Their diagnosis was delivered by a receptionist. On the other hand, Patient 2 had their diagnosis delivered by their specialist. These differences show how prognostic conversations are being mishandled and patients are not given the same attention and care based on their unique communication preferences. Although there were some differences in preferences for the delivery of prognostic information, the majority of Latinx patients felt the delivery was generally lacking in empathy.

The Cultural Competence Model implies that all patients of a particular culture inherently have similar needs and preferences. This in and of itself promotes prejudice. The assumption of the model and application of the model could therefore have a more negative impact on patient care. Given the range in patient preferences related to communication of a prognosis, the objectives of cultural competence are misaligned. According to patients, providers did not reflect awareness of patient preferences for communicating and were not effortful in determining specific patient preferences. This further reveal that the Cultural Competence Model requires more nuance than a general understanding of Latinx patients' needs. Instead, providers should focus on determining how each patient might prefer to be communicated with to properly discern the type of delivery and emotional support needed during the prognostic conversation.

Providers

The communication practices theme for providers reflects how providers approached prognostic conversations when caring for Latinx patients. The sub-themes present in provider experiences include technical communication, referring to medical terminology used by providers, and question-asking, which looks at how providers ask questions to understand their patients' preferences.

Provider 3 commented on the usage of medical terminology, how they communicate in simpler terms to ensure Latinx patients fully comprehend their prognosis:

> *if there's an English language barrier, I would really try to use non-technical terms and I guess describe it more in detail. There may also be stigmas around, you know, cancer and what they've read online, and I think different maybe cultures and groups have different ideas around cancer and illness altogether.*

The provider expresses how important linguistic support is when communicating to a patient that might speak a different native language than that of the provider, consistent with the objectives of the Cultural Competence Model.

Translators are also a key component of care when language barriers are present. For providers, this includes understanding when a patient needs additional support to understand and properly comprehend their prognosis. To that point, Provider 1 details the importance of having an interpreter present even though they are fluent in Spanish:

> *I always made sure that I have an interpreter because medical Spanish is very, very different than the Spanish I speak. I may be fluent in Spanish, but not medically. And I think that's very important…[a] key component to communicating and providing that cultural competency is because you need to be able to explain what's going on. So, that later on, they know every single detail and every single option, and not feel like just because I speak Spanish, I'm going to sway their decisions, or I'm going to hide certain information. So, that's part of what I understand as providing that cultural competency.*

Contrastingly, Provider 2 gives a different perspective of how medical terminology, even when said in a patient's native language, is difficult to understand without further explanations:

> *…if you look at it from the hospital perspective, there are interpreters, right, that provide language assistance, but their role is to translate medical information verbatim. And, you know, unfortunately, when you do that, regardless of the language, it is beyond a patient's comprehension.*

Furthermore, Provider 6 describes the barriers they encounter when providing medical support to Latinx patients that may not fully comprehend the English language or medical jargon:

> *We start using jargon the minute we start treating you as a patient, especially an oncology patient, a cancer patient, we start to expect that you're going to pick up on terminology such as a CBC or…chemo terminology just within the first 72 hours that you become a cancer patient. And it doesn't matter if English is your first language. That's like a whole language in yourself. So then put yourself in the shoes of someone who is Spanish speaking, how are they supposed to navigate this health system that has its own language within itself, right. And then when we're talking about this community that maybe has never engaged at all with higher level of healthcare, since being in this country, um, I think it's very hard to navigate.*

Relatedly, Provider 4 describes the importance of slowing down and making sure the patient understands what is being said to them:

> *Yeah, so I would definitely any kind of medical terms technical terms, I would always explain and define what they mean. So, I would use the words that they would understand and learn what that definition is, in case they encounter it again.*

Translating medical terminology is more than relaying information in Spanish for Latinx patients, it is explaining and ensuring that a patient understands what is being said. For this to be captured, it is vital for providers to ask their patients questions in order to gauge the amount of assistance that will be needed. In asking patients questions, providers can fully assess patient needs. In addition, asking questions could give providers the opportunity to confirm patient preferences to further ensure the best quality of care. An example of question asking is described by Provider 3 as they acknowledge the importance of asking questions during prognostic conversations to ensure the patient understands what is happening and to ensure the team can fill in any gaps to better their care:

> *And so, I always just make it a point to just ask, like, what is it that you understand about your health? What is it that you understand about the updates that you've been receiving from doctors? And so, if I have even an inkling that they don't know, what is really going on? I say can…you give me permission to really explain to you why I'm here.*

The communication practice identified above could facilitate rapport building, particularly with Latinx patients, to establish trust and connection while getting to know the patient's history and needs. Provider 3 goes on to describe their reason for asking a lot of open-ended questions, particularly in regard to the patient's background and beliefs in order to account for them when managing their illness:

> *I can have the work experience and that knowledge base on what a diagnosis is, but nobody's going to know a patient better than the patient themselves…I like to take each interaction as an opportunity for education…I let the patient guide me I let them be the expert on what is important to them. And that's why I ask those questions…how much of a role does your background, does your culture, does your heritage play in your healing process or in you know, this health process, so, that we can incorporate that into your healing into your treatment into your adjustment...being bicultural can set a platform for you to address situations and help people more sensitively. But that doesn't identify you as an expert. It just gives you the lived experience to know that…every opportunity is an opportunity for growth, and you don't want to impose or inflict a treatment or an option, or an ideology on a patient that perhaps that is not their idea of the best approach.*

Similarly, Provider 6 discusses asking the right questions to ensure their patient understands what is being said to them, takes into consideration their situation at home when discussing treatment, and also taking a moment to stop and consider how life changing their situation might be for them, and their families. They state:

> *...I think of you need to press pause, and what was happening in this patient's life prior to them walking through the emergency room doors or into a hematology oncology clinic 48 hours prior, what were they doing to sustain the life they had, and preserve their cultural independence and autonomy?*

Taken together, providers identified the importance of considering language barriers, particularly in regard to technical medical jargon, and question asking as key communication practices in prognostic conversations with Latinx patients. This not only ensures the patient is able to understand both their diagnosis and prognosis, but it also gives patients the ability to vocalize what they need and identify gaps in understanding to enhance the care experience.

Latinx Culture

Patients

This theme captures the ways that patients described their experiences and attachment to the Latinx culture and, in some cases, how that impacts their preferences for communicating about a prognosis. The sub-themes that were identified include bi-cultural identity, cultural beliefs, and family over self. For the sub-theme of bi-cultural identity, patients frequently commented on how traditions were passed down from earlier generations and the importance of those traditions but also the tension experienced due to American culture's influence on their identity.

Patient 5 explains in great detail how their Latinx culture influences their view of the world and how their American education shifted traditional beliefs. The following quote exemplifies the bi-cultural identity that Latinx patients may be navigating as they engage with the American health care system:

> *I think for me…one of the huge…attributes of it [Latinx culture] is definitely being like, first generation. I came here with my family when I was five from Mexico. [You] know I mentioned [I] identify as indigenous, and that's because I, I very much practice, you know, philosophies and epistemologies from, like, my indigenous part of my life, that being Latino definitely means like, being somewhere in between, at least for me, like in terms of, you know, being Mexican American you are swinging between both cultures.*

Similarly, Patient 1 described their bi-cultural identity that illustrates how features of their Latinx identity may influence their perceptions of communication with others:

> *I feel like I have a lot of her [grandma's] ways where she would, you know, she raised me when I was young, and I feel like I have all that instilled in me…it wasn't until I pursued college and got a degree that I'm like you know boys are allowed to cry because I was just you know from that culture.*

Navigating the bi-cultural identity for more acculturated patients gives insight into the range of experiences among Latinx patients. Some patients openly acknowledged their advantage over other Latinx patients who might not understand the health care system due to their limited understanding of Western medicine, large health care system processes, and language proficiency. For example, Patient 7 states:

> *…what I have experienced is because we were able to make a connection with our doctors and nurses and because we had an understanding of what the terminologies mean and what the processes are.*

Patient 4 describes a similar advantage when compared to patients that might not have the education or linguistic capability as them, when they said:

> *Yeah, I definitely feel like the fact that I am English speaking. And my doctors were solely…English speaking was definitely...a privilege I'm grateful for because again, just like medical terms, in general, are so, confusing. Even with, you know, my mom's history and my own history of kind of understanding, it's still like, whoa, like, what are you saying? Like, how can you explain it. So, the fact that I am English speaking, and my doctors, we were able to communicate like that, you know, without needing an interpreter, whether that be a family member, or a hired interpreter through the hospital.*

A bi-cultural identity appears to give patients a greater ability to advocate for themselves, which is different from the experiences of less acculturated Latinx patients. Features of communication common in Latinx families also became evident in-patient responses. Patient 1 described how unaware they were about cancer and attributed that to privacy practices within their culture:

> *So, I thought the cancer diagnosis was basically. That's it. You know when you have cancer, I was just like whoa when do I die? Like I'm literally waiting for a date or something. Like I have no idea…our culture you just don't talk about those things you know? Or when something happens at least in families we try to keep it private.*

If patients are not inclined to discuss specific topics in their family/community due to cultural beliefs and practices, providers may need to know how to navigate this communication behavior to ensure that patients are forthcoming with important information that could impact their care. Cultural norms about privacy can become barriers if health providers do not acknowledge or understand these norms. Providers could gather this information if they take the time to understand and get to know their patient at a deeper level, including the use of open-ended questions. In doing so, providers can better gauge health literacy and distinguish what patients consider private or not.

Moreover, conversations about self-lessness and a longing to protect family also came up across patient experiences. A strong sense of family connection and closeness appeared in patient's accounts of a cancer prognosis and their consideration of how their family's life would be altered as a result. The following quote from Patient 6 illustrates a mother's fear of how cancer would impact her ability to care for her children:

> *I asked the oncologist surgeon who was the first one who saw me there, I asked him to not lie to me. I needed to know exactly what was going on...I made sure I*

> *was clear when talking to him and I wanted clear answers and I told him it was because I have two little kids I truly needed to know if there are chances of me living and what the chances of me dying were before I committed to the to the treatment or would it just be taking a treatment at risk…the only thing I asked him to do was to be very clear with me.*

This expression of honesty and truth is a key component to prognostic conversations especially for patients that have to think about their family and loved ones. This finding is consistent with the idea of familism and highlights the ways in which families impact prognostic conversation. The ability to determine a timeline, treatment plan, and a patient's future is oftentimes a difficult thing to do when patients are worried about how these decisions may impact their family. In cultures where family is a main priority, these examples promote the need for a deeper understanding of culture.

Providers

The Latinx Culture theme for providers reflects the experiences and concerns providers have when working with Latinx patients as well as their level of understanding about the Latinx community. Healthcare workers that identify with the Latinx community such as Provider 2, have a deeper understanding of what the Latinx community represents:

> *So, it's called Latinx for a reason, right? It's not Latino, it's not Latina. It's Latinx, it is all encompassing. I identify myself as a woman of color, more specifically Mexican American woman of color, and I say the term American lightly just because unfortunately, not unfortunately, but I was born here. And when I say identity, I mean like gender identification, you can identify as male, female. Neither both you can be asexual, you can be two spirited, it's whatever or none or non-binary, you know, it's whatever you choose to associate yourself with. But the big part is that you are embracing the cultural part...*

The example above expresses great understanding of the Latinx community from the lived and personal experiences of a Latinx provider. It is important to note the difference between a provider that identifies with the Latinx community compared to providers that do not directly identify with the community. To that note, Provider 7 discusses how important it is for them to use their lived experiences and their ability to understand the community they serve as being important to having an open mind when caring for Latinx or minority patients. They state:

> *By cultural appropriateness specifically, I think that just has to do with keeping an open mind about the world around you, and integrating that openness into the conversation. So for me, at least, it's not about the hospital walls, but it's also keeping an eye out, keeping my eyes open to the world around me in Los Angeles, and my interaction with not just patients and families, but with people where maybe Latin X or Asian or some other race, ethnicity, and just understanding the context in which they're coming from, it's going to be really, it's about keeping your eyes open, and being able to understand that it's not just about the medical diagnosis, but it's about the community and the support system around from which these individuals come from.*

The exposure and ability to understand the community as well as time trying to understand patient culture may equip providers with the tools necessary to deliver better support to Latinx patients. Providers that do not identify with or demonstrate deeper awareness of the Latinx culture mostly identified linguistic differences and religious connections. The below example shows Provider's 4 understanding of the Latinx community.

> *…so my mom has been a church member in her Latin community for many years. So, my, my experience has always been with her, her community really. So you know, I know that it's it was it's really a small community of have a tight group of families basically, that have, that have really supported each other kind of through all of you know, life and, and church and faith. So that's been my experience, myself, but what I know about others and what's out there, you know, I know that there's lots of different organizations that do amazing work for up and coming Latinos and Latinas, and I haven't been a part of that.*

Provider 2 gives an example of their perceptions of family beliefs in the Latinx community and how these often-close-knit families anticipate the need to look after one another. These cultural expectations about the role of family can add another layer of complexity to the prognostic conversation and subsequent decision making:

> *I can only speak to my own lived experience. But you know…at some point, eventually, the children take care of the parents. Here in this country, it's a little bit further than that, in a sense that, you know, by culturally, yes, we still think that our children should take care of the parent as they get older. But then children also, assume the role of thinking that they are the parent. And so, sometimes kids want treatments for their loved ones or family members want treatments for their loved ones that the patient does not want. And so, I think that they should only be involved to the extent that the patient is allowing them or wanting them to be.*

These distinctions are important as it presents the various perceptions that providers have when helping a Latinx patient navigate their cancer illness. It helps pinpoint their understanding of the community in relation to their lived experiences with this particular ethnic identity. For example, the quote that notes the expectations in child caregiving could have implications on how providers involve adult children in the care of a parent's cancer.

Aside from tight-knit families and the possible interjection from loved ones, providers noted the lack of patient understanding of what is being delivered to them. Reasons for this lack of understanding was attributed to low health literacy, shock or emotional blockage, and the direct communication practices provided by the healthcare team. Provider 2 discusses their experience of a Latinx patient not fully comprehending a prognosis as described below:

> *… So, you use what they know, to kind of assist them in grasping those concepts. In, you know, diabetes, for example, is very common. And, or, at least for me, I'm Mexican. So, it is very common in people of my upbringing, and in my culture, and my background. And so, you use as best as you can, to find ways that they understand or experiences that they have to help them assist and understanding, you know feeding certain ingredients that are very common in our food, and essentially, poison your kidneys, they're not functioning the way they need to, they're not flushing out what your body needs to survive at this point. And, again, you, you use what they have you use their tools to help them get that. And sometimes they don't get it right away. Sometimes it takes multiple*

> *hospitalizations across multiple conversations. And as they're feeling, unfortunately, as they are progressing through their trajectory of their illness, they start to understand.*

The importance of family, culture, and language impacts conversations with medical professionals; cultural competence models should encourage providers to explore these dynamics with patients. Especially for patients that depend on their family for support while navigating their health. As examples show above, perceptions of culture and traditions often are not as clear as a model might suggest.

Improvements

Patients

Both patients and providers identified key interpersonal improvements that could enhance cultural competence and better serve the Latinx patient community. In particular, patients highlighted ways in which the medical team could improve care by offering more dedicated time to patients and increase Latinx representation in healthcare. Time dedicated to patients was a priority preference for patients to feel they were receiving adequate care. Patient 5 talked about their desire for providers to take a moment to centralize their focus before entering an appointment and how that could conceivably slow down the pace of the clinical visit:

> *I mean, it's always really nice when the doctor's kind of take a breather before their appointment. And they just, you know, are people in the consultation room…I know that it's really hard sometimes. And I know it because I'm a teacher…You just kind of like, go ahead and do your thing without, you know, without your emotions, just because you got to, like, get the job done.*

Providers are known to have busy schedules in a fast-paced working environment and Latinx patients identified that the time dedicated to them is not enough. Time constraints are particularly problematic for patients that require additional explanation and possibly support during their appointments. Therefore, it is important to ensure that patients receive and perceive an appropriate amount of time and dedication from their providers. Ensuring patients feel that providers are taking the time needed to explain and discuss their health could help them feel more supported through their cancer experience. For example, Patient 5 acknowledges the challenges that providers face to slow down and be present with patients but iterates the importance of providers taking a moment to breathe and take pauses between appointments:

> *…it's always really nice when the doctor's kind of take a breather before their appointment. And they just, you know, are people in the consultation room? Right? I know that it's really hard sometimes. And I know it because I'm a teacher. So, I also, like service the public, right? You just kind of like, go ahead and do your thing without, you know, without your emotions, just because you got to, like, get the job done.*

Representation was another re-occurring sub-theme within the interviews. Having healthcare team members that can support you medically but also provide culturally adequate support was crucial to the prognostic conversation experience. Patient 5 describes the lack of Latinx representation in the care provided:

> *I never felt like my role [ethnic identity] was really represented in the support, or the resources that I was provided, whether it was like resources and support within the hospital or even in the community. Besides, like, this is a Spanish speaking support group.*

Representation is a big component to positive Latinx patient experiences. This includes having providers that understand the language, medical staff providing culturally focused care, or providers that understand the Latinx culture specifically. More Latinx, Hispanic, or indigenous identifying providers, from administrative staff to doctors could enhance culturally focused care for minority patients.

Providers

Similar to patients, the majority of providers identified preferences for improving Latinx patient care. Providers also noted time with patients, as an opportunity to improve Latinx patient care. An additional preference from providers included training for patients and cultural competence training for providers.

Providers conveyed awareness of the importance of time and patience in caring for the patient, particularly in ensuring patient understanding of what is happening to them. Provider 4 pointed to the notion that Latinx patient visits may actually demand more time from providers and suggests that this could be a reason why Latinx patients are not treated equally. In this excerpt, Provider 4 also hints at education for patients, to improve understanding of their medical experience:

> *…maybe there is more education that needs to be given to diverse populations, that it can be perceived as more work, right? If you have a busy clinic day, and you have a patient that needs more time. Maybe just because it takes more time to interpret, it takes more time for them to learn whatever it may be, because they don't have that baseline knowledge, [they] may be perceived as a difficult patient. So maybe just being kind of blown off? Like I don't have the time for that [patient]...*

The challenges with health literacy, linked to culture, may cause more significant distress and hardship for Latinx patients, especially when considering the potential lack of time providers have dedicated to each patient. Providers simply do not have the time or awareness to confirm whether there may be misconceptions surrounding the information delivered. Provider 3 also relates to the lack of time with patients and notes the desire to have more time with them in order to foster a connection as they say: *"... I barely have any time to spend with my patients in the hospital. I always had a desire to be able to help them more and more on a personal level."*

Both patients and providers expressed the same need when caring for the patient. Provider 4 explicitly acknowledges that 'time' spent with patients could be a cultural phenomenon, and giving patients 'equal time' may, in fact, not be equal. The unequal time could partially be alluded to patients that are notably less acculturated, who should be given more time due to the lack of familiarity and differences in understanding. In addition to the lack of time with Latinx patients, providers also expressed a lack of support regarding their cultural competence training. Provider 4 mentions the existence of cultural competence training but the predominant reliance on translators:

> *I think that in terms of what the healthcare organizations are doing for that [cultural competence training], you know, honestly, I, I haven't seen much other than really just trying to educate about cultural competence [model used at their location], in my particular experience…in the organization that I used to work for, you know, other than having translators and things like that.*

Similarly, Provider 2 spoke to the importance of training for providers to improve patient experiences that go beyond just providing information in a native language:

> *And you know, a lot of health care providers or health bigger health care agencies feel that culture is just providing health material written material in multiple languages. And it's like, no, that is that's very ignorant to approach it that way. It goes beyond that. It goes, it even goes past language, it goes with your body language, it goes with how you even enter a room, you know, some cultures, you don't make eye contact with patients when you approach…there is a lot that goes beyond that, that I think the healthcare delivery system does a very, very poor job in addressing and training appropriately.*

Lack of training support suggests that providers must be proactive in locating cultural competence training that enhances interactions with Latinx patients. However, this is contingent on whether the provider is aware of the need for further support. Provider 2 found themselves navigating different resource options to enhance their own cultural competence: *"So, a lot of it is me finding trainings in my community, online trainings. The National Association of Social Workers actually advertises a lot of continuing education treatment on their website."* Provider 2 goes on to describe the lack of training when being hired as a medical professional by noting that:

> *…it's left in a way that a lot of health organizations don't incorporate that [cultural competence training] into their onboarding, which I strongly feel they should and those are things that I have gone to like human resources about or you know my superiors about.*

Provider 1 shared a similar experience:

> *I don't recall really getting trained in anything, I do know that we get kind of… [an] overview when we have orientation of like, what patients we will be serving. But we don't really get any training as in other than just knowing how to call an interpreter or knowing when it's the best time to call for one.*

Provider experiences point to a reoccurrence in the lack of cultural competence training and a focus on simply addressing language barriers as a demonstration of cultural competence. Though providing linguistic support is crucial for patients to understand their health, it only touches the surface of providing culturally competent care. Relatedly, Provider 6 addresses the layers of questions and concerns they consider when caring for a minority patient:

> *For starters, I think that like…information about the medication should all be in the patient's native language. And then I think that, it's important that the medical professionals have some psychosocial backgrounds on the patient so that they have a better understanding of what's realistic and what's not realistic. We all have our ideal perfect patient that's going to be able to come to [hospital] every other day and pay $14 for parking for a lab drug visit, which is 45 minutes. But, this patient might live two hours from [hospital location]. Is that ideal? What can*

> *we do to alleviate some of the medical appointments? Is there ways for them to get daily lab checks closer to home?*

These thoughts, questions, and concerns raised go beyond simply thinking about language and translations. There are also background elements to take into account, which gives space to relevant patient cultural and personal complexities. These improvements can create a more complete understanding of the Latinx culture to create a more well-rounded method for healthcare professionals to use.

Barriers

Patients

In addition to preferences for improvement, patients and providers identified potential barriers to improvements and effective care of Latinx patients. Consistent with much of the existing literature surrounding Latinx patient care, patients in this study identified barriers related to language and resource barriers.

Patients were aware of their own lack of understanding of certain medical information in prognostic conversations. There was a sense of ignorance that reverberated among the interviews with patients, identified as health literacy or a lack of medical knowledge. Among the patients that identified health literacy as a barrier, they openly described their lack of knowledge. An example of this is demonstrated in the interview with Patient 6 as they describe being unaware of what cancer meant and their preconceived notions of what it was, *"I mean yes when one hears the word cancer and they think about death. For many people death and cancer are connected. I mean if you tell a person who is not informed of cancer, they automatically think you know, dead."*

In almost all interviews a common barrier was language. Unable to fully comprehend and communicate with each other, patients and providers are left with a tough obstacle. Many rely on translators to help alleviate this obstacle, but that was not always helpful. Further, some patients noted that the language barrier issue extended beyond themselves to involve their parents' language barriers. Patient 3 discusses how they became a filter and translator on behalf of their parents even though they were the ones with the illness:

> *There's even times were like, I would tell…my mom one thing and then I forgot to tell my dad like another part of [what] the doctor said, because I had already told my mom so it's like sometimes it did feel like a lot. And then also like, the type of translator that they sometimes…provide, it's like a translator that's on the machine. So, it's kind of like having someone on the phone in the room. And it's not very effective.*

Similarly, Patient 7 expresses their thoughts on the challenges with translations from English to Spanish that are verbatim as they state:

> *how they [providers] would take advantage of family members who don't speak language, you know, English…correctly and all the terminology that they [providers] come out with doesn't really translate right into Spanish…So, it's kind of, that's where I can see a lot of the barriers happening.*

At times, not only is there a need for direct verbatim translation, but also an explanation to completely understand what is being said. Participant 3 expresses concern for the lack of availability for interpreter resources, particularly if they become unable to speak for themselves and have to rely on their non-English speaking parents to communicate on their behalf:

> *It's also hard because when my parents don't speak a lot of English or barely any English, and a lot of the times they don't have translators, for them to know what's going on. And if I'm intubated, then I can't really speak for myself or speak much. So, I feel like there's definitely a language barrier a lot of the times.*

Barriers to resources, specifically medication, insurance, and social support was brought up multiple times by both providers and patients. It is important to consider what types of resources are given and how they can be improved for the benefit of patients that identify with different ethnic backgrounds. Patient 1 recalled their traumatic experience with not getting access to medication due to their financial circumstances:

> *And when I was meeting with oncologist, she said that unfortunately she couldn't put my prescription as a reoccurring prescription because I had to prove to her that I was able to afford the prescription. So, I felt targeted in a way. I felt like if I looked maybe Asian or maybe white, I wouldn't have to prove my financial circumstances to a doctor.*

In addition, Patient 5 discusses the difficulty they had finding medical coverage and navigating that space without sufficient support:

> *So, they're like, you know, in January, you're having your surgery, you know, you're gonna obviously have to like rest and recuperate, but no later than April, you should have this treatment. And so, I felt like I was like, on a timeline, not knowing, like, if I could even afford insurance, or where I would get my health care. So, I felt very lost…I just didn't know what I was doing.*

Furthermore, Patient 5 describes the hardships faced while finding support groups to which she felt connected based on her age and background. This becomes an essential factor when looking at resource support and cultural connection to the resources provided by the health care organization:

> *I feel like there was a lot of a lot of missing gaps for me, as much as I tried to look for, like support groups and like counseling, it was really difficult because a lot of the support groups that were given to me as resources, for outlets, consisted of like, older woman in their 40s, who, like, you know, had kids that were my age, and it just felt like that, like, their concerns, were not the concerns that I had, like, I was in college, and, like, I very much wanted to, like fight for my life, and I never was, you know, I never was at a risk of like, you know, facing death or anything.*

Though the barriers to navigating the healthcare system and locating appropriate support resources are consistent with research on non-Latinx patients, Latinx patients could attribute these barriers to unequal care. Doshi et al. (2020) conducted their research focused on Latinx and immigrant patient barriers while navigating the healthcare systems. Their findings suggest that barriers lead to three different types of delay: delay in decision seeking care, delay in traveling to healthcare facilities, and delay in receiving adequate and appropriate care. These barriers may increase existing disparities in healthcare and unequal treatment compared to white counterparts that might have more access to resources or information. Further, these negative experiences can be attributed to patients of any cultural background and identity, meaning our healthcare system further lacks proper attention for better patient provider experiences of all backgrounds, but especially patients of color that already face a myriad of obstacles.

Providers

Providers also identified barriers in caring for Latinx patients. From a provider perspective, the barrier theme is heavily focused on sub-themes pertaining to lack of resources for and socio-economic status of Latinx patients.

Providers acknowledged the lack of resources available to Latinx patients. Provider 4 highlights barriers for Latinx patients and proposes greater family involvement to circumvent barriers:

> *there's not enough resources available for say, people that aren't just educated or for minorities that don't speak English, and that maybe aren't as integrated into the community. I think bringing a family member to support them and who knows the language really helps, but there could be a lot more support available in the community. I think there's a lack of support.*

To add to this, Provider 2 expresses a similar perception in lack of cultural support for Latinx patients: "*Think that cancer resources in general, are insufficient. It has to go beyond just support groups and pamphlets and meal delivery and transportation to and from chemo…not everything is available or dedicated to a person's culture*."

Providers also identified financial barriers as an issue related to caring for Latinx patients. Extensive research supports the fact that health inequities begin with the location, environment, and type of income a family has. Provider 1 discusses the implications of financial barriers on Latinx patients:

> *…do they have some way to be able to just focus on themselves during this time so, that other responsibilities like whether they have bills or a home to pay for or car bills or work or just being able to get food? Do they have all those necessities and then from there do they have the rest of the resources they need in order to pay for the treatments or get support in order to pay for those treatments, or any other funding's?*

Being able to pay for treatment is a big component to all illnesses particularly if they have a long-term prognosis. Provider 3 is in a unique situation where they work in a country that offers universal health insurance. They describe the implications of financial barriers on managing patient illness and subsequent considerations of a cancer prognosis:

> *100%, it adds like an additional huge layer of stress, if you're worried about your insurance covering proper treatments. And I actually did a podcast with a woman who is a two-time breast cancer survivor, and she is now on the verge of losing her house. She's almost bankrupt. Which is crazy. She had a thriving business. And, you know, just to think that people have to worry about, like, paying for their treatment is just, it's completely foreign to me. And I wish I wish it weren't the case.*

The barriers providers face when treating Latinx patients encompasses various issues at both the system and interpersonal level. The system-level concerns such as medication access and medical insurance, coupled with interpersonal-level issues such as underdeveloped provider cultural competence training further enables health equity gaps that effect patient experiences in healthcare. With the sum of all the presented themes, it is evident that there are opportunities to improve care, namely the need to individualize care for Latinx patients, as well as the need to enhance provider cultural awareness and sensitivity to effectively manage Latinx patient care, and multiple barriers that must be addressed in order to change current practices.

Discussion

This study aimed to identify features of cultural competence in the preferences for and experiences with cancer prognostic conversations among providers and Latinx patients. Based on a series of interviews, data pointed to four overarching themes: Communication Practices, Latinx Culture, Improvements, and Barriers. Collectively findings point to the need for more support for Latinx patients in the navigation of prognostic conversations and highlight gaps in current cultural competence model training.

The communication practices theme identified ways that patients preferred to be communicated with and both positive and negative experiences that inform those preferences. Providers focused on their use of medical terminology when delivering a prognosis and the utility in asking questions during the clinical visit to confirm patient understanding as well as their specific care needs.

In reference to the Cultural Competence Model, question asking affords patients culturally grounded and supportive care in various categories beyond just linguistic support. Provider awareness of the array of backgrounds, preferences, and patient perceptions afforded through question asking, gives medical staff a clearer path to providing care consistent with the preferences of the patient without imposing or assuming what a patient needs based on blanket assumptions of race or ethnic identity. Further, findings around communication practices suggest that providers link culturally competent care to language and asking questions, whereas patients describe features of communication such as directness and emotion. These differences highlight the ways in which the broader institution of health care may be shortsighted in viewing and promoting cultural competence and point to opportunities to better address Latinx patient preferences regarding communication such as confirming patient preferences in the delivery of information and navigating emotions.

The Latinx Culture theme reflected patient navigation of bi-cultural identities, how culture impacted beliefs around a prognosis, and the importance of family when considering individual health. Swinging between two cultures is a difficult thing to do; understanding how this dual identity might impact societal perceptions may indicate how patients perceive their health. For example, a bi-cultural identity could contribute to a lack of trust in medical institutions, a lack of knowledge about medicine in general, or a cultural complexity that limits their utilization of health services. Better understanding of the bi-cultural experience in medicine could further enhance culturally competent care by acknowledging that there may be differences in level of understanding and health accessibility, and for providers to gauge understanding early on in the care of the patient. Further, it is important to ensure that cultural competence medical training for professionals' accounts for family impact and subsequent family support when delivering a diagnosis and communicating with a Latinx patient. This could also extend to standardizing culturally focused resources including culturally focused support groups, mental health support resources, and other informational resources such as health literacy materials specific to patient needs.

The Latinx Culture theme for providers detailed understanding (or lack thereof) of the Latinx community. White providers describe the Latinx community with direct identifiers such as education and language whereas Latinx identifying providers introduced the complexities of the actual Latinx culture. For providers, a large part of what identifies the Latinx community is their health literacy and in some cases religion. This suggests that providers have a somewhat limited view of what Latinx patients need in terms of culturally focused care. As patient participants suggest, there is more than just literacy and religion when it comes to being Latinx. Patient responses can better inform how Latinx patients receive information and what is important to them during this experience. As noted earlier, cultural competence training should incorporate how a provider identifies an illness and relates this information back to the patient knowing that the importance of family has a big impact on how that information is received. Many Latinx families depend on one other for work and support, a cancer diagnosis could greatly shift the life of a patient and their broader family system at a higher rate when compared to non-Latinx patients, potentially calling for additional support services (Campos et al., 2014).

The research question regarding cultural competence is further addressed by the themes of Improvements and Barriers. Notably, patients and providers shared similar preferences for improvements in managing care of Latinx patients and identified similar barriers to providing equitable patient care. Overlap in participant responses were found in the sub-themes of communication practices, time constraints, and representation. A key component of the Cultural Competence Model is the ability to call out any biases or cultural perceptions towards patients. That means providers need to be aware of their own beliefs and assumptions of others to ensure that care properly reflects how the patient wants to be treated. This helps to mitigate implicit bias that might be projected toward a patient. According to participant responses, current cultural competence training lacks the core components needed to ensure providers are considering their own positionality, and possibility a limited understanding of the Latinx community, that they bring with them to the clinical encounter. Lack of awareness on behalf of the provider regarding cultural preferences, communication preferences, or even health care support resources for Latinx patients, can be addressed by modifying and requiring cultural training for providers. On an interpersonal-level, provider awareness and acknowledgement of patient considerations of time for example could open a dialogue that promotes trust. On a system-level, affording more time to providers that work with Latinx patients could help to further ensure that there is shared understanding in prognosis and treatment options as well as confirm any additional resources the patient may need to manage their health.

Cultural sensitivity is a term often brought up when discussing prognostic conversations however, it is not enough when considering the goals of culturally competent care (Ahluwalia et al., 1999). Shifting the view from competence and sensitivity, there should be a deeper focus on *cultural grounding*. Researchers Hecht and Krieger (2006) describe cultural grounding as providing a view of culture that acknowledges the "multi layered phenomenon" and that these layers should be used and put into practice when designing a model in healthcare research, "from the ground up". Currently, cultural competence takes a more sensitive approach of unique traits of culture and identity of populations that seek care. The focus of well-rounded care needs to look beyond sensitivity and look at both surface and deep structures. Surface structure looks at the visible or obvious characteristics of a cultural group such as language, food, or physical features (Resnicow et al., 1999). On the other hand, deep structure is far more complex to implement because it requires an understanding of culture, social, and environmental forces that can alter health behavior (Hecht & Krieger, 2006; Resnicow et al., 1999). Understanding the layers of culture by going further and implementing this surface and deep structure gives medical institutions the ability to understand the true layers of culture and uncover numerous obstacles that providers face when communicating with culturally diverse patients.

Ndiaye et al. (2008) propose grounding as one of the solutions to health inequity involving health literacy, online resources and access, and provider patient interaction. Cultural grounding may enable healthcare systems to have a more culture-centered, humanistic approaches to patient care; rather than having culture as an added part of a model it is the center of attention (Ndiaye et al., 2008). Patients describe the need for providers to slow down, take a moment to breathe, and remember they are human before going from one appointment to the next. Doing so helped patients feel like they were being cared for and listened to. The need for further explanations of medical terminology was a key improvement to better patient-provider communication interactions. Instances of patients being confused was quite common. Taken together more targeted training for providers, as opposed to cultural competence training that presents flaws and gaps within the model, could eliminate many of the care inequities that are currently present for Latinx patients. Culture plays an important role in all health messages, communication, and interactions; institutions should consider moving away from the limiting, catchall Cultural Competence Model and instead implement more cultural-based support and resources that consider the nuanced cultural aspects surrounding patient care.

Based on study findings future directions for this research include challenging the normative vocabulary in medical institutions, to move away from the term ‘culturally competent care’. Through the data, experiences, and literature provided in this study, it is safe to suggest that implying that someone is culturally competent means that they are more versed than the patient in the respective culture. With the outlined experiences, it is understood that culture has many nuances and the best approach to provide the most culturally acceptable care is looking at it through a culturally grounded method, keeping culture at the center of focus (Hecht & Krieger, 2006) With this as the core focus of a new model, there is further room for more education and training for medical professionals. Culturally grounded or culturally inclusive care goes beyond linguistic support, considering communication at the interpersonal level regarding listening, body language, and emotional communication. In addition, culturally focused care gives space to further research adequate forms of educating professionals regarding culture to establish a more culturally inclusive environment in the healthcare field.

Practical Implications

Findings point to several practical implications from this research. First, results suggest that further cultural support for patients is needed in addition to more training for medical staff to ensure unbiased and culturally inclusive care. Going beyond just providing linguistic support would ensure that institutions are addressing the various levels of culture such as beliefs and traditions. Culturally appropriate care is going beyond providing translators or giving documentation in a native language. It is looking at what cultural competence is at its core and extending that. This could be provided through more holistic medical support and advocating for patients to take the measures necessary for them to live in a manner that they deem livable. Established policies that foster fear and limit advocacy for patients are a clear form of power from the institutional policymakers. Medical professionals at all levels should feel supported enough to internally call out implicit biases within the workplace without fear of retaliation and to provide resources to their patients from all economic and cultural backgrounds.

Further, this research, through the experiences brought forward, provides evidence that culturally focused care is extremely important for Latinx patients, to ensure proper care. This work signals that more can be done to better Latinx patient experiences. Through the examples in this research, there are descriptive opportunities to modify care practices interpersonally and within the broader health care system. Specifically, study findings offer prescriptive recommendations for enhancing the way cultural competence is applied in medical education training. This paper also speaks to the indirect racial discrimination within the institution of healthcare and establishes a space where bringing to light implicit biases among healthcare professionals is welcome in an effort to address inequitable care. Lastly, this work practically extends the voice of the Latinx community in research. The importance of advocacy within the Latinx community is instrumental to better healthcare.

Theoretical Implications

Study findings deconstruct the ideologies of the Cultural Competence Model. Through the data collected it is evident that further trainings focused on culturally sensitive care are indispensable for providers to give patients culturally focused care. However, this training is not possible without first acknowledging the systemic barriers and connecting with policy makers to facilitate change, such as more time with Latinx patients, which can have a trickledown effect on the patient care experience. Results point to the need to shift away from the Cultural Competence Model to a culturally grounded care approach that considers the individuality of patients and encourages exploration of unique patient values and beliefs. The idea that a medical professional is fully competent in a culture separate from their own defeats the purpose of providing culturally appropriate care. Culture is not something that is learned with one course; it requires constant growth and inquiry to ensure providers have the awareness to offer more culturally grounded care. Critical Race Theory may provide a useful lens for future studies examining cultural competence in healthcare. Application of this theory may afford greater opportunity to unpack the inequities in the medical industrial complex and disrupt the status quo, particularly as it pertains to ideologies of cultural competence.

Limitations

This study includes several limitations. First, recruitment occurred at the height of the global COVID-19 pandemic, making it challenging to recruit participants and ultimately limited the number of patients and providers that were able to partake in the research study. Patients were overwhelmed with the restrictions and difficulties COVID-19 presented during their cancer journey. COVID-19 also limited the bandwidth of providers working with cancer patients at medical institutions. The global pandemic also limited recruitment outreach. It was not possible to physically go into medical facilities and circulate information regarding the research. Fortunately, after the first few interviews in both groups, common themes began to emerge. In addition, a wider range of demographics for the provider participants would have served as a more diverse participant pool. This relates to age, gender, and provider role. For the purpose of this study more oncologist insights would have added greater perspective on the prognostic interactions between patients and providers as well as the system level regulations that impact patient care. Collectively, findings are not representative of all Latinx patients and the providers that work with Latinx patients.

Conclusion

Communicating prognostic information is a difficult conversation to have, especially when the patient’s cultural beliefs and values are not understood. Through the Cultural Competence Model, this research study explored narratives of Latinx oncology patients and the providers that work with this patient population to gather insight on preferences for and experiences with prognostic conversations, determine similarities and differences between Latinx patient and provider perspectives, as well as best practices for improved navigation of prognostic conversations. Findings highlight the importance of understanding how to provide culturally grounded care for better patient interactions during a cancer prognosis. Future research should focus on bringing out more experiences of the Latinx patient population to amplify the problems existing within the medical industrial complex.

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Appendix A: **Patient Interview Guide**

For the interviewer: This is the recording for participant [Unique Identifier]

1. Hello, thank you so much for meeting with me today. I understand you might be recalling difficult experiences during this interview. If you need any support, contact information please take a look at the support information provided to you along with the consent form before this interview. If you'd like me to stop at any moment, please let me know.

2. Great, to begin, I'd like to ask if you could briefly describe your current health status related to your cancer prognosis.

Part I: Demographics

Great, thank you.

Next, I have a few demographic questions for you, if you do not feel comfortable please feel free to say pass:

3. What is your ethnicity?

4. What is your highest level of education?

5. What type of employment do you currently have? What type of employment did you have when you were diagnosed with cancer?

6. Which medical centers did you attend to manage your diagnosis?

7. Could you provide an estimate of your annual household income?

Part II: Active Communication

8. Thank you for that information. Next, I would like to ask about the time you received a prognosis about your cancer. Can you take a moment to explain how the prognosis was delivered to you? Consider how it was communicated? Where were you? Who was in the room?

    a. Also, what was it like to receive this information? How do you feel your doctor did in delivering this information?

9. What would you wish your doctor did differently during the cancer prognosis conversation (i.e., the way it was delivered: over the phone, face to face, etc.)?

   a. Would anyone else from your health care team be involved in the prognosis meeting? (Nurse? Social Worker? Someone else?)

   b. Did you have an interpreter present? If so, how was that experience? Do you feel like the interpreter helped?

      i. If not, would you have wanted one present? Can you explain why or why not?

10. If your doctor wasn't available to provide you with this information, or you didn't have a good relationship with the doctor taking care of you, who would you wish to speak with?

11. Take a moment to think about your past experiences with medical professionals during your cancer treatment.

   a. What do you think impacted your communication with medical professionals the most?

   b. Under the circumstances, what do you think makes a good/productive interaction between yourself and the medical professionals?

Part III: Latinx Experience

Now I'd like to learn about experiences you might have had related to your Latinx culture when you've received medical care. Feel free to pass on these questions or stop at any time for any reason. [Interviewer prepared to define Latinx culture if necessary] 12. Can you tell me what Latinx culture means to you?

12. Can you think back to a time where your Latinx identity influenced the medical care experience? For example, did you experience any changes in your care because of your possible language barrier?

   a. Where there any actions from the medical center/providers to address this?

   b. In your opinion, what actions should have been taken in order to better address your Latinx experience?

13. How do you think your Latinx culture or background played a role in how you received a prognosis?

14. How do you think your language or education impacted how medical staff communicated with you or your family?

15. Can you describe how you felt as a Latinx navigating the healthcare system? a. Can you speak about medical insurance and support navigating treatment costs?

16. Can you speak about the support and communication you received during your cancer prognostic experience from the medical staff?

17. As you think about your interactions with medical providers and your cancer experience, what could the provider have done differently? (prompts: are there certain words that you would prefer the doctor to use, or actions that would have been better than what you experienced?)

General question:

As a final set of questions, I'd like to just ask a general question about what we've discussed.

18. Cultural competence in healthcare looks at healthcare providers' and institutions' abilities to deliver effective services to racially, ethnically, and culturally diverse patient populations. Some of these components may include awareness of one's own cultural worldview, knowledge of the different cultural practices and worldviews, cross-cultural skills, and attitudes toward cultural differences.

    a. What does culturally competent care look like for you?

    b. Do you feel you received culturally competent care throughout your cancer experience?

    c. What are some things you would like to see change in order to have more culturally competent care and communication?

Those are all the questions I have for you today. Thank you very much for your time and allowing me to discuss this topic with you.

Have a great day!

Appendix B: Provider Interview Guide

For the interviewer: This is the recording for participant [Unique Identifier] Hello, thank you so much for meeting with me today. To begin, I'd like to ask if you could briefly describe your role related to caring for patients with cancer.

Part I: Demographics

Great, thank you.

Next, I have a few demographic questions for you, if you do not feel comfortable please feel free to say pass:

- What is your ethnicity?
- What is your highest level of education?
- What medical institutions have you been employed at?
- How long have you been working in your current capacity?

Part II: Active Communication

Great, thank you. Next, I would like to ask you a bit about communicating a cancer prognosis to patients.

1. Can you walk me through how you deliver a cancer prognosis to your patients?
2. Great, thank you for explaining. Are you familiar with the Latinx Community?
    a. If so, can you walk me through your explanation of this community?
    b. If not, the Latinx community can be identified as a group identity used to describe individuals in the United States who have Latin American/Mexican roots. The X is used as a form of inclusivity as it is a gender natural word.
3. What differences might there be in how you deliver a cancer prognosis to a patient that identifies with the Latinx community? How do you determine whether a patient identifies as Latinx?

Part III: Cultural Competence

My thesis incorporates the framework of Cultural Competence in Healthcare. If you are not familiar, Cultural Competence in Healthcare considers both providers and institutions' ability to deliver effective services to racially, ethnically, and culturally diverse patient populations (Fernandez et al., 2004). Some of these components may include awareness of one's own cultural worldview, knowledge of the different cultural practices and worldviews, cross cultural skills, and attitudes toward cultural differences.

4. What do you consider culturally competent communication when delivering cancer prognosis to minority groups?

5. What training have you been given to provide culturally competent communication to minority groups, specifically Latinx? Can you provide some examples?

6. What resources do you think the healthcare system can provide for medical professionals, to ensure culturally competent communication is provided to Latinx patients and other minority groups? (i.e. continuing medical education, specific cultural training sessions)

7. Can you walk me through an instance where you felt you encountered difficulties handling cases with minority patients, specifically Latinx patients? What were some barriers you faced as a medical professional?

8. For a moment, think back to a time when you have provided a Latinx patient with a cancer prognosis.

    a. What was the best experience delivering the diagnosis given the circumstances and why? Can you list the top 3-5 ways in which this was positive?

    b. What was the worst experience that you had and why? Can you list the top 3-5 ways in which this was negative?

    c. Under the circumstances, what do you think makes a good/productive interaction when delivering a cancer prognosis?

Part IV: Latinx Experience

9. What role do you think Latinx family members should play throughout the cancer diagnosis conversations?

10. Some studies show that language and education can become barriers when communicating prognostic conversations. Can you recall and describe an instance where you had a difficult time communicating or understanding a Latinx patient?

    a. What steps were taken to ensure the right communication was provided?
    b. What strategies do you use when communicating a prognosis to a patient who has a difficult time understanding the information due to cultural barriers such as language?
    c. Do you think interpreters are helpful when prognostic conversations are taking place with Latinx patients?
    d. In what ways do you think culture might impact prognostic conversations?

General Questions:

11. Systemic racism is a constant battle for many people of color.
    a. How do you think healthcare institutions are handling cultural disparities with regards to minoritized groups?
    b. What are some things you have experienced that might help create positive change for Latinx patients? (e.g., did you offer specific resources, suggest certain ideas for dealing with their prognosis?)

Those are all the questions I have for you today. Thank you very much for your time and allowing me to discuss this topic with you.

Have a great day

Appendix C: Screening Questions

These questions will be asked any potential participant

1. Do you identify as Latinx?
2. When were you diagnosed?
    a. Is it within the last 15 years?
3. Are you at least 18 years of age or older?
4. Do you have reliable internet access to conduct the interview Via Zoom?

Appendix D: **Participant Resource Sheet**

Bay Area Cancer Connections
Address
Helpline: 650-326-6686 | **Español:** 650-325-6299 ext. 22
Visit info@bayareacancer.org to complete a Support Group Consent Form before joining a group via telephone or Zoom.

Cancer CAREpoint
2505 Samaritan Drive, Building 400, Suite 402
San Jose, CA 95124
Helpline: 408.402.6611

Cancer Support Community
3276 McNutt Avenue
Walnut Creek, CA 94597
Helpline: 925.933.0107

Santa Clara Country – National Alliance on Mental Illness
1150 S. Bascom Ave.
Suite 24
San Jose, CA 95128
Helpline: 408-453-0400

County of Santa Clara Behavioral Health Services
Mental Health Services
Helpline: 1 (800) 704-0900
Hours: 24-hours, 7 days a week

Bay Area Gestalt Institute
Helpline: 415-689-6422

Bay Area Mental Health
1925 Winchester Blvd, Suite 204,
Campbell, CA 95008
Helpline: 408-508-3611

Depression and Bipolar Support Alliance
Helpline: 415-758-1799

Additional Resources:
San Francisco Suicide Prevention's 24-hour Crisis Line
Helpline: 415-781-0500 or 1-800-273-8255
National Suicide Prevention Lifeline
Helpline: 1-800-273-TALK (1-800-273-8255)