

Beliefs, Attitudes, and Understanding of Childhood Cancer Among White and Latino
Parents in the Phoenix Metropolitan Area: A Comparative Study

by

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ABSTRACT

In 2023, it was expected 350 parents in Arizona would have a child receive a cancer diagnosis (Welcome Arizona Cancer Foundation For Children, n.d.). The news of a child's diagnosis with cancer can be overwhelming and confusing, especially for those lucky enough to lack a personal tie to the disease that takes approximately 1800 children's lives each year in the United States (Deegan et al., n.d.). A parent's beliefs, attitudes, and understandings surrounding cancer are vital for medical staff to provide adequate and culturally competent care for each patient, especially across cultural and ethnic lines in regions housing multicultural populations. Arizona's cultural/linguistic mosaic houses a large percentage of White and Latino populations, and English and Spanish speakers. Variations in insurance coverage, from those insured through public insurance programs (e.g., Medicaid) or private insurance plans (eg., employee-sponsored insurance) versus those uninsured, also factor into health-seeking attitudes and behaviors. To further understand parental attitudes, understandings, and beliefs towards childhood cancer, 22 parents (11 of Latino ethnicity, 11 of White ethnicity) were interviewed on these facets of childhood cancer, despite 21 of the 22 never having a child receive a cancer diagnosis. The exploration of these perceptions across ethnic lines revealed a higher report of fear-orientated beliefs amongst Latino parents--hypothesized to be rooted in the starkly contrasting lack of belief in the possibility of recovering for children with cancer, compared to their white counterparts who displayed more optimism in the recovery process.

Further, this study's results lay the foundation for future scholarship to explore avenues of information dispersal to Latino parents that correct misconceptions of health

outcomes and enable earlier intervention to be possible, ultimately correlating to better health and treatment outcomes by increasing parental health literacy rates for childhood cancer in the Phoenix Metropolitan.

DEDICATION

Thank you to my parents, my sisters, and my teammates for their endless encouragement, support, and positivity. Their unwavering support of my dreams has made every step in achieving them mean so much more. While there are many words on the papers that follow, the three in my heart belong to them: thank you always.

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CHAPTER 1

INTRODUCTION

I. Purpose of Research

Introduction

Every three minutes, a child is diagnosed with cancer across the United States (Fragkandrea et al., 2013). In Arizona alone, over 350 families will receive this diagnosis (*Welcome » Arizona Cancer Foundation For Children*, n.d.). This diagnosis will be received by approximately 9,910 children in the United States under the age of 15 in 2023 (*Key Statistics for Childhood Cancers*, n.d.). Of those battling cancer, about 1800 children succumb to the disease annually in the United States (Deegan et al., n.d.). While childhood cancer is the leading cause of death by disease for children in the US and globally, advances in medical research boast an 85% five-year survival rate for children who receive cancer treatment--a significant improvement from 58% recorded just decades earlier in the mid-1970s (Fragkandrea et al., 2013; *Key Statistics for Childhood Cancers*, n.d.). Unfortunately, these recent strides in childhood cancer have not been felt equally across socioeconomic, racial, and geographic line A. Hispanics account for a disproportionate amount of childhood cancer diagnoses in advanced stages and mortalities in comparison to non-Hispanic whites; The incidence rate in Latinos for childhood cancer continued to increase over the last decades disproportionately (Beltrami et al., 2022; Carcioppolo et al., 2019; Perez, n.d.; Ramirez & Trapido, 2023; Tobin et al., n.d.; Whitehead et al., 2016).

Access to and utilization of childhood cancer healthcare services is a central component of health determinants and outcomes; however, (perceived or experienced)

racial, cultural, geographic, and economic barriers to accessing services for childhood cancer could further deter them from accessing needed care. While research has explored these topics for many populations, little research focuses on the Phoenix Metropolitan area across these various lines of analysis. To promote equitable healthcare conditions, it is necessary to work within the communities in this region to better understand their specific beliefs and attitudes of the perceived interplay with race, culture, geographic location, and socioeconomic factors with childhood cancer care, as well as the etiology of cancer itself.

The Phoenix-Mesa-Scottsdale Statistical Region (14,587 square miles), or the “Phoenix Metropolitan,” houses 4.86 million residents (*Phoenix-Mesa-Scottsdale, AZ. Data USA. (n.d.)*). This region is home to 67% of Arizona’s population, making it one of the fastest-growing areas in the nation (*MAG-Region-Infographic-Jan2020.Pdf, n.d.*).

The Hispanic population represents a large and growing proponent of the American population, representing the largest ethnic and racial minority in the country (Patel, Johansen, et al., 2020). A historical shift in minority/majority demographics occurred in 2021, as for the first time, the majority of US population growth came from immigration rather than American reproduction (Gest, 2022). With immigration becoming a primary driver of population growth, the country’s racial makeup is projected to change over the next decades drastically. Coined as the ‘Majority Minority’ shift, demographers project that by 2045 the non-Hispanic white population will no longer be the racial majority and that by 2060 a new “demographic pluralism” will be seen across the American populace (Vespa et al., 2018). By 2060, Hispanic individuals will account for one-third (29%) of America’s population (Patel, Johansen, et al., 2020). In Arizona,

54% of the population is White, and 32% of the Population is Hispanic (*MAG-Region-Infographic-Jan2020.Pdf*, n.d.). In the Phoenix MSA, 55% identify as White and 32% identify as Hispanic (*MAG-Region-Infographic-Jan2020.Pdf*, n.d.). A challenge in assessing this data accuracy of Latino representation lies in the US Bureau's inclusion of Hispanics as white in census data.

The increasing density of Hispanic populations in the United States pushes the question of how one of America's most notable public health crises impacts such a sizable and important sector of the American populace. The term Latino refers to an individual who resides in the United States but has roots in Spanish-speaking regions of the Americas (Central, South) and the Caribbean (Perez, n.d.). Understanding how Latino parents view and understand cancer is vital in reducing disparities in Latino childhood cancer health outcomes.

This study aims to understand knowledge, beliefs, and attitudes about childhood cancer (i.e., what it is and what it looks like in children) in a sample of Latino and White parents from across the Phoenix metro area. This understanding allows for developing informed paths to establish more equitable conditions across all demographic lines for education and accessibility of childhood cancers. As children represent a highly vulnerable population, it is vital to examine their parents' beliefs, attitudes, and understanding as they will, in most cases, be central in determining the child's interaction or lack of interaction with the medical system.

The study's central hypothesis posits that Latino parents' beliefs, attitudes, and behavior around cancer will differ from White parents. More specifically, I hypothesize that Latino parent's beliefs, attitudes, and behaviors around cancer are less likely to

follow those espoused by medical institutions like Centers for Disease Control and Prevention (CDC) and the National Institute of Health (NIH). Furthermore, it is hypothesized that parents with a lower degree of understanding education of the etiology of childhood cancer, racial minorities, residents of more rural areas, and those of lower-socioeconomic and educational status are less likely to understand the course of diagnosis, treatment, recovery, and the financial, cultural/ethnic, and geographic factors that efficacious childhood cancer case management relies upon. To test these hypotheses, this study collected interview data on perceptions, attitudes, beliefs, and understandings. The primary research question for this study is: Do beliefs and attitudes around childhood cancer differ between of Latino and White parents in the Phoenix Metropolitan area? Second: What are barriers or perceived barriers Latino parents face accessing childhood cancer services in the Phoenix metropolitan area? Does this differ compared to White parents?

II. Literature Review

Etiology and Epidemiology of Cancer

Cancer is a disease that originates from mutations and cellular damage (Perez, n.d.). A mutation within the human DNA, containing 23 paired chromosome packages, on an oncogene (gene containing instructions for cellular growth and division), results in uncontrollable cell division--otherwise known as ‘cancer’(Perez, n.d.). Childhood cancers originate from “two or more molecular changes in a stem-like cell that can divide while maintaining an immature state” (Whitehead et al., 2016, p. 320). This uncontrolled division of abnormal cells in the body results in over 100 types of cancers (Perez, n.d.).

There are five main types of cancers: leukemias (originates in the blood tissues), lymphomas (affects the immune system), central nervous system (CNS) cancers (origin in the brain and spinal cord), carcinomas (originates from skin or tissues covering internalized organs), and sarcomas (connective tissue origins) (Perez, n.d.). Leukemia, in particular, is cancer forming in the cells of the blood, moving unrestrictedly, and forms in conditions with fewer genetic aberrations than needed in solid tumor formation (Whitehead et al., 2016, p. 320). Leukemia occurs when blood cells are not functioning as they should, resulting in “blasts” of unhealthy blood cells that push out healthy cells. Leukemia is the most common cancer affecting children, accounting for one-third of diagnosed childhood cancer cases (Perez, n.d.). Fortunately, once diagnosed, treatment quickly ensues, reducing any cancer in the bloodstream within the first treatments (Roswell Park Comprehensive Cancer Center, 2021). The most common subtype of childhood cancer is acute lymphoblastic leukemia (ALL). The standard of treatment for ALL cases is chemotherapy; more aggressive chemotherapy is prescribed for childhood cancer cases than for adults with ALL. Remission rates are promising; the literature boasts a >95% remission rate for children and 78% to 92% for adults (Miller et al., 2022).

Incidence rates of ALL are 20% higher in Latino populations and children of Latino ancestry than non-Latino children (Archer et al., 2016; Giddings et al., 2016; Hsu et al., 2016). Central Nervous System (CNS) cancers are the second most common, accounting for approximately 24% of all cases, and pose risks of long-term neurocognitive effects, specifically in low SES immigrant families; given the treatment, the course is often cranial radiation therapy (Patel, Miranda, et al., 2020). In 2023 alone,

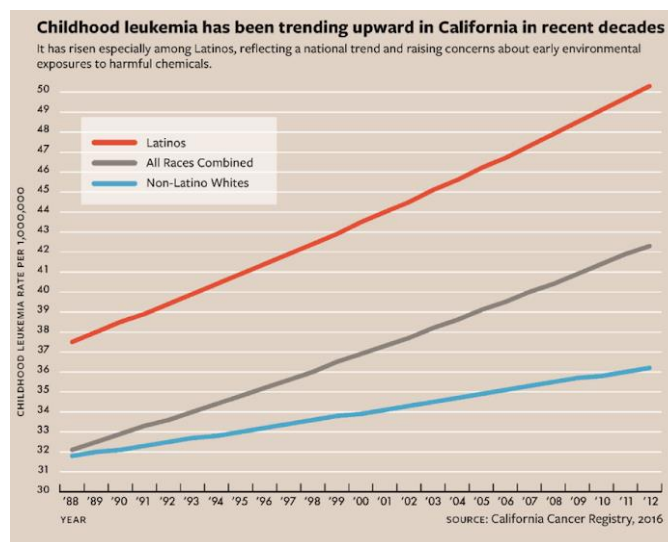
it is estimated that 5,230 CNS diagnoses will be received by children aged 0-19 across the US (*Central Nervous System Tumors (Brain and Spinal Cord) - Childhood - Statistics*, 2012). Except for benign brain tumors, 5-year survival and remission rates for CNS are 74% for children 0-14 (*Central Nervous System Tumors (Brain and Spinal Cord) - Childhood - Statistics*, 2012).

While no racial disparities in incidence rates for CNS are reported, differing survival rates persisted in literature in terms of the race and ethnicity of the child (Perez, n.d.). The literature reveals that Black and Hispanic/Latino children experienced the worst health outcomes of children diagnosed with CNS (Perez, n.d.). The academic literature indicates a variety of tangible rationales for this discrepancy, citing access to care, increased hesitation to access care, and financial/documentation constraints as plausible.

A study examining the trajectory of childhood cancer rates concerning race in California is shown in **Figure 1**.

Figure 1. The incidence rate of Childhood Cancers in California from 1988-2012 by Race/Ethnicity (Whitehead et al., 2016).

Within the century, advancements in research and treatments of childhood cancer have comprised one of the most successful strides in the scientific and medical fields.



Deemed fatal until 1950, the most common neoplasm among pediatric cases, acute lymphoblastic leukemia (ALL), has a 90% survival rate compared to those treated in developed countries (Abrahão et al., 2015). While this is an accomplishment in the medical community, advancing survival rates is not parallel. Racial disparities are palpable in statistics of Latino children diagnosed in more advanced states and with lower chances of survival than their white counterparts. This indicates that medical advancements' reaped benefits are not uniform across socioeconomic, racial, and cultural lines.

Signs and Symptoms

The signs and symptoms of childhood cancer are vast and commonly resemble normal childhood illnesses and pains. While doctors state childhood cancers present differently in each patient, some common symptoms children can experience are unexplained fever or illness that does not seem to go away, palpable lump, swelling, unexplained or extensive bruising or bleeding, back pain (especially in young children), limping or complaints when walking, sudden weight loss, an unusual level of lethargy, pale coloration, drenching night sweats, constant headaches, complaints on the pain that does not go away, and new or worsening vision (Roswell Park Comprehensive Cancer Center, 2021). Fevers occur due to dropping white blood cell counts that limit the body's ability to fight illnesses and infections (Icon Cancer Centre, 2022). Low red blood cell counts also account for observed low energy and pale presentation in a child as red blood cells' primary function to carry oxygen is inhibited, resulting in a lack of red blood cells, and therefore oxygen, flowing through the body (Icon Cancer Centre, 2022).

Additionally, a byproduct of these “blasts” is the crowding out of platelets as well--cells responsible for binding with other blood cells to clot and repair cuts and injuries to the skin. As a result, a child may present with bruising, nose bleeds, or tiny red dots seen under the skin's surface called “petechiae”(Icon Cancer Centre, 2022). Another symptom to look for is an enlarged stomach which may result from an enlarged spleen or liver from the cell “blasts” caused by cancers (Icon Cancer Centre, 2022). A child may present with a constellation of symptoms that differ from another child's. Medical professionals advise parents to follow their instincts and contact their pediatrician if their child’s health, behavior, or duration of pain or illness seems abnormal to them.

Pediatricians will be the primary assessment point for children to decipher cancer from many common childhood illnesses. One-way pediatricians assess a cancer child is by examining the lymph nodes. If the lymph node is soft or easy to move, it is considered normal or a “non-concerning lymph node,”; whereas if it is hard, “matted down,” and proliferating in size, it is considered what doctors refer to as a “concerning lymph node” (Roswell Park Comprehensive Cancer Center, 2021). Once the doctor completes a physical assessment of the child, a review of the family history of cancer, and reviews any potential exposures to carcinogens (substances or conditions that cause cancer), various medical assessments can be used to diagnose the child with cancer. A complete blood count (CBC) or general blood test can reveal if there is a high number of white blood cells and, by contrast, low platelet and red-blood-cell levels, which are indicators of leukemia. Tumor marker tests are another method of diagnosis, where blood, urine, fluid, or tissue is “biopsied” (a collected sample) for cancer markers. Imaging exams are another way a child may be diagnosed, as X-rays, computed tomography (CT) scans,

magnetic resonance imaging (MRI), ultrasounds, bone scans, or positron emission tomography (PET) scan in culmination with a CT scan can provide a clearer picture of cancer present in a child (*Diagnosing Cancer in Children*, 2022).

Structural Disparities

Alongside biological and anatomical foundations to this study, structural barriers in the economic, cultural, and geographic realms are reported in the literature as potential molds for the resultant attitudes, beliefs, and understandings of childhood cancers.

Financial constraints are believed to limit a family's ability to access cancer. These worries bear validation, as Arizona's healthcare system averages an annual cost of \$8,060 for an individual--ranking 6th for most expensive states to receive healthcare in (Court, n.d.). Insurance access comes into play in the financial realm as it represents a major financial driver in access to care for families. Insurance is one understood mechanism for easing financial risk and stress. Unfortunately, in 2019, Latino folks were the second largest uninsured group in the country, behind American Indian or Alaskan natives; Latinos account for 17.7% of the uninsured in the country versus 5.7% of White residents (Bureau, n.d.-d). In 2022, Latino individuals were reported to be the highest uninsured population in the country. The turbulent state of government-sponsored health insurance may be a factor of consideration as Arizona was the only state in 2010 not to reinstate the government-sponsored block grant, Child Health Insurance Plan, more commonly known as CHIP. CHIP provides coverage to children not eligible for other government-sponsored insurance programs. In 2022, 9% of Arizonians were uninsured, 29% were covered through employee coverage, and 44% purchased insurance through

ACA marketplaces (*The State of US Health Insurance in 2022*, 2022). Within ACA marketplaces introduced by Arizona's acceptance of Medicaid expansion, as of November 2021, 2,310,260 Arizonians are covered by Medicaid/CHIP (Norris, 2023).

Attitudes of one's financial state as an indicator of one's health are also grounded in scholarly evidence. Race is an additional perceived axis of inequity regarding one's financial stability. A census released by the US Government on household income supports this understanding of higher likelihoods of financial instability in certain racial groups; this census followed residents of Latino origins' income from 1967 to 2021. This study found that White or non-Latino households were the second wealthiest (Asian population highest reported income) with a median household income of \$77,999, while Hispanic (any race) were below the median line for all races reporting a median income of \$57,981 (Bureau, n.d.-b). Such financial instability can also be understood as a barrier to one's belief in their ability to access childhood cancer services physically. Lastly, caring for a child with cancer can take a toll on a parent's ability to work, leading to parents understanding this is also a financial risk, as taking off long work periods to care for their child may ultimately risk their employment (C. Y. Ochoa et al., 2023).

Government-sponsored care for those deemed eligible must pay for the majority of cancer treatment or chemotherapy patients receive and are protected from medical discrimination based on their cancer diagnosis. However, even with the majority of the costs covered, families still pay \$6,000 to \$10,000 out-of-pocket for cancer treatment with their government-sponsored insurance factored in (Oncology, 2020). The decision incited massive cuts to the state's child care assistance, slashing the budget from \$85 million pre-recession to \$24 million in 2010 (Polletta, 2021). The decision followed a

deep economic recession in 2008 that damaged the Arizonian economy and left many parents in a difficult place financially to take on the costs passed on by the government's decision not to reinstate CHIP. Further, this financial burden increased by the state's decision not to reinstate CHIP in 2010 may have created an influx in medical anxiety surrounding treatment costs for pediatric diseases and illnesses. During this time, Arizona joined 41 other states in their acceptance of Medicaid expansion in July 2013. Medicaid is the nation's public health insurance program for low-income Americans. Although the expansion of Medicaid increased enrollment in Medicaid (and CHIP later on) by 70%, CHIP's unavailability for over half a decade left low-income children with inadequate coverage, as it is intended to build on Medicaid to provide this needed additional coverage for children across the nation (Norris, 2023).

CHIP, or its state-specific program name "KidsCare," was re-installed on July 16, 2016, when the state government announced its reinstatement of the program and acceptance of federal funds once again. However, the six years of insufficient support and investment in the child-health sector leaves the child healthcare system fragile and unequal as years of missing support have not only impacted the health of children specifically in low-income, rural, and single-parent homes but may have created confusion and uncertainty of where support will be provided to parents seeking health services for their child (Polletta, 2021).

Race may also affect a child with cancer's health outcomes. Studies observe that race and ethnicity are notable factors influencing the overall survivability of the disease for a child (Beltrami et al., 2022). This trend is centralized as studies show Latino children in the United States have higher incidence rates of childhood leukemia

(Giddings et al., 2016). Scholars hypothesize that this discrepancy could lie in lack of affluence, inability to access quality health care, lack of resources to comply with prescribed courses of treatment, or other socioeconomic and racial factors (Perez, n.d.). While ample literature discussing access to care highlights cultural beliefs as a factor in lower screening and worse outcomes for other cancers in Latino populations, literature specifically about pediatric cancer cases in Phoenix's Latino population is too scarce to hypothesize why (Perez, n.d.). This literature will specifically work with this dialogue to further explain why Latino children may be disadvantaged compared to their white counterparts.

Pediatric cases represent an additional layer of vulnerability of cancer. A study originating from the University of California Berkeley's School of Public Health identified a heightened environmental risk for children, as they “breathe more air, eat more food, and drink more water per unit of body weight compared to adults” “because they exhibit exploratory behaviors that place them in direct contact with contaminated surfaces, they are more likely to be exposed to any contaminants present,” and that they “are also less developed immunologically, physiologically, and neurologically and therefore may be more susceptible to the adverse effects of chemicals and toxins” (University of California Berkeley School of Public Health, n.d.-b). Additionally, the comprehension level of the child diagnosed being lower than adult cases due to their age results in parents often stepping in as primary caregivers and advocates for their child's health. Reports of helplessness, insecurity, and fear from the uncertainty of their child's future are found in the literature documenting parents' experience caring for a child with cancer (Rosen, n.d.).

Given the layers of vulnerability children with cancer face in a minority population, the parent's role as an advocate for their child's health is crucial in their health outcomes. However, a parent's ability to advocate for their child's health throughout their cancer journey can be affected by language barriers, the parent's spiritual or religious beliefs, level of education, source of the information dispersed, documentation status, and cultural values of the parent. The longest study to running longitudinal birth cohort study examining environmental exposures to children residing in a farming community in Monterey Country, California, labeled CHAMACOS, meaning 'little children' in Mexican Spanish," reported emotional and health attitude and behavioral information regarding the SARS-CoV-2 pandemic (University of California Berkeley School of Public Health, 2020). In the study, it was revealed "only half of the farmworkers are extremely likely to get vaccinated, mostly because of the fear of side effects but also because they did not trust the government" (University of California Berkeley School of Public Health, 2020, p.2). Thus, this evidence further supports the literature's discussion of how attitudes, beliefs, and understanding in Latino communities directly impact health behaviors.

A study from a research team at the University of Illinois at Chicago found concerning illness and disease that a large proportion of Latino families saw their child's disease/disability as a sign from God (Salkas et al., 2016). The perceived signal from God could be perceived as the "child as a blessing," "child is part of God's plan," or that "God gives special children to parents"(Salkas et al., 2016, p. 48). A study conducted by Johns et al. (2009) unveiled religion as the primary coping mechanism for mothers dealing with

a recent diagnosis of a child with cancer (Salkas et al., 2016). Values specific to Latino cultures, such as *simpita* (sympathy) and *personalismo* (closeness with others and the warmth of personal connections), were shown to protect parents from mental health burdens and aided them in their ability to be caregivers to their ill child (Salkas et al., 2016). The literature defines culture as “the values, beliefs, traditions, symbols, language, and social organization that become meaningful to a group’s way of life and is transmitted through interactions among its members” (Munet-Vilaró, 2004, p. 1). In healthcare settings and crises, behaviors reflecting these cultural values become increasingly prevalent (Munet-Vilaró, 2004). The importance of holistic health conceptualized alongside emotional health and well-being arose as a common theme and value expressed by Latino parents. This spiritual and emotional pain is referred to as *sufrimiento*: “the feeling of the heart or soul (sentimiento del alma)” (Munet-Vilaró, 2004, p. 2). *Sufrimiento* is often managed in Latino culture with candle-lit prayers. Moreover, this cultural understanding of pain contrasted with the physical concept of pain may confuse Latino parents and require further explanation by the medical team working with the family. This ideology connects to the collectivist cultural values commonplace to Latino families, as they place a high value on familial interactions and the value of the opinions within their tight-knit network when navigating health challenges (Perez, n.d.). Not only is this seen as an essential component of their child’s health journey, but it is an essential consideration for hospital staff to deliver culturally competent care that addresses the needs of Latino family values. An additional part of Latino culture essential in the support process for parents is the concept of *familismo*: a loyalty and commitment to one’s family in Latino culture. One study that explored the

implementation of familismo by Latino families in childhood cancer settings found that the emphasis on unity in the family and extended family “includ[ed] the responsibility to take care of family members and discussions for medical decision-making [which] may influence the frequency of communication within parents and CCS [childhood cancer survivors]” (Ochoa et al., 2021, p. 2). These findings indicate the importance for providers to communicate not solely to one family member but to the extended family, who are seen as vital in the health decisions and beliefs regarding the child’s cancer care.

Religion is an additional key consideration in understanding potential differences in the white versus Latino experience of parents coping with a child diagnosed with cancer. A recent religious landscape analysis census shows that 77% of Latinos identify as Christian, with 48% of those under the umbrella of Christianity adhering to Catholicism (NW et al., n.d.). This number is noticeably down from the 80% figure reported in 2013 and even more from 92% in 2002 (Salkas et al., 2016). In a study conducted with a sample of 15 Hispanic/Latino parents (English and Spanish speaking) from a safety-net hospital in Los Angeles County, religion played a different role than other accounts suggest. In this study, some parents revealed that religious figures blamed the parent for the child's illness (C. Y. Ochoa et al., 2023). For example, one excerpt from an interview with a parent in the study communicated religion as a negative force in their experience coping with their child's cancer diagnosis: “One parent recalled being told that their child’s diagnosis was a punishment for the parent’s sins and that they were ‘paying [their] dues’”(Ochoa et al., 2023, p. 157). This negative cultural stigma suggests that places of religious practices for Latino families may be a source of misinformation and negatively affect the health behaviors of the parent of the ill child. Other spiritual beliefs

emerging from the Latino culture refer to the conceptualization of disease. Scholarship denotes Latino parents of children with a disability or illness use the concept of *aguantar* (to endure) to cope with their child's diagnosis/condition (Salkas et al., 2016). According to this belief, one must accept their “disability as an act of God and not try to fight against their fate” (Salkas et al., 2016, p. 41). This belief may discourage parents adhering to these spiritual beliefs from taking a child in for medical care if their illness is viewed as one they must accept. Further, the importance of partnerships with religious institutions and faith-based organizations as primary areas to address the distribution of pertinent information to raise health literacy rates of Latino parents to ensure they seek the proper care for a child with cancer.

A parent’s role coincides with that of a primary caregiver upon diagnosing a child with cancer--especially for Latino families who are often medically underserved (C. Ochoa et al., 2023). Culture proves important in this respect as scholarship indicates Hispanic/Latinos value social support for their child with cancer and themselves as the primary caregiver (C. Ochoa et al., 2023). Parents who take on the role of caregivers for their newly diagnosed child experience immense stress described as “overwhelming,” and the role itself deteriorates their own health and well-being (C. Y. Ochoa et al., 2023). Support to deal with the profound new stresses introduced by a cancer diagnosis for a child can be found in religious faith, as studies show caregivers relied on their relationship with God to cope with the psychological distress that accompanied caring for their child with cancer (C. Y. Ochoa et al., 2023).

Parents' knowledge of family cancer history and utilization of cancer preventive services are imperative in catching their child's cancer in its earliest stages. However,

studies show that Latino's understanding of genetic risk is low (Kinney et al., 2010). This understanding is hypothesized not due to a low engagement from the Latino community, but due to the ineffective vehicles of information currently being used. Studies support this assertion, as one research study found the medical information that came from a Latino health professional instead of a white one increased *confianza* amongst Latino families and from medical professionals/hospital sources rather than internet sources (Kinney et al., 2010; C. Y. Ochoa et al., 2021).

An additional consideration lies in the general demographics of Latino/Hispanic parents versus those of white parents. One study focuses on the correlation between age, education, and race and found that “Hispanic parents of Hispanic childhood cancer survivors (HCCS) tend to be younger, less educated, and earn less than non-Hispanic parents of CCS” (Slaughter et al., 2022, p. 762). The difference in age and education could be additional barriers.

Additional factors noted by existing data suggest parents’ education, knowledge of cancer, socioeconomic status, workplace conditions (e.g., pesticide exposures), health insurance status, and the lack of Latino enrollment in clinical trials are all seen as potential factors in shaping current attitudes, beliefs, and understandings amongst Latinos, who are experiencing higher childhood cancer incidences and lower survivability. Academic literature acknowledges a general understanding of the significance of language in one’s cancer journey. This study’s aims will explore these issues through a qualitative research methodology to address the lacunae identified in existing scholarship discussing these structural inequities.

III. Theoretical Framework: Explanatory Models of Disease

Arthur Kleinman, a renowned medical anthropologist, developed the concept of "explanatory models" to illuminate how health and illness are understood within cultural and social contexts. This concept serves as a tool to elucidate individuals' personal interpretations of their health conditions, including their perceptions of causes, symptoms, severity, required treatment, and prognosis. These subjective understandings constitute an individual's or group's "explanatory model" of a health condition.

Kleinman's model is particularly beneficial in cross-cultural studies and healthcare settings, where contrasting beliefs about health and illness may exist between patients and healthcare providers or among different patient groups. It assists in capturing culturally shaped beliefs and practices concerning health and disease, thus enabling a comprehensive understanding of patients' health behaviors and attitudes.

In the context of childhood cancer, Kleinman's explanatory models could provide profound insights into the attitudes, beliefs, and behaviors of Latino and White parents. It allows researchers to compare and contrast these groups' conceptualizations of cancer, highlighting potential cultural nuances and disparities. This, in turn, might influence their respective approaches to care, their interactions with healthcare providers, and their adherence to treatment regimens.

By bridging the cultural gap and promoting understanding, Kleinman's explanatory models can facilitate more effective communication between healthcare providers and diverse patient groups. Furthermore, they can guide the development of culturally sensitive interventions and improve health outcomes. In essence, Kleinman's

model foregrounds the importance of considering the socio-cultural factors at play in health and disease, encouraging a more holistic, patient-centered approach to healthcare.

CHAPTER 2

METHODS AND RESULTS

IV. Methods

This study was conducted using a mixed-methods approach to fill gaps in the existing literature. The Arizona State University Research Integrity and Assurance office approved the research objectives, procedures, and criteria. A total of 22 parents, 11 of Latino ethnicity and 11 of White ethnicity, located in the Phoenix metropolitan area, were interviewed.

Participant Recruitment and Data Collection

Data for this study were gathered primarily through semi-structured interviews guided by a flexible interview structure (as shown in Appendix I). This approach allowed for directed conversation while encouraging additional insights not anticipated in the initial guide. These interviews were conducted via Zoom, each lasting approximately 30 to 60 minutes. A research team member facilitated the interview, and the entire process, including the attainment of verbal consent, was audio recorded.

Participants were recruited through a snowball sampling approach. Initial contact was made through the professional and community networks of the research team members. Each participant was then asked to refer additional potential participants from their networks. The criteria for inclusion in the study included being a parent of a child aged 0-15 years, a resident of the Phoenix Metropolitan area, and being at least 18 years old. Participation was entirely voluntary, with each participant receiving a twenty-five-dollar gift card upon completion of the interview as a token of appreciation for their time and engagement.

Data Analysis

Thematic analysis techniques were employed to gain rich theoretical insights into the beliefs, attitudes, and behaviors around childhood cancer. This process involved coding and

memoing to identify emerging themes. Memoing is a qualitative analytical technique used to identify recurrent or notable themes and concepts to form the foundation of their research's theoretical argument. The codebook was developed using Kleinman's explanatory models as a guide, with codes including etiology, diagnosis, clearly defined inclusion and exclusion criteria, and memos were made during the interview process. The research team (graduate student Florence Awde, Dr. Gilberto Lopez, Dr. Irasemena Coronado, and Dr. Swapna Reddy of Arizona State University) then reviewed these themes to name and define them.

V. Results

Sample

Twenty-two interviews with parents from across the Phoenix metropolitan were conducted. Responses were collected from 18 females, 4 males. Eleven (11) parents identified as Latino, and 11 identified as White. The mean age of the parent's children in the study was 9.2 (51 children total). Parents had 2.3 children (ranging from 1 to 5) on average. Geographically speaking, participants reside in a diverse array of neighborhoods across the Phoenix metropolitan. Participants generally had a higher level of education than the US population, with 50% of participants' highest level of education being at the Masters or Doctoral level (compared to the national average of 13% (Bureau, n.d.-a). The second highest level of education reported was a bachelor's degree, followed by high school graduates, with only one reporting an associate degree. While many cited personal experiences with cancer within family and friend circles, only one parent in the sample has a child currently battling cancer. This child has had four types of cancer, with their initial diagnosis being at the age of 9 of Ewing Sarcoma, rare cancer originating in the bones or soft tissue (*Ewing Tumor Types* / *American Cancer Society*, n.d.).

Table 1. Descriptive Statistics of Participants (N=22). Latino (n=11), White (n=11).

Variable	Overall (%)	Latino (%)	White (%)
Sex			
Female	18 (81.8)	9 (81.8)	9 (81.8)
Male	4 (18.2)	2 (18.2)	2 (18.2)
Education			
High School	2 (9.1)	1 (9.1)	1 (9.1)
Associate's Degree	1 (4.5)	1 (9.1)	0 (0.0)
Undergraduate Degree	8 (36.4)	2 (18.2)	6 (54.5)
Graduate School	11 (50)	7 (63.6)	4 (36.4)
Number of Children			
1	6 (27.3)	3 (27.3)	3 (27.3)
2	7 (31.8)	4 (36.4)	3 (27.3)
3	6 (27.3)	2 (18.2)	4 (36.4)
4	2 (9.1)	2 (18.2)	0 (0.0)
5	1 (4.5)	0 (0.0)	1 (9.1)
	5 (9.8)	(n=25)	(n=26)
	6 (11.8)	2 (8.0)	3 (11.5)
Age of Children (n=51)			
0-1	21 (41.2)	4 (16.0)	3 (11.5)
2-5	14 (27.4)	10 (40.0)	10 (38.5)
6-10	5 (9.8)	5 (20.0)	9 (34.6)
11-15		4 (16.0)	1 (3.8)
16+			
Neighborhood of Residence			
Mesa	5 (22.7)		
Phoenix	5 (22.7)	3 (27.3)	2 (18.2)
Tempe	2 (9.1)	3 (27.3)	2 (18.2)
Chandler	2 (9.1)	1 (9.1)	1 (9.1)
Peoria	1 (4.5)	1 (9.1)	1 (9.1)
Queens Creek	1 (4.5)	0 (0.0)	1 (9.1)
Arcadia	1 (4.5)	0 (0.0)	1 (9.1)
Gilbert	2 (9.1)	0 (0.0)	1 (9.1)
Goodyear	2 (9.1)	1 (9.1)	1 (9.1)
Glendale	1 (4.5)	2 (18.2)	0 (0.0)
		0 (0.0)	1 (9.1)

Definition

When asked, “What is cancer?” “how do you define it?” and “Does it have any other names?” Latino parents discussed the upsetting nature of the disease, the diseases range in scope of severity, and its ability to affect different parts of one’s body, different

types of cancers (e.g., leukemias, breast cancer, melanomas), and cancerous tumors (e.g., benign or malignant), and that the disease lacked curability. Emotion was also captured as an important proponent of their answers, as some referenced children's increased nature of fragility and vulnerability being especially heartbreaking, evoking feelings of fear, sadness, and the need to protect their child. One parent referred to cancer as the "C-word," while others defined it as "evil," scary," "a death sentence," and "something I wish I'd never have to have and never have my children have any type of." The sole parent in the study with a child currently battling cancer explained their experience defining cancer for their child when diagnosed: "There are cells in her body that do not belong there, and they are hurting. What do I say to a little one? So, they are hurting her body, and we need to get rid of them."

Researchers asked the same questions to white parents in the study, who cited abnormal cells and cell growth as a definitive factor in the disease. White parents admitted to lacking specific knowledge of the disease but acknowledged its complex and enigmatic nature, citing its perceived lack of curability amongst the sample. A select few of the sample were also aware of more specific diagnostic terms for cancers, like Hodgkin's Lymphoma, melanoma, leukemia, and brain cancer. Again, emotional connections intertwined with their definitions of cancer provided, as many cited personal experiences and the potential of the fear and the disease being referred to as a "nightmare" or a "health battle." White participants also expressed a muddled understanding of what they knew cancer to be as well:

The meaning of cancer is an enigma. It's sort of a confusing topic to me, based on the fact there's no cut and dried answer to it, and it can progress in many different

ways, so it's not in my brain. I like things not like, but I'm used to structures that are open and a shut case to understand them. So, it's hard for me to understand cancer.

This confusion was expressed by other parents who referred to a range of implications the disease could evoke, as one participant stated "it can be a death sentence. It can be just a normal part of life." Other parents were unable to hazard a guess, simply stating, "I don't even know how to answer that question," "I don't know what cancer specifically is."

Based on the respondents' answers, common themes across both Latino and White parents were generally a basic understanding of cancer and its relation to uncontrolled cell growth that can result in tumors across both samples. The emotional component of the disease was also apparent in both groups' answers. Both mentioned more specific diagnoses of leukemia and melanoma, and Hodgkin's lymphoma. However, Latino parents generally offered more detail within their definition of the disease's etiology, explaining tumors as a product of the abnormal and uncontrollable cell growth seen in cancer. One Latino parent offered classifications of cancerous tumors, citing "benign" and "localized" as essential pillars of the diagnosis and etiology of cancer. Interestingly, both groups of parents' responses indicated that the definition of cancer and its emotional and physical meanings attached highly correlated to the timeline of diagnosis.

Causes

The sample's understanding of the cause of cancers, specifically childhood cancer, revealed three common areas of concern across both groups: genetic, environmental, and lifestyle factors.

Latino participants discussed genetic causes in terms of an “incorrect gene formation” or “a gene was not developed correctly, either at birth, or maybe it changes[d]”, or genetic predispositions/hereditary, embedded in one’s family history. Alongside genetic mutations and predispositions, Latino participants expressed a belief of exposures to certain chemicals (e.g., pesticides and other man-made chemicals), pollutants, and toxins in the environment (e.g., poor air quality) as factors that can increase the risk of cancer. Other environmental factors cited in specific to their area of residence was sun-exposure. In relation to one parent’s understanding of the cause of cancer, a Latino parent explained the geographic consideration of the study’s pertinence, stating, “When we live in Arizona and it’s hot I think one of the most common things here would be being exposed to the sun or too much sunlight that could be potentially dangerous for especially the little ones and their skin.” Trauma, although in the context of breast cancer, was also mentioned by some parents as a potential factor in developing cancer. Some parents also chalked the cancer up to luck of the draw, explaining, “cancer can be seemingly random, and they can strike anybody any time.”

Based on the white participants' responses, several factors were mentioned as potential causes of cancer. Parents mentioned environmental factors like pollution and chemical exposures, genetic factors, such as a predisposition, that could be triggered by an environmental factor, and lifestyle factors, for example one’s sun exposure/sun safety, smoking, diet, etc. Smoking was one of the most common answers from white participants. One parent provided a personal experience growing up in a farming town in Washington state: “I don't know if it's pesticides, or what. But so, in a small town everyone knows about it, and it's very sad for the community, and a lot of these children

die.” Additional factors noted by white parents lay in the socioeconomic realm, as access to quality food is not a choice but a reality for some families, and education and access to healthcare services play a role in these choices as well. Nutritional factors seemed to prevail as central in many parents' understandings of causation, noting additives, non-organic, or processed food as lifestyle factors that may increase one's chance of cancer. One white parent explains the role of nutrition, while mentioning environmental factors of air pollution, in a more significant light, asserting, “I think like in our air and the food that we eat, there's so many toxins and contaminants, whether it's pesticides or, um. Just junk in the air. That we expose ourselves to and then the lack of. Eating healthy foods that can, not necessarily get rid of cancer, but help keep it under control.” Some mentioned reading different articles and hearing from social media how “dies in your food and the cereal that you're feeding your kid” in connection to their understanding of the causes of cancer. Further, the role of nutrition, smoking, and environmental toxins were initial causes mentioned by participants, followed by genetic considerations, lifestyle and potential socioeconomic roots of those choices.

Therefore, both groups demonstrated relatively the same general understanding of what can cause cancer or increase one's risk of developing cancer--identifying genetics, environmental, and lifestyle factors as the three major causes of childhood cancer. Further, cancer across both groups is seen as not accounted for by a single cause, but an interplay of factors. As one participant sums it up, “there are many factors that can relate to the diagnosis [cause] of cancer. But I don't think there's one cut and dried reason for getting cancer.”

The only difference in the respondent's answers between the two groups was that Latino participants tended to be more specific in their answers --mentioning the "impact of genes" and more in-depth lifestyle factors and geographic factors as possible causes. The only aspect white parents did bring up in more specifics than Latino was they mentioned vaccinations as an important precautionary measure--not mentioned by any of the Latino participants. Latino participants did account for genetics slightly differently, as not just noting a potential hereditary and genetic predisposition component, but an actual genetic mistake at birth as the potential cause of the cancer.

Severity

Table 2. Perceived remission rates amongst the sample; No guess (n=7); Provided Estimate: Overall (n=15); Latino (n=8); White (n=7).

Variable	Overall (%)	Latino (%)	White (%)
Estimated Chance of Survival/Remission Rates for Childhood Cancer (n=15)			
(If in relapse) 0%			
<50%			
50%			
>50%			
	1 (6.7)	1 (12.5)	0 (0.0)
	5 (33.3)	2 (25.0)	2 (28.6)
	4 (26.7)	2 (25.0)	2 (28.6)
	5 (33.3)	3 (37.5)	3 (42.9)

The level of perceived seriousness when it comes to childhood cancer, varies across the study's sample. Numerically, of the 11 participants, 7 of the participants answered, while 3 did not provide a guess of the remission rates of cancer. While two participants guessed remission rates of 30%, (less than 50%), 2 guessed 50%, and 3 said

remission rates of over 50% (70%, 75%, and 95%). One participant wandered a guess of 0% survival if the cancer was a result of relapse following a child's remission period. While a general understanding of the array of survival rates is evident across the sample in reference to the stage of diagnosis, the efficacy rate of treatment, and the type or aggressivity of the cancer, the perceived degree of survivability and the gravity of cancer reveals common misconceptions and varying levels of knowledge on the subject amongst both ethnic groups.

In cohesion with earlier answers provided in the diagnosis section, fear shaped many Latino parents' answers in this section of the interview, as the same idea of cancer as a "death-sentence." Many expressed they struggled to understand what the lifelong impacts of cancer are, and how language barriers may further this gap in understanding the degree of severity cancer entails. Parents expressed a level of confusion in their answers, acknowledging cancer as complex and the belief that "cancer is murky water." Receiving the diagnosis of cancer is seen as something that may be difficult to grasp for those who are not educated on the subject or whose first-language isn't English. One parent acknowledges in their response on the topic:

You run into parents that might not be educated enough on the subject or that English might not be their first language. The terminology is very difficult to understand, even for somebody that does speak and understand English. So, I think for some parents it's very difficult to accept that and realize that, but then you have a little bit, you have more educated parents, I guess, that maybe have gone through it or if it's genetic, they've already gone through it with family, they know kind of what to expect.

The need for translators to bridge this language gap was mentioned by multiple Latino parents as a part of a larger need for culturally competent care. Across the sample, Latinos perceived cancer as a very severe and “debilitating illness.” The level of debilitation is cited in reference to the stage it is diagnosed at, treatment efficacy rates, and the nature of the cancer itself/how aggressive the child’s particular cancer is. One parent highlights the various degrees of severity associated with childhood cancers, voicing, ““I think it can be very severe because you might be catching it at a higher stage than something that just requires a quick little surgery and a short round of medication per se.” The other side of that case entails more intervention. A parent explains: “If it’s caught on the latter side, you’re... subjecting this child to surgeries and chemo and radiation and long hospital stays or maybe something that... they will have to have it for the rest of their lives in order to survive.” Severity is also mentioned in the realm of treatments, as Latino parents expressed the invasiveness of treatments taking a toll on their bodies. While some treatment parents described as “quick and easy,” others described treatment as lasting for days, months, or even years.

The degree cancer impacts childhood growth and development was perceived as high, emphasizing cancer is especially damaging during the developmental year’s childhood cancer occurs within. Acknowledgement of the long-term effects of children even if the child is in remission was also noted by parents, who mentioned potential check-ups and monitoring of the illness being necessary following entering remission. Some even expressed the belief that even if their child entered remission, their overall life expectancy would shorten. Overall, an understanding of the disease as life-threatening,

scary, and requiring highly invasive and life-altering treatments were common amongst the Latino participants in the sample.

On the other hand, white participants expressed some common beliefs regarding their understanding of the severity of childhood cancer. The impact on life expectancy, its potential to be long-lasting, and an emphasis on early-intervention as a key factor in the cancer's severity were common themes in the white participants' answers. Early intervention was noted as pivotal by parents, as comments like “if you catch them too late, it will be super-fast,” “the sooner you get treatment probably the better,” and as “something that eventually kills them, and they're dealing with it for the rest of their life [or] It could be something that they go into remission, and they're fine.” Furthermore, while some parents reported cancer as a survivable disease, explaining “there are a lot of people that live with cancer for a long, long time, and they end up living for a long time,” others see it as resulting in a “shorten[ed] life expectancy” even if cured.

Overall, both groups of participants made the same estimates on remission rates. Both groups guessed cancer's duration as a very short (e.g., one round of treatment) or very long (e.g., a child's whole life) period of time--demonstrating an understanding of the different range of outcomes across childhood cancers and individual cases. While Latino parents mentioned language barriers as a potential factor in the severity of a child's cancer, White parents focused more on the disease characteristics itself rather than the care beyond the stage at which it began.

Pathology

Parents were then asked questions surrounding pathology, or their knowledge of the science of diagnosing cancer in a child through samples, autopsies, or medical examinations, or symptoms (*What Is Pathology?* n.d.). Participants in the study communicated a concern of the aggressive nature of the disease, visibly and developmentally. Parent's expressed various areas in which cancer impacts a child; labeling the impact of cancer as "debilitating" "life-threatening" and "separating them from their normal course of life." A breadth of differing understanding of symptoms/markers of cancer were expressed by the two groups; unveiling values and collective beliefs and perspectives that may be at play in shaping health behaviors amongst each group.

Latino parents indicated an understanding of weakness, being "brittle", lethargic or less life/energy in a child, weaker than normal immune system, bleeding, coughing up blood, bumps on skin, weight loss, fevers, loss of appetite, physical changes, behavioral changes or a sudden change of personality in a child, discoloration, and pain as common markers of childhood cancers. Several parents expressed a key indicator for them would be the length of the symptoms or unexplained prolonged illness. The parent whose child is currently battling cancer identified their child's inability to bear weight on their right leg as a pivotal symptom in prompting them to go to the hospital for further examination. Opinions differed in terms of the weight emotional or behavioral symptom versus physical had as indicators of cancer, with some parents weighing physical as more significant, with others acknowledging a combination of both equally guide their identification of potential cancer in their child. Some parents admitted their only frame of reference was movies or television programs. From a biological standpoint, parent's

expressed varying levels of comprehension. Many respondents referenced some variation of a “growth” being a biological manifestation of cancers. One parent compared cancer to a cluster of a popular American candy; analogizing that the clusters of “nerds” stick together, mirroring his understanding of the biology of cancer in a child. A few Latino parents accounted for the spread of cancer as cells picking up “an incorrect code,” with another parent making the analogy of a computer error: “It's almost like a computer. If there's an error in the code, and you reproduce it, it just keeps growing and growing.” Latino parents also expressed an understanding of the heterogeneous rate of onset of childhood cancers, identifying some may spread fast, while others are slow-moving.

White parent's place a particular emphasis on the importance of parental intuition in their answers, something absent from the Latino group's response. One parent explained the importance of intuition and “follow[ing] your gut” as a parent for them, explaining, “trusting your gut and being to some degree the crazy mom that makes the political doctors continue to test until they figure it out, because sometimes they're like oh, well, that's just normal for their age. Well, this doesn't feel normal.” Another parent expressed similar values, expressing the difficulty of diagnosis and the importance of being an advocate and attentive to your child's health:

I think it depends on how neurotic you are as a parent. I'm a little bit on the neurotic side. So, I think that I am more hyper vigilant when it comes to that kind of stuff. But I do think that people aren't educated, or I mean they/I would assume most people's first thought Isn't ‘Oh, my set, my child says they have a headache, they have cancer’ right? So, I think that it just becomes something that they just can't get better. Eventually, I think a parent would say something's not right.

The role of one's intuition as a parent prevailed as a common theme across the White sample, being referred to as "gut feeling" "parental knowing" "intuition" or simply knowing "there's something different that's wrong with my kid." Other parents recalled similar identifiable symptoms as their Latino counterparts did, only mentioning a few different symptoms of swollen lymph nodes, sudden loss of balance/slow reaction times, unexplained falls, loss of language skills, vision loss, or potentially asymptomatic as plausible indicators of potential cancer in their child. Some parents expressed there is no way to identify cancer unless scanned by professionals--highlighting a sense of inability to identify cancer themselves in certainty. Within the biological sphere, mixed understandings of how cancer metastasizes was expressed by the White participants. One parent admitted their lack of understanding of this area, stating, "I don't think it's different from a virus. How that propagates, like infection as a host. But I don't know at the cellular level what's going on." Others mentioned the cancer growing into nearby tissues and cells, while some expressed no knowledge of how the cancer itself would spread.

The multiplicity of ways cancer can present itself prevailed as a common theme across the entirety of the sample. Both groups expressed an understanding that cancer can affect every child differently. While one parent correctly identified cancer's path of metastasizing through the body as the "blood stream," four Latino parents identified the blood as the vehicle for metastasis throughout the body. White parents also mentioned bruising as a potential symptom, a marker not mentioned by Latino parents. The role of parental intuition and trusting your gut was emphasized greatly by white parents, but, interestingly, not mentioned by Latino parents.

Diagnosis

In response to interview questions concerning the diagnosis of a child with cancer, Latino respondents cited early detection, race and diagnosis, access to medical care, prior negative experiences, symptom recognition/acknowledgment and misdiagnosis, and economic disparities as factors in the diagnosis journey for a child with cancer. Across the sample, participants expressed the need for a medical professional to make the diagnosis of cancer for their child; many citing that they would schedule a visit with their pediatrician or a doctor if they were suspicious of their child's symptoms. In terms of how the cancer itself is diagnosed, Latino and White parents provided different points of emphasis amongst the sample's group.

Latino parents expressed in the study that early detection was vital in the outcome of the cancer, and emphasized screening as a key component. Parents had mixed reactions towards the proposed question of screenings being available in school for cancer, as one participant relayed that they believe screening may evoke more fear than comfort amongst parents. This participant explained, "I think we're in an era where it's like we're more open to things, but then again, when you talk about cancer, everybody's like, no, no. Like it's a big kind of taboo. Like if you screen my kid for cancer, then it can potentially lead to something." The word taboo appeared in another participant's answer who spoke of the consternation that accompanies a child's cancer diagnosis. In response to the same prompt of a suggestion of screening for cancer in schools, the parent voiced, I just think that parents don't... like I mean, like none of us want to hear like bad news, right? Or sometimes I feel like cancer is like a taboo word, like nobody wants to think

about it or you know that it's up there, but it is out there." This desire for avoiding a cancer diagnosis out of fear can directly impact the length of time one spends prior to seeking out diagnosis, as a parent explained "I do think that a lot of time the ignorance is embedded into what some communities are offered, and then, by the time they realize that something's wrong, it's something severely wrong."

Access to medical care was cited as an additional factor, as Latino parents believed quality of care or quantity of healthcare providers to diagnose children reflect geographic disparities and result in diagnosis inequities for children in more rural areas of Arizona, such as Yuma, compared to those residing in urban centers, like Scottsdale. Negative experiences were factored in, especially in more rural communities, as "poor mannerisms," (e.g., rudeness, inadequate listening skills, disregarding patients emotional and/or physical needs) and a perception of small-town doctors being less educated appeared to be a dissuading factor for parents to take their child in to enable early detection to be plausible. One parent joked about the small-town collective ideology in her hometown, and a border-town, of Yuma:

The doctors who are there, and granted they are doctors, obviously got their degree and certificates, but we, and maybe it's just the thinking that the care is better up here. I do feel that even growing up it was just that to come up to Phoenix, or we would go to San Diego, would be one or the other [...] I don't know if it was the bedside manner of the doctors or us, just thinking that a bigger city would have more experience or knowledge.

Further, urban centers have more technology and collective expertise to treat patients than small town medical personnel and institutions do. Doctor's dismissal or failure to

take their child's symptomatic complaints seriously was also a barrier identified to parents seeking care for their child; as one parent expressed. Misdiagnosis frequented answers as a concern as well, as monetary exploitation of unnecessary tests or medications was perceived by participants as a possible outcome of taking their child to a doctor--a palpable lack of *confianza*. Other parents cited fear as a potential deterrent, as one participant said "I know how kids get right. Oh, I don't want to go to the doctor's office and needles." This dislike of doctor's offices or invasive medical procedures was also met with distaste by Latino parents. Some participants cited this as generational mistrust in doctors and western medicine; one participant shared her experience with this mistrust and education's role in building a foundation of trust grounded in research that is different than the generation prior:

The generation before me, a lot of 'em were hesitant to go to the doctor in general. So, their view on, I mean that would just totally distort their view of getting treatment versus my generation who's had more exposure to research. And it could just be me because I work in higher education, so I look for knowledge I guess, versus people who don't work in education. But I would say that a lot of the older generations, like my grandmother, had two miscarriages and they were because of doctor's errors versus natural childbirth. So, she hated it, she would not go to the doctor. And that was just how things happened back in the day. There were so many errors in healthcare that a lot of them from that generation refused to go where I do not hesitate to take my children to the doctor or go to a doctor to have a baby or go to a hospital.

Finally, economic disparities were mentioned as one of the overriding factors preventing diagnosis--cited over race by many as a primary barrier to diagnosis. The barrier to timely and appropriate healthcare services in lower-income communities or rural communities may ultimately affect one's ability to seek early detection of cancer for their child. One participant offered their explanation of why financial limitations play a more critical role in diagnosis than race in their opinion:

Money talks. What's your prices here? Boom Done. All right, let's get it going. Right, compared to the whole red tape that you would probably get here in America right with jumping through hoops. You may or may not have insurance because you may or may not be legal, because you may or may not have the financial income, because you may or may not live on the right side of town, because you may or may not get treated a certain way because of your skin color. Like I said, money talks.

Overall, the responses of Latino parents communicated an understanding of the importance of early detection, mixed opinions on the appropriateness or acceptance of having screenings, a general consensus that doctors would be the one to diagnose a child, with a mixed understanding on the method and accuracy of diagnosis'. General emotional responses of fear coeval in diagnostic questions as well, pointing to the strength of the fear reaction the subject itself evoked in participants.

When asked the same questions, white parents also identified a visit to the pediatrician as the initial step they would take, then mentioned the need for follow-up testing. In terms of the diagnostic technology needed, white parents alike their Latino counterparts mentioned "scans" or "lots of blood tests," and potential "scraping a skin

sample” as diagnostic measures medical staff may use to diagnose a child with cancer. Interestingly, while Latino parents placed financial barriers over race, white parents' perception of the role of race in the diagnosis was much larger than Latino parents expressed. White parents perceived racial equity and being denied medical care based on legal status as significant concerns in one's diagnostic journey for a parent seeking care for a child with cancer. White parents also mentioned legal status may dissuade parents from bringing a child into a medical facility out of fear, documentation status was not mentioned by Latino parents as a perceived barrier to diagnostic care. Instead remarks of parents doing “whatever they have to” despite documentation status for their child came up.

A common barrier mentioned across both groups was the invisible nature of cancer, often unrecognizable from a common cold to most parents in the study who expressed a lack of knowledge on how to decipher between the two illnesses. Symptom recognition and knowledge of symptoms were described as a perceived barrier to early detection--leading us to inquire further regarding parental beliefs towards what cancer looks like in a child.

Treatment

Across the sample, a common understanding of what treatment entails and confusion around coverage were common themes amongst both Latino and White participants. While Latino parents expressed concerns of medical intervention and prescription medicine, White parents expressed a perceived understanding that Latinos

would have this hesitation towards western medicine that may be absent in white parent's considerations.

When asked about cancer treatments, Latino parents cited chemotherapy, “blood products” radiation, surgery, play therapy, clinical trials, therapy, counseling, “lot of pokes,” medications, regular screenings and medical visits, homeopathic options, and adding additional vitamins and supplements to their diet as options. Most common responses were chemotherapy, radiation, and surgery. A desire to try homeopathic treatments over medical intervention was highlighted by some participants who accounted for their familial views on medicine. One participant explains the use of the earth and its resources as a treatment plan they would try before more invasive treatments like chemotherapy:

Based on my own experience, my grandmother and my mom and such, there's such firm believers in homeopathic medication. Let's make tea and you're going to mix this, this and this. And you know, put so much trust into the land and what the land can give you that the medical side of it is kind of the plan B. Let's go ahead and exhaust everything we can do with these roots and teas and that kind of thing. And then if that doesn't work, then we're going to go see the doctor. So, you have that type of mentality that they're still holding true to their culture and their history and well, I had this and my mom gave me this tea and they would always take it away, that kind of thing. And yeah, I'm a tea believer.

Some parents communicated an understanding that perhaps certain treatments would only be given if a child was at a certain age, or in “lower doses” to younger patients. The invasive nature of treatment was a concern voiced by some parents, one who expressed “I

mean I think if I feel like as a mom I wouldn't want to put my kid through chemo, but then if that's the only option then you know, I would be open to that. I think that there should be a lot more research on the types of treatment that kids should receive, um, that are not as invasive.” The perceived side-effects of treatment were hair loss, low energy, weakness, and “lots of sleeping.” The participant whose child has cancer provided a very different outlook on what treatment looks like in connection to the astounding resiliency kids display: “she would go jump on her trampoline afterward. So, it was very after getting chemotherapy, so it was very hard to identify that she had cancer from the outside visually because and I think most kids are like this, but they just want to be a typical child, and like, go play and go swim, and you know. So, it is so hard to see.” The treatment the child endured reflects a long and wearing process childhood cancer can create. The parent retold their child’s treatment journey in their interview with our research team:

In our instance, like her chemotherapy, we know her chemotherapy from her initial treatment, has caused so many other problems, so she has to continue to fight. I know most medications have some side effects; may cause a headache, but like to actually cause another cancer that is incredibly aggressive and very hard to fight, just seems so disheartening, you know, because we did everything we could, and showed up to every appointment, and I keep notebooks and documents, and I mean so much. But like at the end of the day, this is how it is affected her. She we're 4 years later, and we're still fighting, you know, and our whole. We have hit the end of the line for treatment at [Phoenix Children’s Hospital] PCH. So now we're being put on trial. So, we just interviewed with

Seattle children. We're hoping to consult with the Children's Hospital in [Los Angeles] next, just hoping to progress. It's like a t cell therapy, but hoping there's something else out there that can solve this because we just felt so devastated by it all, and having gone through this several times, it. Just it really wears on you.

Some participants mentioned faith as an important component of treatment; one participant expressed in their discussion of cancer treatment that "Love, faith, all kinds of plays in so." Latino parents said they would seek treatment for childhood cancers at various places, most commonly saying clinics or larger hospitals like examples given of Phoenix Children's Hospital, Mayo Clinic, Los Angeles Children's Hospital, St. Jude Children's Research Hospital. Hospital stays were mentioned as ranging from potentially nights to months. Parents explained their perception of these stays as frightening for their child: "I just think of big hospital rooms and for kids. And I'm like, Oh, that's so scary for them, like I wish it would be that they felt not as scared, or, you know, more welcome[ed]." In terms of treatment length, the parent's answer varies. Some believed it lasted hours while others answered years.

White parents expressed similar understanding of treatment types; naming surgery, radiation, chemotherapy, medication, occupational therapy, and intravenous devices (IV's). Lengths of treatment as short as a few days, to "6 weeks," "90 days," months, to years were posed by the respondents. Participants perceived the spaces in which treatment would be received as cold and scary environments; many expressed not wanting to confine their child to such fearsome conditions. White parent to express similar concerns to Latino participants to avoid invasive medical-interventions and hospital stays as a first options:

If the doctor said, ‘okay you're going to come into this sterile environment and you're not allowed to act with your family, and you're only going to stare at these 4 stainless steel walls, and be hooked up to this medical equipment, with no entertainment for the next 90 days, and that's the only way that you can win. I'm going to do quite a bit of research before that.

Parent’s cited reliable sources on the internet, such as “Johns Hopkins,” “CDC,” or “NIH,” “Cancer Center of America,” or “Just a big cancer institute stuff” as research options alongside seeking additional consultations from other medical professionals for “Second and Third opinions.”

Overall, the primary course of treatment across both groups was understood to be surgery, chemotherapy, medications, radiation, and “a slew of other drugs.” Treatment for both the physical and mental symptoms of cancer were acknowledged across both groups as well. Both sets of parents explained lethargy, hair loss, and a “shotgun effect” (a perceived catalyst effect on the course of the disease) or “sped-up version of cancer” as the side effects of treatment. In contrast to this perception of the treatment’s side effects as very physically evident in a child, the parent in the study whose child is currently undergoing chemotherapy provides an alternative narrative of what treatment can look like.

Across the groups socioeconomic status was tied to health outcomes, perceiving low-income families at a disadvantage to access treatment options in comparison to high-income individuals. While both groups stated in response to if health insurance is covered by government insurance plans like Medicaid and Medicare, “I hope so,” a lack of

understanding, knowledge, and general confusion on what insurance does and does not cover was expressed by both groups.

Recovery

Table 3. Beliefs toward Recovery in Childhood Cancer; Overall (n=22); Latino (n=11); White (n=11)

Variable	Overall (%)	Latino (%)	White (%)
Question: <i>Is there such a thing as recovery?</i>			
Yes	10 (45)	3 (27.3)	7 (63.6)
No	6 (27.3)	5 (45.4)	1(9.1)
Maybe	6 (27.3)	3 (27.3)	3 (27.3)

The last step in one’s cancer journey is recovery, or a lack of. Across the sample, a general understanding of scans coming back clear or cancer-free was understood as the starting point of recovery, if that was perceived as existent at all by the participant--which was a divisive issue amongst the sample. Discussions of recovery met different understandings of what recovery looks like in a child, what recovery entails, the length of the recovery period, factors that dictate one’s ability to recover, and if it was perceived as possible or not. As depicted in **Table 3**, Latino and White participants shared very different ideas on whether recovery exists for a child with cancer.

Almost all Latino participants shared the opinion that after medical intervention, either in the form of a clear scan, bloodwork, an official note/declaration that the child is cancer-free, or a “clean bill of health.” One Latino parent described the beginning of recovery differently, explaining “I feel like recovery just means like you’re done with the treatments.” A general understanding of the recovery process as a continual monitoring of the child’s health emotionally, physically, and mentally, alongside the transition back

to school, and therapy, support groups, and psychological monitoring as well as important facets of this process.

Physically parents described recovery in a child as “their hair coming in again,” and being “able to gain their way back the lost weight.” The mental recovery process for children is also identified by several Latino parents, explaining there is “psychological baggage that kind of gets left behind even after you’re quote ‘cured’.” Other parents noted the introduction of mental illness as a watershed effect of the physical disease, mentioning “PTSD” as a potential diagnosis for a child in recovery from cancer.

In general, they describe it as gaining a sense of normalcy again. Parents explained this regaining of normalcy in terms of “going back to the normal before diagnosis,” “back to normal development,” “back to their normal routines,” “return to normal activities like going back to school or participating in sports,” simply “seem[ing] normal,” “returning to normal bodily functions,” and “regain[ing] their normal activity levels.” One parent notes how this sense of normal found in recovery differs for every child: “The whole spoken normal that you are trying to recover [happens] differently,” demonstrating an understanding of potentially new normal becoming normal for a child after having cancer. Parents noted that those “born with it” who did not have this sense of normal before, are “assume[d] that they would just developmentally start progressing.” In terms of support available for childhood cancer survivors, Latino participants mentioned suicide hotlines, Ronald McDonald House, Amanda Hope, therapy, support groups,

When asked, “is there such things as recovery”, only 27.3% answered yes, with 27.3% stating maybe, and the largest percentile, 45.4%, answering no. One participant whose child is going through cancer treatment recalled a personal story when asked this

question: “That’s funny that you say that. I did yell at one of the doctor’s and said ‘you’re not curing my child. You’re just--’ [...] oh what did I say... I don’t know. I had a little outburst at one of my doctors. We’re very close so she understood.”

Latino participants also identified their role as parents in understanding the steps of the recovery: “Your children are so little and to them it hurts or they don’t understand what’s wrong with them. And as a parent, you’re supposed to digest as much as you can and try to make decisions for your child that’s best for them.” Other Latino participants deemed responsible for helping this transition were schools; one parent explained the lack of support they saw for students transitioning back to school from health leave. However, one parent did share a story of how recovery may build community amongst the students in the school:

My son’s school does have support in the sense that they do have a wheelchair that this child has at the school where when the parents drop off the child, they have somebody there with a wheelchair and they wheel them to class. But as far as the child moving from class to class, the kids are the ones that actually help push her. So, I don’t know what other stuff they’re doing for this person, but I’m not aware of any overall assistance getting kids back into the school once they’ve been through something medical.

Other parents noted the opposite, explaining bullying as a potential roadblock for children returning to school after cancer treatment.

White participants shared the same understanding as Latinos of recovery being assessed on medical tests indicating the absence of any cancer in the child’s body. When asked if recovery exists for a child with cancer, the majority of participants (63.6%)

answered yes, with only 3 participants (27.3%) who said maybe, and just one who answered no (9.1%). They also mentioned the same theme of normalcy, answering with statements like “back to normal levels,” and “get[ing] back to a normal life;” further, confirming normalcy as a key pillar of recovery perceived by both Latino and White parents. They also noted physical signs of recovery as a resumption of development and rising energy levels. Mental ramifications were also highlighted by White parents, often in reference to the isolation and intensity of treatments endured by the child, noting “It can create, you know, years and years of trauma. I mean, I think it is just a hot mess in general [...] Nothing good can come with that.” White participants also acknowledged the continuity of appointments and monitoring essential in recovery, as one parent explained, “It’s not like a broken bone that heals and you’ve recovered. It’s kind of something that can reappear at any time.”

While both groups agreed on medical assessment via scans or bloodwork being the method of indicating recovery, a return to normalcy being an essential part of recovery, and acknowledging the mental and physical aspects of recovery for a child, understandings of the possibility of recovery and the parent’s role in this differed. While the majority of white participants believed recovery is possible (63.6%), Latino participants held the majority in answering no (45.4%) or maybe (27.3%), as only 3 of the 11 parents confidently were able to answer yes (27.3%). Interestingly enough, only 1 parent from the White participants stated outright no that recovery does not exist, a stark contrast from the Latino participants majority answering no. Socioeconomic factors were cited by both as indicative factors in a child's ability to successfully recover. However, the importance of removing language barriers was mentioned as a key factor in recovery

amongst Latinos, while White participants did not mention language barriers in response to questions regarding recovery.

Structural Factors

Throughout the interview, culture and race were underlined as interconnected aspects of parent’s thoughts, beliefs, attitudes, and understandings of childhood cancer. While Latinos provided generational values and stories, White participants provided their perceptions of racial and cultural barriers and considerations Latino parents and their child may experience when going through the cancer process for their child. One cultural component mentioned by Latino parents was *confianza* or trust. Depicts what Latino and White participants answer when asked if you would trust the medical system with the life of your child if battling cancer are captured in **Table 4**.

Table 4. Expressed Trust in the Medical System. Overall (n=22); Latino (n=11); White (n=11)

Variable	Overall (%)	Latino (%)	White (%)
<i>Question:</i> Do you trust the medical system with the life of your child if battling cancer?			
Yes	11 (50.0)	5 (45.5)	6 (54.5)
No	1 (4.5)	1 (9.1)	0 (0.0)
Mixed	10 (45.5)	5 (45.5)	5 (45.5)

The levels of trust displayed by parents remains level across the sample’s demographics, only being 9% lower in Latino participants. However, the level of trust across both samples indicates a lapse, as 50% of participants answered “yes,” and those that did answer yes, used vocabulary like “I would have to” or that you are “forced to” trust them.

Latino participants emphasized faith and religion as a central component of care and trust in the hypothetical cancer journey. As one parent put, ““Ultimately, it’s not up to them or myself. Right? I don’t know, I am kind of religious. It’s in the hands of God at that point.” Trust in medication also intersected with trust, as treatment courses involving western medicine and/or prescription medications were met with hesitations amongst the Latino participants. One parent explained the generational roots of this hesitation:

I don't think there's a lot of trust like with prescription medications, too. They're like, oh, I don't. I don't need to take that. Or it's not going to make me feel better. And I think I'm gets passed down to our kids, because even I as right now as an adult, I'm like I get prescribed a medication. But I'm like, do I really want to take it? So, I think I just get to pass down to each of us.

However, one Latino participant acknowledged that trust was something that medical staff could build, explaining in reference to the question posed in **Table 4** that in this hypothetical situation they would trust their medical team due to being “connected to the right medical team.” Insurance was another cited source of trust that Latino participants relied on in the medical realm. Lastly, participants cited the potential of information distribution on the topic not being culturally in sync with channels most utilized in Latino culture. One Latino participant recalls a personal experience, explaining “Maybe putting out journals and articles on the latest trends in medicine Isn't: the best way to reach the community. Maybe a different way is better [...]I think my aunts watch those television programs a whole lot. But there's you know, there's other ways to like going to community fares and stuff I do. I have seen health organizations out there, especially for skin cancer and things like that.”

White participants did not mention religion or faith in their answers. Homeopathic medicine was also mentioned by White participants, but more as an option in supplement to their ideal hypothetical course of medical treatment, as opposed to being untrusting of medications as some Latino participants expressed. A lack of trust in western medicine was a perceived consideration in Latino family's healthcare decisions by White participants, as one parent recalled with their grandmother's experience who identified as Latina, "I understand that there can be mistrust of the medical community. My grandmother got cancer when I was very little, and she was Latina, and she didn't necessarily want to go through treatment because of cultural mistrust." This mistrust was accounted for through White participant's lens, as one White parent stated, "I think there are probably very legitimate reasons. I'm sure that you know that the medical community has not always treated minority groups in the United States well in the past. I think incidents that have happened in the past have been passed down through culture." Some white participants acknowledge potential prejudice or racist behaviors towards Latinos being a part of their experience accessing cancer care for a child, while others did not see the potential for a journey to differ for a White versus Latino family. The idea of Latino parents being more skeptical of authority or "less willing to accept help."

Moreover, when asked if they believed the experience of a white versus Latino parent would differ in the process of seeking childhood cancer services for their child or if culture/race would play a role, the majority of participants answered yes as seen in

Table 5.

Table 5. Perceived impact of cultural/race in access to childhood cancer resources; Overall (n=22); Latino (n=11); White (n=11)

Variable	Overall (%)	Latino (%)	White (%)
<i>Question/Prompt: Do Latinos have a different understanding of childhood cancers? Does culture play a role? Does race? Do you believe families' experiences would differ based on if they were white versus Latino?</i>			
Yes	13	7	6
No	(59.1)	(63.7)	(54.5)
Maybe	1 (4.5)	1 (9.1)	0 (0.0)
Unsure	7 (31.8)	3 (27.3)	4 (36.4)
	1 (4.5)		1 (9.1)

With only 4.5% of the sample believing race/culture as having “anything to do with it” in shaping the experience of Latino families' experience/ability accessing childhood cancer services, a common understanding of the role of race and culture to some degree being impactful is displayed by the group. Some accounted for racist or prejudice attitudes in the medical occupation being a hallmark of one’s potential experience, as one participant puts, “there’s going to be people who are racist or prejudice, and they might think the parent is overreacting or something like that and not do tests that need to be done to diagnosis a kid.” This goes hand in hand with other participants' comments of “certain people [in reference to minorities] are taken less seriously in some ways or less believed.” Another participant describes this as a large societal problem in the United States (US): “I think by nature of living in America during these times folks who are not like white people have less of an opportunity based on the life we’ve created here [...] It’s an inequitable society.” Although the majority of participants identified this interaction of culture, race, and childhood cancer care, many parents cited education, income, and insurance as more significant factors in determining one’s health outcomes and ability to access care for their child. Parents ultimately said “it would come down to finances and

insurance” and that “if you’re a hard-working Hispanic, you can get the same stuff as what other people necessarily deem higher up.” Other participants explained the role of education in the cultural disparities in care:

I do feel that a lot of the Latino community even though they're part of the US, they are a minority, and there's always this barrier of we are not part of this entire country, or like we have. We're part, but not really this. There's always that tension. And there's also like. obviously, some economic differences. Most of Latinos are working class, low income. and to be honest, low income determines a lot of what you have available. I do feel that Latinos might not have a lot of information.

A lack of information may also connect to the perceived severity of cancer from Latino culture that perhaps heightens fear above actual death rates provided modern day treatments and early intervention. The generational fear of cancer is captured by one Latino participant who recalls that “growing up cancer was still something foreign and it was always a death sentence.” Further, the lack of education, incorporation of culturally competent care, socioeconomic supports, and understanding of the importance of trust or *confianza* in caring for Latino childhood cancer cases were palpable cultural intersections in the perceived experience of Latino families by participants in the study.

Across the board, participants agreed socioeconomic status shapes a family perceived experience and ability to help their child battle cancer if put in that position; To what degree differed, but a general consensus of financial stability, as the foundation for the best health outcomes, prevailed as a key component in a child’s chances of survival.

A parent's ability to advocate for their child was believed to be critical in a child's cancer care and overall treatment efficacy. Participants felt one's ability to advocate for their child depended on the parent's education level and language skills (e.g., first language being English or not, high school versus doctorate degree). One Latino participant explained how they expect a family whose first language is Spanish instead of English would be at higher risk of facing increased barriers to care in this situation:

I think there would definitely be a language barrier because I mean, you go to the hospital, you have translators, but you know, don't know if it's translated correctly. And I just don't think, like me, I hate to say this, but if I don't agree with something, I can definitely make it clear and the doctor is hearing me. If somebody comes in speaking another language, they can say their concerns, but you're going through a third party. So, I do think I'd have an advantage at being an advocate versus somebody who needed somebody to translate.

One parent suggested that this can be overpowered by the willingness to just ask questions and get the most out of whatever coverage you do have. However, coverage itself became an area of confusion for many parents when asked how much of cancer services are covered by government sponsored insurance. Some believe it "just covers the basics," while others mentioned insurances like Arizona Health Care Cost Containment System "AHCCCS" (Arizona's Medicaid agency that offers health care programs to serve Arizona residents) and "private-employer health insurance" as covering most if not all costs. Generally, people mentioned "AHCCCS" as the only one they think would cover everything; this was an area of frustration for some, as one parent said "I'm just outside of the line that's arbitrarily drawn in the sand. I don't have access to the same.

I'm not saying they're getting posh care or anything on access, but they're getting it [...] There's lots of families in the middle that do not have the ability to even get basic care."

An additional consideration parents of both groups posed was the impact caring for a child with cancer has on one's work schedule and their ability to work in general. On the low-socioeconomic status side of the spectrum, participants identified this as being even more of a challenge to balance: "Needing to constantly adjust work schedules and fit appointments into these schedules I think somebody with an upper socioeconomic status could probably focus on that child without having any financial repercussions versus somebody in the lower." One participant gave the example of contrasting a low versus high socioeconomic status mom:

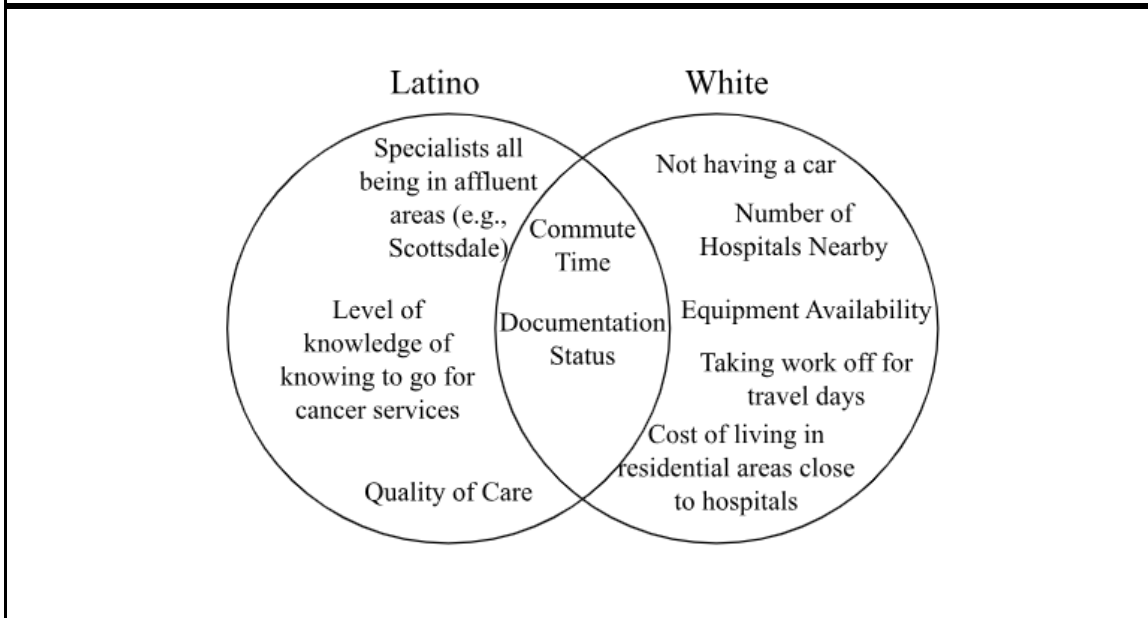
Maybe it's a single mom, and she's the one that works all the time. And now her son is sick. And now she has to take person to all these treatments and like how she's supposed to work a full-time job while also doing this versus a mom who, with an upper status that might be able, you know, that doesn't work and can focus on taking her child to receive treatment without having to think 'Oh, my house needs to be paid. My light needs to be paid, my water needs to be paid.'

One parent whose child is in their fourth year of battling cancer, highlighted their experience utilizing these services as a single mom, stating, "When we were in [for a] bone marrow transplant, the social worker said you should apply to see if they'll help you pay your mortgage. And so, this company or this foundation paid our mortgage for 3 months, which was incredibly helpful." Other ways to overcome financial hardships were noted by the same mom who outlined trials funded by the Federal Drug Administration (FDA) that their child was supposed to participate in this year. However, experimental

trials are strict in terms of rounds and not always worth it or effective. The mother said they were going to start at Seattle Children's hospital, but has decided to rethink it after the first 4 kids in the trial saw no anti-leukemic effects and the relocation costs despite the treatment being covered would be high. Other than the clinical trials mentioned by few parents, most parents other than the one who used the resources for her own family did not know government programs in place across Arizona, besides a few mentions of the Ronald McDonald house, to specifically help parents going through the financial upheaval of childhood cancer.

Furthermore, the impact of socioeconomic status on a family's ability to give their child optimal health outcomes is highlighted by all participants as a pivotal factor for childhood cancer care. The level in which it prevents families from accessing care varies in opinions, as some believe government programs such as "AHCCCS" fill in the financial gaps, while others recognize a lack of money may mean no treatment. Having a motor vehicle or living in an area closer to hospitals and urban centers, which are in the more affluent areas of town, also were noted areas of potential inequities in cancer treatment along socioeconomic lines; further, tying geographic considerations, into the conversation of the inequitable conditions of childhood cancer families experience across the Phoenix metropolitan area.

Figure 2. Perceived Geographic Barriers to Care Identified by the Sample Latino and White participants in the study.



In correlation to the cultural and socioeconomic underlining of the respondent’s answers to the research team’s questions, geographic conditions and barriers were central themes in discussing perceived barriers to optimal health outcomes for children with cancer in the Phoenix Metropolitan area. As displayed in **Figure 2** participants believed the distance and time needed to commute to cancer services as a significant geographic barrier, explaining in connection to financial considerations that it “goes back to how much time you can afford to stay away from work as well.”

Documentation status was the other barrier mentioned across both groups of participants, identifying options are viewed as more limited, especially in terms of their ability to travel over the border to Mexico and re-enter if they are of undocumented status. Families who have legal documentation in the United States indicated they may seek out treatment in Mexico for their child if diagnosed with cancer as they expressed “families in Mexico have better health care available to them that are not better but are

cheaper.” Many Latino participants cited going to Mexico to seek health care as a good option if their insurance would not cover the treatment in the United States. Others claim Mexico’s state of health is not accessible for the poor either, as one parent puts, “If you live in the south of Mexico in the poorest area, then you’re not going to have access to it [care] [...] or the poorest state, and with the most indigenous communities, you’re not going to get access to it”; further circling the issue back to being understood as a socioeconomic issue rather than geographic for US cancer care.

Latino participants noted that after going to their pediatrician or doctor for an initial visit, they would likely be referred out from a less affluent area to nicer neighborhoods where the best doctors reside. As one parent summarizes the inconvenience and steps for someone in a poorer area of town, where “minorities tend to live” versus someone in an affluent area:

I would have to go to the clinic just to get better just to get referred out to Phoenix children, which was a little bit more on the upper end of town. just to get referred to an actual specialist that's located in Scottsdale. you know. So, it was kind of like levels to it rather than like if I was in Scottsdale, and I knew. Oh, hey, we got the best or so right down the road. I can check out your foot like let's just go there, and our insurance covers that type of thing.

This quality of care in the higher socioeconomic areas as an indicator of good doctors being in urban centers versus rural and more poor centers also impacts parents' impression that they must go to the city to receive better quality of care as these doctors in “a bigger city would have more experience or more knowledge.” These same barriers to care in rural areas were ranked more pertinent than those in urban to this point that

proximity to hospital and clinics, quality of doctors, and general socioeconomic status level were understood as better in urban centers of Arizona (e.g., Phoenix, Scottsdale) than those in rural Arizona (e.g., Yuma, San Luis).

White participants shared this sentiment, ranking the experience of those in rural areas more burdensome of geographic barriers than those in urban centers. In relation to the answers given by White participants in **Figure 2**, respondents noted beliefs of participants in terms of the importance of a method of transport, a flexible job, and the quality, proximity, and equipment/supply levels of the hospitals as direct geographic factors that can shape a child's ability to battling cancer. While Latino parents were more welcome to travel to Mexico if it meant treatment would be more affordable, White parents perceived fewer barriers to care in the Phoenix metropolitan area than in Mexico.

Moreover, despite commute and documentation status being central points of discussion across both groups, palpable differences in perspective on accessing treatment options in Mexico and identifying which barriers themselves are at play geographically met different answers from the Latino and White participants. While Latinos mentioned more regarding the quality of care and the extra steps those in less affluent area they believed would be necessary to access better quality care (e.g., getting referrals), White parents discussed the availability of equipment, job flexibility, proximity to hospitals, and owning a vehicle as pivotal in their ability to provide adequate health chances for their child if battling cancer.

CHAPTER 3

DISCUSSION AND CONCLUSION

VI. Discussion

This study looked at beliefs, attitudes, and behaviors of childhood cancer in a sample of Latino and White parents in the Phoenix metropolitan area. Our findings add to the limited evidence base regarding explanatory models of childhood cancer in the U.S. Southwest. This study suggests that Latino and White parents share similar beliefs and attitudes, but important differences exist.

Similarities

Despite Latino parents expressing a graver understanding of childhood cancers, remission rates across both samples reflected a lack of understanding of the efficacy of modern pediatric cancer treatments. While the 5-year survival rate of cancer lies at 85% globally, only one out of 16 participants hazard a guess placed survival chances over 80% (American Cancer Society, 2023). With some parents even indicating a 0% remission rate, the gravity of the disease warrants a look into why parents are perceiving cancer as a “death sentence” rather than a “disease” that can be treated in most instances. It may be that the infomercials, ads, and images of children in the media going through cancer treatment seem to be more damaging than helpful when encouraging parents to bring their child in to be tested if something is wrong. While these tactics may work for donation measures, it is feared based on the misconceptions of the survivability of cancer that these campaigns imagery may be painting it as graver than a large percentage of the cases are if caught early enough. Perhaps the chances of survival being viewed as much lower than they actually are is indicative of why parents are not taking their child in for

early detection. Furthermore, there is a recurring theme of fear mentioned amongst participants discussion of diagnosis and mortality associated with childhood cancer.

Differences

While fear was a palpable emotion associated with cancer treatment by both groups, Latinos understanding of cancer treatment and settings was reportedly more dire than the conditions described by white parents. Perceptions of hospital spaces as fearsome for the child reflect traditional hospital interiors, rather than facilities newly renovated in the Phoenix Metropolitan. Phoenix Children’s Hospital for example has incorporated interior designers into their renovations to make these spaces as colorful, lively, and fun-packed as one can make a children's hospital. **Figure 3** displays the incorporation of colors and designs that are meant to make the child feel the most at

home as possible, opposed to the “4 cement walls” parents feared their child would be placed in for months if not years.

Figure 3. A visual of one of the room’s at Phoenix Children’s Hospital (Healthcare Specialties | Dalton Interiors, n.d.)



Figure 4. Provides a glimpse into the patient care building where children with cancer would be treated (St. Jude Child’s Care Center, Integrated Patient Care and Research Building, n.d.).



This incorporation of colors and designs to make the hospital a vibrant and welcoming place for children is not isolated to just one hospital. **Figure 4** shows the other major hospital, St. Jude Children's Research Hospital, which again incorporates non-traditional hospital colors to add an element of youth to the space. Further, the public perception expressed by participants in the study, but specifically Latino participants, reflects a larger atmosphere of panic that accompanies the word “cancer” in their culture. This overriding fear of cancer expressed by Latino parents was evident in their answers in contrast to the White participants of the study in terms of their belief of if recovery was a possibility for children with cancer. The stark contrast in the majority of White parents stating they did believe in recovery as a possibility, versus the majority of Latino parents stating they did not believe recovery was a possibility is reflective of the doomed attitude the culture seems to associate with doctors’ visits as a larger concern.

Rationale

Although results were split of parents in favor or against routine screening for cancer in schools, as a hypothetical if made possible to screen non-invasively becomes an option, one parent made a strong point regarding the intersection school plays in the lives of children. It may be beneficial to conduct a study amongst a sample of teachers to see if they are knowledgeable enough to identify cancer symptoms to help be diagnosed as some suggested they already do for parents. When asked if screenings in school for cancer would be helpful, one participant who worked as a teacher in schools exclaimed that she “knew a lot of my students who didn't have consistent primary care doctors. So, it was unknown. If they were actually getting well checked. So yeah, that would be helpful.” A third of Americans do not have a primary care doctor, further highlighting

school as potentially the only place a child may receive diagnostic care or have symptoms identified (A Third of Americans Don't Have a Primary Care Provider, Report Finds, n.d.). Future scholarship may collect a survey of how many believe that would be a beneficial training of the signs and symptoms of cancer as primary communicators to parents within the community, and a study could be done to see if they are knowledgeable good identify cancer symptoms to help be a stepping stone in identifying something wrong as parents already have suggested teachers do. One parent suggested giving parents a "checklist with things to look out for," to provide a non-invasive way of mentally screening children if they present with any constellation of the symptoms on that checklist, and communicating that to the parent so they can take the next steps.

It is hypothesized that the difference in perceived chances of recovery amongst Latino and White parents connects to the generational lack of trust in the medical profession amongst Latinos. This lack of trust may be indicative of why parents may not take their child in or be too scared to if they are under the impression it is not something you can recover from. If such fear and helplessness is associated with receiving a cancer diagnosis for a child. In that case, the avoidance of seeking out diagnosis may be a reason Latino child experience worse health outcomes. If this vision of cancer as a "death sentence" is corrected in Latino communities and cultural conceptions of the disease itself, perhaps parents will be less hesitant and fearful of screening their child and potentially detecting things early rather than later when recovery chances do dwindle. Further, doctors delivering care that is personalized and culturally competent, builds this trust and changes the narrative of mistrust that is passed down generation to generation in Latino cultures.

Building off of this, the literature says Latinos are less persistent on following up after going into remission for cancer recovery care and monitoring but Latino participants in this study offered different insights into this and perhaps indicate a need for the child themselves to perhaps be educated upon entering adulthood on the importance of this. Perhaps parents' desire to shield their children from the gravity of the situation and disease translates into a lack of understanding of the importance of following up on care as an adult. This need for parents to receive info in a language they may not fully understand and then have to recall this info later on to explain to their child when they are old enough to start being responsible for their own health may be a potential block in follow up care that the literature is showing.

In terms of how these misconceptions can be fixed, the avenue in which information is being displayed and released is an important component to consider in the message's efficacy. One parent recalled the impact of having a message given to her so frequently and in an academic setting that has stuck with her so thoroughly that she still cited smoking as a primary cause of cancer 20 years later: "I would say things like as a person who went to high school in the nineties. That was like hammered into your brain. Smoking causes cancer. That was like a big prop." It was interesting that white parents cite smoking as one of the most common causes of cancer, as generally, we do not perceive children as a smoking population. This may further reflect our lack of knowledge of childhood cancers as smoking (and not second-hand smoke but first-hand) as a primary cause of childhood cancer, especially before the pre-teen and adolescent ages, fails to make sense. Furthermore, if we provide this message in schools to children or to parents at school board meetings, would this theory not warrant the same or similar

results and improve parents' ability to navigate carcinogens to give their child the best chance of avoiding a cancer diagnosis?

For those not in academic spaces, other platforms to reach Latino parents should be considered to reach those with lower literacy levels than those already in academic institutions. Utilizing platforms outside academia for health information campaigns is especially important given the high percentage of Latinos who work in agricultural spaces or as parents who hold multiple jobs, and as one participant highlighted, “Many of the Latinx families that I worked with had to have back-to-back jobs where there wasn't open time for them to casually or of interest, research, medical information.” One participant suggested Latino doctors doing appearances with “talk show hosts that will share resources with the community.” The participant explained how specifically addressing Latino audiences through channels they use is a key consideration for future health infographics and campaigns:

Mexican Television [watched through cable typically] I don't see a lot of doctors going on there and explaining different things, maybe there'll be one doctor like 2, 3 times a year to like. Come on and talk about like the latest dieting fad, or something like that, but never like oh, cancer! Oh, diabetes like these! These illnesses. So, I think maybe if we had more Latino doctors they would understand, like. hey? Maybe putting out journals and articles on the latest trends in medicine Isn't: the best way to reach the community. Maybe a different way is better.

Contrasting opinions regarding healthcare in Mexico provided another cultural insight into the differences between Latino and White health behaviors. While White parents perceived less barriers generally in the Phoenix metropolitan area than Mexico, several

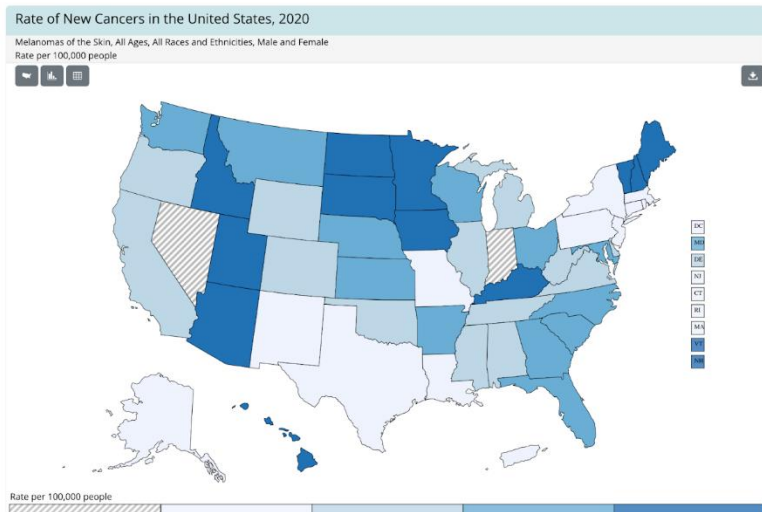
Latino parents said they would go over the border for care if it was cheaper. This result connects back with a level of familiarity with our border and fitting into a larger picture of medical tourism of Latinos going over to Mexico for cheaper services. This again emphasizes the geographic barriers one would face if undocumented, as this would limit options to find financially affordable care as one is unable to cross the border without risking their citizenship.

Conversations surrounding geographic factors spark further conversation regarding the potential intersection of employment trends amongst ethnic groups and cancer rates. One participant's discussion of their childhood farming town raised concern of how many Latinos work in agricultural settings and may be actively exposed to chemicals disproportionate to the exposure levels of the general population. While data specific to Arizona shows a low enrollment of just 4.5% of Arizonans of Latino descent actively working in agriculture, national polls indicate 43.0% of the Latino labor force in the United States is in farming, fishing, and the forestry sector (Arizona Agriculture: Not Your Average Farmers – Arizona's Economy, n.d.) (Hispanics in the Labor Force, n.d.). Thus, although this study's results do not reveal a disproportionate potential effect of pesticides and chemical exposures in the agricultural industry with Latinos occupation in Arizona, this does propose a potential correlation in other areas of the country. Other geographic concerns raised in this study connected to the level of sun exposure in Arizona kids experience and its potential to cause cancer. National data supports this concern, as Arizona ranked as the sunniest state in the US, reporting an average annual sunlight of 5,755 kJ/m² versus the national average of 4,408 kJ/m² (Sunniest States 2023, n.d.) Based on a report from the CDC in 2020, **Figure 5** has Arizona ranked as one of the

worst states in the country for melanoma rates, boasting 26.6 cases for every 100,000 people (USCS Data Visualizations, n.d.). Although skin cancer, otherwise known as squamous cell carcinoma, is rare in children, it can be hypothesized based on this data that Arizonan children if not informed of sun safety and skin cancer risks may be report

more cases of squamous cell carcinoma than children in other regions of the country.

The section outlining socioeconomic considerations of childhood cancer care



reflected as expected that those who had not interacted with childhood cancer resources were not as familiar with the resources in the community. While some participants were able to name some of the financial netting in place for families going through cancer treatment for a child in Arizona, the extent of programs and scope was only understood by the one parent whose child had gone through cancer. Without knowledge of the breadth of resources in Arizona that families are provided free of charge to help alleviate if not all, most to some of the costs, the perceived level of the financial burden of cancer may be adding to a culture of fear already established. Further, these resources need to be better circulated through communities across the Phoenix Metropolitan Region to minimize financial concerns and hesitations that may be preventing some parents from acting on taking their child in for cancer services.

VII. Limitations

Although this study provides rich and nuanced understandings of how parents understand cancer, it is not without its limitations. First, the demographics consists of a highly educated sample. Education is directly correlated with knowledge about health and this could have biased our findings. In future studies, a stratified sampling approach that controls for education could provide a more representative sample. Second, our sampling approach consisted of snowball sampling. Although this approach is common in qualitative social research, it is possible that we tapped into a network of individuals who share similar beliefs and attitudes. Third, all interviews were conducted in English and omitted Spanish-speakers. Having Spanish and English speaking Latinos could have provided us with a more nuanced understanding of how different subgroups of Latinos understand childhood cancer.

VIII. Conclusion

In conclusion, the study's results indicate a level of fear rooting from cultural mistrust, lack of education/understanding of childhood cancer, and financial hesitations may be barriers to early-intervention. The removal of such barriers relies on information dispersion through culturally aimed channels that will provide information to counter the narrative in the media and in society of cancer being a death sentence.

Although Arizona's recent history reflects a lack of attention to the child health sector, the reinstatement of KidsCare (Arizona's Children's Health Insurance Program (CHIP)) in the recent decade, and even the unveiling of a new medical school to the existing three currently in place (housed by Midwestern University, and University of

Arizona - Phoenix and Tucson locations) represents are steps towards showing the state's commitment to Arizonan children's health. With an expansion of health literacy and education on the horizon in Arizona amid the news of the introduction of a fourth medical school in the state, and third within the Phoenix Metropolitan area, the prominence of cancer as the current leading cause of death worldwide (second in the United States), and the growing Latino and migrant population, the time is optimal to place emphasis on the importance of rewriting the narrative of childhood cancer for Arizonans (Center for Disease Cause and Prevention, 2022). The lack of scholarship acknowledging direct gaps in health literacy in connection to health outcomes in Arizona regarding childhood cancer demands attention from academics, as this study demonstrates a clear misunderstanding of the curability, implications, and support in place surrounding childhood cancer.

Reducing mortality rates is not a responsibility limited to those in biomedical labs working endlessly to find a cure, but to scholars, healthcare professionals, teachers, citizens, and parents to educate ourselves on the warning signs of cancer to optimize chances of early intervention. By providing information in accessible language, on platforms Latino and White cultures actively engage in, and as a check-up rather than a death sentence, it is believed more parents would access diagnostic services at greater ease than they currently are. Achieving more equitable health outcomes for children with cancer across racial, socioeconomic, and geographic lines starts with establishing equal education for families. In order to change this narrative of fear to hope, the writing on the wall must not only be in high income communities, and in a language that one may not understand.

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APPENDIX A

FOCUS GROUP MODERATOR GUIDE TOPICS AND QUESTIONS

Topic	Questions
Etiology of childhood cancer	<p>What is cancer? [how do you define it?]</p> <p>Does it have other names?</p> <p>What does cancer mean to you?</p> <p>What causes cancer?</p> <p>Hereditary? Environmental? Social? Etc.,</p> <p>How does it metastasize?</p> <p>How is cancer diagnosed?</p> <p>Is it screened for?</p> <p>In schools?</p> <p>What does it do to people?</p> <p>Signs/symptoms?</p> <p>What does cancer look like</p> <p>How severe is it?</p> <p>How long does it last?</p> <p>What kind of treatment should be received?</p> <p>What does treatment look like?</p> <p>Where do you go to receive treatment?</p> <p>Is treatment covered by insurance plans like CHIP?</p> <p>What do they give you/do? What does cancer treatment entail?</p> <p>How long does treatment last?</p> <p>What are the efficacy rates of treatment?</p> <p>What happens if treatment is not received?</p> <p>Do you trust the medical system with the life of your child if battling cancer?</p> <p>How do you know when your child has recovered from cancer?</p>

Perceived Cultural and Racial Factors	<p>What does recovery look like?</p> <p>Is there such a thing as recovery?</p> <p>Is it likely for childhood cancers to come back, chances of remission?</p> <p>Compared to other communities, do Latinos have a different understanding of childhood cancers? Does culture play a role? Does race?</p> <p>How do you think race interacts with medicine in terms of childhood cancer?</p> <p>Do you believe race plays a role in treatment? Diagnosis?</p> <p>Do you believe families' experiences would differ based on if they were white versus Latino?</p>
Perceived Socioeconomic Factors	<p>What are some barriers you would imagine facing/experiencing accessing childhood cancer services (whether that be diagnostic, treatment, or recovery) in Phoenix?</p> <p>Do you think there are less obstacles in the Phoenix Metropolitan for families accessing these services than in other areas of Arizona?</p> <p>Further, do you think there are less obstacles in the Phoenix Metropolitan for families accessing these services than those in Mexico? Globally?</p> <p>Do you think families in rural areas would face more barriers accessing childhood cancer services than those residing in more urbanized and metropolitan regions?</p> <p>How, if at all, do you think this would affect diagnosis and treatment rates for those in rural versus urban areas?</p>

Do you believe that families socioeconomic status affects their ability to access cancer services?

How would you imagine the experience of an upper versus lower socioeconomic status family would differ?

Is childhood cancer a financial burden on families?

Do you believe enough government support programs are in place to enable families of lower socioeconomic status to access care? Have they done enough? Should they do more?

APPENDIX B

ASU IRB APPROVAL/EXEMPTION FOR HUMAN SUBJECT TESTING

EXEMPTION GRANTED

Gilberto Lopez
CLAS-SS: Transborder Studies, School of (STS)
-
Gilberto.Lopez@asu.edu

Dear [Gilberto Lopez](#):

On 4/10/2023 the ASU IRB reviewed the following protocol:

Type of Review:	Initial Study
Title:	Parental Beliefs and Attitudes of Childhood Cancers: The Intersection of Race, Socioeconomic, and Geographic Factors in Health Literacy and Health Outcomes
Investigator:	Gilberto Lopez
IRB ID:	STUDY00017761
Funding:	None
Grant Title:	None
Grant ID:	None
Documents Reviewed:	<ul style="list-style-type: none">• Consent form, Category: Consent Form;• Interview Guide, Category: Measures (Survey questions/Interview questions /interview guides/focus group questions);• Protocol, Category: IRB Protocol;• Recruitment Flyer, Category: Recruitment Materials;

The IRB determined that the protocol is considered exempt pursuant to Federal Regulations 45CFR46 (2)(ii) Tests, surveys, interviews, or observation (low risk) on 4/10/2023.

When consent is appropriate, you must use final, watermarked versions available under the "Documents" tab in ERA-IRB.

In conducting this protocol you are required to follow the requirements listed in the INVESTIGATOR MANUAL (HRP-103).

If any changes are made to the study, the IRB must be notified at research.integrity@asu.edu to determine if additional reviews/approvals are required. Changes may include but not limited to revisions to data collection, survey and/or interview questions, and vulnerable populations, etc.

Sincerely,

IRB Administrator

cc:

Florence Awde

BIOGRAPHICAL SKETCH

Florence P. Awde earned her B.A. in History and Psychology, with a minor in Spanish and Latin American Studies, from St. Thomas University in Fredericton, New Brunswick, Canada. This thesis was completed in consonance with her Masters of Advanced Studies in the Department of Transborder Studies at Arizona State University, where she investigated the interaction of race/ethnicity, the institutional impacts of the US-Mexico border, and the US political sphere at play in cultivating the current conditions of pediatric health care in the Phoenix Metropolitan Region. With research interests in pediatric oncology, health disparities, Latino health, and health policy, Florence will be attending Johns Hopkins University Bloomberg School of Public Health, where she will pursue a Master's of Science in Public Health within the Department of Population, Family, and Reproductive Health.