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Association Between Decisional Conflict and Quality of Life Among Parents with a Child Undergoing Hospital-based Treatment for a Recent Cancer Diagnosis

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Association Between Decisional Conflict and Quality of Life Among Parents with a Child Undergoing Hospital-based Treatment for a Recent Cancer Diagnosis

A Clinical Dissertation Presented to

The University of San Francisco
School of Nursing and Health Professions
Department of Health Professions
Clinical Psychology PsyD Program

In Partial Fulfillment of the Requirements for the Degree
Doctor of Psychology

By
Augustine Provencio

June 6th, 2024
PsyD Clinical Dissertation Signature Page

This Clinical Dissertation, written under the direction of the student’s Clinical Dissertation Chair and Committee and approved by Members of the Committee, has been presented to and accepted by the faculty of the Clinical Psychology PsyD Program in partial fulfillment of the requirements for the degree of Doctor of Psychology. The content and research methodologies presented in this work represent the work of the student alone.

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Acknowledgments and Dedication

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I dedicate this dissertation to my parents. My mother, Robyn, has shown me the strength of unconditional love and compassion for all those we meet, and she has been my unwavering support throughout my pursuit of higher education. My father, Augustine, has taught me the value of using the things one is passionate about to attempt to provide services to all people who need them, regardless of their backgrounds. Without them, I would not be where I am today.
Abstract

Having a child with a chronic illness, such as cancer, can cause families significant distress. Parents of these children must make frequent decisions relating to their child’s care. Depending on factors such as health literacy and support from medical staff, parents may have varying levels of decisional conflict (DC) throughout the decision-making process. Compounding stress throughout their child’s illness can often contribute to lower levels of health-related quality of life (HRQoL) while their child is receiving hospital-based treatment. Parents with a non-English language preference (NELP) often have greater challenges navigating healthcare systems due to a lack of resources and limited health literacy. The present study investigated the association between parental DC and HRQoL among 35 Latinx and White parents caring for a child with cancer. Differences in DC and HRQoL between three language groups: monolingual English, monolingual Spanish, and bilingual English and Spanish were also examined. Results indicated that higher DC was a statistically significant predictor of lower HRQoL. Additionally, there was no significant difference between language groups on either DC or HRQoL. Results suggest the need for further support for parents making decisions for their children to limit possible impacts on their HRQoL while caring for their child. Possible supports could include decisional aids, collaborative decision-making, and targeted mental health interventions for parents. Future research should include studies in various geographic locations to gain data from more diverse hospital systems and improve the generalizability of results. Furthermore, qualitative research studies could be implemented to provide parents with opportunities to explain their experiences more in-depth, which could help inform directions for additional quantitative studies.
Chapter I. Introduction

Statement of the Problem

In the United States, socioeconomic disparities and communication barriers often have a negative impact on the health status of Latinx individuals with non-English language preference (NELP) and their families (Cohen & Christakis, 2006; Seid et al., 2003; Weinick & Krauss, 2000). Although hospitals have access to interpretation services, Spanish-speaking individuals often report inconsistent use of translators, leading to confusion while navigating the medical system (Schenker et al., 2011; Zurca et al., 2017). Disparities in access to, and quality of, language-aligned services for Spanish-speaking patient populations can lead to misinterpretation of medical information and subsequent uncertainty in decision-making (Knapp et al., 2014). These issues are also present with caregivers navigating medical systems and treatments for their children (Flower et al., 2021). Caregivers often report access to translation services, the presence of bilingual medical staff, and informational material written in Spanish as significant factors contributing to their perceptions of care in the hospital (Flower et al., 2021). However, these services are often lacking or underutilized within hospital systems, which contributes to gaps in caregivers’ understanding of information regarding their child’s care and the quality of services provided (Flower et al., 2021; Schenker et al., 2011). This misinterpretation and uncertainty may worsen when Spanish-speaking parents are making medical decisions for a child with a serious illness.

Gaps in availability and utilization of language translation/interpretation services for Latinx patients and families with NELP can lead to substandard health outcomes compared to English-speaking White individuals (Cohen et al., 2005). Specifically, children with health conditions like asthma and diabetes with parents with NELP have worse long-term prognosis and
lower health-status compared to children with English proficient parents (Arif & Rohrer, 2006; Chan et al., 2005). Furthermore, caregivers with NELP with obese children rate the quality of life of their child to be worse compared to English-speaking parents with children with similar conditions (Arif & Rohrer, 2006).

Uncertainty in decisions is often referred to as decisional conflict (DC), which can impact the well-being of the individual making a choice (Knapp et al., 2014; O’Conner, 1995). Within medical settings, DC generally refers to the amount of conflict an individual has regarding a medical treatment decision (Garvelink et al., 2019). Often, uncertainty regarding these treatments negatively impacts parents and children, increasing their overall levels of stress while in the hospital (Knapp et al., 2014). This effect is more notable for non-English-speaking parents because of insufficient resources to provide adequate interpretation services to parents (Gulati et al., 2012; Schenker et al., 2011; Simon et al., 2003; Zurca et al., 2017). This lack of communication can have a negative impact on the experiences of families during treatment including the perceived level of support from their healthcare team (Zamora et al., 2016), which in turn may exacerbate parental stress and have a negative effect on family and child wellbeing in the hospital setting (Boland et al., 2017; Knapp et al., 2014; Stewart et al., 2012). However, in some cases, parents will use religion as a source of external guidance to cope with the stress of their treatment decisions, which can bolster feelings of support (Hexem et al., 2011). I sought to examine the impact of parental decisional conflict (DC) and primary spoken language on the health-related quality of life (HRQoL) of parents with children who were within one year from the end of their initial hospitalization for a cancer diagnosis. I also looked at the potential impact of religiosity and trauma symptoms among parents as potential covariates that may have explained differences in HRQoL.
Purpose and Rationale of the Study

Within hospital settings, DC has adverse outcomes for families and children, such as increased stress, preoccupation with the treatment choices, indecision, and dealignment with personal values (Cohen et al., 2005; Knapp et al., 2014; O’Conner et al., 2003). This effect is more notable when assessing DC among culturally diverse individuals and parents with NELP. Children of parents with NELP are at a higher risk of experiencing medical events requiring hospitalization, more likely to return to the hospital after discharge, and have lower HRQoL while in the hospital (Cohen et al., 2005; Samuels-Kalow et al., 2017). Additionally, when parents experience DC in making decisions about their child’s healthcare, they have additional stress, which in turn may have a negative impact on their interactions with healthcare providers and their own HRQoL (Knapp et al., 2014). Understanding parent HRQoL is important because lower parent HRQoL has been found to be predictive of lower perceptions of child HRQoL (Eiser et al., 2005; Link & Fortier, 2016). In turn, parent perceptions of their child’s HRQoL are significant contributors to their decision-making and healthcare utilization (Eiser & Varni, 2013; Janicke et al., 2001). Particularly, parents may over-rely on physician support and demonstrate hypervigilance towards their child’s well-being, which can reduce child coping behaviors to manage pain (Janicke et al., 2001).

Previous research has demonstrated that increases in DC can impact the HRQoL of individuals making decisions for themselves (Kate, 2018; Zhuang et al., 2022). However, limited studies discuss this relationship between DC and HRQoL when people are making decisions for others (Hickman et al., 2012), with only one other study finding poorer parental HRQoL after going through a lengthy decision decision-making process about their child’s tracheostomy (October et al., 2020). Though, October et al. (2020) did not directly assess the association
between DC and HRQoL with a statistical analysis. Instead, they longitudinally saw changes in mean HRQoL scores in the context of decision-making, without establishing a direct relationship (October et al., 2020). Overall, there is a lack of research assessing DC or HRQoL among ethnically and linguistically diverse families (Raghuram Pillai et al., 2020). To address this gap in the research, the goal of the present study was to examine the impact of DC in healthcare decision-making on the HRQoL of Latinx and White parents with children diagnosed with cancer who are receiving hospital-based care. Furthermore, I assessed if there are differences in DC and HRQoL based on the language abilities of the parent while making treatment for their child. Specifically, this study:

1) Examined the association between healthcare-related DC and HRQoL of parents with children within one year of the end of their initial hospitalization for a cancer diagnosis.

2) Assessed whether there are significant differences in DC scores between different language groups of the parents.

3) Assessed whether there are significant differences in HRQoL scores between different language groups of the parents.

**Definition of Project-Specific Terms**

In this study, there are several terms frequently used. The term *parents* in this study referred to the child’s primary caregivers (biological, adopted, or legal guardian). *Parental decisional conflict (DC)* signified the level of uncertainty an individual has in their ability to make treatment decisions for their child (Knapp et al., 2010; Knapp et al., 2014; O’Connor, 1995). *Health-related quality of life (HRQoL)* was a term used to denote the overall well-being of an individual, including physical, social, and emotional (Landolt et al., 2006). The term *Latinx* referred to individuals who have Mexican, Central American, and/or South American heritage.
(including individuals born in the United States or another country). I used the terms Latinx and Hispanic interchangeably throughout this study. For this study, the term health care team denoted the hospital staff treating the parent’s child, such as physicians, nurses, and social workers. The term serious illness referred to medical conditions that had a significant impact on a child’s health and may have required the use of medical treatments for survival (Hill et al., 2014). Lastly, the term Non-English language preference (NELP) referred to individuals who reported a lack of comfort or confidence in their ability to comprehend, speak, read, and write in English.
Chapter II. Literature Review

Between 2010 and 2020, the Latinx population showed the fastest growth among any cultural group in the United States, representing 52% of the overall population increase (Noe-Bustamante et al., 2020). With this increase, Latinx is currently the second-largest ethnic group, with 62.1 million individuals in the United States (Jones et al., 2022), and it is critical to recognize health challenges specific to this growing population (Noe-Bustamante et al., 2020).

Health disparities in the United States disproportionately impact Latinx populations. Social determinants of health (SDH), including educational attainment, language proficiency, income stability, and access to health care, account, in large part, for the disparities (Held et al., 2020; Velasco-Mondragon et al., 2016). Latinx individuals experience inequities in all these SDH. Compared to non-Hispanic Whites, Latinx individuals are significantly more likely to live in poverty, have lower educational attainment, and are less likely to speak English proficiently (Velasco-Mondragon et al., 2016). Inequities in educational attainment and language competencies impact an individual's health literacy and ability to navigate health care systems (Held et al., 2020; Velasco-Mondragon et al., 2016). Many disparities among this population also impact children with serious illnesses such as cancer.

Pediatric Cancer Diagnoses among Latinx children

There are several disparities in the prevalence and death rates of cancer among Latinx children compared to White children (Kehm et al., 2018; Miller et al., 2021). Leukemia (28%), central nervous system tumors (26%), and neuroblastomas (6%) are the most prevalent cancer diagnoses among pediatric populations (American Cancer Society [ACS], 2019a). Among these illnesses, acute lymphocytic leukemia (ALL) is the most common (ACS, 2019a). This diagnosis is significantly more prevalent among Latinx children, with a rate 20% greater than among
White non-Hispanic children (Miller, 2021). At this writing, the reasons for this significant disparity in ALL rates between Latinx and White non-Hispanic children are not well understood, but some researchers hypothesize that genetic or environmental factors are likely implicated. Other than ALL, White non-Hispanic children have notably higher rates of cancer diagnosis in comparison to Latinx. However, there are notable differences in the mortality rates for many cancer diagnoses among this population (Miller, 2021).

Latinx children between birth to 14 years old have lower diagnosis rates but higher mortality rates than White non-Hispanic children (Miller, 2021). For example, the survival rates for ALL are lower among Latinx children. This phenomenon occurs because Latinx children have higher relapse rates for this condition, eventually leading to more deadly recurrences of the illness (Bhatia et al., 2002). Similarly, survival rates for cancers such as lymphomas, tumors of the central nervous system, and other forms of leukemia are also lower among Latinx children than among White non-Hispanic children (Kehm et al., 2018). The lower socioeconomic status (SES) of Latinx children is a possible explanation for some of these between-group differences (Kehm et al., 2018). Lower SES for this population correlates with lower rates of survival for cancers like acute lymphoblastic leukemia, acute myeloid leukemias, neuroblastomas, and non-Hodgkin lymphomas (Kehm et al., 2018). Latinx families with lower SES have less access to quality healthcare services and often receive care when their child is at a later stage in their illness (Cabral & Cuevas, 2020; Harvey et al., 2017). Another possible explanation for worse survival rates among Latinx children is drug efficacy for treating some of these cancer diagnoses. It is possible the treatments in the United States for Latinx children with cancer do not consider genetic or cultural variations in the effectiveness of interventions for this population (Bhatia et al., 2002). To mitigate this, physicians could identify unique drug regimens or treatment
interventions to serve diverse pediatric patient populations (Bhatia et al., 2002). Currently, research assessing differences in responses to treatment and treatment trajectories among Latinx children is limited and requires further investigation. However, many factors influence Latinx families’ abilities to access care within the United States (Cohen & Christakis, 2006; Seid et al., 2003; Weinick & Krauss, 2000).

**Barriers to Pediatric Health Care for Latinx Communities**

**Access to Care**

Latinx individuals generally have less access to health care systems (Castañeda et al., 2015; Cohen & Christakis, 2006; Held et al., 2020; Seid et al., 2003; Vega et al., 2009; Weinick & Krauss, 2000). This discrepancy often leads to fewer preventative care measures for patients and less utilization of health care services among this population (Held et al., 2020; Velasco-Mondragon et al., 2016). Latinx families are less likely to have a reliable source of health care (Seid et al., 2003), with up to 18% being uninsured in 2022 (United States Census Bureau, 2022). In their study, Seid et al. (2003) discovered that parents were the least likely to have health insurance compared to all other major racial groups in the United States, with 36.8% uninsured individuals among a representative sample ($n=1292$). This proportion was significantly greater than White parents, who only had 6.7% uninsured individuals among a representative sample ($n=479$) in the study (Seid et al., 2003). Beyond access to insurance, Latinx individuals with NELP experience additional barriers to accessing health care services (Chang, 2019).

Parents who are either limited in their English proficiency or are monolingual Spanish speakers have challenges maneuvering the health care system (Cohen & Christakis, 2006; Weinick & Krauss, 2000). In many cases, difficulties with language may lead children and
families to have less consistent access to regular health care services (Flores & Tomany-Korman, 2008; Weinick & Krauss, 2000). In their retrospective cohort study, Cohen and Christakis (2006) discovered that infants with parents with NELP were half as likely to receive the necessary preventative care visits during the first year after birth compared to those whose primary language is English (Cohen & Christakis, 2006). Often, this trend occurs because parents with NELP do not have the language competencies necessary to choose between available services (Chang, 2019; Edward et al., 2018). Families need to have general health literacy skills to appropriately choose care options fitting their needs and ensure payment is covered through insurance (Edward et al., 2018). Latinx individuals immigrating to the United States, many with NELP and without documentation status, often experience additional barriers to utilizing medical care (Chang, 2019).

Latinx immigrant populations coming into the United States often experience additional barriers regarding access to care (Castañeda et al., 2015; Held et al., 2020; Vega et al., 2009). Specifically, these individuals may have less knowledge about the health care system in the United States and fear discrimination from providers (Held et al., 2020). Also, immigrants have less access to preventative care measures, which affects their ability to detect chronic and life-threatening illnesses. These inequities are worse among undocumented immigrants (Cabral & Cuevas, 2020). This population has significantly less access to insurance services like Medicaid. (reference needed here) Due to a lack of insurance protection, this group relies on emergency room services to cover their medical treatments (Cabral & Cuevas, 2020; Samra et al., 2019). Often, this population only uses these medical services in extreme circumstances, leading those with an undocumented status to receive crucial diagnoses at later stages in their illnesses (Cabral & Cuevas, 2020). Once these individuals eventually access medical treatment,
their documentation status and NELP introduce added difficulties in receiving quality care from physicians, which impacts their experiences and well-being in the hospital (Cohen et al., 2005; Samuels-Kalow et al., 2017).

Quality of Care

In the United States, Latinx parents with NELP with hospitalized children receive poorer communication and less access to the health care team compared to White parents (Cabral & Cuevas, 2020; Seid et al., 2003; Stephen & Zoucha, 2020; Williams & Wyatt, 2015; Zurca et al., 2017). Many of these caregivers feel they have inadequate knowledge around their child’s conditions and do not believe they can confidently manage their care (Chan et al., 2005). Often, these parents feel uncomfortable asking questions because of their limited English language proficiency and fear of discrimination from providers (Chan et al., 2005). Also, parents may experience anxiety around their ability to understand providers and feel they are missing important information regarding treatment planning and consultation (Abbe et al., 2006). Beyond perceptions of communication, investigations show access to providers is more limited for Latinx individuals with NELP while in the hospital. In their study, Zurca et al. (2017) demonstrated that NELP families were less likely to receive adequate communication at the bedside despite being available to communicate with the health care team. Similar results were found by Stephen and Zoucha (2020), who discovered NELP families were less likely to feel competent in the content discussed in rounds. Also, parents did not believe they had adequate access to the health care team during their child’s treatment (Stephen & Zoucha, 2020). Without proper support, many parents with NELP lack the necessary health literacy to access and comprehend the treatment options for their children (Chan et al., 2005; Forner, 2020). When these language barriers exist, caregivers may feel less trust in their providers and have added
levels of stress, which can impact their abilities to provide emotional support for their children (Eiser et al., 2005; Tremolada et al., 2011). This phenomenon is relevant because the overall well-being and stress levels of parents can impact their perceptions of the HRQoL their children experience in the hospital (Eiser et al., 2005; Tremolada et al., 2011). In many cases, hospital settings will use interpreters to attempt to overcome these disparities (Stephen & Zoucha, 2020).

In many healthcare systems, providers attempt to overcome language barriers by using interpreters who speak the language of the patient (Stephen & Zoucha, 2020; Zurca et al., 2017). Often, this service can help mitigate some of the communication barriers related to treatment decisions for parents (Weinick & Krauss, 2000). However, inconsistent access to these services also contributes to the disparities in the quality of health care. In their cross-sectional study, Schenker et al. (2011) assessed the rates of interpreter use among hospitalized Chinese and Spanish-speaking patient populations. They discovered that only 43% of the patients were offered an interpreter when admitted to the hospital. Furthermore, only 60% of participants reported having an interpreter present while interacting with the physician since their admittance to the hospital. These numbers are concerning because 93% of the participants noted a preference for interpreter services when communicating with their physician (Schenker et al., 2011). Zurca et al. (2017) reported similar findings, with only 53% of NELP families stating they had access to an interpreter “most of the time” during hospital interactions with physicians. Additionally, 14% of families claimed they “rarely or never” had access to these services. Even with the use of interpreters, some communication barriers remained. Only 42% of families felt they understood the treatment plan after consulting with the health care team (Zurca et al., 2017). Despite the attempt to use interpreters, there are health-related consequences resulting from inequities in the access and quality of care for Latinx families with NELP.
**Health Outcomes**

Children of families with NELP often have poorer health outcomes compared to English-proficient individuals (Cohen et al., 2005; Flores & Tomany-Korman, 2008; Samuels-Kalow et al., 2017; Stephen & Zoucha, 2020). Many of these parents do not have the adequate health literacy to confidently manage their child’s chronic condition and do not receive proper support from medical staff (Chan et al., 2005). In their article, Chan et al. (2005) demonstrated this inequity, finding children of non-English-speaking families with asthma generally have poorer long-term health outcomes and more progressed conditions later in life compared to children of English-speaking families (Chan et al., 2005). Flores and Tomany-Korman (2008) found similar results, demonstrating children with parents with NELP were more likely to be obese and have a lower overall health status. One explanation for these children's poorer health is families with NELP are less likely to receive preventative care visits, which allows the child’s conditions to worsen without medical intervention for extended periods (Cohen & Christakis, 2006). Also, in the United States, minority groups are less likely to receive necessary procedures and interventions to manage their conditions compared to White individuals (Williams & Wyatt, 2015).

The potential health risks among NELP Spanish-speaking patients also extend to outcomes individuals experience when in the hospital. Children of Spanish-speaking parents with NELP have a significantly higher risk of experiencing serious medical events while in the hospital (Cohen et al., 2005). This effect remained even though most of these families requested interpreter services to interact with their providers. One possible explanation for these adverse outcomes among this population is physicians are more likely to attempt to use their limited Spanish skills to communicate with Spanish-speaking families (Cohen et al., 2005). Furthermore,
patients may rely on non-clinically trained interpreters, such as family or friends to help communicate with the health care team (Suarez et al., 2021). These actions may cause vital information to be lost in translation, leading to errors in care and progressive health conditions for Latinx children (Cohen et al., 2005; Flores et al., 2000). As a result of this inadequate care and consequential health outcomes, these children are also more likely to return to the hospital after discharge (Samuels-Kalow et al., 2017). With the existing communication and care disparities for families with NELP, it is necessary to consider the mechanisms these families use to make treatment decisions when interacting with the hospital. It is significant to consider specific factors impacting decision-making among these families because having NELP makes them more susceptible to misunderstandings and uncertainty while caring for their children.

**Treatment Decision-Making for Parents**

*Theoretical Framework*

I conceptualized the present study through the lens of the conflict theory model of decision-making and the Ottawa decision support framework. The conflict theory model of decision-making discusses weighing negative and positive consequences in decision-making (Mann & Janis, 1982). This theory asserts that every individual makes decisions to accept or deny a particular outcome of their decision by assessing the various benefits and drawbacks. Individuals experience decisional conflict (DC) when they want to accept and reject a particular choice or outcome, which can lead to significant stress (Mann & Janis, 1982; Pozzar et al., 2019). Theorists later built upon concepts from the conflict theory model of decision-making to develop the Ottawa decision support framework, which serves as the underlying theoretical model in the development of tools measuring DC and is most frequently used within healthcare settings (O'Connor, 1995; Pozzar et al., 2019). This framework suggests each person has unique
decisional needs that contribute to decision-making and conflict (O’Connor et al., 2011; Stacey et al., 2020). Needs like patient expectations, values, presence of support, social pressure, and available resources all play a role in an individual's decision (O’Connor et al., 2011). The extent to which these needs are met influence potential outcomes, such as the alignment of the decision with patient values, the overall quality of the decision, and the likelihood they continue with their choice (Stacey et al., 2020). The presence of decisional support can impact the individual’s decision-making process in health care (Hoefel et al., 2020). For example, clear communication, forming rapport, and implementing decisional aids can influence how a health care team meets the decisional needs of a patient (Hoefel et al., 2020; Stacy et al., 2020).

The conflict theory model of decision-making and Ottawa decision support framework theories served as the theoretical basis for this study because parents of children with cancer must choose between treatment options presented to them by their providers, each with its own benefits and drawbacks (Mckenna et al., 2010; Pyke-Grimm et al., 2006). Each family has unique decisional needs that impact their decisions for their child’s cancer treatment (Hoefel et al., 2020; Stacy et al., 2020). For example, Latinx parents with NELP may require additional translation services and provider communication to bolster their knowledge of the various options (Stephen & Zoucha, 2020; Zurca et al., 2017). However, many hospitals do not have adequate language support for patients with NELP and do not sufficiently incorporate them into treatment discussions, which can create more DC and reduce the quality of their decisions (Stacy et al., 2020; Stephen & Zoucha, 2020; Zurca et al., 2017). Furthermore, patients with varying levels of English proficiency and from diverse cultural groups may have lower access to resources and fewer interactions with providers whose cultural values align with their own (Baenziger et al., 2020; Gulati et al., 2012; Schenker et al., 2011; Simon et al., 2003; Zurca et al.,
Recognizing these disparities in decision-making for my participant population helped ground this study and was a primary motivation to critically assess the impact of healthcare systems on the decision-making experiences of parents of children with serious illnesses.

**Factors Impacting Decision-Making for Parents**

Several factors influence parental decision-making in health care settings. When interacting within the hospital system, the parent-provider relationship can impact decision-making for caregivers (Mckenna et al., 2010; Pyke-Grimm et al., 2006). Specifically, parents stress the importance of collaboration with their provider in establishing trust regarding their child’s treatment decisions. This need reflects the significance of medical professionals to effectively communicate with parents about their child’s care (Pyke-Grimm et al., 2006). Parents expect physicians to keep them informed in treatment discussions, value their opinions, and allow them to be collaborators in the process (Mckenna et al., 2010; Pyke-Grimm et al., 2006). Furthermore, the severity of the child’s health condition can impact a parent’s treatment decisions. When the child’s illness requires immediate care, parents are more likely to rely on their health care provider to make big decisions (Pyke-Grimm et al., 2006). In these cases, parents may feel a sense of urgency because of the limited time to make decisions for their child, restricting their ability to collaborate (Gruccio & Steinkrauss, 2000; Pyke-Grimm et al., 2006). Parents may also feel forced to trust in their providers when considering the impact of the health emergency on the families’ lives, the possibility of death for the child, and the importance of the treatment decision toward recovery (Gruccio & Steinkrauss, 2000). Providers must also consider the patient’s religious background in their interactions with families because these factors significantly influence the decisions families make for their children (Pinto-Taylor & Doolittle, 2020).
Faith is often another factor influencing decision-making for parents with children with cancer (Linnard-Palmer & Kools, 2004; Michelson et al., 2009). Families with religious beliefs express the importance of their theological perspectives and faith-based communities in coping with stress and making treatment decisions (Hexem et al., 2011). Specifically, utilizing religion helped these families feel they had more control over their child’s treatment decisions, increasing the levels of support they felt (Hexem et al.). Furthermore, the use of prayer and the Bible may impact the overall decisions parents who are religious make for their children (Hexem et al., 2011; Linnard-Palmer & Kools, 2004; Michelson et al., 2009). Religious perspectives can lead families to make decisions for or against aggressive treatments (Linnard-Palmer & Kools, 2004; Michelson et al., 2009). Depending on their religion, some caregivers may feel God, for example, should be in control of their child’s destiny and refuse treatment, while others believe it is a moral imperative to keep their child alive as long as possible (Linnard-Palmer & Kools, 2004; Michelson et al., 2009). It is significant to note not all parents with religious beliefs utilize or lean on their faith during their child’s cancer treatment course (Hexem et al., 2011). Some families express anger toward God for their child’s illness and may question their beliefs altogether (Hexem et al., 2011). Religious coping was considered an important factor to consider in this study because it may influence the level of support a parent feels when making treatment decisions (Hexem et al., 2011; Linnard-Palmer & Kools, 2004; Michelson et al., 2009); and therefore, could have the potential to act as a confounding variable impacting DC.

**Decisional Conflict in Parents**

Within health care systems, parents can feel uncertainty relating to treatment decisions for their children. This phenomenon is often referred to as decisional conflict (DC) in treatment decisions (Knapp et al., 2010; O'Connor, 1995). Several factors influence the extent of conflict
parents may feel when their child interacts with the health care system, such as education level, recency of the decision, relationship with the provider, and extent of collaboration (e.g., shared decision-making) with the provider (Forner et al., 2020; Knapp et al., 2010; Hong et al., 2016; Knapp et al., 2014; Stewart et al., 2012).

Health literacy has been demonstrated to be significantly associated with the level of DC in parents (Forner et al., 2020; Knapp et al., 2010). For example, individuals with more exposure to medical terminology feel lower levels of uncertainty when interacting with the hospital and may have higher levels of health literacy (Forner et al., 2020; Knapp et al., 2010). In many cases, the vocabulary physicians use to discuss a child's health information with parents is complex and uses medical terminology challenging to comprehend for patients (Forner et al., 2020). As a result, parents with higher levels of vocabulary acquisition feel less conflicted about the decisions they are making for their children (Forner et al., 2020; Knapp et al., 2010). Currently, many hospital systems do not have the resources to properly differentiate between different levels of health literacy, which exacerbates disparities in the quality of healthcare between families (Knapp et al., 2010). The recency of decisions parents make can also influence their conflict.

Parents often report a higher level of doubt regarding their child’s care before major procedures (Hong et al., 2016). Generally, conflict decreases as more time passes after receiving a diagnosis and treatment is completed (Knapp et al., 2010; Hong et al., 2016). This factor was important to consider when deciding at what point in their child’s care to allow parents to participate in the current study. Due to the potential increases in anxiety and depression close to the initial diagnosis (Stremler et al., 2017), I excluded parents who were within a month of receiving confirmation of their child’s illness.
Parents often report a higher level of doubt regarding their child’s care before major procedures (Hong et al., 2016). Generally, conflict decreases as more time passes after receiving a diagnosis and treatment is completed (Knapp et al., 2010; Hong et al., 2016). This factor was important to consider when deciding at what point in their child’s care to allow parents to participate in the current study. Due to the potential increases in anxiety and depression close to the initial diagnosis (Stremler et al., 2017), I excluded parents who were within a month of receiving confirmation of their child’s illness.

The extent of support given to parents by their provider was another notable factor contributing to parental uncertainty regarding their child’s treatment. When interacting with the hospital system, parents receive varying levels of support from their clinicians and medical staff. Research indicates parents experience higher levels of DC when they feel they are receiving less support from their child’s clinician (Boland et al., 2017; Stewart et al., 2012). One potential reason for this phenomenon is parents often feel a surmountable pressure to make decisions on their own regarding their child’s care (Stewart et al., 2012). In many cases, parents do not receive extensive support from their extended family members, and their children cannot assist in the decision-making process (Stewart et al., 2012). As a result of this pressure, the support medical staff provides to parents can impact their abilities to confidently make decisions and their level of stress during the process (Boland et al., 2017; Stewart et al., 2012). Within the hospital, there are several ways interactions with medical staff can impact the level of conflict parents may feel. The level of support from clinicians and healthcare workers directly impacts DC in parents (Boland et al., 2017; Hong et al., 2016). Often, parents feel they do not have significant involvement in the child’s treatment decisions with their healthcare providers. This lack of collaboration leads parents to have higher levels of DC when confronted with treatments for their
children (Boland et al., 2017; Stewart et al., 2012). This can lead to a lack of understanding among parents in understanding the risks and benefits of treatments, and they may feel they do not adequately comprehend their child’s treatment options (Boland et al., 2017). Parents involved in discussions around these significant decisions often feel more competent and informed regarding the child’s care (Boland et al., 2017; Hong et al., 2016). However, perceptions of support and involvement in a child’s care can also vary among cultural groups.

Culturally diverse groups often do not trust the medical system, which impacts their collaboration with providers around treatment (De Silva et al., 2020; Knapp et al., 2014; Rajakumar et al., 2009). Knapp et al. (2014) investigated the differences in uncertainty between racial and ethnic groups among 266 parents of children suffering from a serious medical ailment (e.g., cancer). Their study revealed Black and Latinx groups reported high levels of DC, while White parents had notably lower levels. Also, parents from minority groups felt less supported by the medical staff while their child was in treatment (Knapp et al., 2014). One possible explanation for this disparity is a general mistrust among minority groups toward medicine (De Silva et al., 2020; Knapp et al., 2014; Rajakumar et al., 2009). Furthermore, parents from different cultural groups may fear discrimination from the health care team (De Silva et al., 2020). This wariness of providers can influence the extent to which parents want to engage with their medical provider and lower their overall confidence in their child’s medical care and treatment decisions (De Silva et al., 2020; Knapp et al., 2014). A lack of trust and communication can lead to poorer parent psychological well-being during their child’s illness and misalignment between treatment decisions and the family’s values (Baenziger et al., 2020). Parents with NELP often experience additional barriers in their abilities to engage in treatment
decisions, which can lead to increased DC (Gulati et al., 2012; Simon et al., 2003; Zamora et al., 2016).

**Decisional Conflict in Latinx Parents with Limited English Proficiency**

Language competencies impact parents’ decision-making processes and levels of DC while interacting with the health care system (Gulati et al., 2012; Simon et al., 2003; Zamora et al., 2016). Parents with NELP who have children suffering from serious medical conditions report higher levels of DC than caregivers who speak English fluently (Knapp et al., 2014). A notable factor impacting this doubt in parents is poor health literacy around the terminology providers use to discuss the child’s condition and prognosis (Forner, 2020; Knapp et al., 2014). In many cases, Spanish-speaking caregivers feel they would better understand their child’s needs and have an overall more positive experience with the healthcare system if they spoke English as a primary language (Zamora et al., 2016). Furthermore, due to the language discrepancies in this population, parents are often reluctant to ask questions to their providers, which furthers the communication gap around the child’s treatment (Simon et al., 2003; Zamora et al., 2016). Disparities in this communication can lead parents to miss opportunities for valuable resources for these children and may cause them to feel alienated while navigating the hospital systems (Gulati et al., 2012). Other possible negative outcomes arising from language disparities in treatment decisions include general fear of unknown health outcomes and parent embarrassment because of a lack of comprehension of medical terminology (Seltz et al., 2011). These factors can inhibit the extent to which parents with NELP engage with their child’s treatment and can lead to increased uncertainty in the decisions made (Knapp et al., 2014; Seltz et al., 2011). Furthermore, when parents experience financial stress on top of poor communication, it can lead to an overall decrease in their own HRQoL, which can worsen over time (October et al., 2020).
The relationship is reciprocal: as parents HRQoL decreases, their rating of their child’s well-being decreases (Eiser et al., 2005).

**Quality of Life of Parents with a Child Diagnosed with Cancer**

Chronically ill children with cancer generally undergo a series of life changes impacting all facets of their daily functioning and independence (Hockenberry-Eaton et al., 1995). The stressors from these shifts cause significant impairments in children’s levels of self-esteem, overall mental health, and physical functioning (Hockenberry-Eaton et al., 1995; Peeters et al., 2009; Sitaresmi et al., 2008). For example, these children may experience higher levels of anxiety, sadness, and physical pain during their treatment (Arslan et al., 2013). For many parents, managing these changes and witnessing their child suffer can be difficult and may impact their HRQoL after their child is diagnosed.

Parents receiving news of their child’s cancer diagnosis often experience notable changes in their HRQoL while their child is in the hospital (Klassen et al., 2011; Litzelman et al., 2011; Santo et al., 2011). Specifically, these parents have lower reported HRQoL scores compared to parents with healthy children (Litzelman et al., 2011; Santo et al., 2011). In their study, Litzelman et al. (2011) discovered that one notable factor contributing to this decline in HRQoL relates to changes in the child’s ability to engage in normal activities that other children their age can complete (Litzelman et al., 2011). Furthermore, children receiving treatment often have notable functional and emotional impairments; navigating these challenges throughout treatment was also associated with lower reports of HRQoL among parents (Litzelman et al., 2011). However, both elements were mediated by the level of stress and burden the parent felt while caring for their child (Litzelman et al., 2011). Similar results were found by Santo et al. (2011) among a sample of parents in Brazil. In their study, they discovered that caregivers of children
with cancer experienced higher levels of burden, including isolation and disappointment. These parents also reported lower levels of HRQoL compared to the control group (Santo et al., 2011). Klassen et al. (2011) found similar results relating to the impact of caregiver strain on parental HRQoL. However, they found the effect to be more prominent within the first 12 months of the child’s diagnosis (Klassen et al., 2011).

To date, there are limited studies directly assessing the association between the level of DC and HRQoL a parent might experience while caring for their child. Existing literature on this relationship has established that higher DC can negatively impact an individual’s HRQoL when they are making decisions around their own care (Kate, 2018; O’Connor, 2010; Zhuang et al., 2022). However, only one longitudinal study looked at this relationship for parents making treatment decisions for their children, specifically those deciding on tracheostomy surgery (October et al., 2020). They assessed HRQoL at different points after the decision had already been made to see if there were decreases in the context of the stressful decision-making process, which there were. However, this study did not directly measure associations between DC and HRQoL among parents using a formal statistical analysis, but instead, used a qualitative semi-structured interview to allow parents to describe the most influential factors contributing to decreases in HRQoL after making their decision (October et al. 2020). Furthermore, research has not been conducted to understand the impact of DC on HRQoL among parents caring for their child with cancer, let alone among those with varying language abilities.

**Quality of Life Among Latinx Parents of a Child with Cancer**

Latinx families, especially those with NELP, navigating a child’s cancer diagnosis may have unique challenges impacting their HRQoL. Among this group, parents from predominantly Spanish-speaking backgrounds are at risk of lower QoL than English-speaking families (Wahi et
al., 2016). This phenomenon relates to the overall levels of anxiety these parents have when interacting with the hospital. Specifically, Spanish-speaking families experience higher levels of anxiety in the hospital compared to English-speaking families, which can negatively impact their HRQoL while managing the cancer diagnosis and treatment of the child (Wahi et al., 2016).

Other factors that may affect Latinx parents’ HRQoL relate to social determinants of health, such as SES.

The SES of parents with children with cancer may also contribute to their HRQoL while their child is receiving treatment. In the United States, Black and Latinx populations have notably lower SES compared to White populations (Morales et al., 2002). In many cases, Latinx individuals immigrating to the United States have equal or better health outcomes than White populations, creating a paradox in contemporary literature (Morales et al., 2002). However, studies show low SES among parents with children with chronic conditions can significantly influence their reports of HRQoL (Landolt et al., 2011; Lawoko & Soares, 2003). In their study, Landolt et al. (2011) found that parents of children who recently went through open heart surgery were more likely to report lower levels of mental HRQoL. Similar results were found in a study done in Sweden, which demonstrated that parental income and financial status were significant factors in predicting HRQoL (Lawoko & Soares, 2003). This is an important factor to consider because Latinx and Spanish-speaking families generally have lower SES compared to White populations (Morales et al., 2002). Individuals living in households experiencing lower SES, and thus, heightened food insecurity, have significantly lower HRQoL scores in physical, social, and emotional domains (Gany et al., 2015). These data are relevant to this study because minority groups, particularly Latinx families with NELP, are at a higher risk to experience food insecurity in the United States (Polk et al., 2020).
Impact of Parent Quality of Life on their Perceptions of their Child’s Quality of Life

Health-related quality of life (HRQoL) of parents with children with cancer is often associated with their perceptions of their child’s HRQoL. This relationship is significant because parent perceptions of their child’s HRQoL significantly predict their utilization of healthcare services and dependency on provider support (Eiser & Varni, 2013; Janicke et al., 2001). In many cases, parents will rely more heavily on physician support in decision-making and overparent their children when they perceive the child’s HRQoL as lower, which can have negative effects on the child’s self-coping abilities (Janicke et al., 2001).

During periods closely following diagnosis, parents commonly identify concerns related to the child’s emotional functioning and behavior (Clark et al., 2005). In their study, Eiser et al. (2005) assessed the overall HRQoL in 87 children with various cancer diagnoses using a parent proxy of the Pediatric Quality of Life Inventory (PedsQL). The study discovered mothers with a child with a cancer diagnosis rated their child’s overall HRQoL significantly lower than the population average. This finding was associated with the overall level of worry and lower HRQoL scores of the mothers (Eiser et al., 2005). In many cases, elevated levels of anxiety experienced by parents influence their perceptions of their child’s HRQoL while managing a cancer diagnosis (Link & Fortier, 2016). Furthermore, receiving news of a child’s cancer diagnosis can be traumatizing and lead to symptoms of post-traumatic stress among parents, which may impact their perceptions of their child’s HRQoL (Kazak et al., 2005). Tremolada et al. (2011) had similar findings in their study with 128 children with leukemia and their families. The investigation utilized the Ecocultural Family Interview—Cancer (EFI-C) to assess overall health-related HRQoL. They discovered parents rated their children as having a significantly lower HRQoL during periods shortly after receiving their diagnosis (Tremolada et al., 2011).
These ratings were influenced by the parent’s levels of trust in their medical staff, their perceptions of their child’s abilities to cope with the stressors of the diagnosis, and how they viewed their child’s ability to emotionally and physically adapt to their condition using positive coping strategies (Tremolada et al., 2011).

**Clinical and Theoretical Relevance**

This literature review discussed parent's experiences interacting with hospital systems while navigating their child’s cancer diagnosis and making decisions regarding their treatment. There are notable disparities in the access to, and quality of care, for individuals from diverse cultural and linguistic backgrounds (Cohen & Christakis, 2006; Seid et al., 2003; Weinick & Krauss, 2000). These inequities can lead to poorer health outcomes for children from families with limited English proficiency, lack of familiarity with the medical system, and lower levels of academic attainment (Forner et al., 2020; Knap et al., 2010). Parents often experience high levels of DC when attempting to make treatment decisions for their children (Forner et al., 2020; Hong et al., 2016; Knapp et al., 2010; Knapp et al., 2014; Stewart et al., 2012). In some cases, this conflict is mitigated by religious coping because parents will rely on external support in their decisions (Hexem et al., 2011). Parental uncertainty is often lower in parents with limited English proficiency because they may feel uninformed or incapable of comprehending the medical terminology used by doctors, which was assessed in this study using the Decisional Conflict Scale (Knapp et al., 2010; O’Connor, 1995). This phenomenon may lead to anxiety among parents when making decisions in the pediatric inpatient setting, which may negatively impact their HRQoL (Eiser et al., 2005). Parents with children with cancer already present with lower HRQoL due to the caregiver strain and significant life changes their children experience (Klassen et al., 2011; Litzelman et al., 2011; Santo et al., 2011). However, to my knowledge (or
“at this writing”), no studies directly assess the relationship between DC and HRQoL for parents of children with cancer. Furthermore, the existing literature investigating the effect of language on these factors is scarce. For this reason, my study focused on the association between DC and HRQoL among parents with children within one year of the end of their initial hospitalization for a cancer diagnosis. I also examined differences in DC and HRQoL by language use and ability while interacting with the hospital staff (Spanish only, English only, and bilingual English and Spanish).

This study added to the body of literature utilizing the Ottawa Decision Support Framework, which establishes the need for patient-provider collaboration and additional support to help improve decision-making processes for individuals in navigating healthcare systems (Mann & Janis, 1982). Potential findings from this study were considered clinically relevant because they aimed to prompt healthcare providers to invest more resources into support for parents experiencing high levels of DC, such as increased use of decisional aids and collaborative decision-making. The more emphasis providers place on assisting parents to feel competent in making decisions about their child’s health care, the more agency the parents will feel and the less they will rely on others to make decisions (Carr et al., 2016; Elwyn et al., 2012). This phenomenon is especially true for parents with NELP because they may have lower health literacy and rely more heavily on the providers to make decisions (Elwyn et al., 2012; Sajeev et al., 2017). Reducing stress and indecision in parents may help improve their HRQoL and their child’s overall experience at the hospital.

**The Present Study**

**Research Questions**

The following research questions were addressed:
1. What is the association between DC and HRQoL among parents who have a child receiving hospital-based treatment for a cancer diagnosis?

H₁: Parental DC will be inversely associated with parent HRQoL for parents who have a child receiving hospital-based care for a cancer diagnosis. This association will be statistically significant for the total Decisional Conflict Scale (DCS) score and the total PedsQL Family Impact Module - Parent HRQoL Subscale (referred to as PedsQL throughout this paper) score.

H₀: Parental DC scores will not be associated with the parent HRQoL score for parents with a child receiving hospital-based care for a cancer diagnosis.

2. What is the association between DC and HRQoL when accounting for any variance explained by religious coping behaviors and trauma symptoms among parents making cancer treatment decisions for their children?

H₁: The association between DCS and PedsQL total scale scores will be statistically significant even after controlling for total Brief RCOPE positive and negative religious coping subscale scores and the total trauma symptom score on the Primary Care PTSD Screen for DSM-5 (PC-PTSD-5).

H₀: The association between DCS and PedsQL total scale scores will be statistically significant even after controlling for total Brief RCOPE positive and negative religious coping subscale scores, and the total trauma symptom score on the Primary Care PTSD Screen for DSM-5 (PC-PTSD-5).

3. Do overall levels of DC differ between a) monolingual English-speaking parents, b) monolingual Spanish-speaking parents, and c) bilingual English and Spanish-speaking parents?
H1: Decisional conflict (DCS total scores) will be greatest for monolingual English or bilingual English/Spanish-speaking parents. Decisional conflict total scores will be lowest for monolingual Spanish-speaking parents.

H0: There will be no difference in overall levels of DCS total scores between the three language groups.

4. Do overall levels of parent HRQoL differ between a) monolingual English-speaking parents, b) monolingual Spanish-speaking parents, and c) bilingual English and Spanish-speaking parents?

H1: Spanish-speaking and bilingual Spanish/English-speaking parents will have overall lower levels of HRQoL (total PedsQL score) compared to parents who are monolingual English speakers. Total PedsQL scores will be highest for monolingual or bilingual English-speaking parents.

H0: There will be no difference in mean parent PedsQL total scores between the three language groups.
Chapter III. Methodology

Study Design

This study featured a prospective, cross-sectional research design to assess the impact of parental decisional conflict (DC) concerning treatment decisions for their child’s care on the health-related quality of life (HRQoL) of parents whose child is undergoing hospital-based treatment for cancer. After consenting to participate in the study during an outpatient hospital-based clinic visit, parents were asked to complete a survey with questions about parent/patient/healthcare provider characteristics and validated measures assessing parental DC, parental HRQoL, parental religious coping, and parental trauma symptoms. The study took place within an outpatient oncology clinic at UCSF Children’s Hospital Oakland, with the help of Dr. Agrawal, the department director. The study proposal was submitted to the Institutional Review Board for the Protection of Human Subjects (IRBPHS) at the University of San Francisco (IRB # 1857), and the University of California, San Francisco IRB (IRB # 2338942), and final IRB approval was obtained on 10/19/2023.

Participants

Eligibility Criteria

Participants for this study consisted of Latinx and White parents (See project-specific terms for the definition of Latinx and White) of children undergoing treatment for a cancer diagnosis. Parents of children at any phase of their cancer treatment were eligible to participate in the study. Participants consisted of three main groups based on parents’ self-reported language abilities: Monolingual English-speaking parents, monolingual Spanish-speaking parents, and bilingual English/Spanish-speaking parents.

To be eligible to participate in this study, parents must have met the following criteria:
• Identify as a Latinx or White parent/primary caregiver;
• Be the parent or primary caregiver of a child aged birth to 17 years, diagnosed with a solid tumor or hematological cancer;
• Have a child who was within 1 year from the end of their initial hospitalization for a diagnosis or treatment of their cancer;
• Have a child who was diagnosed with cancer $\geq 1$ month prior to enrollment. The decision to including parents with children who were in treatment for at least one month post-diagnosis was to account for the initial shock that is often experienced following a positive cancer diagnosis. This time bound was also meant to allow families some time to process their child’s condition before being asked to participate in a research study (Hong et al., 2016; Knapp et al., 2010);
• Have made a decision regarding their child’s treatment/care within the past 6 months;
• Be $\geq 18$ years of age or older;
• Be able to provide verbal informed consent in their preferred language;
• Be the primary decision maker for their child;
• Be able to speak and comprehend English and/or Spanish; and
• Have a child receiving cancer-directed treatment at the University of California (UCSF) Benioff Children’s Hospitals, Oakland.

Parents or primary caregivers were ineligible for the study if they did not meet all of the eligibility criteria and if:

• They were unable to provide informed consent;
- They self-reported significant active use of Schedule 1 drugs in the past 14 days or excessive alcohol use in the past week ("active use" for drugs refers to the self-reported intake of Schedule 1 drugs, except for cannabis, at any point within two weeks before completing the survey. Schedule 1 drugs do not include prescription medication. For alcohol, substantial active use referred to the intake of more than 14 drinks in a given week);

- They self-reported an untreated serious mental illness;

  *It was important to exclude parents with significant recent substance use (e.g., meth use) and/or with untreated serious mental illness (e.g., schizophrenia) as it has been shown to negatively impact a person’s ability to reliably recall their experiences in the hospital and accurately assess their HRQoL (Jeste et al., 2018; Tracy, 1994).*

I developed and implemented a screening questionnaire (see Appendix A) that potential participants completed to determine eligibility for this study.

**Targeted Sample Size**

I initially sought to recruit a total of 68 participants from the Oncology Department at UCSF Children’s Hospital Oakland to detect a medium effect size ($f^2 = .15$). I calculated this sample size using an A priori F-test for a linear multiple regression (fixed model, $R^2$ increase) in G Power (Faul et al., 2009). The number of tested predictors for this beginning model was 4, including the DCS total score, positive and negative religious coping subscales on the Brief RCOPE, and the PC-PTSD-5 total scores. I attempted to recruit an equal number of participants per language cluster (monolingual English-speaking, monolingual Spanish-speaking, bilingual in English and Spanish). However, it was difficult to recruit a large sample size with equal groups.
because of a lengthy IRB approval process and time to train staff to administer surveys with parents.

**Study Procedures**

**Sampling Methodology**

I recruited parents using non-probability convenience sampling methods by identifying eligible participants at UCSF Children’s Hospital Oakland (UCSF CHO). Convenience sampling is a nonrandom sampling method that relies on the accessibility of participants, which is valuable when it is not possible to sample an entire population (Etikan et al., 2016; Martinez, 2021). However, this type of sampling method is subject to a greater risk of bias related to the representativeness of the sample concerning the larger population (Etikan et al., 2016). The convenience sampling approach was ideal for this study because the population sample of parents with a child in the healthcare system is vast, making it unrealistic to sample the group in its entirety. Recruiting participants from a local pediatric hospital is a convenient way to recruit a target sample of participants from a larger population (Etikan et al., 2016; Martinez, 2021).

**Identifying, Locating, and Recruiting the Sample**

I recruited parent participants from the pediatric hospital-based hematology-oncology unit at UCSF CHO. I formed relationships with existing medical staff within the hospital system, such as pediatric oncologists and nurse practitioners, which is often a successful approach to hospital recruitment (Hendricks-Ferguson et al., 2013; Yancey et al., 2006). This process was imperative to recruitment for the study because these providers already knew their patients and families and had established trust and a rapport, and they were also helpful in determining if a family should not be approached for research for some reason. These providers also had access to electronic medical record (EMR) systems, such as Epic, which was used to identify eligible
families (Milinovich & Kattan, 2018). For this particular study, I met with Dr. Anurag Agrawal, a pediatric hematologist-oncologist and bone marrow transplant specialist at UCSF Children’s Hospital Oakland, to discuss the study design and possible recruitment strategies. He agreed to allow me to conduct the study within the clinic at the hospital.

I provided Dr. Agrawal with a description of the study, along with general inclusion and exclusion criteria. Due to hospital regulations, I was not able to go into the hospital to administer surveys myself. Instead, I met with Dr. Agrawal on multiple occasions to go over survey administration procedures. We discussed how parents would be approached at the hospital, the use of interpreter services for parents with NELP, procedures for assessing eligibility, strategies for survey administration, and how to field parents’ questions and concerns throughout the survey. Dr. Agrawal shared this information with the Oncology clinical staff (medical assistants and social workers) at UCSF CHO and ensured they understood the study aims and procedures.

**Survey Administration and Data Entry**

Having a child with cancer is stressful for children and families (Rabineau et al., 2008); therefore, parents completed a one-time survey, limiting the amount of stress and burden placed on them to participate in the study and increasing the chances they were willing to engage. Each week, staff in the Oncology department at the hospital met with eligible participants in a private area of the clinic to provide a description of the study and verify eligibility. They then informed eligible parents of their ability to engage in the study, provided an opportunity to ask questions, asked if they wanted to participate, and obtained written informed consent if parents were interested in proceeding.

Forty-two parents were initially approached to complete the survey by hospital staff, with two of these parents declining to participate. Forty total participants completed the self-report
survey at the hospital clinic. After reviewing the eligibility criteria, five participants were ineligible because they did not identify as Latinx or White. A total of 35 remaining parents were deemed eligible and were able to participate in the study.

Once consent was obtained, participants independently completed a physical survey in the clinic in their preferred language (English or Spanish) including parent and family characteristics, preferred language to discuss their child’s care, the perceived race of their provider, presence of translation services offered while interacting with the provider, and the validated measures (the DCS, PedsQL, PC-PTSD-5, and RCOPE-Brief). To accommodate the language capabilities of families in the study, survey administrators used language-aligned surveys, including Spanish-validated measures, for monolingual Spanish-speaking parents. When necessary, on-staff hospital interpreters assisted with the administration of the Spanish surveys. Over the course of recruitment, I met with Dr. Agrawal on two separate occasions in San Francisco to collect the anonymous paper surveys completed at the hospital.

**Data Security**

Informed consent documents were scanned at the hospital and kept in an encrypted folder through a UCSF virtual private network (VPN), which only Dr. Agrawal could access, to ensure confidentiality. To guarantee data were kept safe, all confidential patient information (i.e., name and assigned code) was stored in a password-protected Excel sheet that Dr. Agawal created on a UCSF VPN. This master list of parents was stored at the hospital to keep track of parent participation throughout the study. For data entry, I entered all interview responses directly into Qualtrics, an encrypted data software accessed through the University of San Francisco server. During collection, I only entered the participant ID number into Qualtrics and did not include their names or contact information. For analysis, I downloaded data from Qualtrics onto my
password-protected computer and did not utilize cloud storage. Only the research team (Dr. Agrawal, my committee members, and myself) had access to survey data through the encrypted Qualtrics website. At the end of the study, parents were entered into a raffle to win one of five $50.00 gift cards to recognize them for their time and effort.

Measures

Decisional Conflict Scale

The Decisional Conflict Scale (DCS) was designed for use with adult healthcare consumers that may have uncertainty regarding health-related decisions (O’Connor, 1995). The DCS is used among patients (adults and children) deciding on a treatment or intervention within an inpatient or outpatient healthcare setting (O’Connor, 1995). Furthermore, researchers have used the scale to measure the level of conflict among individuals making decisions for children, such as parents and clinicians (Garvelink et al., 2019).

The DCS is a 16-item measure that uses a 5-point Likert scale (0=Strongly Agree to 4=Strongly Disagree) to assess DC across five theoretical dimensions of DC (O’Connor, 1995). The total scores between the dimensions range from 0 to 100, with higher scores reflecting higher decision conflict (O’Connor, 1995). The five dimensions are uncertainty (e.g., I feel sure about what to choose), feeling uninformed (e.g., I know the risks and benefits of each option available to me), feeling unclear about values (e.g., I am clear about which risks and side effects matter most), feeling unsupported (e.g. I have enough advice to make a choice), and perceptions of the ability to make sound decisions (e.g., I feel I have made an informed choice) (O’Connor, 1995). The total score is determined by adding the points from all 16 questions on the scale, dividing this sum by the total number of questions, and then multiplying the result by 25. Similarly, the subscale scores are calculated by averaging the points for the questions within
each subscale and then multiplying the average by 25. For this dissertation, I only used total DCS scores (sum of all subscales) throughout my analysis plan and did not include individual subscale scores within my analysis. The DCS is validated in Spanish, which was necessary to administer the survey to monolingual Spanish speakers in the study (Garvelink et al., 2019; O'Connor, 1995; Urrutia et al., 2008).

Several measurement properties define the DCS (O'Connor, 1995). In a widely cited study by O’Connor (1995) of 909 individuals deciding to receive an influenza immunization or breast cancer screening, internal consistency was good, with Cronbach’s alphas ranging from 0.78 to 0.92. The DCS revealed adequate construct validity using the known groups approach, which compares scores between two groups known to have different levels of the construct (O'Connor, 1995). The DC construct assumes that individuals who are unsure of or delay their treatment decisions are likely to have higher scores on the DCS. One study compared DCS scores to the level of participant ambivalence to receive an intervention (influenza immunization or breast cancer screening), which showed that more uncertainty was associated with higher DCS scores (demonstrating construct validity of the measure) (O'Connor, 1995). For this study, parents were instructed to consider the most recent treatment decision they had made to answer the questions on this questionnaire.

**Pediatric Quality of Life Inventory- Family Impact Module**

The primary dependent variable for this proposed study was parents’ overall HRQoL, which was measured by the PedsQL Family Impact Module - Parent HRQoL Subscale (PedsQL; Varni et al., 2004). This measure has been validated for use in parents of children with chronic illnesses, such as cancer. The PedsQL is a 36-item survey. Sixteen of these items assess overall family functioning, communication, and worry. The remaining 20 items are used to calculate the
parent’s HRQoL summary score, which was the primary focus of this study. These questions are divided into four domains: Physical (e.g., "I feel tired during the day"), Emotional (e.g., "I feel sad"), Social (e.g., "I feel isolated from others"), and Cognitive (e.g., "It is hard for me to think quickly") (Varni et al., 2004). Each question uses a 5-point response scale (0=Never to 4=Almost Always). Items are reverse scored, with higher scores reflecting better parent HRQoL (Varni et al., 2004). The measure is also validated in Spanish, which was necessary to administer the survey to monolingual Spanish speakers in this study (Ortega et al., 2023).

In a study conducted with 23 parents of children with chronic health conditions, the PedsQL Family Impact Module - Parent HRQoL Subscale’s internal consistency score was high (α=0.96) (Varni et al., 2004). To test for construct validity, Varni et al. (2003) used the known-groups method by comparing scores on the measure between inpatient and outpatient populations. Results showed a large effect size for the parent subscale (d=1.17) between the groups, suggesting it can adequately differentiate varying levels HRQoL (Varni et al., 2004).

**Religious/Spiritual Coping Scale- Brief**

The potential role of religious coping as part of the decision-making process for parents was treated as a potential covariate in analyses because research has shown that religion as a coping mechanism may impact scores on the DCS (Pargament et al., 2011). Particularly, individuals with high religious coping may feel external support from their faith which could lessen the level of DC they have (Hexem et al., 2011; Linnard-Palmer & Kools, 2004; Michelson et al., 2009; O'Connor, 1995) To assess this construct, I used the Brief Religious/ Spiritual Coping (RCOPE) Scale. This tool measures both positive and negative religious coping in individuals (Pargament et al., 2011).
The Brief RCOPE has 14 items, which include two subscales: positive (e.g. I sought God’s love and care) and negative (e.g. I questioned the power of God) religious coping (Pargament et al., 2011). Each question uses a 4-point Likert scale (0=Never to 3=Always). Each subscale is scored and interpreted separately because each assesses opposite aspects of religious coping. Scores are calculated by adding the total points in each subcategory, with a total of 28 possible in each section (Pargament et al., 2011).

High internal consistency for the Brief RCOPE has been demonstrated for positive coping ($a=0.92$) and negative coping ($a=0.81$) (Pargament et al., 2011). Concurrent validity has also been demonstrated, with the positive coping subscale correlating with measures of positive psychological functioning like post-traumatic growth ($r = .37$) and the negative subscale correlating with measures of poor psychological well-being like negative affect ($r = .61$) (Harris et al, 2008; Van Dyke et al., 2009). Furthermore, predictive validity has been demonstrated for both the positive and negative subscales, with each predicting good mental health and poor adjustment, respectively (Pargament et al., 2011). Adequate reliability has also been demonstrated for the Spanish version (Garcia et al., 2021).

**Primary Care PTSD Screen for DSM-5 (PC-PTSD-5)**

Trauma symptoms among parents may contribute to their reports of HRQoL (Kazak et al., 2005). For this reason, I used the Primary Care PTSD Screen for DSM-5 (PC-PTSD-5) measure as a covariate in the study because of the potential impact of parental trauma on their HRQoL. This measure consists of 5 questions with dichotomous yes or no answer choices (e.g. Had nightmares about your child's diagnosis when you did not want to); each “yes” response is assigned a value of 1, and respondents can get up to a maximum score of 5 (Prins et al., 2016). Generally, a cutoff of 3 out of 5 positive responses is indicative of PTSD. For this study, I treated
the total scores on the PC-PTSD-5 as a continuous variable (with higher scores denoting more trauma) to view possible effects on my primary regression model between DCS and PedsQL scores.

Previous versions of the PC-PTSD-5 demonstrate good test-retest reliability \((r=0.83)\) and predictive validity toward clinician-administered PTSD screenings (Prins et al., 2016). The current version of the measure is identical, but it has an additional question relating to guilt and blame (Prins et al., 2016). This version showed excellent accuracy in diagnosing PTSD in medical settings \((AUC = 0.941; 95\% \text{ C.I.: } 0.912–0.969)\). For this measure, I adapted the instructions to relate to the parent’s experiences after receiving their child’s diagnosis. Furthermore, I translated the brief scale into Spanish for monolingual Spanish-speaking parents in the study because a Spanish version was not available.

**Demographic Data**

Demographic information was collected via a questionnaire in the survey (Appendix B). The information collected for this study consisted of: the race and ethnicity of the parent (Latinx or non-Hispanic White), age of the parent and child, gender of the parent and child (male, female, or nonbinary), working status of the parent (working, disabled, student, other), marital status of the parent (single, married, or divorced), annual income of the parent ($25,000 or less, 25,001 to 50,000, 50,001 or more), highest educational attainment of the parent (some high school or less, GED, high school degree, some college, college graduate, vocational school, graduate degree), years living in the United States, comfort level speaking in English (not at all, somewhat, quite a bit, complete comfort), the presence and frequency of translation services during treatment discussions throughout their child’s care (not at all, sometimes, most of the time, or every time), parent perceptions of the race and ethnicity of their child’s provider (White,
Hispanic/Latinx, Black or African American, Asian, Native American or Alaska Native, two or more races, other, or prefer not to respond), trust in provider (scale of 1 to 4, with 1 being no trust at all and 4 being complete trust), the stage of cancer of the child (1 to 4), type of cancer of the child (e.g., leukemia), time since the child was diagnosed (months), the level of support the child needs to conduct daily living activities compared to their peers (a little support or a lot of support), and an open-ended question about the most recent healthcare-related decision the parent made on behalf of their child.

Data Cleaning and Analytic Plan

All data for this study were entered into Qualtrics software and then downloaded as an SPSS file for analysis. These files were then uploaded onto Jamovi software, v. 2.3.21.0 (The Jamovi Project [TJP], 2022). All analyses for this study occurred on the Jamovi statistical platform.

Univariate Analysis of Primary Study Variables

I conducted a univariate descriptive analysis of the primary study variables (total DCS, total PedsQL, positive and negative religious coping subscales on briefs RCOPE, and total PC-PTSD-5) to inform the distribution of scores among the sample. I viewed data distributions (e.g. means, medians, and standard deviations) between language groups and of the overall sample. This analysis assisted in identifying potential group differences that may have impacted the results of the primary regression analysis between the DCS and PedsQL scores.

Bivariate Correlations

I used Jamovi statistical software to conduct bivariate correlations to explore relationships between the primary independent and dependent variables and covariates in the study (TJP, 2022; Field, 2018). For this analysis, I included: total Parental DCS scores, total
PedsQL scores, total positive and negative religious coping scores from the Brief RCOPE, and total trauma scores from the PC-PTSD-5. I also conducted correlations between all demographic variables and with primary study measures to examine general trends and to determine whether significant correlations were aligned with the expected directions. This matrix provided insights into the associations between these variables before further analysis. Pearson correlation coefficients (r-values) were computed to assess the strength and direction of linear relationships between pairs of variables, with higher r-values denoting stronger correlations and negative values suggesting inverse relationships (Field, 2018). Statistical significance was determined using a significance level of $p < 0.05$. I used the results to identify significant correlations and assess the magnitude (minimum Pearson’s r effect size = 0.20) and direction of associations to inform further regression analyses (Field, 2018).

**Associations Between DCS and PedsQL**

To evaluate the association between healthcare-related DC and HRQoL among parents with children undergoing cancer treatment in the hospital setting, I conducted a linear regression model. For this analysis, the total DCS score served as the independent variable, and the total PedsQL Family Impact Module-Parent HRQoL Summary score served as the dependent variable. The model also showed whether the independent variable (total DCS score) predicted the dependent variable (total PedsQL score), using a p-value of $< 0.05$ (Field, 2018). Beta values demonstrated how much the dependent variable changed for every one unit of change in the predictor variable within the model.

In this analysis, I tested parents’ religious coping and trauma symptoms as potential covariates because of their possible effect on total DCS and PedsQL scores in the regression. To control for religiosity, I used the positive and negative religious coping subscale scores of the
Brief RCOPE (Hexem et al., 2011). To determine if it was necessary to control for the possible effects of trauma on parents’ HRQoL, I used the PC-PTSD-5 questionnaire total scale score (Prins et al., 2016). Before running the primary regression analysis, I included total scores from each covariate into the model with total PedsQL scores. Running these analyses allowed me to view potential significant associations of the covariates on the overall model, denoted by a p-value of less than .05 (Field, 2018). Non-significant covariates were not included in the primary analysis between total DCS and PedsQL Scores.

**Mean Differences in Total DCS and PedsQL Scores Among Language Groups**

Two separate one-way analyses of variance (ANOVA) were conducted to assess statistically significant mean differences ($p < 0.05$) in DCS and PedsQL total scores among the three participant groups (15 monolingual English speakers, 11 monolingual Spanish speakers, and 8 bilingual speakers). Due to varying sample sizes between groups, I also conducted a Levene’s test that confirmed equal variances between groups ($p > 0.05$), which suggested that an ANOVA was an appropriate analysis. If the ANOVA yielded a significant mean difference between one or more language groups, a post-hoc Tukey’s test would be conducted to identify specific pairwise differences between groups. These analyses assisted in identifying notable differences in DC and HRQoL among parents with different language classifications.

**Parent’s Feedback for Hospital Staff**

At the end of the survey, parents were asked how their experiences interacting with the hospital could have been made better. This question aimed to provide the hospital staff with actionable suggestions from the parents about ways to improve their child’s care, though it was not part of the main study. I used a simple content analysis approach in order to categorize and make meaning of participant responses (Harwood & Garry, 2003). With this analysis, I grouped
parent responses into basic themes related to their experiences within the hospital. I then counted and reported the total number of participants who aligned with each theme (Harwood & Garry, 2003).
Chapter IV: Results

Demographic Data

Demographic data were collected from 35 eligible participants who completed the survey measures. Some parents omitted responses from certain demographic questions, which I denoted as “Not Reported” throughout this section to keep the total n at 35. As shown in Table 1, the mean age of the parents caring for children receiving treatment for a cancer diagnosis was 38 years (range = 21-54 years; SD = 8.1). Over half of the participants identified as Latinx (n=25, 71.4%) compared to White (n=10, 28.6%). Nineteen parents (44.3%) were born in the United States, and the next largest demographic group was from Mexico (n=7, 20.0%). Among the sample, 15 (42.9%) of the parents were monolingual English speakers, 11 (31.4%) identified as monolingual Spanish Speakers, eight (22.9%) were bilingual in English and Spanish, and one (2.9%) did not provide their language abilities.

The mean age of children with cancer receiving treatment was 9.7 years (range=1-17 years; SD = 5.7), and most of these children were female (n=18, 51.4%). The parents reported their children to have a range of diagnostic etiologies, the most common general forms of cancer being leukemias (n=20, 57.1%) and lymphomas (n=7, 20.0%). The mean length of time since the child’s initial diagnosis was 5.9 months (range = 1-14 months; SD = 3.8).

Univariate Analysis

Table 2 details a univariate descriptive analysis of mean scores across primary measures in this study (total DCS scores, total PedsQL scores, positive and negative subscales on the Brief RCOPE, and total PC-PTSD-5 scores). In addition to total scores, the mean and standard deviations of the variables were also calculated for each language group in the study. Overall, parents reported relatively low levels of DC (M = 14.3, SD = 12.7) and mid-range HRQoL (M =
64.0, SD = 15.2), with moderate utilization of positive religious coping (M = 1.91, SD = 1.06) and lower levels of negative religious coping (M = 0.27, SD = 0.42). While the overall mean score on the PC-PTSD-5 was below the clinical threshold (M = 1.71; SD = 1.49), 12 out of 35 participants (34.29%) endorsed three or more of the five trauma symptoms on the questionnaire, meeting the threshold for clinical significance commonly used in professional settings. Of the parents with clinical levels of PTSD symptoms, all 12 (100%) were mothers, seven (58.83%) had an annual household income of less than $50,001, and 11 (91.67%) identified as Latinx. Notably, monolingual Spanish-speaking individuals had the highest mean positive religious coping scores on the Brief RCOPE (M = 2.74, SD = 0.43) and trauma scores on the PC-PTSD-5 questionnaire (M = 2.55, SD = 1.21), but similar scores on the DCS (M = 12.3, SD = 12.1) and PedsQL (M = 64.4, SD = 17.0) compared to other language groups. Mean differences across language groups for DCS and PedsQL scores are further discussed in the analyses of variance (ANOVA) section below.

**Bivariate Correlations**

There was a moderate negative correlation between DC and parental HRQoL while caring for their child (r = -0.37; p<0.05), indicating that higher total Decisional Conflict Scale (DCS) scores were associated with lower total HRQoL scores on the PedsQL Family Impact Module (Table 3). Higher scores on the negative religious coping subscale of the Brief RCOPE were significantly correlated with overall trauma scores on the PC-PTSD-5 questionnaire (r = 0.49; p<0.01), indicating that parents with maladaptive religious coping beliefs were more likely to report trauma symptoms while caring for their children or vice versa. Because over 1/3 of the sample (12/35 parents) had clinical levels of PTSD symptoms, and there was a strong positive correlation between the Brief RCOPE negative religious coping subscale and the PC-PTSD-5
total score, I ran a simple regression to determine if there was a significant predictive relationship between the two constructs. I chose to look at negative coping as the independent variable because research shows that negative coping styles can moderate the presence and severity of trauma symptoms for individuals (Gerber et al., 2011; Zukerman & Korn, 2014). I found that greater negative religious coping was a statistically significant predictor of more trauma symptoms in parents ($p < 0.01; B = 0.14$), with the model explaining 24% of the variance ($R^2=0.24, F(1,33) = 10.6$).

In addition to the primary study variables, I also inputted continuous and ordinal demographic data into the correlation matrix to assess trends for further analysis and ensure the correlations were aligned with expected directions. There was a statistically significant positive correlation between the age of parents and the number of children ($r = 0.70; p < 0.01$). As expected, there was an inverse correlation between comfort in speaking English and the frequency of translation services offered ($r = 0.63; p < 0.01$). Furthermore, positive religious coping and comfortability speaking in English were negatively significantly associated ($r = -0.53, p < 0.01$). Somewhat unexpectedly, no participant characteristics were significantly correlated with the primary study measures (DCS and PedsQL total scores); therefore, I did not include them in subsequent analyses.

**Regression Between Decisional Conflict and Parental Quality of Life**

The results of the linear regression analysis between total DCS and PedsQL scores indicated that the model explained 14.0% of the variance ($R^2 = 0.14, F(1,33) = 5.22, p < 0.05$) (Table 4). These findings suggest that greater DC is a statistically significant predictor of lower HRQoL among parents with children undergoing treatment for a cancer diagnosis ($B = -0.31, p < 0.05$). Total scores on the PC-PTSD-5 questionnaire and the positive and negative religious
coping subscale scores on the Brief RCOPE were included as covariates before the analysis to assess possible effects on HRQoL. However, none of these variables were found to be significant predictors of total PedsQL scores ($p > 0.05$) and were thus excluded from further analysis.

**ANOVA: Decisional Conflict Among Language Groups**

As seen in Table 5 there were no significant mean differences between the three language groups regarding the overall total score for the Decisional Conflict Scale, so the null hypothesis was accepted ($F(2, 17.2) = 0.21, p > 0.05$).

**ANOVA: Quality of Life Among Language Groups**

As seen in Table 6, there were no significant mean differences between the three language groups in this study regarding the overall total score for the PedsQL measure, so the null hypothesis was accepted ($F(2, 16.2) = 0.18, p > 0.05$).

**Parent Feedback for Hospital**

Parents were asked to provide suggestions regarding any changes the hospital staff could make to improve their experiences while caring for their children. Twenty-four parents (69%) responded to the question at the end of the survey. Eighteen of these parents (75%) had positive experiences with the hospital and did not have any additional suggestions. For example, one parent stated, “No suggestions. They have been attentive, and I have no complaints,” and another responded, “Everything is good. They pay good medical attention.” Other parents said they would like more in-depth explanations of the current health statuses of their children ($n=2$; e.g., “They could explain a little bit more about the health of our daughter.”), more mental health services for parents ($n=1$; e.g., “There could be more mental health services for parents/caregivers.”), more in-person translation services ($n=1$; e.g., “There could be more in-person translators available.”), better organization during hospital admittance ($n=1$; e.g., “On days they
were admitted for hospital stays, I wish the coordination of being admitted was more organized.”), and more consideration of the child as a whole (n=1; e.g., “Maybe more consideration of the whole child.”).
Chapter V: Discussion

The purpose of this study was to examine the association between DC and HRQoL among parents caring for a child receiving treatment for a cancer diagnosis. Furthermore, the study sought to determine whether there were differences in DC and HRQoL among three participant groups based on language: monolingual Spanish speakers, bilingual English and Spanish speakers, and monolingual Spanish speakers. The purpose of this analysis was to assess whether the experiences of parents with non-English language preference (NELP) were significantly different from those who speak English fluently within health care systems and specifically while caring for children with cancer.

Research Implications

Association Between Decisional Conflict and Health-Related Quality of Life

The primary aim of this dissertation was to understand the relationship between DC and HRQoL among parents caring for a child receiving treatment for a cancer diagnosis. All parents in this study identified as either Latinx or White and had varying language abilities in English and Spanish. I expected that higher decisional conflict regarding treatment for their child would be associated with a lower parental HRQoL. The findings from the regression analysis were consistent with the primary hypothesis, with higher levels of DC predicting lower HRQoL among all three parent groups. These findings remained true even after controlling for presence of trauma symptoms, and religious coping skills (positive and negative) among the parents.

It is well established in the literature that caring for a chronically ill child can lead to increases in DC (Knapp et al., 2010; O'Connor, 1995) and negatively impact parental HRQoL (Klassen et al., 2011; Litzelman et al., 2011; Santo et al., 2011). Results from the current study align with the conflict theory model of decision-making, which asserts that individuals
experience DC when they must weigh the various benefits and drawbacks of a particular decision (Mann & Janis, 1982). Adding to this model, the Ottawa decision support framework asserts that each individual has unique factors, such as cultural values and socioeconomic status, that contribute to their ability to make a decision (O’Connor et al., 2011). The concept of DC, based on these frameworks, is common among diverse parents with children with cancer who must constantly consider the health and long-term prognosis of their child when making decisions (Knapp et al., 2010; Mann & Janis, 1982). However, to date, few studies directly assess the association between DC and HRQoL. The results from this study are aligned with previous research suggesting that higher DC can negatively impact the post-decisional HRQoL of an individual (Kate, 2018; O’Connor, 2010; Zhuang et al., 2022). Existing literature focuses on the relationship of DC with HRQoL for individuals, but only one other study explored this relationship among people making decisions for others, such as parents making decisions for their children (Hickman et al., 2012; October et al., 2020). Specifically, October et al. (2020) conducted a longitudinal study that suggested that parents making difficult decisions about their child’s tracheostomy had decreasing HRQoL scores from 2 weeks to 3 months post-decision. However, their study did not directly assess the association between DC and HRQoL using a statistical analysis but rather used the parent’s lengthy decision-making process to contextualize decreases in HRQoL scores over time (October et al., 2020). The current study found similar results using a cross-sectional regression model, directly demonstrating that higher DC among parents making decisions for their children is inversely associated with their HRQoL while caring for a child with cancer.

A possible explanation for the association between DC and HRQoL is the increased levels of stress that come from having a child with cancer and how constant decision-making can
exacerbate this stress (Knapp et al., 2014). Different cancer treatments have different effects on children’s physical and emotional well-being (Arslan et al., 2013; Hockenberry-Eaton et al., 1995). Having to constantly consider these consequences while making decisions for another individual can also negatively impact the physical and emotional well-being of parents (Arslan et al., 2013), which may lead to increased stress and decreased HRQoL during the decision-making process (Litzelman et al., 201; Santo et al., 2011). Furthermore, many families caring for children with cancer may become overwhelmed and isolated due to their child’s treatments and constant decision-making, which may worsen social domains of HRQoL, such as quality of social interactions (Litzelman et al., 2011; Santo et al., 2011).

It is also significant to note that religious coping and trauma symptoms were not significant predictors in the regression model between the DCS and PedsQL, which affirms my initial hypothesis. Previous research suggests that certain individuals will utilize religion to cope when making stressful decisions, which may help to improve their HRQoL while caring for their child with cancer (Hexem et al., 2011). Conversely, some individuals feel castigated or abandoned by God because of their child’s illness (Hexem et al., 2011). Negative religious beliefs could have left parents in this sample feeling less supported while making treatment decisions, which could have negatively impacted their HRQoL (Hexem et al., 2011; Linnard-Palmer & Kools, 2004; Michelson et al., 2009). Although negative religious coping was not a significant predictor of HRQoL in this sample, it did significantly predict a greater number of trauma symptoms among the parents. These findings were shared by Gerber et al. (2011), who found that negative religious coping was a significant predictor of trauma among undergraduate students at a university in the Southwest United States. Similarly, a study viewing religiosity as a possible moderating factor for trauma symptoms among undergraduate students in Israel found
that negative religious coping was significantly associated with negative world assumptions and avoidance symptoms for participants (Zukerman & Korn, 2014). This relationship may be evident within the present sample because the parents were unable to justify their child’s life-threatening diagnosis as a blessing or part of their God’s plan. Instead, they may have resorted to avoidance, self-blame, and feelings of abandonment, which are maladaptive coping mechanisms consistent with the trauma symptoms reported by the parents in the survey. It is notable that among the parents in the sample, 12 of 35 met the criteria for PTSD, which could have negatively impacted their HRQoL while caring for their child (Kazak et al., 2005; Tremolada et al., 2011). However, total scores on the positive and negative subscales of the Brief RCOPE and total PC-PTSD-5 scores were not significantly associated with lower PedsQL scores for parents. For this reason, these covariates were not included in the final analysis. It is possible that religious coping and trauma were not significant contributors to the regression analysis because of the small overall sample size, which reduced the power of the model (Field, 2018).

**Differences in Decisional Conflict Among Language Groups**

An additional research question in this study aimed to examine differences in the level of DC among three language groups (monolingual English, bilingual, and monolingual Spanish). Results from an ANOVA did not yield significant differences between language groups. These findings are not consistent with my hypothesis that Spanish-speaking parents would have higher levels of DC compared to those with higher levels of English proficiency.

The results from this analysis differ from existing literature (Gulati et al., 2012; Knapp et al., 2014; Simon et al., 2003; Zamora et al., 2016), which has established notable differences in DC between parents with varying language abilities. Specifically, parents with NELP and poorer health literacy have been shown to have more uncertainty and less confidence in the decisions
they make for their children (Forner, 2020; Knapp et al., 2014). However, participants in all groups within the current study reported nearly identical mean scores on the DCS. A possible explanation of inconsistencies in this finding from other research is that this study had a smaller sample size due to delays in recruitment, whereas similar studies assessing DC in Spanish speakers had over 100 participants, and likely had greater variability in their sample (Knapp et al., 2014; Simon et al., 2003). Furthermore, some parents in other studies did not receive consistent or adequate translation services throughout their child’s care (Gulati et al., 2012; Simon et al., 2003), which may have contributed to group differences in DC. Conversely, all the parents in this study were provided translation services during their child’s treatment, which may explain why all language groups reported similar DC. Research shows that the frequency of interpreters and quality of translation services are integral to families with NELP’s understanding of their child’s diagnosis (Cohen et al., 2005; Flower et al., 2021). In their study on interpreter use for families in a PICU at a tertiary hospital in the United States, Zurca et al. (2017) found that only 53% of Spanish-speaking families had access to interpreters “most of the time” during interactions with physicians. Additionally, 14% of families reported having access to these services “rarely or never.” Similarly, Schenker et al. (2011) reported that only 43% of Chinese and Spanish-speaking patients with NELP at two hospitals in the Bay Area were asked if they needed interpreters since their admission. Anne Fadiman’s book, *The Spirit Catches You and You Fall*, illustrates the repercussions of inadequate interpretation services and healthcare providers’ neglect in incorporating cultural nuances into parents’ understanding of their child's medical decisions (Fadiman, 1999). The author describes the progression of a child's epilepsy which results in brain death brain death, highlighting the consequences of failing to involve interpreters during treatment to facilitate culturally informed collaboration with the child's parents. This lack
of cultural and linguistic consideration diminished the parents' trust in the providers and impacted their adherence to medical advice throughout the treatment process (Fadiman, 1999). The services offered at UCSF Children’s Hospital Oakland (UCSF CHO) starkly contrasted these accounts, with all monolingual Spanish-speaking parents within this study’s sample reporting having access to quality translation services throughout their decision-making process most of the time (53.8%) or every time (46.2%). The quality of services and notable attention to the language abilities of the parents within the oncology department at UCSF CHO may have been a factor in the lower DC found among the bilingual and monolingual Spanish-speaking language groups in this study; although, additional examination would be necessary to provide a more definitive explanation.

**Differences in Health-Related Quality of Life Among Language Groups**

I also examined whether there were differences between the three language groups (monolingual English, bilingual English-Spanish, and monolingual Spanish) on their total HRQoL scores. Results suggested there were no significant mean differences in total HRQoL scores by language ability. These findings are not consistent with my hypothesis that Spanish-speaking parents would have lower HRQoL scores compared to those with higher levels of English proficiency while caring for a child with a cancer diagnosis.

The results from this analysis also differ from the existing literature demonstrating differences in HRQoL based on parental English language proficiency. Previous research has reported lower HRQoL scores among parents with NELP due to various factors (Landolt et al., 2011; Lawoko & Soares, 2003; Wahi et al., 2016). Families with NELP often have more difficulties navigating health systems within the United States due to lower levels of health literacy in English (Held et al., 2020; Velasco-Mondragon et al., 2016). For this reason, many of
these families experience higher levels of anxiety while interacting with hospital systems, which negatively impacts their HRQoL while caring for their children (Wahi et al., 2016). Furthermore, many families with NELP may have less trust in their providers due to language barriers (Eiser et al., 2005; Tremolada et al., 2011) and limited translation services (Schenker et al., 2011; Zurca et al., 2017). This lack of confidence and trust may exacerbate levels of anxiety and further diminish their quality of life (Eiser et al., 2005; Tremolada et al., 2011; Wahi et al., 2016). It is possible that parents with NELP in this study did not report notably lower levels of HRQoL because of the quality of care their children were receiving at the hospital. Specifically, most parents reported having “complete trust” (60.6%) or a “fair amount of trust” (30.3%) in their provider. This, in addition to the high frequency at which translation services were provided at CHO, may have reduced the amount of anxiety these parents felt while interacting with the hospital.

Existing research also suggests Latinx individuals with NELP may have lower levels of HRQoL because this group often has lower socioeconomic status compared to White populations with English proficiency in the United States (Morales et al., 2002). Factors associated with poorer socioeconomic status, such as lower annual income and food insecurity, can negatively impact the HRQoL of individuals across physical, social, and emotional domains (Gany et al., 2015). However, I did not find the same disparities in annual income among parents in the three participant groups for this study. Among the parents in the sample, the mean annual household income of each of the three language groups was between $25,001 to $50,000, with no notable differences between them. The lack of significant economic disparities among the families who completed the survey may further explain why there were no significant differences in HRQoL across language groups.
Clinical Implications

The presence of DC among families caring for chronically ill children is well-established in the literature (Knapp et al., 2010; O'Connor, 1995). Higher levels of DC can negatively impact the HRQoL of individuals (Klassen et al., 2011; Litzelman et al., 2011; Santo et al., 2011), including parents caring for children with cancer. This was a key finding among participants in the current study as well. I found an inverse association between DC and HRQoL for parents regardless of their language abilities while interacting with their care team at the hospital. These findings are relevant to medical providers because increased levels of uncertainty and lower HRQoL can negatively impact the extent to which parents engage in their child’s treatment (De Silva et al., 2020; Knapp et al., 2014) and can create greater reliance on providers to make decisions without considering input from parents (Janicke et al., 2001) or the potential consequences these unilateral decisions may have in children with cancer and their families. To mitigate some of these consequences, funding for further resources to diminish DC among parents caring for chronically ill children could be beneficial. One possible strategy could be the increased use of decisional aids within hospital systems to help decrease the amount of uncertainty parents may feel about their treatment decisions and increase overall confidence post-decision. Parents may have varying abilities to understand informational material presented to them based on their level of English proficiency, literacy, and educational attainment. An example of these aids is visual descriptions of treatment options utilizing graphics to bolster comprehension (Klassen et al., 2011; Litzelman et al., 2011; Santo et al., 2011). Providers can create informational material of different lexical levels in the parent’s preferred language to make these materials more accessible for parents with varying reading abilities and health literacy.
In addition to providing decisional aids and modifying existing materials for parents, medical staff can also track parental DC throughout their child’s treatment using the DCS periodically throughout their child’s treatment. The DCS provides valuable information on five domains relating to DC: Uncertainty, feeling uninformed, feeling unclear about values, feeling unsupported, and perceptions of the ability to make sound decisions (O'Connor, 1995). Using this, or similar tools, can help staff identify parents who are experiencing the highest levels of conflict and provide further consultation or check-ins around their child’s care. Specifically, providers can use shared decision-making strategies to collaborate with the child’s parent around treatments and provide them with evidence and efficacy of the different options (Elwyn et al., 2012). Shared decision-making is a proven method to help mitigate DC in parents and improve overall satisfaction with their decisions (Elwyn et al., 2012; Mack et al., 2016).

In addition to using the DCS, providers can use the PedsQL-Family Impact Module to measure parents’ levels of HRQoL at different points in their child’s care. Experiencing a child going through treatment for cancer can cause immense levels of stress for parents, which can negatively impact their well-being (Arslan et al., 2013; Hockenberry-Eaton et al., 1995). Similar to tracking DC, this technique could provide physicians with more specific information about which parents are experiencing the greatest emotional, physical, social, and cognitive distress throughout their child’s treatment (Arslan et al., 2013; Varni et al., 2004). Providers could use this information when making decisions about referring to existing mental health clinicians (e.g., psychologists, social workers) to deliver targeted interventions to these parents. These clinicians are trained to provide parents with coping strategies and to provide emotional support to with the goal of reducing stress and improving their HRQoL while caring for their child with cancer.
Limitations

There are a few notable limitations. First, having a smaller sample reduced the overall power of the primary regression analysis, which could explain why the covariates in the regression (Brief Rcope and PC-PTSD-5) did not significantly influence the model (Field, 2018) despite them being correlated with each other. Also, having a smaller sample size made it difficult to recruit equal numbers of participants across the three groups based on language abilities for comparison analyses. When conducting statistical analyses, it is often important to have roughly equal numbers of participants in each group because it helps to ensure that the characteristics of all the participants are adequately represented in the results, which helps to increase the reliability of the findings (Field, 2018). Having similar group sizes also improves the statistical power of the analysis, which can increase the chances of detecting true significant differences between groups in the study (Field, 2018). In addition to having a low sample size, the study data were all collected from one hospital, which reduces the external validity of the study findings. Factors like geographic location, accessibility of resources, diversity of staff, and use of interpreters may differ between hospital settings and can influence the quality of care that families receive. If I had been able to collect a larger sample size and extend recruitment, the study would have had more power to detect differences across groups based on language.

Despite evidence of significant associations between DC and HRQoL, the study had a relatively small sample size for a cross-sectional design, which could have resulted in random error and variability, affecting the reliability of the study results (Thiese et al., 2016).

Another notable limitation of this study related to the administration procedures at the hospital. Due to hospital policy and procedures, I was not permitted to physically go to the clinic at UCSF Children’s Hospital Oakland to administer the surveys myself. Instead, hospital staff,
mostly medical assistants, provided the surveys to the parents under Dr. Agrawal’s supervision. As a result, I was not able to field parents’ questions or conduct recruitment procedures in Spanish. Furthermore, parents’ response styles may have differed because the medical staff was administering the survey (i.e., there may have been a tendency to respond more favorably about the hospital experience if the parents thought that the hospital staff would be reviewing their responses). This is significant because many of the questions on the surveys addressed experiences with the hospital throughout their child’s treatment. It is possible that parents were reluctant to report negative or critical experiences for fear of offending their child’s oncology team or impacting their child’s care. I might have mitigated this limitation by conducting the study outside of the hospital, possibly over the phone. Collecting data in this manner could have helped parents feel more comfortable by reducing their association of the study with the hospital. Additionally, it would have allowed me more time to reassure them that their responses would remain confidential and their identities would not be shared with the care team.

**Suggestions for Future Research**

This study highlighted important findings relating to parent experiences while caring for a chronically ill child, which provides insight into future directions for research. As discussed, this study was only conducted at one site in the Bay Area. Future studies assessing parental DC and HRQoL, especially as they relate to language abilities, should be conducted at various geographic locations. It would be interesting to compare data relating to DC and HRQoL among parents with NELP in settings with varying levels of diversity, urbanization, and socioeconomic status. Collecting data from multiple sites would enhance the generalizability of the results and offer further opportunities to compare parents’ experiences in different hospital settings.
Further research is also needed to assess the association between DC and HRQoL, especially among parents with children with cancer. To date, only one other study has directly assessed this association with parents making decisions for their child’s tracheotomy (October et al., 2020). However, parents caring for children with cancer and other chronic illnesses often make various treatment decisions throughout the length of their child’s illness. It could be beneficial to conduct studies to assess differences in DC and HRQoL between different treatment decisions (surgery vs. chemotherapy). In a future study with a greater number of participants, one could also analyze the specific domains of HRQoL that are most impacted by higher DC among parents. This information would allow hospitals to allocate more impactful resources to parents during their child’s treatment. Researchers could also assess changes in DC and HRQoL longitudinally throughout their child’s treatment progression. Findings from these studies may help clinicians to identify parents at higher risk for experiencing DC, so they can provide quicker and more targeted interventions to mitigate its effects on their HRQoL. In this study, a greater number of mothers participated in this study compared to fathers, but I did not find any significant differences in DC based on the gender of the parent. Future investigations that include a sample comprised of parents with NELP could consider recruiting an equal number of mothers and fathers to assess whether and how the gender role of caregivers may contribute to differences in the amount of DC parents experience while making decisions for their children. In many cultures, fathers are often seen as the primary decision-makers; however, this responsibility may not be as evident when it comes to healthcare decisions for their children (Raffaelli & Onta, 2004). These studies could also include more formal measures of parental trust in their child’s provider to gain more detailed data on how this factor may impact decision-making and whether there are any differences based on the gender of the parent.
I also found that negative religious coping was a significant predictor of trauma symptoms among parents, but my sample size was too small to run more in-depth analyses. Future studies with larger sample sizes can look at potential moderating factors that impact this relationship between negative religious coping and trauma (e.g. SES, gender, ethnicity). Providing hospitals with more detailed information about the impact of negative religious coping and trauma on parents’ experiences during their child’s treatment, especially when making difficult decisions, may help providers utilize more mental health and spiritual resources for this population. This approach could prevent decreases in their HRQoL while their child is sick. Furthermore, because 12 of the 35 participants had clinically elevated PTSD symptoms, researchers could examine additional demographic characteristics that contribute to parental trauma to better inform clinical decisions. For instance, they could identify the percentage of Spanish-speaking participants who are immigrants or undocumented, which would help inform interventions for parents experiencing trauma beyond focusing solely on their child’s cancer diagnosis.

In addition to quantitative research, future investigators could implement qualitative methods to learn more about the specific experiences of parents in a less structured and intimidating way. This approach may help to add additional context to existing quantitative studies and provide these parents with a voice to fully discuss their experiences while caring for their child, which may also help to inform directions for future quantitative studies. A qualitative interview format may be especially helpful to parents with NELP who often have less trust in the medical system (Eiser et al., 2005; Tremolada et al., 2011). Using a more intimate interview format and recruiting researchers who can speak languages other than English could help these
families better explain their experiences in their native language, enhancing the accuracy and richness of the findings.

**Conclusion**

To date, there is limited research assessing the impacts that decision-making can have on the experiences of parents caring for a chronically ill child. Even fewer studies have been conducted looking at the unique experiences of Latinx families with NELP navigating treatment decisions within healthcare settings. Through this study, I aimed to elucidate whether there was a significant association between a parent’s DC and HRQoL while making treatment decisions for their child with cancer. Furthermore, I wanted to see if there were significant differences between DC and HRQoL based on the language abilities of the White and Latinx parents. Present findings suggest a significant association between DC and HRQoL among all participants in the sample, regardless of their language abilities. However, no significant differences were found in mean scores for either variable between languages.

Although this study has limitations relating to sample size and administration procedures, the results still have important clinical and research implications. To reduce parental DC and its effects on their HRQoL, hospitals can provide more decisional aids, track parental DC throughout their child’s treatment, and adapt existing materials to match parents’ language and educational abilities. The results from this study also highlight the need for more research assessing DC and HRQoL among parents across various settings with diverse demographic profiles to better generalize the results. Furthermore, researchers can try to identify differences in DC and HRQoL among different types of treatment decisions and at different time points in their child’s illness, including advanced cancer. These strategies will help to improve the experiences
of parents during their child’s illness and may improve the overall quality of care their child receives.
References


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[https://doi.org/10.1080/00332747.2017.1324697](https://doi.org/10.1080/00332747.2017.1324697)


DC AND HRQOL FOR PARENTS

https://doi.org/10.1016/j.anpede.2022.10.007

https://doi.org/10.3390/rel2010051


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Thiese, M. S., Ronna, B., & Ott, U. (2016). P value interpretations and considerations. *Journal of Thoracic Disease, 8*(9), E928. 10.21037/jtd.2016.08.16

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https://doi.org/10.1016/j.ejca.2011.04.038


https://doi.org/10.1038/s41372-019-0403-0


Tables and Figures

Table 1

*Sample Demographics (N=35)*

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<th>Mean</th>
<th>Standard Deviation</th>
<th>Frequency</th>
<th>Percentage (%)</th>
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<td>-</td>
</tr>
<tr>
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<td>5.7</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>Number of Children</td>
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<td>-</td>
<td>-</td>
</tr>
<tr>
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<td>-</td>
</tr>
<tr>
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<td></td>
<td></td>
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<tr>
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<td>5</td>
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<td></td>
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<td>Yes</td>
<td>-</td>
<td>-</td>
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<td>71.4</td>
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<td>54.3</td>
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<td>-</td>
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### Demographic

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<th>Frequency</th>
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<td>Peru</td>
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<td>-</td>
<td>1</td>
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<td>El Salvador</td>
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### Language Abilities

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<td>English Only</td>
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<tr>
<td>Bilingual</td>
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<td>22.9</td>
</tr>
<tr>
<td>Spanish Only</td>
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### Time in the US

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<td>Born in the US</td>
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<td>51.4</td>
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<td>1-5 Years</td>
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<td>8.6</td>
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<tr>
<td>6-10 Years</td>
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<td>2</td>
<td>5.7</td>
</tr>
<tr>
<td>11-15 Years</td>
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<tr>
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<td>-</td>
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<td>2.9</td>
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### Martial Status

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<td>Divorced</td>
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<td>31.4</td>
</tr>
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<td>2.9</td>
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### Employment Status

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<td>Working</td>
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<td>42.9</td>
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<td>Demographic</td>
<td>Mean</td>
<td>Standard Deviation</td>
<td>Frequency</td>
<td>Percentage (%)</td>
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<tr>
<td>----------------------</td>
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<tr>
<td><strong>Employment Status</strong></td>
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<td>Disabled</td>
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<tr>
<td><strong>Education Attainment</strong></td>
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<td>GED</td>
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<tr>
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<td>17.1</td>
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<td>College Grad</td>
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<td>8.6</td>
</tr>
<tr>
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<td>$25,000 or Less</td>
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<td>$50,001 to $100,000</td>
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<td>14.3</td>
</tr>
</tbody>
</table>

*Note:* A right indent is used to demonstrate subcategories. A total N of 35 was used for this analysis, including responses omitted by parents referred to as “Not Reported”. For employment status, participants only reported “other” who were housewives.
Table 2

**Total Sample and Language Group Mean Differences on Primary Study Variables (N=35)**

<table>
<thead>
<tr>
<th></th>
<th>Total M(SD)</th>
<th>English M(SD)</th>
<th>Spanish M(SD)</th>
<th>Bilingual M(SD)</th>
</tr>
</thead>
<tbody>
<tr>
<td>DCS</td>
<td>14.3(12.7)</td>
<td>15.5(13.2)</td>
<td>12.3(12.1)</td>
<td>14.1(14.3)</td>
</tr>
<tr>
<td>PedsQL</td>
<td>64.0(15.2)</td>
<td>64.3(13.2)</td>
<td>64.4(17.0)</td>
<td>60.3(16.9)</td>
</tr>
<tr>
<td>Positive RCOPE</td>
<td>1.91(1.06)</td>
<td>1.19(0.97)**</td>
<td>2.74(0.43)**</td>
<td>1.96(0.96)**</td>
</tr>
<tr>
<td>Negative RCOPE</td>
<td>0.27(0.42)</td>
<td>0.15(0.20)</td>
<td>0.42(0.57)</td>
<td>0.20(0.45)</td>
</tr>
<tr>
<td>PC-PTSD-5</td>
<td>1.71(1.49)</td>
<td>1.40(1.55)</td>
<td>2.55(1.21)</td>
<td>1.25(1.49)</td>
</tr>
</tbody>
</table>

*Note. DCS = Decisional Conflict Scale; PedsQL = Pediatric Quality of Life Inventory; RCOPE = Brief Religious/ Spiritual Coping (RCOPE) Scale; and PC-PTSD = Primary Care PTSD Screen for DSM-5.*

* p <.05; ** p <.01.
### Table 3

*Bivariate Correlations of Primary Study Variables and Continuous Demographic Variables (N=35)*

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<th>13</th>
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</thead>
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<tr>
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<td>-0.04</td>
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<td>Months Since Diagnosis</td>
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<td>15</td>
<td>Time in US</td>
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</table>

*Note:* DCS = Decisional Conflict Scale; PedsQL = Pediatric Quality of Life Inventory; RCOPE = Brief Religious/Spiritual Coping (RCOPE) Scale; and PC-PTSD = Primary Care PTSD Screen for DSM-5.

* p < .05; ** p < .01.
**Table 4**

*Regression Between DCS and PedsQL Family Impact Module (N=35)*

<table>
<thead>
<tr>
<th>Predictor</th>
<th>$R^2$</th>
<th>$B$</th>
<th>SE</th>
<th>t</th>
<th>p</th>
<th>95% CI</th>
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<td>0.03</td>
<td>[-0.58, -0.03]</td>
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</table>

*Note: CI = Confidence interval. DCS total scores are the independent variable and total scores from the PedsQL Family Impact Module are the dependent variable.*
Table 5

ANOVA of Mean Differences Between Language Groups for Total DCS Scores (N=34)

<table>
<thead>
<tr>
<th></th>
<th>F</th>
<th>df1</th>
<th>df2</th>
<th>p</th>
<th>Mean</th>
<th>SD</th>
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<td>2.00</td>
<td>17.2</td>
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<td>-</td>
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<td>-</td>
<td>-</td>
<td>-</td>
<td>15.5</td>
<td>13.2</td>
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<td>-</td>
<td>-</td>
<td>-</td>
<td>12.2</td>
<td>12.1</td>
</tr>
<tr>
<td>Bilingual</td>
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<td>-</td>
<td>-</td>
<td>-</td>
<td>14.1</td>
<td>14.3</td>
</tr>
</tbody>
</table>

*Note: DCS = Decisional Conflict Scale.*
Table 6

ANOVA of Mean Differences Between Language Groups for Total PedsQL Scores (N=34)

<table>
<thead>
<tr>
<th></th>
<th>F</th>
<th>df1</th>
<th>df2</th>
<th>p</th>
<th>Mean</th>
<th>SD</th>
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</thead>
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<td>2.00</td>
<td>16.2</td>
<td>0.84</td>
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<td>-</td>
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<tr>
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<td>-</td>
<td>-</td>
<td>-</td>
<td>64.3</td>
<td>13.2</td>
</tr>
<tr>
<td>Monolingual Spanish</td>
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<td>-</td>
<td>-</td>
<td>-</td>
<td>64.4</td>
<td>17.0</td>
</tr>
<tr>
<td>Bilingual</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>60.3</td>
<td>16.9</td>
</tr>
</tbody>
</table>

Note: PedsQL = Pediatric Quality of Life Inventory.
Appendix A

Eligibility Survey

English

1. Do you identify as Latino or White?
   a. Yes
   b. No

2. Are you 18 years or older?
   a. Yes
   b. No

3. Are you the primary decision-maker regarding your child's care?
   a. Yes
   b. No

4. Are you the parent or primary caregiver of a child between 0 and 17 years who is diagnosed with cancer?
   a. Yes
   b. No

5. Has more than one year passed since the end of your child's first hospitalization for their cancer diagnosis or treatment?
   a. Yes
   b. No

6. Was your child diagnosed with cancer more than a month ago?
   a. Yes
   b. No
7. Have you made a decision regarding your child’s treatment/care within the past 6 months?
   a. Yes
   b. No

8. Other than marijuana, nicotine, or alcohol, have you used any NON-PRESCRIPTION drugs (eg. heroin, cocaine) in the past 14 days?
   a. Yes
   b. No

9. Do you have any significant mental illnesses (eg. schizophrenia) that you have not received treatment for?
   a. Yes
   b. No

**Spanish**

1. ¿Se identifica como latino o blanco?
   a. Sí
   b. No

2. ¿Tienes 18 años o más?
   a. Sí
   b. No

3. ¿Es usted el principal tomador de decisiones con respecto a la atención de su hijo?
   a. Sí
   b. No
4. ¿Es usted el padre o cuidador principal de un niño entre 0 y 17 años a quien se le diagnostica cáncer?
   a. Sí
   b. No

5. ¿Han pasado más de un año desde el final de la primera hospitalización de su hijo por su diagnóstico o tratamiento de cáncer?
   a. Sí
   b. No

6. ¿Su hijo fue diagnosticado con cáncer hace más de un mes?
   a. Sí
   b. No

7. ¿Ha tomado una decisión con respecto al tratamiento/cuidado de su hijo en los últimos 6 meses?
   a. Sí
   b. No

8. Aparte de la marihuana, la nicotina o el alcohol, ¿ha consumido alguna droga SIN RECETA (p. ej., heroína, cocaína) en los últimos 14 días?
   a. Sí
   b. No

9. ¿Tiene alguna enfermedad mental importante (p. ej., esquizofrenia) para la que no haya recibido tratamiento?
   a. Sí
   b. No
Appendix B

Demographic Surveys

English

Information about parent and provider:

1. What is your age? ___________

2. Who else lives in your home with you and your child?
________________________________________________________________________

3. How many children do you have (including the child with the cancer diagnosis) and what are their ages? These children do not need to live in the same house as you.
   a. Number of children _______
   b. Ages of children ______________________

4. What is your country of origin? _____________________________________________

5. Do you identify as Latinx or Hispanic?
   a. Yes
   b. No

6. Do you identify as White?
   a. Yes
   b. No

7. What is your gender?
   a. Male
   b. Female
   c. Nonbinary

8. What is your working status?
   a. Working
   b. Disabled
   c. Student
   d. Other

9. What is your marital status?
   a. Single
   b. Married
   c. Divorced

10. What is your household annual income?
11. What is your highest level of educational attainment?
   a. Some high experience school or less
   b. GED
   c. High school degree
   d. Some college
   e. College graduate
   f. Graduate degree

12. How many years have you lived in the United States?
   a. Born in the United States
   b. 1 to 5 years
   c. 6 to 10 years
   d. 11 to 15 years
   e. More than 15 years

13. What is your preferred language?
   a. English
   b. Spanish
   c. Other (Specify) __________

14. What is your comfort level speaking in English?
   a. Not comfortable at all
   b. Somewhat comfortable
   c. Quite a bit comfortable
   d. Completely comfort

15. Do you require the use of a translator when interacting with the healthcare team at the hospital?
   a. No
   b. Yes

16. How often were you offered translation services while discussing treatment options for your child? (Select NA if the parent does not require translation services).
   a. Not at all
   b. Sometimes
   c. Most of the time
   d. Every time
   e. NA

17. What was the race/ethnicity of their child’s provider?
   a. White
b. Hispanic/Latinx
c. Black or African American
d. Asian
e. Native American or Alaska Native
f. Two or more races
g. Other (specify) __________
h. Prefer not to respond

18. What level of trust do you have in your child’s primary healthcare provider?
   a. No trust at all
   b. Some trust
   c. A fair amount of trust
   d. Complete trust

Information about the child:

19. What is the age of your child? __________

20. What is the gender of your child?
   a. Male
   b. Female
   c. Nonbinary

21. What type of cancer does your child have? _______________________

22. What stage of cancer does your child have?
   a. 1
   b. 2
   c. 3 (ineligible)
   d. 4 (ineligible)

23. How much time has passed since your child was diagnosed? __________

24. What level of support does your child need to conduct daily living activities compared to other children their age?
   a. a little support (e.g. can eat, bathe, dress, or get around the house mostly independently but may need support from others on occasion)
   b. a lot of support (e.g. unable to eat, bathe, dress, or get around the house independently and requires significant support from others)

25. Briefly describe a healthcare related decision you made for your child in the past month.

________________________________________________________________________
________________________________________________________________________
________________________________________________________________________

26. How could your experience interacting with the hospital be made better?
Información sobre los padres y el proveedor:

1. ¿Cuál es su edad? __________

2. ¿Quién más vive en su casa con usted y su hijo?

3. ¿Cuántos hijos tiene (incluido el niño con el diagnóstico de cáncer) y cuáles son sus edades? Estos niños no necesitan vivir en la misma casa que usted.
   a. Numero de niños ______
   b. Edades de niños ________________

4. ¿Cuál es su país de origen? _________________________________

5. ¿Te identificas como latinx o hispano?
   a. Sí
   b. No

6. Te identificas como persona blanca?
   a. Sí
   b. No

7. ¿Cuál es su género?
   a. Hombre
   b. Mujer
   c. No binario

8. ¿Cuál es su situación laboral?
   a. Trabajando
   b. Discapacitado/a
   c. Estudiante
   d. Otro
9. ¿Cuál es su estado civil?
   a. Soltero/a
   b. Casado/a
   c. Divorciado/a

10. ¿Cuál es el ingreso anual de su hogar?
    a. $25,000 o menos
    b. 25,001 a 50,000
    c. 50,001 to 100,000
    d. 100,001 or more

11. ¿Cuál es su nivel educativo más alto?
    a. Alguna escuela de alta experiencia o menos
    b. GED
    c. Título de instituto
    d. Alguna educación superior
    e. Graduado de la Universidad
        Diploma de graduación

12. ¿Cuántos años ha vivido en los Estados Unidos?
    a. Nacido en los Estados Unidos
    b. 1 a 5 años
    c. 6 a 10 años
    d. 11 a 15 años
    e. Más de 15 años

13. ¿Cuál es tu idioma preferido?
    a. Inglés
    b. Español
    c. Otro (especifique por favor) ______________

14. ¿Cuál es su nivel de comodidad hablando en inglés?
    a. Nada cómodo
    b. Algo cómodo
    c. bastante comodo
        Completamente cómodo

15. ¿Requiere el uso de un traductor cuando interactúa con el equipo de atención médica en el hospital?
    a. No
    b. Sí

16. ¿Con qué frecuencia le ofrecieron servicios de traducción mientras discutía las opciones de tratamiento para su hijo? (Seleccione NA si el padre no requiere servicios de traducción).
    a. No en absoluto
b. Algunas veces
c. La mayor parte del tiempo
d. Cada vez
e. NA

17. ¿Cuál era la raza/origen étnico del proveedor de su hijo? Caucásico/a
   a. Hispano/Latinx
   b. Negro o afroamericano/a
   c. Asiático/a
   d. Nativo americano o nativo de Alaska
   e. Dos o más razas
   f. Otro (especifique por favor) __________
g. Prefiero no responder

18. ¿Qué nivel de confianza tiene en el proveedor de atención médica primaria de su hijo?
   a. Sin confianza en absoluto
   b. Algo de confianza
   c. Una cantidad decente de confianza
   d. Confianza total

Información sobre el niño:

19. ¿Cuál es la edad de su hijo? __________

20. ¿Cuál es el género de su hijo?
   a. Niño
   b. Niña
   c. No binario

21. ¿Qué tipo de cáncer tiene su hijo? __________________________

22. ¿Qué etapa del cáncer tiene su hijo?
   a. 1
   b. 2
   c. 3 (ineligible)
   d. 4 (ineligible)

23. ¿Cuánto tiempo ha pasado desde que su hijo fue diagnosticado? __________

24. ¿Qué nivel de apoyo necesita su hijo para realizar las actividades de la vida diaria en comparación con otros niños de su edad?
   a. Un poco de apoyo (por ejemplo, puede comer, bañarse, vestirse o moverse por la casa en su mayoría de forma independiente, pero puede necesitar el apoyo de otros en ocasiones)
   b. Mucho apoyo (por ejemplo, no puede comer, bañarse, vestirse o moverse por la casa de forma independiente y requiere un apoyo significativo de los demás)
25. Describa brevemente una decisión relacionada con la atención médica que tomó para su hijo en el último mes.

________________________________________________________________________
________________________________________________________________________
________________________________________________________________________

26. ¿Cómo se podría mejorar su experiencia de interacción con el hospital?

________________________________________________________________________
________________________________________________________________________
________________________________________________________________________
________________________________________________________________________
________________________________________________________________________
________________________________________________________________________
________________________________________________________________________
________________________________________________________________________
Appendix C

IRBPHS Approval Notification

University of San Francisco

To: Augustine Provencio
From: Richard Gregory Johnson III, IRB Chair
Subject: Protocol #1857
Date: 03/21/2024

The annual report for your research (IRB Protocol #1857) with the project title Association Between Decisional Conflict and Quality of Life Among Parents with a Child Undergoing Hospital-based Treatment for a Recent Cancer Diagnosis was approved on 03/21/2024.

This approval is good through 04/25/2025.

If you have any questions, please contact the IRBPHS via email at IRBPHS@usfca.edu. Please include the protocol number assigned to your application in your correspondence.

On behalf of the IRBPHS committee, I wish you much success in your research.

Sincerely,

Dr. Richard Gregory Johnson III
Professor & Chair, Institutional Review Board for the Protection of Human Subjects
University of San Francisco
irbphs@usfca.edu
IRBPHS Website

University of California, San Francisco

Human Research Protection Program
Institutional Review Board (IRB)

Expedited Review Approval
No Continuing Review

Principal Investigator
Andrea C Postier

Co-Principal Investigator
Augustine R Provencio

Type of Submission: Submission Correction for Initial Review Submission Packet
Study Title: Association Between Decisional Conflict and Quality of Life Among Parents with a Child Undergoing Hospital-based Treatment for a Recent Cancer Diagnosis
Study Status: Active - Expedited - No Continuing Review
IRB #: 23-38942
Reference #: 374926
Committee of Record: Laurel Heights Committee
Study Risk Assignment: Minimal
Approval Date: 07/07/2023