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Pediatric Cancer and the Cost of Hope

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This is to certify that the doctoral dissertation by

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Walden University
2023

Abstract

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MSN, Walden University 2011

BSN, Hampton University 2009

Dissertation Submitted in Partial Fulfillment

of the Requirements for the Degree of

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Abstract

The concept of hope is well known to the medical community, but how hope and prospect of outcomes impact financial and treatment decision making on the part of the parents/guardians of a child with a terminal cancer diagnosis is a gap in knowledge that must be explored. The purpose of this qualitative phenomenological study was to provide context for decision making by the parents/guardians of children with terminal cancer diagnoses. Improved understanding of what influences how and why choices are made may allow for more robust discussion of treatment goals between the providers and the parents/guardians of children diagnosed with terminal cancer. Through the theoretical lens of Snyder's hope theory and Kahneman and Tversky's prospect theory, the contextualization of the lived experiences of the parents/guardians of these terminal pediatric cancer patients was examined. Data collection was performed through semi structured interviews, thematic identification, and analysis using MAXQDA software. Results yielded five themes: (a) Explanation of disease and treatment; (b) medical team support in identifying novel treatments; (c) treatment selection and goals; (d) financial impacts; (e) hope; and (f) treatment selection regrets. Treatment and financial based decision making was consistent with Snyder's hope theory, but the concepts of risk and reward in the treatment selections was nonexistent. Implications for positive social change include better understanding regarding how hope impacts decision making. Such understanding can result in better support, more meaningful goals of care conversations, and reduced financial burden.

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Dedication

This study is dedicated to my family. This study first and foremost is dedicated to Gavin Lee Morales. Your light was taken from this world, but it still shines brightly through the life you lived while you were here, and your light still touches so many. You will always be an inspiration to me and a true demonstration of resilience and faith. Because of you, I have been able to see the world in a way that requires empathy and not pity, understanding and not judgement, and love above all else. To my wife Ashlee Campbell, you have supported me and encouraged me at every step along the way and I could not have achieved all that I have without your support. To my mother Dr. Peggy Rayman, you have instilled in me the love for reading and inquisition and have shown me how to set and achieve goals no matter how insurmountable they might be.

I also dedicate this to my good friend and mentor Dr. Jeffery Doucette. You have set the bar for me professionally and have demonstrated what it means to be an impactful nurse leader and I thank you for the chance that you took on me so long ago, it set the trajectory for my career, and I value all that I learned from you.

Lastly, I dedicate this dissertation to my Father Dr. Willamus Alexander Campbell, you have demonstrated what leading with compassion, integrity and competence means. You achieved more in your short time here on earth than most will in a lifetime, and I aspire to be half the man you were.

Acknowledgments

I wish to thank my committee members who have provided me with their expert council and valuable time. A special thank you to Dr. Bewley, my committee chair who has provided me with great suggestions and guidance on how to make this study as impactful as possible. A special thank you to Dr. Winington, who joined my study in the last hours of my study and jumped right in and provided another point of view.

I would like to thank all participants in this study as they shared with me a very private and painful part of their lives and were selfless in their time and input. These participants are the reason for the study and also the reason for closing the gap to better meet the needs of those that will have similar experiences.

Finally, I would like to thank all my professors, student advisors, dean, and members of various administrative functions that I have encountered along my journey. You have each touched my life and although I do not remember all your names, I will forever remember the impact you have had on me as it relates to my journey.

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Chapter 1: Introduction to the Study

In the United States, approximately 15,000 children are diagnosed with cancer each year; of these diagnosed cases, 15% are terminal (Siegal et al., 2018, 2020). Siegal et al. (2020) reported that the cancers with the highest mortality in the pediatric population were leukemia, lymphoma, and brain, bone, and soft tissue cancers. Outcomes have improved in recent decades; however, some cancers still significantly impact the death rate. Death rates for leukemia and lymphoma have improved; however, the mortality rates of brain, bone, and soft tissue cancers remain unchanged (Siegal et al., 2020). Following diagnosis with a terminal form of cancer, the parents/guardians of pediatric cancer patients must choose a treatment option. If they are pursuing clinical trials, they must choose quickly as certain forms of care disqualify participation in clinical trials (Unger et al., 2019). Furthermore, they must analyze how much they are willing or able to spend and the financial impact of treatment (Salsman et al., 2020). Although treatments have advanced for some cancers, the costs related to these treatments have also increased (Marriotto et al., 2020).

Like many other cancers, there are treatment-related costs and nontreatment related costs incurred by the families of pediatric patients. Understanding what factors impact these costs will help provide context to the financial impacts experienced by the parents/guardians of terminal pediatric cancer patients. Viega et al. (2018) stated that cancer treatment far outweighs the cost of other chronic conditions. There can be an increased financial burden depending on the costs of the standard therapies and the level of insurance coverage needed. The factors surrounding the cost, location, and perceived

efficacy of novel cancer therapies also have implications. Nontreatment-related costs include travel, food, lodging, and underemployment. These factors vary in impact based on preexisting financial status, insurance level, and access to resources to cover these expenses, which may be provided by the trials in certain circumstances (Huey et al., 2021). Mitchel et al. (2020) reported that the price of newer therapeutics for cancer treatment is high for patients with more lethal forms of cancer and is the primary and most expensive cost for patients and their families.

There is an abundance of literature examining the cost of pediatric oncological treatments. In my study, I aimed to understand how the concepts of hope and prospect impact treatment decisions based on the presence of a terminal diagnosis and the financial impact of novel therapeutics. Examination of what factors impact the selection of the chosen treatment will help highlight and potentially predict decision-making rationale and tendencies in the affected population. The concept of hope in healthcare is not new; the influence of hope on complex financial decision making by the families of pediatric cancer patients with terminal diagnoses is an area that warranted further investigation.

Robertson et al. (2020) examined the ways in which treatment decisions are made based on their desired level of involvement. Even though the authors examined decision making, no context was provided as to how the family's decisions were influenced by hope or the prospect of the outcome. The study was valuable but was limited as it evaluated the effect of anxiety alone. I examined the financial decision making of families of pediatric cancer patients through the lens of the hope and prospect theories

and what impact they have on the decision making process. A gap existed in the understanding of what factors drive decision making in this population and what factors influence the acceptable level of medical financial expenditures based on hope and the prospect of the outcome in the presence of a terminal diagnosis.

In Chapter 1 I describe the purpose of the study, the problem identified that motivated the research, the theoretical framework, and details on how this study was conducted. I also describe the rationale and potential impact of the study and the theoretical lens through which the study was approached. How choices are made regarding the care and financial utilization of resources by the parents of terminal pediatric patients from a phenomenological perspective and seeks to provide context for decision making for future parents/guardians when faced with similar choices were examined.

Background

To understand the need for this research, baseline knowledge was needed on what the current literature reports regarding the prevalence of pediatric cancer, the cost of treatment, and how medical choices are made when a terminal diagnosis is given to the parents/guardians of these patients. From this base understanding, the gaps in the literature were assessed. An abundance of literature on terminal cancer rates, current treatment modalities, and novel treatments for terminal pediatric cancer exists (Hlvankova et al., 2019; Parabochi, 2021). The statistics on pediatric cancer reveal that 157 out of 1 million children will be diagnosed with cancer each year (Siegal et al., 2018). Of the children diagnosed with pediatric cancer, 2,000 die each year (Johnson,

2020). Although there have been improvements over recent decades in therapeutic and radiation treatments, the mortality of pediatric cancer remains at approximately 15% (Johnson, 2020). There are many novel treatments; however, their efficacies have not yet achieved a meaningful impact on mortality. Harris et al. (2020) and Siegal et al. (2018) discussed cancer as the leading cause of disease-related death in children. There is an increased need for novel therapeutics to improve survival (Cunningham et al., 2018; Ferrari et al., 2021 Harris et al., 2020). The drawback of these novel therapeutics is their efficacy; however, to identify safe and effective treatments that can become the future standard of care, patients must participate in trials and use these treatments (Scavone et al., 2019). The advances in novel therapeutics have been focused on precision oncology, as certain types of cancers do not respond to a "one size fits all" treatment approach.

Genomic sequencing is the most recent focus of pediatric oncology; it provides targeted therapies and screening for pediatric cancer (Rusch et al., 2018). Rusch et al. (2018) described how sequencing the genome opened new possibilities in oncology as it can be used to detect variants within a type of cancer. The new focus on precision oncology is necessary for advances in therapeutics for the more fatal forms of cancer (Harris et al., 2020; Sun et al., 2019; Zodwa et al., 2020). Precision oncology can be used by oncologists to individualize treatments to specific genetic defects or cancer types to target unique characteristics of various forms of cancer (Harris et al., 2020). Meggendorfer (2022) described these novel treatments as costly and not widely available but hold great promise at individualizing care. Novel therapies cost on average $150,000 per patient per year but can be as high as $300,000 to treat a patient if they use

combination therapies, which results in the insured patient reaching their catastrophic coverage limits with a single treatment and causes underinsured or uninsured patients to face significant financial burden (Zhao et al., 2020). The financial burden that results from novel therapeutics and/or participation in clinical trials contributes to the economic burden for the parents/guardians of terminal pediatric cancer patients. How this financial burden impacts each family varies. The Federal Reserve Bank (2020) conducted a survey that revealed that 37% of adults in the United States would have difficulty paying an unexpected expense greater than $400. Deciding which types of treatments selected and what financial impact the family will experience based on what is known or what is possible through the lens of hope or prospect is vital to improving our understanding of how and why choices are made.

Understanding what influences costs is important to when making informed decisions about care choices. The hospital bills tend to be higher for pediatric cancer patients than for adults (Nathan et al., 2019). Nathan et al. (2019) further explained that the annual cost for pediatric cancer can be as high as $300,000 and up to 38% higher than the cost of care for adults depending on the phase of care they are in; however, the out-of-pocket costs for all patients are capped due to catastrophic limit protections. There are few care pathways at the disposal of terminal pediatric cancer patients. The first pathway is focused on symptom management and the use of proven therapies but does not alter the terminal progression of the disease. Current, standard nonexperimental cancer treatments include surgery, chemotherapeutics, radiation therapy, physical therapy, occupational therapy, radiation therapy, immunotherapy, stem cell, and precision therapy (National

Cancer Institute, 2020). Each of the standard treatments are covered by insurance but rapidly drive out-of-pocket costs toward catastrophic limits depending on the type of insurance and comprehensiveness (Smith et al., 2019). The second more aggressive option is to enroll in a clinical trial based on innovative, experimental therapies that are not yet proven but have demonstrated clinical promise and have progressed to human clinical trials. Depending on the inclusion and exclusion criteria, some of the standard therapies may dictate participation in a clinical trial (Denicoff et al., 2022). Participation in clinical trials involve a shift in decision making regarding the type of care received by the child and the goal to be achieved by the parents/guardians, potentially increasing the overall cost of care. Families must take multiple factors into consideration when researching treatment options for their children. Treatment goals, insurance coverage, prognosis, fiscal resources, potential side effects of treatments, and distance to the treatment center all factor into deciding what course of treatment the family will take.

There is a gap in the literature regarding the factors that influence medical treatment decisions in the presence of a terminal diagnosis and have significant future implications for parents and oncology teams alike. It is unknown what drives caregivers of pediatric cancer patients to pursue novel, unproven treatments with unproven efficacy and high costs. As noted in the literature review, no studies to date have examined this concept through the perspectives of these families using the hope and prospect theories.

I investigated the lived experiences of families through the lens of the hope and prospect theories, and their relationship with decision making. Hope is a theme that is often referred to in the medical community. Hope is essential to the providers, the

recipients of the care, and their families. Jin and Kim (2019) described the premise of Snyder's hope scale and its application to impact decisions directed toward achieving a goal. Snyder (2002) described the hope theory as the presence of a goal that can be achieved through agency and a pathway. Snyder discussed human actions as goal oriented. A person's ability to navigate effectively between agency and the pathway directly determines the level of hope one experiences while attempting to achieve a goal. The other lens through which investigations were conducted in this study was the prospect theory. The prospect theory by Heppner and Krauskopf describes how information is received, examined, and converted into a plan that is perceived to be achievable (Heppner & Krauskopf, 1987, Pachur et al., 2018). No existing literature has examined the impact of hope or prospect on treatment decisions and the resulting financial implications. In the next section, I reviewed what influences treatment based financial decision making through these theoretical lenses. Understanding the facts surrounding outcomes relative to costs and the factors that drive the decision to participate in novel treatments based on these facts is valuable for the parents/guardians involved in this decision making and the healthcare providers who must lead the discussions regarding treatment choices.

Problem Statement

Cancer is one of the leading causes of pediatric death in the United States (Siegal et al., 2018). Siegel et al. (2020) reported that between 2001 and 2015, the average death rate for pediatric cancer patients was 14.9%. A significant improvement in mortality has been achieved over the past few decades, however, bone, brain, and soft tissue cancers

have seen minimal improvements in mortality (Siegal et al., 2020; Withrow et al., 2019). The types of pediatric cancers with the highest incidence in mortality have had modest improvements in treatments; however, no meaningful advances leading to significant improvements in mortality have occurred (Siegal et al., 2020). New therapies are possible with the advent of genomic sequencing, and many novel approaches have been developed; however, there have been no significant breakthroughs resulting in cancer-curing therapies for brain and central nervous system cancers (Delinge et al., 2020; Findelberg et al., 2020; Rutkowski et al., 2019; Withrow et al., 2019). Advanced novel gene therapies have been developed for leukemia, which is also one of the primary pediatric cancers with the highest mortality (Brivio et al., 2022; Lin et al., 2020; Szabo & Murthy, 2020). The frequency of pediatric deaths related to cancer warrants identification of ways to help understand decision making and provide resources to support the parents and guardians who must make tough decisions regarding the plan of care for their child. The choices surrounding therapies are many and each have unique consequences, both physical for the child and financial for the parents.

The treatments for pediatric cancer patients are both necessary and expensive (Siegal, 2020). The presence and comprehensiveness of insurance are essential factors for the parents of children with terminal pediatric cancer. The type of health insurance and financial resources available to those with pediatric cancer will directly impact the type, quality, and frequency of the care they receive (Berdahl et al., 2020; Gentili et al., 2018; Rees et al., 2020; Wisk, 2019). Determining the best care path for a terminal pediatric cancer patient takes a great deal of thought and consideration by the

parent(s)/guardian(s). Discussions about the cost of care, expected outcomes, and negative implications surrounding novel treatments are needed to ensure that the parents are well informed and have the tools to make the most appropriate decision for their child. The information provided by the healthcare team regarding the course of treatment, prognosis, best practices, available clinical trials, and other considerations need to be provided in addition to the historical context of decision making for parents who have been presented with similar decisions. Improved treatment goals conversations will help the parent/guardian make an informed decision (Cheng et al., 2020; Myers et al., 2018; Vaccaro et al., 2019).

How the diagnosis and treatment options are provided may impact the parent or guardian's level of hope when choosing a course of care for the child. Based on the information, the family may choose from several pathways. The first pathway is symptom management with no medical intervention to alter the disease's course. The second pathway includes standard treatment, such as generic chemotherapeutics and/or radiation therapy and symptom management. The third course of treatment involves clinical trials and the use of novel treatments, therapeutics, and symptom management. With hope, treatment options provided such as clinical trials, novel therapies, and targeted therapeutics, is processed through a lens of agency and pathway. It is vital to understand how hope influences the financial decisions of the parents/guardians of terminal pediatric patients. When deciding upon the course of treatment, questions arise regarding the cost, potential necessary travel, physical effects, insurance coverage, and available financial resources both personally and in the community. Through the

literature review, I found no meaningful studies that clarify how the prospect and hope theories can impact medical and financial decision making and navigation of the lived experience. Improved treatment goals conversations with a more in-depth understanding of complex decision-making in the presence of a terminal diagnosis can lead to improved resource use and expectations of outcomes for the parents and guardians of these children.

Purpose

I examined the lived experience through the lens of the prospect and hope as it relates to the concept of medical and financial decision making. Making medical and financial decisions related to healthcare costs were examined applying the hope and prospect theories. The impact of these theories on decision-making along the healthcare continuum from the diagnosis of a terminal disease to death was reviewed. I examined the lived experiences of the participants through the lens of these theories to provide context to the decisions that were made. I focused on the rationale behind treatment related costs but did not exclude nonmedical costs. Through the narrative of the participants' experience, descriptions of medical bills, insurance type, education, annual salary, months survived postdiagnosis, and costs related to providing medical treatment and other related expenditures were evaluated. To obtain a complete picture of expenditures, I was specific in defining the treatment costs, out-of-pocket spending, and non-medical costs related to the care of the terminal child.

The literature on terminal pediatric cancer describes many aspects of the care and treatment and promises of future advances. I sought to provide context and rationale in

decision making and the impact on decision making based on care goals. Many factors impact care coordination for both standard treatment and clinical trials (Leet et al., 2018; Weaver & Jacobson, 2018), but I aimed to understand why the selected treatment choices were made. When analyzing the cost outside of care covered by insurance, many variables affect the level of expenditures. Each family has different baseline levels of available resources, including insurance, savings, types of transportation, income, and other assets. Understanding the decision making pathways for uninsured or underinsured, who will likely face a more considerable financial burden for the same treatment than their fully insured counterparts assists in treatment goals conversations. The accumulated themes revealed through the qualitative datasets addressed the knowledge gaps related to medical and financial decision making by parents/guardians of terminal pediatric patients. The research completed aimed to clarify unanswered questions surrounding how and why medical treatment choices are selected and used based on the parent/guardian's processing of information and perceptions of hope.

Research Questions

The study has one principal research question with two sub questions:

RQ: How are medical-based financial decisions made by the families of terminal pediatric cancer patients using the lens of hope and prospect?

Sub question 1: Were the healthcare and financial decisions made based on the concepts of agency, pathway, and goal, as described by the hope theory?

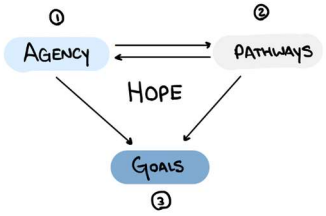
Sub question 2: Are the financial choices made in the care of terminal pediatric cancer patients' representative of the concepts of risk versus reward, as described by the prospect theory?

Theoretical Framework

The first theoretical framework for this study was Snyder's (2000) hope theory and was applied to the families of pediatric patients with terminal cancer and their decision making. The hope theory suggests the relationship between the parents' high and low hope levels of terminal pediatric patients and the impact on financial decisions based on care goals. The hope theory allows for examination of the study through the context of a parent/guardian of a child with terminal cancer to achieve their desired outcome. Goals are attained through the actions resulting from the other two components of the triad of hope, as described by Cheavens and Whitted (2022). Figure 1 indicates the hope triad composed of goals, agency, and pathway; the goal is the identified desired endpoint, whereas the agency and pathway are how the goal is achieved (Gallagher & Lopez 2018). Agency refers to goal-directed energy, while the pathway refers to the plan to meet the goal (Cheavens & Whitted, 2022). This theoretical viewpoint was used to provide context for choices made in the presence of a terminal diagnosis.

Figure 1

Snyder's Hope Theory



The second theory referenced throughout the study is the prospect theory described by Kahneman and Tversky (1979). The prospect theory is well known in the financial sector but has not been extensively applied to medical decision making. Tversky and Kahneman used the prospect theory to describe decision making when multiple options or pathways were available. There are two phases of thought based on the prospect theory. The first phase is known as the editing phase. In the editing phase, the individuals' interpretation of the risk of the choice made determines how the choice is perceived. The framing supports placing the choice made into context. After the editing phase, the individual moves into the evaluation phase. A decision is made based on potential outcomes and risk aversion during this phase. The concepts surrounding the evaluation phase are certainty, relative positioning, probability, and risk aversion. These concepts, when applied to decision making, provide context to why the decision was made. The "why" is rooted in the perception of the outcome. Parents use financial resources to achieve desired outcomes with their child or the prospect of a cure for their child through costly yet unproven therapeutics.

Nature of the Study

The study was a phenomenological qualitative study. Data collection was conducted through the interviews of parents/guardians who have lost a child to terminal cancer. Participant selection was conducted through peers, support groups, and social media-based groups dedicated to the parents of terminal pediatric cancer patients and those who have lost a child to cancer. The participants were provided with a detailed description of the survey, the research questions I aimed to answer, and procedures and

expectations for protecting confidentiality. I used semi structured interviews to collect data on the child's diagnosis, survival from diagnosis, treatment-related costs, the rationale behind the medical and financial decision making related to the care of the child with terminal cancer. The interview navigated the participants through the entire experience, from diagnosis to passing.

In addition, I explored how decisions were made along the healthcare continuum from diagnosis to demise. I examined the meaning of the lived experience by applying the concepts of the hope and prospect theories. the decision making surrounding financial expenditures related to medical treatments and other out-of-pocket costs based on the desired treatment goals was examined.

Possible Types and Sources of Data

In-depth interviews were the primary source of data. The semi structured interviews helped me guide the participants through crucial topics related to their experience along the healthcare continuum of their child post terminal diagnosis. The interviews allowed the parents/guardians of terminal pediatric patients to describe their healthcare decisions and why they made these decisions. The interviews enabled parents/guardians of terminal cancer patients to explain the financial impact and rationale for the decisions made regarding the treatment of the terminal child. The first part of the interview demographic information was collected and allowed the participants to describe their education level, income level, financial support from outside sources, and other topics they felt were important to their lived experience. The second source of data included a rich description of their lived experience describe in their own words. The

study was a retrospective review, and the responses examined their experience from diagnosis through the self reflection that occurred after their child had passed away.

Definitions

Agency - Goal-directed energy (Snyder, 2002).

Clinical Trial – Experimental treatment(s) in which specific patient populations are included and experimental interventions are administered (Madrid et al., 2015).

Goals - Goals provide a point of mental focus; for some people, these are projections of a desired future state. Some goals may be visual, but they also have verbal components (Snyder, 2002).

Hope - The perceived capability to derive pathways to desired goals and motivate oneself via agency to use those pathways (Snyder, 2002).

Income – The income regularly received (exclusive of certain money receipts, such as capital gains) before payments for personal income taxes, social security, union dues, and Medicare deductions (Census Bureau, 2019).

Pathway - Planning to meet goals (Snyder, 2002).

Prolongment of life - Any amount of time that someone with a terminal disease lives past the average life expectancy postdiagnosis (Warren, 2012).

Radiation therapy (stereotactic radiation therapy) - Radiation therapy that delivers precise and high radiation doses, typically take over 6 weeks. Because the radiation dose for each stereotactic treatment is so high, the approach is used for small tumors in targeted areas (Knoll & Rosenzweig, 2019).

Treatment-related costs – Costs that are directly related to medical treatment (Lentz et al. 2019).

Tumor progression - Tumor growth or advancement of the disease. Progression can occur multiple times as various interventions act on the tumor to temporarily restrict or inhibit tumor growth (Hseih & Tsai, 2019).

Assumptions

The participants in the study are parents or legal guardians of a child with terminal cancer. The participants have chosen one of three courses of treatment for their children: symptom management only, chemotherapeutics/radiation therapy and symptom management, and clinical trial. Each participant has incurred treatment-related costs for their child. The parents/legal guardians were informed of a terminal cancer diagnosis and chose the treatment plan for the child accordingly. The inclusion criteria for the study were having had a child with a terminal cancer diagnosis who died from the disease. The assumption, at the minimum, is that the parent or legal guardian would have chosen symptom management for the disease. I assumed that self-reported data related to treatment type, quantity of expenses, length of survival postdiagnosis, and assessment of their lived experience was honest and accurate. The participants were guided through a semi structured interview. The interview questions were written so that any person with a fifth-grade level of reading proficiency could interpret and follow without difficulty.

Bias can exist for researchers and participants alike, and I took steps to acknowledge and mitigate these biases where possible through reviewing pitfalls in research integrity and bias (see Johnson et al., 2020). Participants in the study were

sought from various education levels, ethnic backgrounds, varying social networks, and various economic classes, which will impact the resources they had available to them. Furthermore, I assumed the presence of other factors affecting resource utilization. Through the study, I investigated the connection between hope, the prospect of outcomes, and the use of available resources (Curley et al., 2019; Levin et al., 2019; Sick et al., 2020; Martins et al., 2018). I assumed that the small number of children diagnosed with terminal cancer would lead to a sample size that is commensurate. Participants in the study were chosen through various terminal cancer bereavement networking websites created by multiple entities.

Scope

Participants in the study have had a child/dependent who received diagnostic testing to confirm a terminal cancer diagnosis. At no point did any parent/guardian of any child diagnosed with terminal cancer undergo testing for participation in the study. The expenses discussed in the study were both healthcare and non healthcare related. To be included in the study, a participant had to meet the following inclusion criteria:

- The participant must have had a child who they are the parent or guardian of who was diagnosed with terminal cancer.
    - An oncologist must have confirmed the diagnosis via diagnostic testing.
    - The participant must have access to a device capable of virtual meeting applications.

- The participant must be able to read and comprehend English at a fifth grade reading level.
- The participant must have completed one of three or combination of treatment choices:
    - Symptom management only
    - Radiation/chemotherapy and symptom management
    - Clinical trial
- The child must have died from the disease process.

Through this research, neither deception nor the use of placebo conditions were used to develop the research questions. The questioning pertained to the content of the established financial status, educational status, economic resources, survival time from diagnosis, and available financial resources used for treatment-related expenses. The questions allowed the participant to describe their lived experience and examine the choices made throughout their child's continuum of care.

The study was a retrospective review and the content of the survey did not address all possible treatment options. All the diagnosis of terminal cancer were made through diagnostic testing. Treatment options were selected independently of the study. Financial and treatment choices were made independent of the study. The inclusion criteria were purposefully chosen to coincide with the form of sampling chosen for the study. The criteria ensured that the population was appropriate, they could participate in a virtual-based study, and that they were able to comprehend a basic level of English to achieve meaningful results.

Limitations

The study describes the lived experiences of a specific and focused population of parents/guardians of children with terminal cancer. Due to the specificity, the phenomenological approach does not allow generalization of findings to a larger population with diverse circumstances. The study was initiated to inform future researchers and illuminate the need for additional research. Due to the retrospective nature of the study, there was no expectation that the participants had detailed financial records to validate their recall of medical bill amounts; if the participant did not have a copy of their financial records, I trusted their memory as true and accurate. The financial expenditures were categorized as either out-of-pocket medical treatment, nontreatment-related, or miscellaneous expenditures related to the child during the time frame and was to be estimated.

The questions were administered via virtual interview; therefore, the integrity of the responses cannot be validated. Some of the respondents may have responded based on their agenda to meet their personal needs. There may have been responses influenced by outside factors unrelated to the study.

There was a concerted effort to reduce the effects of these limitations. Participants were permitted to perform the interview in the comfort of their own homes virtually to allow for time to reflect on the questions in a safe and familiar environment. There is a paucity of participants as there are only 15,000 newly diagnosed pediatric cancer patients per year in the United States; capturing these participants in one place at one time would not be possible (Warren, 2020). Furthermore, of the 15,000 patients, only 2,250 are

terminal. The participants who are part of online bereavement support groups and social networking sites are comfortable sharing their experiences and were identified as the target participant pool. Where limitations are present, future opportunities exist for identifying the impacts that terminal cancer can have on the qualified participants.

Significance

The results of the study may be significant to two key groups for several reasons. Cancer treatment team members, such as providers, researchers, and social workers, are the largest benefactor of the results of the study. The study could be meaningful to those in the pediatric cancer field. The second group to benefit from this study are the families of children diagnosed with terminal pediatric cancer. My results provide data to a discussion point on supporting and informing clinical decision making for families of terminal pediatric patients. Furthermore, I provided actionable data to help guide and provide context for factors impacting medical decision making about treatment plans and participation in clinical trials.

I also illuminated how hope, or the lack thereof, can affect financial choices related to the care of children with terminal cancer. I explained how and why certain medical treatment options are chosen based on the level of hope and the prospect of successful treatment through clinical trials and other treatment modalities. With the information provided, the family can decide whether making the trip for clinical trials is worth the financial costs if they must bear the burden, or if their resources should be used in other ways. Through the study, I examined hope, risk versus reward, the prospect of outcomes, and the cost to care for the child with terminal cancer before the end of life.

A complete review of these costs could provide the pediatric oncology field with a better understanding of the impact on parents of terminal pediatric cancer patients and how the concepts of hope and prospect affect medical treatment choices and fiscal consequences. This understanding may motivate better planning to improve both financial resource utilization and treatment goals. My results provide insights into the impact that hope can have on medical treatment choices and inform both parents and providers of terminal pediatric cancer patients on the best way to balance treatment goals and resource utilization.

Summary

Cancer is one of the top three leading causes of death in the pediatric population (Center for Disease Control, 2019). Much is known about the effects of cancer physiologically on the child; however, there is a lack of studies investigating how the concepts of hope and prospect impact medical and financial decision making by parents/guardians of terminal pediatric cancer patients. The most common types of cancer contributing to mortality for adolescents are lymphomas, leukemia, and brain, bone, and soft tissue cancers (Delinge et al., 2020; Findelberg et al., 2020; Rutkowski et al., 2019; Withrow et al., 2019). Parents of children with a terminal cancer diagnosis must make difficult decisions related to treatment (Keshvani et al., 2019; Maggiore & Godes, 2020; Sherestha et al., 2019). One of the most challenging decisions is to enroll their child in a clinical trial. Each clinical trial has inclusion criteria; they typically consist of therapeutic radiation, some form of chemotherapy, and symptom management (El-Kouley et al., 2019). These clinical trials provide novel treatments available to select patients based on

the clinical trial criteria Furthermore, they deliver a measure of unpredictability and may provide the family with hope. For the parents and guardians of terminal pediatric cancer patients, critical drivers of the treatment choices made, and other related expenditures need to be identified . What was not known was how the level of hope and prospect of a cure guide the medical decision makers' choices in this population. By using the theoretical framework of Snyder's hope theory and Kahneman and Tversky's (1979) prospect theory, I aimed to obtain a better understanding of what drives the financial choices made by the parents and guardians of children with terminal cancer. By identifying the various levels of hope of the participants along the continuum of the disease, I aimed to provide context for the financial expenditures they incur.

I examined how financial decisions are made based on the hope and prospect through the goals of care that the parents/guardians have for their child. This knowledge could allow for more precise and appropriate communication of expectations during participation in clinical trials and the previously unidentified costs associated with them. By understanding the context of what impact treatment goals have on hope and prospect, the healthcare team and clinical researchers can provide achievable goals. I aimed to demonstrate whether and how the goals align with the parent/guardian's ultimate pathway in the context of their financial expenditures. Chapter 2 provides a review of the existing literature on terminal pediatric cancer and hope in the context of the families of the pediatric patients with terminal illness.

Chapter 2: Literature Review

There is an abundance of information on the physical implications of various types of terminal pediatric cancer (Cheung et al., 2021; Marusak et al., 2018; Nathan et al., 2019; Siegal et al., 2020; Warren, 2020). In addition, there is an abundance of literature examining the costs of care related to the treatment of pediatric cancer (Amandeep et al., 2018; Galtieri et al., 2022; Lansun et al., 2019; Maggiore & Godes, 2020; Santacroce et al., 2018; Weisman et al., 2018). Fatal forms of cancer have many adverse effects on patients and impact those caring for the patients. These impacts affect employment status, financial expenditures, and treatment options chosen on the patient's behalf (Cheng et al., 2020; Schroeder et al., 2019; Vaccaro et al., 2019).

In this study, I aimed to provide context for the financial decision making of parents/guardians of children with terminal pediatric cancer through the application of the hope and prospect theories. The economic burden for transportation, daily care, and underemployment fall on the parents/guardians. The questions asked in the study were related to what drives parents' or guardians' decision making based on hope or the prospect of achieving a predetermined goal. I sought to understand the lived experiences of the parents/guardians of terminal pediatric cancer patients to better inform treatment goals conversations for the families of children who are diagnosed with terminal cancer in the future.

The literature review provides clarity on current knowledge about hope, healthcare, prospect, decision-making, financial decision making in the face of a terminal illness, and the disease and its effects on the child's functioning. In the literature review, I

examined what is understood about what impact the condition, associated financial costs, outcomes, and treatment choices have on the parents/guardians of terminal pediatric patients.

In the literature review, I describe the impact of pediatric cancer and statistics related to the disease. I then discuss what effects the condition has on the quality of life of the child and how these effects impact the parents/guardians. The financial implications of care for terminal pediatric cancer patients and patients with other similar terminal illnesses are then focused on. The next aspect examined in the literature is the theoretical framework and applications to various settings.

Literature Search Strategy

The strategy I used to conduct the literature search included using various search engines, including PubMed, CINAHL, Medline combined search, ProQuest, ProQuest Science Journals, Science Direct, Sage Journals, Academic Search Complete, and the Cochrane Database. The search terms and phrases used during the literature search included the following: *pediatric cancer, leukemia, lymphoma, brain cancer, bone cancer, soft tissue cancer, pediatric cancer clinical trials, leukemia treatment, lymphoma treatment, brain cancer treatment, bone cancer treatment, radiation, leukemia diagnostic testing, lymphoma diagnostic testing, brain cancer diagnostic testing, soft tissue cancer diagnostic testing, pediatric chemotherapeutic drugs, pediatric cancer treatment costs, insurance coverage and pediatric cancer treatment, pediatric cancer financial impact, catastrophic insurance limits, copays, pediatric cancer statistics, prospect theory, Snyder's hope theory, Snyder's hope scale, hope and dying, hope and decision making,*

hope and terminal cancer, terminal illness and hope, financial burden in cancer, caregiver role strain, hope versus expectation, hope and medicine, hope questionnaires and financial, and *medical questionnaires*. I used these terms and phrases in various forms to achieve the results of the literature review. I have made every effort to restrict all literature to publication within the past 5 years. If the source was published outside of this time frame, I used it only for historical perspective or to review a seminal work topic. In addition to the sources provided in the online library for Walden University, I used the library catalog at the Department of Veterans Affairs to access journals that were not available through the Walden University Library.

Terminal Pediatric Cancers

Leukemias, lymphomas, brain cancers, bone cancers, and soft tissue cancers are the leading causes of terminal cancer deaths in children in the United States (Cheung et al., 2021; Marusak et al., 2018; Nathan et al., 2019; Siegal et al., 2020; Warren, 2020). Each type of pediatric cancer has unique characteristics, symptoms, treatment, and associated mortality (Delinge et al., 2020; Findelberg et al., 2020; Rutkowski et al., 2019; Withrow et al., 2019). The literature review on these cancers was performed to provide context for the families' experiences based on the unique features of cancers with which their children were diagnosed. According to Kaplan (2019), leukemia has various subtypes and originates from the body's hematopoietic system, including bone marrow, spleen, tonsils, and lymph nodes.

Acute lymphoblastic leukemia (ALL) causes more deaths in the population under 15 years old than any other form of cancer (Feng et al., 2021; Siegal, 2019; Yang et al.,

2021). The symptoms commonly preceding an ALL diagnosis can be either specific or non-specific. Shaverdi et al. (2020) described the nonspecific symptoms as cachexia and other more specific symptoms of weakness, general malaise, and anorexia. These specific symptoms are more impactful as they can significantly alter the quality of life for the child. Rico et al. (2020) further described specific symptoms as frequent infections of the skin, gastrointestinal, urinary, and respiratory tracts, with fever and hepatomegaly being the most prevalent symptom. Roger et al. (2019) described how anxiety and depression as symptoms can become relevant and impactful on the overall quality of life postdiagnosis. The treatments for ALL vary but focus on chemotherapy, stem cell and bone marrow transplantation, and radiation (Inaba & Pui, 2021; Rotz et al., 2020). Chemotherapy, a standard treatment modality for pediatric cancer, has been shown to have negative consequences and can lead to mortality due to cardiotoxicity (Elena et al., 2020). For leukemia, other compounding factors contribute to mortality. A study by Siliwa-Tytko et al. (2022) found that treatments for leukemia can also have severe side effects and indirectly contribute to mortality. Lymphomas are another form of cancer that contribute to the mortality rate in the pediatric population (Czogala et al., 2020; Siegal et al., 2020). Treating the disease to alter the terminal diagnosis is the goal for parents/guardians of terminal pediatric patients; however, symptom management is often the focus when a terminal diagnosis is determined. Roger et al. (2019) examined the symptoms and their effects on quality of life. Common symptoms related to ALL are fatigue, pain, fever, nausea, vomiting, depression, and sleep disturbances. The treatment for these symptoms is critical to optimizing the quality of life, especially fir terminal cancer patients.

Standard symptom management includes pharmacological and non-pharmacological interventions (Roger et al., 2019). Lymphomas are also a significant contributor to pediatric cancer mortality in the United States.

Lymphomas are a type of cancer that affects the body's immune system, including the lymph nodes, spleen, thymus gland, and bone marrow(Siegal et al., 2020). The main types of lymphoma are Hodgkin's lymphoma and non-Hodgkin's lymphoma. Non-Hodgkin's lymphoma has a higher mortality rate of 15% versus Hodgkin's lymphoma, which has a 5% mortality rate (Siegal et al., 2020). The symptoms of non-Hodgkin's lymphoma are fatigue, weight loss, and swollen or enlarged lymph nodes. Chemotherapy, radiotherapy, immunotherapy, tyrosine kinase inhibitors, and stem cell transplants are all accepted therapies with favorable outcomes (Craig et al., 2021; Colanco et al., 2020; Di et al., 2020; Heroes et al., 2021; Thurston et al., 2021). Although ALL and lymphoma are significant pediatric cancers, bone, soft tissue, and brain cancers also impact overall pediatric mortality.

Brain cancer accounts for 25% of all pediatric cancer deaths in the United States and has increased in prevalence over the past decade (Siegel et al., 2019). There are various types of brain cancer, with varying levels of associated mortality. Central nervous system cancers, neuroblastomas, and astrocytoma's are highly lethal and challenging to remove surgically. The only treatments are chemotherapeutics, corticosteroids, and radiotherapy. Although there have been advances in treatments over the past decade, no meaningful impact on outcomes has been reported. The symptoms are usually depressive to the central nervous system. The symptoms are often caused by hydrocephalus or

crowding due to the size of the tumor. Crowding can cause disturbances to various systems, vision, balance, sensation, bowel and bladder control, the ability to protect the airway, headaches, and general motor function (Elhemaly et al., 2022). These symptoms require significant intervention from dietitians, occupational therapists, and physical therapists to maintain the optimal quality of life for brain cancer patients (Hansesn, 2020; Ovans et al. 2018; Schwartz et al., 2018). Brain cancer is impactful to the overall mortality of pediatric cancers; however, less significant contributors exist, such as bone and soft tissue cancers.

Bone cancers account for 9% of all pediatric deaths in the United States and only 1% of the total cancer incidence (Siegel et al., 2019). Bone cancer symptoms include bone pain, swelling, and tenderness in the affected area, weakened bones, frequent fractures not resulting from severe trauma, fatigue, and unintended weight loss (Lunk et al., 2020). Treatments for bone cancer include surgery, chemotherapy, and radiation therapy, depending on the form of the bone cancer (Geyikoglu et al., 2019; Zambanini et al. 2021). The final prevalent type of cancer that is a significant contributor to the pediatric cancer rate is soft tissue cancers.

Soft tissue cancers are responsible for 7% of pediatric cancer deaths in the United States annually (Siegel et al., 2019). Common symptoms of soft tissue cancers are pain, fatigue, insomnia, nausea, and vomiting (Deng, 2019). Treatments for soft tissue cancer depend on the stage. According to the American Cancer Society (2020), these treatments are surgery, radiation, chemotherapy, and other targeted therapeutics. These forms of

cancer have financial, psychosocial, and physical impacts and affect families in multiple ways.

Understanding the clinical consequence of the disease allows for a better understanding of the experiences that the child with these various forms of terminal pediatric cancer encounter and that the parents must consider when making treatment decisions. The literature demonstrates the incidence of the various cancer types and provides context to what the children and parent/guardian will experience.

Caregiver Role Strain

In terminal illness, there is a disease-associated physiological decline in the patient for which they require supportive measures usually provided to them by their immediate family. The family must take on the caregiver role for the child (Eche et al., 2020; Galtieri et al., 2022; Hampton & Newcomb, 2018; Jibb et al., 2021). The family members of a terminally ill child become caregivers to provide necessary assistance with ADLs and other supportive therapies (Eche et al., 2020; Hampton & Newcomb, 2018). Nicklin et al. (2019) discussed how some forms of brain cancer present a unique set of circumstances for the caregivers to address. Each form of cancer has its challenges; patients may experience paresis, pain, nausea and vomiting, visual loss and decline, sensory reduction or loss, cognitive decline, reduction or loss of primary motor function, and the inability to swallow, eat, and perform basic tasks. Within the family unit, these changes can have significant psychological, financial, and emotional impacts, leading to caregiver burden and role strain (Eche et al. 2020; Galtieri et al., 2022; Hampton & Newcomb, 2018; Keim et al., 2021). The new roles of the family as caregivers result in

changes to the traditional flow of household responsibilities. Combining these new responsibilities with other fixed responsibilities, such as work, school, and personal commitments, results in conflicts that have both a physical and psychological impact on the caregivers (Galtieri et al., 2022). The caregivers must develop new skills depending on the symptoms experienced by the child. The family may require education on aspects of care such as aspiration precautions, gait training, use of assistive aids, bowel care, pressure sore prevention, proper diet, gastric tube care, tracheostomy care, nasal gastric tube care, medication administration, safe patient handling techniques, proper use of medical equipment (Hampton & Newcomb, 2018). According to Hampton and Holcomb (2018), of the most frequent effects of caregiver role strain, depression has the most significant impact; however, physiological effects are also reported. These physical impacts are typically related to the increase in focus on their loved one and the lack of attention to their physical health (Eche et al., 2020; Hampton & Newcomb, 2018). Studies have examined the caregiver role and the factors that can reduce role strain. There is a direct connection between the knowledge of what to expect, how to perform their new duties, and basic education on the disease process leading to a decrease in the levels of stress and depression (Hampton & Newcomb, 2018; Keim et al., 2021). Based on future goals and expectations, the family must balance what is possible for them to provide as caregivers based on their knowledge about the disease process, necessary treatments, and the expected outcomes and duration of the role of caregiver.

What the family experiences while caring for their terminal child is important to understanding possible motivations to decisions made. The parent/guardian witness first

hand what the child is experiencing while simultaneously experiencing the taxation of the requirements necessary to meet their child's need. In order to understand the lived experience, we must understand more than just what the child experiences due to the illness, but what the parent/guardian of the terminal child experiences as direct result of the responsibility of meeting the child's needs.

Financial Impact on Families

Finances are essential in providing access to medications, clinical trials, and access to care and symptom management for patients with terminal cancer. Financial resources are relevant to the family's ability to maintain their economic status while ensuring the selected course of care. Informed decisions based on what type of care will be needed, where the care is to take place, insurance status and coverage, care-related costs not covered by insurance, and other out-of-pocket costs all affect the financial health of the family with a child with terminal cancer (Hong et al., 2020; Huey et al., 2021; Rai et al., 2020). Factors such as education, insurance status, employment status (full-time, part-time), family unit makeup, income level, disposable income, cost of living, and distance to care centers comprise the variables relevant to assessing the resources that are available to the family of the terminal pediatric cancer patient (Hiyoshi et al., 2018; Kazak et al., 2018; Robertson et al., 2019; Smith et al., 2019). Employment status is often affected when parents become caregivers for their children with cancer (Duimering et al., 2020; Kazak et al., 2018). A study by Lentz et al. (2019) discussed the implications that having a child with a terminal illness can have on parents and their employment status in the short and long term. They revealed short-term effects on the

employment status of both mothers and fathers. Fathers were able to recover to their prior to diagnosis financial status reasonably quickly; in contrast, mothers tended to experience longer-lasting economic damage due to the care requirements of parents of a child with cancer. Hiyoshi et al. (2018) discussed the family unit structure as relevant when assessing the financial impact of caring for a child with cancer. In single-parent households, the economic impact was significantly greater than in dual-income family units in which a mother and father were present. Hiyoshi et al. also discussed the effects of social benefits reducing the financial burden for the families of pediatric cancer patients, such as state food, housing, insurance, and other social benefits provided when employment status changes due to caring for a child with cancer.

The presence and type of insurance are essential determinants of how much financial impact and psychological distress the disease will have on the family unit regarding care-related costs (Santacroce et al., 2020). Insurance can be categorized as private or public and can vary according to the amount and types of care that are covered (Chiu & Yang, 2019). Chiu et al. (2019) highlighted that with the growing healthcare costs in the United States, resources to assist with the financial impact of having a child with cancer have become limited. The Patient Protection and Affordable Care Act was intended to assist in reducing the catastrophic financial impact of ensuring that children receive cancer care by removing the lifetime limit placed by insurance companies. However, the effect remains understudied, as identified in the literature review.

Insurance coverage often determines the level, location, and quality of the care provided to cancer patients (Diaz & Pawlik, 2021; Rai et al. 2020; Yabroff et al., 2019).

The type of health insurance the parents possess determines how much out-of-pocket healthcare-related expenses they will incur (Boo-Pathy et al., 2019; Rai et al., 2020; Santacroce et al., 2020). Insurance coverage may determine the provider they use, identified as "in-network" or "out-of-network." Most health insurance now includes coverage for out-of-network providers. The coverage aims to help reduce healthcare costs and even improve quality; however, treatment still results in high out-of-pocket expenses (Nicolas, Olivera, Fitzgerald & Beverley, 2020; Tran & Zafar, 2018). Insured families may experience high unexpected and unreasonable out-of-pocket costs due to inaccurate information on network participation, lack of clarity regarding out-of-pocket costs, less than adequate provider networks, and utilization of out-of-network providers at in-network hospitals (Carrera et al., 2018; Tran & Zafar, 2018). Having public insurance results in even more challenges for cancer patients. A study conducted by Kehm et al. (2018) demonstrated that patients with cancer who had secure socioeconomic status experience far better outcomes that those that were economically disadvantaged. One of the most significant differences in insurance types is the healthcare-related out-of-pocket expenses and the non-healthcare-related expenses incurred during the continuum of care for terminal pediatric patients.

Education also correlates with the financial impact of the disease and the financial recovery of the parent over time (Eveans et al., 2023; Kazak et al., 2018; Hiyoshi et al., 2018; Rai et al.2020; Santacroce et al., 2020;). Evans et al. (2023) reported that changes in employment place and status usually occur following a cancer diagnosis in a child, regardless of education level, but impacts in less educated parents far outpace those in

parents possessing higher forms of education. However, during the recovery period after remission or death, the parent with a higher level of education can usually recover financially within a few years. Furthermore, the level of education coincided with higher pay and more substantial social structures in place for the family (Lentz et al., 2019). Education is positively correlated with the ability to provide a stable income. However, Hyoshi et al. (2018) reported that gender also plays a role, as men typically tend to earn more, experience less of the financial impact of the cancer diagnosis and recover more rapidly than women. In addition to education, insurance status is a critical determinant of access to treatment for cancer patients.

Treatment-related out-of-pocket expenses, underemployment, and unemployment lead to financial hardship. According to Gordon (2018), on average, cancer costs $5,000 annually for out-of-pocket medical expenses related to treatment. The costs do not include the maintenance of the monthly premiums required to maintain coverage, and the cost of premiums varies based on the coverage.

Furthermore, the ambiguity of coverage may confuse the insurance policyholder. Providers often do not publicize their fees, and insurers typically do not provide out-of-pocket reimbursement information to their patients (Nicolas, Olivera, Fitzgerald & Beverley, 2020). These expenses are solely related to care provision and do not account for the costs associated with transportation, food, lodging, and memory-making costs often accompanying pediatric terminal illnesses.

There are many aspects of treatment and non-treatment-related activities that contribute to out-of-pocket costs for cancer patients (Lentz et al., 2019). A study

conducted by Lentz et al. (2019) reported that, on average, cancer patients and their families incur out-of-pocket costs resulting that significantly impact their income. Using out-of-network providers can largely be determined by proximity to appropriate providers. Cancer treatment centers are not traditionally close to the patients they serve. Proximity to care is essential to the level of success and consistency of appropriate treatment (Ringstrom et al., 2018). Cancer patients must travel to not only receive standard radiation treatments but to participate in clinical trials. The cost of travel depends on the location of the cancer center relative to the patient's residence; therefore, the cost of travel varies significantly between families. A study by Coumoundouros et al. (2018) examining the indirect costs of cancer-related treatment revealed the financial impact that travel can have on the out-of-pocket expenses that cancer patients and their families incur. However, there are many other forms of costs. According to Coumoundouros et al. (2018) and Galtiere et al. (2022) travel, food costs during travel, time lost from work, making memories, lodging, and seeking novel treatments are all significant costs related to the diagnosis and treatment stage of the cancer. Iragorri et al. (2021) reported that the average the out-of-pocket cost for cancer care is $2,500 per month in the United States. The duration of the illness from diagnosis to demise directly impacts the financial burden experienced by the family.

The literature surrounding the various considerations for what is supportive or prohibitive of financial wellness in the presence of sever illness was vital to present. The parent/guardian of the terminally ill child must navigate the financial forces that are present and consider the resulting impact based on the plan of care selected.

Understanding the weight of the financial forces are provided to allow insight into the treatment selections made.

Justification of Framework

Through the literature review, several themes have been identified as it relates to the application of the Snyder's hope theory as well as concepts of hope in the population of pediatric cancer patients and their families. A study performed by Rafferty and Beck (2020) in which they examined understating concepts of hope and hopelessness in medically complex children. This study focused on how parents sustain and maintain hope while navigating complex care transitions and decisions for their child. The study demonstrated the appropriateness of the application of Snyder's hope theory to the examination of the lived experience of parents navigating the health care setting and the impact of external factors. A study by Eche et al. (2022) sought to understand the protective factors created through the application of hope in the population of parents with pediatric cancer patients. This study identified several protective factors that support the sustainment of hope and decrease psychological stress. Another study assessing hope in this populations was performed by Sisk et al., (2021). This study examined the impact of the concepts of uncertainty has on hope in the population of parents/guardians with pediatric cancer patients. The results of this study described the impact of appropriate and clear conversations with the medical team, usually the doctor, could reduce the feeling of uncertainty and impact concepts of hope. This concept directly aligns to clarity of pathway to achieving a goal as described by Snyder's hope theory. Another study that supports the use of Snyder hope theory as the framework for this study is the study by

Kaye et al. (2020) in which the conflict between hope and realism in accepting the prognosis and likely outcomes. This study provided context to the fluid concept of hope and its impact on the parents of pediatric cancer patients. These studies all support the application of a framework of hope and the various types of impact that it can have in this population. Although these various studies provided some foundational examination of hope in this setting a gap in understanding the impact of hope on goal setting through the application of Snyder's hope scale was not pursued and left open for future studies. This study aims to fill this specific gap in the literature. This study further seeks to understand, though comparative framework of applying Snyder's hope theory and Kahneman and Tversky's prospect theory and concept of risk versus reward as it applies to the decision-making process of pursuing a care goal. Does one framework weigh heavier than the other as critical decisions are made while establishing the goals of care.

The concept of risk versus reward has robust literature. In pediatric field of pediatric cancer as aforementioned, there are many novel therapies available to the pediatric cancer patient. The conundrum faced by parents and guardians is what method of treatment they should select. Recently there have been several studies that support the very specific application of the concepts of risk versus reward as described by Kahneman and Tversky's prospect theory. Johnston et al. (2020) examined end of life care in pediatric cancer patients. This research sought to understand utilizing qualitative analysis what clinical treatment selections were made by the parent sand guardians. This study was focused on understanding what support is needed as this population reaches end of life and what type of treatment choices are selected to better understand and support the

parents. This study demonstrated that in some cases, even when death was imminent, aggressive treatment choices were made by some parents but not by others. This supports seeking to better understand the rationale behind those decisions in future studies. Novel therapeutics and clinical trials introduce a dynamic of risk versus reward. The therapies are often not yet proven, but they have shown promise in early-stage clinical trials. Pearson et al. (2022) describes that with new early-stage therapeutics, parents must decide does the risk and associated side effects warrant the potential reward of the possibility and not guarantee of improved longevity or quality of life. The concept of risk versus reward does not only extend to the course of care, but also the future potential for future financial toxicity as result of the treatment selections made. Oberoi et al. (2022) performed a review on the influence of socioeconomic factors as it relates to decision making process about support of the siblings of children with cancer. This examines the impact of the care and how socioeconomic factors play a role in the decision making. This approach supports this studies analysis of the concept of risk versus reward in the treatment decisions of the terminal pediatric cancer patients. Previous studies have leveraged the concepts and hope to answer questions surrounding the lived experience of the families of pediatric cancer patients. No studies however have sought to understand what theoretical framework if most applicable in understanding the treatment selections and their corresponding financial impacts. This study seeks to build on concepts laid out in previous studies to fill gap that can better inform the goals of care conversation and a more support program for the parents of terminal pediatric cancer patients.

Summary

The literature is clear on a few key points regarding pediatric cancer. Several forms of pediatric cancer are responsible for the most cancer-related deaths in the United States (Siegal et al., 2019). There are several treatment options based on the treatment goals chosen by the parents of the terminal pediatric child. The costs related to the treatments dictated by the treatment goals can result in significant out-of-pocket expenditures for families. There is sparse knowledge on the impacts that these choices have on the treatment goals and the resulting financial burden. The effects that cancer has on the pediatric patient often cause family members to alter their employment status to take care of the child. Some cancers can cause the child to require total care and assistance with ADLs (Walker, 2020). Taking care of a loved one can negatively impact the caregiver, which is referred to as caregiver role strain (Eche et al. 2020; Galtieri et al., 2022; Hampton & Newcomb, 2018; Keim, et al., 2021; Liu et al., 2020). In addition to the psychological aspects of caring for a terminal child, there are financial factors to consider surrounding medical and non-medical out-of-pocket costs (Coumoundouros et al., 2018; Gordon, 2018; Hyoshi et al., 2018; Kazak et al., 2018; Santacroce & Kneipp, 2019; Santacroce et al., 2020; Rai et al., 2020; Warner et al., 2014). The concept of hope and death is extensively studied in the literature. Snyder (2002) developed a method to quantify hope using a Likert scale based on the ideas of agency, pathway, and goals. Achieving a cure, prolonging life, and symptom management are all goals that families of terminal cancer patients experience. However, it remains unclear how hope and the prospect of a cure or health maintenance affect the financial decision-making of the

families of children with terminal cancer related to their level of hope along the continuum of the disease process. Answering this will illuminate the gaps identified in the literature review.

In the next chapter, a description of the study process and procedures will be provided. The next chapter will define the research methods that are used in this study. Furthermore, it will outline the design and rationale of the study. An explanation of the participant selection criteria will be provided. Equally as important as the design and participation criteria, the next chapter will also describe the composition of the quantitative instrument utilized to conduct the study and how the data will be analyzed.

Chapter 3: Research Method

The purpose of this study was to provide context for the lived experiences and financial decision making of the parents/guardians of children diagnosed with terminal cancer, from diagnosis to demise. Using phenomenology to allow the parent/guardian to describe their lived experience in their own words provided insights that would not be possible to elicit from a quantitative study. Framing the research through the lens of the prospect and hope theories allowed me to perform a meaningful evaluation regarding how information is processed, how hope is derived, and its impact on decision making. I aimed to promote social change in how information passes to the child's parent/guardian. By examining the lived experiences and compiling themes in decision making, I provide context for the treatment goals conversation that every parent must have with the healthcare team postdiagnosis. These discussions could improve and inform decision making and hopefully reduce the economic harm resulting from choosing more aggressive and expensive therapies that may not result in extension or enhancement of the quality of life.

The literature review revealed a paucity of studies regarding medical decision-making in terminal pediatric patients (see Baumbusch et al., 2018; Crespo et al., 2020; Li & Champan, 2020; Robertson et al., 2018; Sisk et al., 2020). The selected studies examined decision making, but not through the lens of hope and prospect. These studies addressed concepts of regret, desire to be involved in decision making, and a systematic review on shared decision making with patients (see Baumbusch et al., 2018; Crespo et al., 2020; Li & Champan, 2020; Robertson et al., 2018; Sisk et al., 2020). Through the

literature review, no research examined through the lived experience how and why chosen treatment and other resulting financial decisions were made by the parents/guardians of terminally ill pediatric patients. The selected design was chosen to allow for the participants to define their lived experience through their own words and provide insight into their decision making, without the bias of inference.

Research Design and Rationale

The research design chosen for this study was a qualitative phenomenological approach. This approach was chosen based on its ability to guide the collection of experiences of the participants and organize them into themes that can provide context to the phenomenon being discussed. Nuebauer et al. (2019) stated qualitative phenomenological design allows for researchers to remove the bias of assumption about a phenomenon and transition into a deep understanding of how the participants lived experience interacts with the stimuli of the phenomenon being researched. The format of the interview in qualitative phenomenological research is critical to ensure that the data coding and analysis are meaningful, and the participants are free to describe their experience and are not led to a preformed conclusion through researcher bias (Cypress, 2018). The purpose of using the qualitative phenomenological research design was to understand, through the interviews, the lived experiences of the parents of terminal pediatric patients and the factors that impacted their decision making regarding financial and care needs. The approach focuses on examining a phenomenon that previously occurred or is ongoing with additional experimental factors (Errasti-Ibarrondo et al., 2018). Halling (2020) described phenomenology as the best method for understanding

human nature by allowing subjects to describe their lived experiences by elaborating and expressing their experiences through their own words. By providing the opportunity for participants to describe their experiences without forcing them to choose from a set of answers or encouraging them to compress their thoughts into a short answer, the participants are free to describe all the factors and experiences that affected or are currently affecting them through their lived experiences (Zahavi & Martiny, 2019). The qualitative research approach helps a researcher analyze data through observation and documentation of language via the open expression of a subject's experiences (Levitt et al., 2018). Furthermore, qualitative studies provide a systematic approach to acquiring in-depth data and conceptualizing the meaning of this data (Braun & Clark, 2022). The advantages of qualitative and phenomenological design allow for open-ended questions surrounding the parents' healthcare financial decision making. The themes identified through the subjects' explanations provided a context for a phenomenon affecting the lives of at least 2,500 families each year (see Siegal et al., 2018).

The research questions chosen to guide the focus of the study are as follows:

RQ: How are medical-based financial decisions made by the families of terminal pediatric cancer patients using the lens of hope and prospect?

Sub question 1: Were the healthcare and financial decisions made based on the concepts of agency, pathway, and goal, as described by the hope theory?

Sub question 2: Are the financial choices made in the care of terminal pediatric cancer patients' representative of the concepts of risk versus reward, as described by the prospect theory?

Role of the Researcher

Through the research data collection and interview processes, I documented observations, perform the interviews, and collect the data relevant to the research questions. Through the interview process, I asked questions focused on eliciting open-ended dialogue regarding the decisions made for the treatment and other related expenditures for the children diagnosed with terminal pediatric cancer. To prevent bias in the research, I implemented safeguards to protect the validity of the study through the application of risk of bias assessment. The assessment exposed or ruled out various forms of bias, such as selection bias, information bias, analytical bias, and confounding factors. Stone et al. (2019) suggested using safeguards, such as equal ascertainment, equal implementation, equal prognosis, equal recruitment, equal retention, sufficient analysis, and temporal precedence, to protect against research bias. Building these concepts into the research methodology protects the validity and meaningfulness of the study. The interviews were recorded to ensure the integrity of the communication. Following transcription of the interviews, the participants had the opportunity to review them for accuracy and to clarify the content of their interview and my findings. In addition, I ensured that the consent form is thoroughly reviewed and signed before the study's commencement.

Methodology

Participant Selection

The participant selection criteria are grounded in the phenomenon that the study aims to understand. Mello (2021) described the importance of appropriate population

selection to ensure that the selection criteria target the accessible populations after specifying the general population using sampling methods to ensure proper sample size and complexity. To achieve the appropriate sample, I chose to use purposive sampling, which is the process of selecting participants who are knowledgeable about the phenomenon (see Gill, 2020).

The participants in the study were either the parent or guardian of a child diagnosed with terminal pediatric cancer. Participants in the study were recruited through various social communities for grieving parents of pediatric cancer victims. This method allowed me to access to participants who met the specific participation criteria. The inclusion criteria of the study were

- The child of the participant must have succumbed to their terminal illness within the past 5 years before participation in the study.
- The participants are a resident of the United States; however, citizenship status and/or legal status will not exclude them from the study.
- The participant speaks English and has at least a fifth-grade level of reading comprehension to understand the consent form.
- The child's cancer diagnosis must have been confirmed by diagnostic testing.
- The participant must have access to a device supporting virtual video teleconferences.
- The participant must have chosen one or a combination of the three modes of care (symptom management, radiation, and chemotherapy, and or clinical trial) for the child.

The sample size was 11 participants. Albine and Korstjens (2018) asserted that fewer than 10 participants are required to reach saturation for phenomenological studies. Thematic saturation is achieved when no additional data are found or meaningfully achieved by collecting additional data by performing more interviews (Hennick & Kaiser, 2021). Understanding the required sample size to reach saturation will provide a rough approximation of how many participants are needed to ensure a robust understanding of the phenomenon. Once the participant pool is identified, they were contacted and provided with information on the interview process, interview date, research questions, research methods, and were provided with the consent form. The participants' selection criteria will be strictly followed to ensure consistency in the population in which the phenomenon is to be understood.

The participants were recruited through online pediatric cancer grieving social media sites to which I have been granted permission from the administrators to solicit participation for the study. Participants received an email with the introduction and intent of the study (Appendix A). The inclusion criteria, study explanation, and consent form were provided in the communication. If the members of the participant pool chose to participate in the study, they signed and returned the informed consent form. These steps allowed the individuals to move from the selection pool to the participant pool. Every measure must be taken to ensure that the participants can make an informed decision.

The interview questions were designed to draw attention to the critical factors of the study and allow for the participants to thoroughly discuss their lived experiences. Well-constructed interview questions with appropriate follow-up questions were used to

gather rich data. The focus of the interview questions were to explore the rationale for healthcare choices and what they expended resources on while caring for their child diagnosed with terminal cancer. The questionnaire had nine questions to build on each other and highlight the experience from diagnosis to demise. The questions were then coded to monitor for saturation. The data collected through the interviews was analyzed using processes consistent with qualitative research design. Once saturation was reached, the interviews were stopped, and complete data analysis occurred. Data collection took place after each interview. No time limit was imposed on the interviews to allow whatever time was needed for the participants to describe their lived experiences based on the interview guide. The following sections describe what the research question is and how the study was carried out.

Instrumentation

The instrumentation used in the study was the semi structured interview. I administered the interview and used the Microsoft Teams platform to record and provide initial transcription. The semi structured interview lasted approximately 1 hour, depending on the participant. How the question instrument was developed was critical to the outcomes of the research. Elangovan and Sundaravel (2021) described the four phases of the instrument design: Stage 1, introduction; Stage 2, general information related to the topic; Stage 3, awareness and attitudes toward the phenomenon; and Stage 4, attitudes toward specific target objectives. Adequate attention and scrutiny occured in the design phase, ensured I as the researcher would experience less probability to encounter topic focus issues during the interview. Although a questionnaire was used to collect the data,

as the researcher, I was the instrument through which data were collected. As the vital instrument for collecting qualitative data, I had to ensure the integrity of the data collection by taking steps to mitigate instrument-as-a-researcher effects. Ensuring the prevention of instrument-as-a-researcher effects was achieved by using the funnel approach, as described by Wa-Mbaleka (2020). The questions were developed utilizing the funnel approach ensure the interview would start broadly and narrow to the topic of most significance to the study. As the instrument, I ensured that clarity was maintained throughout the interview. In addition to the guide, observation field notes were used. The method of data collection was not the primary data source; however, according to Phillipe and Lauderdale (2018), the instrument can provide support in constructing detailed descriptions of the study context, participant objective responses, and provide meaning to pieces of the interview.

The style of inquiry for the instrument was open-ended questions. If used appropriately, open-ended questions allow the participant to explore their experiences and describe them in a meaningful way (Wilvdasky & Hammer, 2018). In addition to the open-ended questions and the funnel approach, follow-up questions narrowed the focus to better meet the targeted objective. As questions were developed, emphasis on how the participant connects to the phenomenon, what impact the phenomenon had on them, and how they navigated the lived experience of the phenomenon were addressed.

To ensure that the instrument was appropriate and provided the depth of the lived experience, I had to ensure I asked the proper questions. The questions addressed what the participants thought about the phenomenon, what they felt during the phenomenon,

and a description of how they reacted to the stimuli of the phenomenon (Miles & Gilbert, 2008). Miles and Gilbert (2008) described additional steps for a successful semi structured interview, such as ensuring that the order of questions is logical/chronological, developing prompts if the participants go off-topic or need a gentle nudge to get back on track without leading the participant, and knowing the content of the questionnaire instrument thoroughly. The source of the data in qualitative studies is the interview, which can be either semi structured or unstructured (Berner-Rodoreda et al., 2020). The semi structured nature of the interviews in this study allowed me to address specific information while providing the participant with freedom to express their lived experience and provide robust data. The preference of the study was to perform face-to-face interviews; due to restrictions related to the pandemic that occurred concurrently with the study, the interviews were virtual. While creating the questionnaire, the following questions were essential:

- Are these questions easily understood?
- Do the questions make sense?
- Do the questions allow the participants to describe the desired subject and experience of the question freely?

As the data collection instrument and the instrument's author, I have researched aspects of a successful interview and am prepared to administer an effective interview. As described in the funnel method by Saheed et al. (2022), the interview should be opened by thanking the participant for participating, a brief description of the study,

disclosure of intent to record, and confidentiality procedures. In this phase of the interview, trust was gained, and expectations were made known.

After completing the content of the instrument, a debriefing occurred. The debriefing allowed the participant to clarify answers and ask about other aspects of the processes. Understanding the researcher's effect as an instrument in the interview provided self-awareness and greater adherence to effective interview strategies.

Procedure for Recruitment, Participation, and Data Analysis

After developing an effective instrument and mastering the instrument's content, the next step was to prepare the appropriate logistical considerations. These considerations concern what was needed for the interview to occur. For the study, access to either a smartphone, tablet, Chromebook, or laptop was required. In addition, access to the internet was necessary. However, because these participants were recruited through online grieving social media forums for parents of children having died from cancer, access was a logical assumption. The participants could either download the free application or access the web-based version from a computer; as the interviewer, I had the paid version of the application to make use of the recording and transcription functions. Instructions were provided for the participants to engage in the interviews in a quiet place that is free of distraction. The benefit of the virtual interviews is that the participants could engage from the security, familiarity, and comfort of their own homes. Another critical aspect of the interview was the opening. This provided an opportunity to engage with the participant and build trust.

The questions asked within the study focus on understanding the lived experiences of the parents/guardians of terminal pediatric patients related to medical/financial decision making. With the aim of achieving saturation at eight interviews, I recruited 14 participants for the study, but began with eight. The participant pool size ensured that if saturation was not achieved at eight participants, I could continue the research without interruption. The participants were selected through several Facebook pages dedicated to the patient population I intend to study. Prior to the interviews, I reached out to the site owner and received permission to question the participants when approval was provided for the study by the Institutional Review Board (IRB). Social media platforms have provided new access and opportunities for research. Green and Thorogood (2018) described how social media has become a part of daily life for many and has provided access to research participants in ways that were unintended in their creation. Because these sites often have specific groups based on similar experiences, religious and political views, and interests, a researcher can readily find a participant pool with a simple search. The ease with which these groups can be located makes purposive sampling more achievable.

After securing access to the specific population, I will sent a blast email to the participants who met the inclusionary criterion. The email introduced the study and provided baseline information for the potential participants to decide whether they were interested in participating in the study. After the email is sent to the potential participant pool, I will awaited the responses and established a participant list from the positive responses. Once the participants were selected, I will sent out informed consent forms for

them to review and sign. Informed consent ensured that the participants have been provided with the appropriate information about the study and can officially participate based on acknowledgment.

After collecting and verifying the informed consent forms, I scheduled the interview sessions with the participants. Step-by-step instructions on how to access Microsoft Teams were provided to each participant with contact information for technical assistance before the interview. The interviews lasted approximately 1 hour each and were conducted via Microsoft Teams. I chose to use Microsoft Teams for its ability to record audio and sound and transcribe data (Hubbard & Bailey, 2018). Once all the participants confirmed that they had the application downloaded, I began the interviews and collection of data.

After the first interview, I began collecting data. Once data saturation was achieved, I notified all the remaining participants, thanking them for their willingness to participate and informing them that their assistance is no longer needed. The Microsoft Teams application recorded audio from the interviews and transcribed conversations. I compared the transcripts to the recordings to ensure accuracy and to reduce error. Furthermore, I transcribed my field notes to improve the richness of the data obtained from each interview. I anticipated the process of interviewing, transcribing, and confirming the validity of transcriptions to take 12 weeks. Validity was confirmed through personal review. A copy of the transcript was also sent to the participant for review and concurrence. Once concurrence was received, all data was prepared for analysis.

Data Analysis Plan

The Interview protocol used in this study allows for a consistent experience, interview structure, and funneling approach to achieve rich data with deep meaning. Kross and Giust (2019) discussed the importance of establishing a plan and following the plan to ensure consistency. I prepared an interview protocol that was adhered to. With the data collected from the interviews, coding began promptly.

Through coding, I processed the data collected through the interviews and interpreted it to gain a better understanding of the phenomenon. Coding consisted of identifying and categorizing themes into a thorough description, including closing gaps in the data through instinctive understanding, and coding segments of text based on the researched phenomenon (Coates et al., 2021). Coding began at the highest and most intuitive level, which is known as open coding. In the first step of the coding process, I organized and created broad domains of themes for categorizing the data at an intuitive level (Williams & Moser, 2019). Utilizing the qualitative MAXQDA software, I entered all the data and allowed the software to assist with the process. In addition to using the software I completed manual coding to have interrater reliability. When attempting to determine codes, I will use the Who, What, Where, When, and How (5W-1H) method described by Flick (2019). This approach supports separating and organizing thematically similar data so that unique codes can be applied.

Coding occurred after each interview to apply meaning to the data collected during the interviews. Williams and Moser (2019) described the coding process as one that allows data to be amassed, categorized, themes derived, and sorted to derive meaning

using the three levels of coding: open, axial, and selective. MAXQDA Plus software will be used to assist in performing the coding functions.

Axial coding was the next step in the coding process. Axial coding differs from open coding as the coding moves beyond thematic categorization to identifying emergent themes and allows for further refining of the data (Williams & Moser, 2019). The process allowed for associations between open codes to be utilized to develop core codes. Archer (2018) described core codes as codes resulting from the overlapping of open codes showing correlation and strong evidence of themes present within the data. During this process, the use of both inductive and deductive approaches allowed for further refinement of the themes (Williams & Moser, 2019). After axial coding, selective coding can take place.

Selective coding is complex and must be performed with care. I used the software to input and interpret the data during the coding phase in addition to manual coding. Williams and Moser (2019) discussed how selective coding allows researchers to frame data to ensures greater thematic specificity. Selective coding categorized the data identified through axial coding into an overall theme to explain the story of the lived phenomenon. Data collation and interpretation of thematic consistencies was facilitated by the qualitative software and manual coding.

The software package I chose to use was MAXQDA for its ease of use and ability to input various data sources, such as audio, video, transcripts, surveys from Microsoft Excel, surveys from SurveyMonkey, and spreadsheets. The software was also able to assist in various coding functions, such as assigning codes, code organization, code

summary, and coded data search (MAXQDA.com). The data was visualized through the software program. The software was used throughout the coding process, during the different levels of coding. I then prepared results and conclusions based on the data analysis of both software supported and manual coding.

Issues of Trustworthiness

Qualitative studies are often criticized regarding their as there is an apparent lack of clarity on misunderstood aspects of the studies and how they are performed (Shufutinsky, 2020). To alleviate these concerns of trustworthiness, the researcher had to ensure process transparency. As a researcher, I am able to articulate the specific methods I implemented to ensure that trustworthiness was achieved. Through my description of the research design and implementation, the process, procedures, and potential bias were discussed. Safeguards to protect the trustworthiness of the study were present at every level of the study.

Credibility

The credibility of qualitative studies is rooted in the accuracy of the data, the participants' views on the data, and how the researcher interprets and presents findings (Fitzpatrick, 2019). Credibility is heightened when the researcher makes every effort to be transparent with the study participants. Credibility can be achieved by authenticating the research findings with the study participants (Shufutunsky, 2020). A good credibility test is whether individuals who share similar lived experiences can recognize and relate to the descriptions of lived experiences in the study (Liao & Hitchcock, 2018). Another way to achieve credibility is through triangulation.

To improve credibility, multiple checks and balances were used. A critical resource for accomplishing credibility was triangulation. In triangulation, researcher uses multiple external data collection methods focused on the same events, and the research is strengthened by applying multiple external analysis methods (Fusch et al., 2018). Triangulation occurred through the interviews, field notes, and observations of verbal responses surrounding the discussed themes. The strengthening of the data could not occur if these aspects of triangulation were considered independently.

Transferability

The nature of the study and the narrow focus of the research ensured transferability with a degree of certainty. The study sought to understand the behavior and decision making of a very narrow group. Future studies could expand the participants to include patients with various illnesses across the spectrum of health. I addressed the potential for transferability as I proceeded through the collection of data and analysis. Munthe-Kaas et al. (2019) stated that an effective indicator of the transferability of a study is the similarity of the participants' experiences to those of participants outside of the selected pool. Transferability means that I can remove the current pool of participants, insert another based on other factors, and obtain rich data to define the human experience (Munthe-Kaas et al., 2019).

Dependability

The dependability of the research resided in the research design and adherence to the design process. Brink (1993) listed four significant influences on the dependability of a study: the researcher, the subjects, social context, and methods of data collection.

Dependability was ensured by the researcher adhering to the research design and referring to the design for clarity. I ensured that the participants understood their role, the study's intent, and met all the inclusion criteria assist in supporting dependability. Data collection and analysis was the most significant aspect of ensuring dependability. Using audio recordings accurate transcription verified by the participants, and supportive software programs all contribute to dependability by ensuring transparency and reproducibility based on the process. To validate the process for collection and interpretation has met the required rigor, this study used an inquiry audit performed by an outside researcher. The inquiry audit allowed a PhD level auditor to review the process of collection and data interpretation to confirm the researchers practice fall within the professional norms (McGinley et al., 2021).

Confirmability

Confirmability in research is vital to establishing the trustworthiness of the findings. This is accomplished through ensuring the data are communicated in a way that the accuracy of the provided data and results can be confirmed by others (Nassaji, 2020). This was achieved through this study by providing step by step explanations for how the data was collected, coded and themes were developed. Providing the how for collection, analysis and interpretation allows for future researchers or those reviewing the study to confirm the conclusions based on the robust explanations of the data collection, coding and analysis process. Great effort was afforded to ensuring that the reader could follow the data from collection to analysis to draw the same conclusions and provide confirmability to the study.

Ethical Procedures

The primary source of ethical guidance for researchers' students at Walden University is through their Institutional Review Board (IRB). The IRB requires demonstration of protection of human subjects, ethical partnerships, alignment with universities social change mission and appropriate use of scholarly tools. Based on this information the IRB makes the determination if the study can proceed as is or needs adjustments or further clarifications (Walden University, 2022). Ethical procedures in research are a primary consideration to ensure integrity and trust in the final outcomes of the study (Paled-Raz, 2021). The IRB approved the ethical procedures for this study on March 27th, 2023. The IRB approval provided was 03-27-23 # 0190317. To build trust, participant confidentiality was built into the research methodology. To achieve reliable data from participants, their understanding that their identities will be protected allowed them to speak freely. Palys et al. (2018) stated that failure to ensure confidentiality has the potential to cause harm to the participants through consequences varying from public humiliation to loss of employment. To ensure confidentiality, considerations were taken to ensure that no personal identifying information was included in the published research. Personal identifying information includes birth date, name, employment, and social security number; I will take practical security measures, as described by Campbell (2018), such as storing data in a secured area with limited access, stripping personal identification data, and password-protecting electronic storage devices. The participants were given unique identifying number to protect their identity but allow the researcher to distinguish between the participants. Once my degree conferred, all information was

stored on a password-protected flash drive and will be stored for 5 years, after which time the flash drive will be erased and destroyed (Appendix B).

Another aspect of ethical research is the process by which informed consent is obtained. Informed consent refers to what and how information is communicated from the researcher to the participant in an accurate and easy-to-understand way to ensure that the participant understands what the study entails, its purpose, and potential implications (Simon et al., 2018). The participants were provided with an electronic form of the informed consent form (Appendix A). In addition, I verbally spoke with the participants to ensure that any questions were answered to facilitate their understanding. According to Klykken (2022), the informed consent process must involve communication of the purpose of the research, the right to decline participation at any time during the study, state any potential risks to the participant, the benefits of the research, confidentiality procedures, incentives for participation, and contact information for further questions. The informed consent document I choose covered these topics and provided contact information for follow-up clarification, if needed.

I had no association with any of the participants in the study. My employment status and job duties did not intersect with the topic of the study, as I work exclusively with adult veterans. I had no conflicts of interest. I ensured that all participants were aware of my education, clinical background, and role as a student researcher. There was no monetary incentives for the study. Furthermore, there was no scenario in which a power differential was present.

Summary

Through Chapter 3, I provided details pertinent to understanding my research design and rationale. I have described what was researched, how the participants were selected, how the data was collected and analyzed, and the ethical considerations that were practiced during the study. Furthermore, I explained how I maintained the integrity of the data analysis and the measures I took to maintain the confidentiality of the participants in the study. In the next chapter, I present the research findings based on the implemented the research design described in Chapter 3.

Chapter 4: Results

This study was derived from the need to understand the rationale behind medical treatment–based decision making by the parents and guardians of terminally ill pediatric patients and the weighting of the corresponding financial impact of those decisions. This was a qualitative phenomenological study that examined the lived experience of the participants through their own words, including descriptions of their thoughts and actions during their child's battle with terminal cancer. I aimed to answer the following research questions.

RQ: How are medical-based financial decisions made by the families of terminal pediatric cancer patients using the lens of hope and prospect?

Subquestion 1: Were the health care and financial decisions made based on the concepts of agency, pathway, and goal, as described by the hope theory?

Subquestion 2: Were the financial choices made in the care of terminal pediatric cancer patients representative of the concepts of risk versus reward, as described by the prospect theory?

In this chapter, I present a summary of the study findings. To understand how the results were derived, I also include explanations of the demographic data, data collection, data analysis, study setting, evidence of the study's trustworthiness, and the unabbreviated results. Through the phenomenological view, the participants in this study described their lived experience of medical decision making for their child with a terminal cancer diagnosis. These participants described their lived experiences of facing difficult treatment choices to determine the appropriate care path and whether to

approach their selection through the lens of hope or prospect. The results are based on themes that emerged through the interviews of the 11 participants who experienced the diagnosis of terminal cancer for their child who subsequently died from the disease. This study was intended to provide clarity about the medical decision-making process for the parents of pediatric cancer patients and possible pitfalls based on their reflections on lived experience. The themes that emerged provide context and clarity to the rationale and reflection of medical decision-making and answer the central research question and subquestions related to this specific population.

Setting

Once participants responded to the request for participation, posted with the permission and letter of cooperation of the social media site moderator, I sent the consent form for review and concurrence. After the signed consent was received back, the interview date and time were scheduled by the participant. The scheduled interviews were conducted via the virtual Microsoft Teams platform. This platform requires access to a smartphone, mobile device, or computer, which I assumed was possible since the participant pool being derived from social media. Microsoft Teams also allows for recording and automatic transcription of the interview, which was agreed upon as a condition of participation. The interviews were conducted after establishing the privacy of the participant's location and their ability to interview uninterrupted for 60 minutes. Although scheduled for 60 minutes, no interview lasted longer than 40 minutes. To begin the interviews, I asked general conversational questions about where the participants lived, how the weather was, and how their week had been. Once rapport was established,

I explained the process for the interview and advised that I would begin recording, start with demographic questions, and then proceed to the interview questions. All interviews took place with the participants in either their home or their private work office, with me in my home office.

Demographics

The participants were from various socioeconomic classes, education levels, and locations around the United States. Their singular commonality was that their child or dependent had been diagnosed with and died from cancer. The identity of the participants was protected by the creation of questions that would not allow others to identify them through deduction. To further protect the participants from being identified, the social media platform from which they were recruited was not included. The participants were labeled with an alphanumeric system that removes any personally identifiable information and replaces it with a combination of letters and numbers that only the researcher can access and is password-protected for added security (Table 1).

Table 1

Demographics of Parents and Guardians

Participant ID	Gender	Employment before dx	Employment after dx	Education	Insurance status	Income	Type of cancer
A101	F	Employed	Decreased	Master's	Insured	>100k	Brain
A102	F	Employed	Unemployed	Bachelor's	Insured	51k–70k	Bone
A103	F	Employed	Decreased	Master's	Insured	>100k	Bone
A104	F	Employed	Employed	Ph.D.	Insured	>100k	Soft tissue
A105	M	Employed	Employed	Bachelor's	Insured	51k–70k	Leukemia
A106	M	Employed	Unemployed	Master's	Insured	51k–70k	Brain
A107	F	Employed	Unemployed	High school	Insured	0–25k	Bone
A108	M	Employed	Unemployed	High school	Insured	0–25k	Lymphoma
A109	F	Employed	Unemployed	High school	Insured	0–25k	Lymphoma
A110	M	Employed	Decreased	High school	Insured	26–50k	Brain
A111	M	Employed	Unemployed	High school	Insured	0–25k	Soft tissue

Data Collection

The data collection was performed following review and approval by the Walden University Institutional Review Board, granted on March 27, 2023. The participants in the study were recruited through an advertisement placed in bereavement social media groups for parents of children who have died from terminal cancer (Appendix D). This advertisement indicated the time required for participants, how their privacy would be protected, what the inclusion criteria were, how the interviews would be conducted, and how to contact the researcher. A total of 26 potential participants responded to the advertisement, of whom seven did not meet the inclusion criteria. The remaining 19 were provided with a consent form to participate; 15 returned their signed consent and were

sent a welcome email. I did not take down the advertisement because I anticipated dropouts; three of the scheduled interviews did not take place as scheduled. Two were rescheduled, and one new participant was recruited.

The 11 participants each received an introductory email thanking them for their willingness to participate. They were also asked their preferred date and time to conduct the interviews. Once they responded, they were sent a Microsoft Teams invitation for the selected date and time. The participants accepted, and I received confirmation of their intent to interview. Emails were sent one day before the interview to provide a reminder as well as the opportunity to reschedule if needed.

Before starting the interview, I reminded each participant that if they felt the need to stop the interview, they were free to do so at any time. A semistructured interview approach was used to ensure that core questions were asked but allow the participant to explore their lived experience without the rigidity of a structured interview (Appendix B). Once the interview began, I started with the demographic questionnaire (Appendix C), then transitioned into the semistructured questionnaire (Appendix B). All interviews were recorded and transcribed by Microsoft Teams. No participants experienced technical issues with the platform, and all completed the interviews without interruption. Although they used the same platform, the interviews were conducted in different modalities: seven participants used a computer and the remaining four used a smartphone.

The interviews took place over 8 weeks. None were interrupted by any external factors. During the interviews, I followed the interview protocol (Appendix B) to ensure the consistency of the semistructured questions but allow the participant to elaborate on

their experience in a way that was meaningful to them. This protocol was checked off for each participant using their alphanumeric code for identification. After each interview was completed, the participant was thanked and received an explanation of what to expect next. They were informed that I would transcribe the interview and send it to them for review and edits if necessary.

All transcription took place within 24 hours of the interview. The data collected from each interview was recorded and transcribed at its conclusion. Each transcription was first reviewed as is from the Microsoft Teams platform, then corrections were made based on the software's inability to understand certain words or phrases. Each transcript was reviewed twice to ensure accuracy. After I completed the transcription, an email was sent to the participant to review the transcript and either concur or request edits. The participant was then sent the document via DocuSign to sign that they approved of the content. DocuSign sent me a confirmation and signature document to notify me of concurrence. The participants all completed their reviews within 2 weeks. I sent weekly reminders to the participants, as explained after the interview. Three of the 11 participants provided minor wording amendments to the provided transcripts. These changes were made, and the participants concurred with the revised transcripts. One of these three participants added some more specific information related to medications taken by their child and the costs of certain medical and nonmedical expenses described in their interview.

Variations in Data Collection

Because access to a computer or smartphone was needed to complete the interviews via Microsoft Teams, I chose a social media platform for obtaining participants. The nature of the social media bereavement groups improved the potential for finding appropriate candidates who met the inclusion criteria. A risk existed that the participants would not be technologically skilled enough to use Microsoft Teams via the link provided or the internet connection would not support the accurate recording of the complete interview. No unexpected occurrences impacted the quality of the interviews or recordings. Two participants requested to pause the interviews for a few moments due to the emotion of recounting events but were able to continue. Before restarting, I reminded the participants of the mental health resources provided in the consent document; they declined and chose to proceed.

Saturation

The interviews were scheduled so that I would have time to review for themes. The first two interviews, A101 and A102, were used to establish a pattern in themes from which the data coding could begin. Each additional interview was reviewed and coded to assess for saturation. Interviews were conducted until no new themes were present and the coding mirrored the previous interviews. The key themes presented through the interviews revealed core themes related to medical treatment team assistance with identifying novel treatments, hope theory in action, financial impact, treatment selection, and treatment goals. Although it was not a focused intent, the participants were spread evenly along the distribution of education and household income, better representing the

population at large. A benefit of using the social media platform is that it is not exclusive to one segment of the population and thus captured a representative sample.

The coding process was both manual and using the software MAXQDA. After each interview, I performed manual coding and compared this with the results from the software. I found little variance in the coding. As I progressed through the interviews, core themes began to emerge and become prominent. By the time I reached the sixth interview, I began to see less variation in additional themes but consistency in the core themes of medical treatment team assistance with identifying novel treatments, hope theory in action, financial impact, treatment selection, and treatment goals. The ninth interview revealed several new themes and required me to continue until the 11th interview to reach saturation. This was due to a unique experience that no other participant described concerning how and when the diagnosis was provided, as well as the course of treatment timing and options made available.

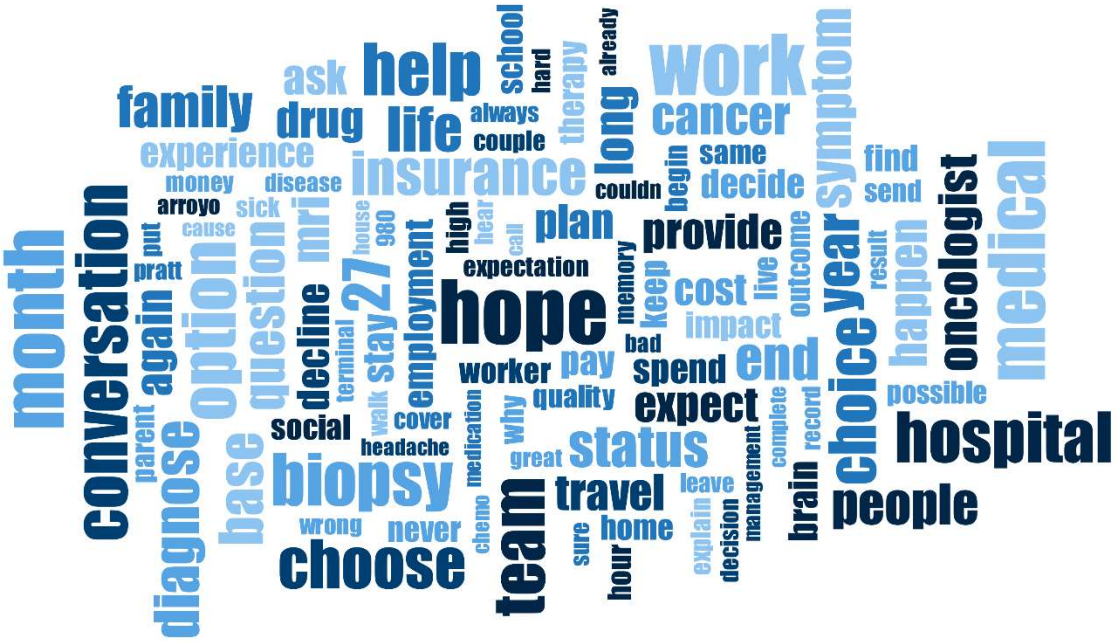
Data Analysis

The data collected was a direct result of accurate transcription and review. The Microsoft Teams platform used to record and transcribe the interviews allowed for the conversion of the data into a usable format that was easy to read and for confirming accuracy with the participants. The analysis of the data occurred once the confirmed accuracy of the interview transcription was reviewed and concurred with by the participants. I chose to perform concurrent coding to strengthen the validity of the resulting data. MAXQDA is relatively new software so I performed concurrent coding to

ensure consistency. MAXQDA was beneficial because it allowed for different ways to meaningfully visualize the data that would not be easy with manual coding (Figure 2).

Figure 2

Word Cloud



In MAXQDA, the recording and transcription were uploaded into the document system. I then ran the word frequency function to identify common terms and phrases used. This function was completed with the addition of each new transcript uploaded. After reviewing the word frequency function, I ran the word combination function to assess for any connecting themes and their frequencies. The most useful function of MAXQDA was the interactive word tree function. This grouped words and themes at a glance and allowed me to drill down to the response level to evaluate. Once the transcript was fully reviewed using the tools within the software, I established a code system. This was based on the maxdictio function and examined the provided transcripts by reviewing

word frequency and combinations, creating codes related to treatment type, treatment goals, hope, risk, and financial impacts. I found that although the software captured and coded similar themes, it could not break them down further to create more meaningful codes that better explained and provided context to the experience. The value of this software was the interrater reliability of the data analysis and the visual tools that assisted in identifying themes across all the uploaded transcripts individually and concurrently.

The manual review and coding used a Microsoft Excel spreadsheet. I segmented the data into two workbooks. The first was for demographic data only. The demographic data provided data related to both the parent and the child. The parents' data included income, employment status before and after diagnosis, and education level (Table 1). The child's demographic data included age, months survived after diagnosis, gender, and insurance status (Table 2). The second tab I created was labeled RQ Subquestion 1 and had the sub-question listed. The third tab was labeled Research Question Subquestion 2 and had the corresponding question listed. The fourth tab was the interview questions, and the verbatim responses to those questions aligned with the alphanumeric coding system for the corresponding participant. The fifth tab was created to categorize themes and was initially filled in based on a comparison of the interviews A101 and A102. The themes and codes were developed based on consistencies noted in the question responses from Tab 4. The data aligning with the codes was then placed under the corresponding codes using verbatim statements from the participants in response to the interview questions.

Table 2

Demographics of Children

Participant ID	Gender	Time in months from diagnosis to death	Age
A101	M	6	8
A102	M	9	15
A103	M	11	7
A104	F	14	9
A105	M	8	11
A106	M	12	4
A107	F	5	7
A108	M	7	7
A109	F	4	4
A110	M	10	17
A111	M	12	15

The process for identifying and labeling the codes in Tab 5 was based on a review of Tab 4. To fully understand the lived experience of participants, I chose to use inductive coding to pull themes from the review of the responses versus starting with preconceived themes. The codes came from the analysis of tab 4 and were color-coded to delineate the different codes. The codes were organized based on the timelines of the participants' lived experiences from diagnosis to the death of their child. The developed codes were then organized into categories, and the themes became clearer across all the data. The transcripts were reviewed after coding to validate accuracy.

The process of inductive coding of the data resulted in codes of explanation of disease, ability to process information, clinical trial assistance, treatment team support, treatment goals, agency, pathway, treatment choice, cure, miracle treatment goal, regret, radiation, more time, peace, cost, travel, making memories, and financial impacts. The categories created from these codes were explanation of disease, medical treatment team

support, treatment goal, treatment selection, hope theory, employment impact, source of financial impact, and reflection on choices. Using inductive coding allowed me to be open-minded to the coding possibilities and revealed unexpected truths about the participants' lived experiences. Some themes emerged that I did not anticipate, such as a lack of assistance from the medical team in searching for clinical trials and that no participants chose symptom management only as their course of treatment for their child.

Divergent Data

The lived experience of participant A109 was vastly different from the other participants. This participant's child did not receive the correct diagnosis and appropriate treatment options for their type of cancer. Therefore, their code was different from the others because they believed for 9 months that they were receiving treatment for a curable form of cancer and then were told that the initial diagnosis was incorrect. The treatment plans and possibilities for the newly and then correctly diagnosed cancer types were vastly different and limited. This affected their levels of hope and prospect for a cure. The parent ultimately chose after pursuing treatment for the curable form of cancer to forgo any other treatments or clinical trials. They did not face an initial terminal diagnosis for their child as the other participants did. This difference in experience provided data that was not consistent with the other participants. The delay in appropriate diagnosis created a divergent experience from the other coded data. Other data diverged on a smaller scale; all divergent data was noted in tab 6 of the coding worksheets.

Evidence of Trustworthiness

The evidence of the trustworthiness of this study is demonstrated by its built-in safeguards to ensure the accuracy of data collected, the ability of the findings to be applied to similar situations, reproducibility, and mitigated bias. These safeguards are demonstrated through credibility, transferability, dependability, and confirmability.

Credibility

The first step taken to ensure the credibility of the data was performing bracketing to catalog what I believed I knew about the topic. This allowed me to be aware of perceptions and knowledge and create an openness so that my experiences and knowledge had no bearing on the lived experience of the participants. The next way that credibility was ensured was by ensuring the accuracy of the interview data input. Transparency means that the description of the research process is clear so that those reviewing the study can understand how the data was collected and accuracy was ensured. Member checking allowed me to confirm the accuracy of the data being analyzed. This took place by allowing the participants to review the data and make any changes, allowing for the full representation of their lived experience as defined by them. Participants were afforded the opportunity to review their data, and three provided corrections. This ensured the accuracy of the data before analysis. Another method used to enhance credibility was theory triangulation. Adler (2022) described the benefit of theory triangulation when investigating complex social phenomena. Examining the data through the perspective of the hope theory and the prospect theory allowed me to look at the same data differently.

Transferability

To establish transferability, presenting the case for the study's applicability to various situations, populations, and contexts was considered. Providing robust descriptions through the participant's accounts of their lived experiences was the most salient way to achieve this. Due to the complex nature of the experience of having a child diagnosed with terminal cancer and having to make decisions based on various factors, the applicability is vast. Understanding of how decisions are made can be applied in various situations and be meaningful for various populations experiencing different phenomena. In the spirit of this study, understanding how decisions are made and what influences them allows those surrounding the phenomenon but not directly impacted by it to be of service to those living it. Through the participants' words, the study can allow detailed descriptions of their lived experiences and provide the most data. This was achieved through the semi-structured interviews that focused the participants on an event or thought but allowed them to describe whatever place their thought process guided them. The participants could have no wrong or right answers, just their detailed description of their lived experience. Through their verbatim descriptions, the completeness of the experience was captured and disseminated in a way that tied the experience to the theoretical framework. By allowing for the participants' rich descriptions, their experiences were not oversimplified. Other tools to demonstrate the transferability of the study included explanation of the demographics and sampling methods. The demographics demonstrated that the population sampled came from various backgrounds, including their socioeconomic status, gender, education

background, and form of insurance possessed. The sampling methods solely focused on identifying participants with a shared experience and had no other requirements that would limit the composition by adding more population-limiting inclusionary criteria.

Dependability

The dependability of this study is rooted in a defined research design and methodology that could be reproduced to achieve similar results, as described in Chapter 3. To ensure this, I have provided well-defined processes for how the participants were chosen and the data collected and analyzed. Aligning the research method with the research questions also ensured the dependability of the study. The participant and researcher roles were made clear in the consent document. To strengthen the dependability of the study, concurrent coding was both manual and using MAXQDA software. The results yielded similar coding, categories, and themes. At multiple points during the data collection and analysis process, peer review collaboration took place. This process also ensured that the process described was followed and confirmed.

Confirmability

Confirmability is rooted in the objectiveness of the research and the mitigation of researcher bias. Bracketing was used to predetermine my understanding of the topic to better define any potential biases and mitigate their impact during the analysis of the data and interpretation of results. Additionally, using theory triangulation to view the data through two different theoretical lenses provided unique perspectives during the data interpretation process (Valencia, 2022). Steps were taken to reduce bias and increase the likelihood that a separate researcher could reproduce the study process and results.

Results

As the study progressed toward saturation, themes emerged and became clearer among the different participants' lived experiences. The themes were identified by evaluating word combinations, similar descriptors used, word use, and synonym comparison during the coding process that took place after each interview. These themes revealed the application and lack of application of the theoretical principles of hope and prospect in the decision-making process for this participant population. The themes that emerged were rooted in how the participants received information, trust, and support from medical providers; their treatment choices and rationales; socioeconomic impacts; and desired outcomes. The themes' connections to the theoretical lenses were applied by examining key words and phrases that aligned with principles of the hope and prospect theories.

The baseline themes that emerged were critical to determining the presence or absence of the theoretical considerations when making treatment and financial decisions related to their child with a terminal cancer diagnosis. These themes surrounded the explanation of disease and treatment options, medical teams' roles in identifying clinical trials, treatment selections and goals, hope, financial impacts, and the presence or absence of regret. These themes helped to illuminate the presence or absence of the theoretical frameworks of hope and prospect theories.

Answering the first research question required connecting the themes to the core tenets of the hope theory: agency, pathway, and goal. Following is an analysis of the themes that were used to answer the research question: were the health care and financial

decisions made based on the concepts of agency, pathway, and goal, as described by the hope theory?

Theme 1: Explanation of Disease and Treatment Options

Receiving a terminal diagnosis and understanding the treatment options present a difficult conversation but one that is critical to making the next informed treatment selection (Brouwer et al., 2021). This theme was the key moment that informed the actions to come. The evidence from the participants' explanation of their lived experience revealed that this theme defined the possibilities and limitations of what was to come for their child.

The participants were asked in the semi-structured interview to describe the conversation in which the medical team provided the diagnosis and treatment options available to their child. As they began to describe their experiences, some consistencies emerged surrounding how much information they received, their ability to understand the information provided, and the timeliness of the information provided. The participants shared additional information such as their emotional state at the time of the terminal diagnosis. They were solemn as they described this event and often paused to collect their thoughts. No difference in tone was noted between participants whose children died 10 years ago and those whose children died as recently as last year. The descriptions revealed 29 codes within the bucket of explanation of disease and treatment options: three codes related to inadequate explanation of the disease and treatment options, eight described the explanation of the disease and treatment options by the medical team as adequate, four participants described being unable to comprehend what was being

discussed at the time, three described not being helped by the medical team in pursuing a clinical trial, and nine stated that they were aided in locating a suitable clinical trial.

The participants prepared for their interviews and referred to notes to provide the fullest and most accurate account of their experience. Although it was not asked, all participants referred to notes and asked for a minute to review them before answering the questions. After the interviews, four participants stated that reflecting and reading their statements during the member-checking process allowed for some emotional healing because they had not previously talked through their experience. Under the theme of the explanation of the disease and treatment options, the words used to describe the process ranged from *thorough*, *helpful*, and *informative* to *inadequate*, *abrupt*, *short*, and *delayed*. On the spectrum of responses, eight participants felt that the explanation was adequate, whereas the other three felt that they did not receive a satisfactory explanation. The following are examples of the experiences of participants who believed that the explanation provided gave them the information they needed:

- PA101: The medical team told the participant the prognosis and what to expect with their child. They told the participant about the standard treatment options and introduced the idea of clinical trials.
- PA104: The medical team shared the diagnosis and emphasized that it was terminal. They highlighted the treatments that were primarily aimed at symptom management and slowing disease progression. The medical team shared the possibility of clinical trials but did not suggest them.

- PA108: The doctor explained the diagnosis and took time to allow the participant to ask questions. He stated that the diagnosis was terminal and that to date no cure existed. He recommended chemotherapy to slow progression. He explained that clinical trials existed but suggested against them. The participant had the information needed to make the best possible decision based on what they wanted for their child.

The following are summaries of some of the experiences in which the explanation was deficient:

- PA109: Providing the final diagnosis to the participant took several weeks, without the prognosis being shared. The family was only made aware a week later that the diagnosis was terminal. The explanation of treatment options was relegated to standard treatments, without the option for clinical trials provided. The family only found the availability of trials through online searches. When they confronted their oncologist about the lack of information, they were told that it was not worth their time and that he did not advise it.
- PA107: The participant went 6 months with the wrong diagnosis. Once they identified the correct diagnosis, the oncologist only described that there was no cure and that the child should receive chemotherapy and radiation to help reduce some of the physical symptoms. No explanation was provided at the time about susceptibility to future infections and the need for prolonged steroid use.

The participants described how the information impacted their decision-making and that this conversation was vital to their treatment selection. The conversation also directed choices concerning what resources would be needed, as well as where and how, to achieve the treatment goals for their newly diagnosed child with terminal cancer.

Direct Quotes from Thematic Descriptions for Theme 1

- PA102: "Yeah, they told us the prognosis for sure. Um, they, they said 6 to 9 months. We did not get much of an explanation about the cancer, but they did tell me what some of my treatment options were."
- PA109: "No, they didn't go into the different phases of it. But they said that the prognosis is like roughly about a year or so."
- PA106: "They were very careful in giving us the information in small bits and pieces. And although at the time maybe and many times, actually, after thereafter, sometimes you felt quite frustrated with that because sometimes it did feel like withholding information."
- PA105: "He had told us that he had cancer in his blood, and that it was serious, and that we needed to go to see some doctors who could deal with that. They made a consult and then they explained everything very well and what options that were available to us."
- PA110: "But then when I sat with Doctor Bartells, I said so, it is DIPG? And she said: nobody told you yet? And I said no because nobody sat down and had the conversation. They had been so much testing and talking about trials that that conversation just didn't happen. So after she confirmed what I had

looked up on my own, then they told me about all of my types of things that we could do for my son."

- PA104: "Then they just came down and told us that she has cancer and once that they said tumor, we thought, OK, well, maybe you know we could treat it and get started to get it removed and move on with our life and then they told us that there was no treatment other than radiation and that it's a terminal diagnosis and that our daughter won't survive. And after that point, everything kind of went numb."
- PA104: "They said my son has a soft tissue cancer and that unfortunately, it is widespread, and it is a terminal diagnosis. They then explained options and palliative care."
- PA111: "So, they came in, the doctor oncologist came in and explained to us that his disease was terminal, that he was only expected to live 9 months, and that they would be setting us up with radiology and clinical trials."
- PA106: "I was told that there was no treatment. That the only thing they would be able to provide was radiation therapy, which would help in giving him a better quality of life. And I was also told that if I wanted to participate in a clinical trial for this particular cancer, DIPG, that I would need to get Gavin radiation treatment as well as a brain biopsy to identify a particular mutation."
- PA107: "And yeah, they will set us down. They said it's gonna be a longer conversation. And they. Yeah, showed us in the MRI. They said there is a

> tumor in your child's spine. They told us the treatment options but said no cure is available."

Through the semi-structured interviews, the participants all recounted their experiences surrounding the time when their child's medical team explained the disease and the treatment options. Intense feelings one way or the other were evident surrounding how that conversation took place. I found the participants to be on one side or the other concerning whether they felt the explanations were satisfactory. I took the analysis a step further and examined whether the feeling of satisfaction with the diagnosis and treatment options correlated with education. Of the four participants who were not satisfied, two had a high school diploma, one had a bachelor's degree, and one had a master's degree. The participants who were satisfied with the explanation also had varying education levels: one Ph.D., one master's, one bachelor's, and four high school diplomas. All participants described the diagnosis conversation as one of the defining moments in their journey that helped determine what treatment selections were made.

Theme 2: Medical Team Support and Assistance in Identifying Novel Treatments

After the diagnosis and treatment options were discussed, the participants began to probe their medical treatment teams for the availability of novel treatments. Ten of the 11 participants chose to pursue a clinical trial for their child and sought recommendations from their medical teams and oncologists. The codes attached to this theme were helpfulness, lack of helpfulness, oncologist supportive of trials, and oncologist not supportive of clinical trials. Seven of the 11 participants felt the medical team was helpful in identifying clinical trials for them to enroll their child in. However, two of these seven

felt that their oncologist was slow to recommend a trial. Two participants felt that the medical team was not helpful and were forced to find clinical trials for their child on their own and bring the information to their medical team to act on. Five of the 11 participants described that their oncologist provided a strong opinion on participation in the trial, either for or against. Three oncologists were against the clinical trial due to the travel that would be necessary, and two oncologists would not recommend or provide an opinion on any clinical trial to pursue. The following examples of their experiences highlight some of the challenges:

- Participants described some hesitancy by their oncologist to recommend clinical trials.
- Participants stated that the medical team was well-organized and provided a spreadsheet of all of the clinical trials available, along with the locations and requirements to enroll.
- Participants recounted that they were puzzled that the oncologists would not provide a recommendation on which clinical trials they would choose if it were their child.
- The medical team mentioned the availability of clinical trials, but some participants were forced to do the work of finding the right trial for their child. This involved countless hours on the internet and making calls to clinical trial sites.

The participants sought guidance on what novel treatments would be best for their child. They expected that the medical team would make it easy for them to review and select a clinical trial site. Seven of the 11 participants felt that the medical team, which

included nurses and social workers, was helpful and supportive. Three felt that they had to fight with their medical team to get the support that they needed during this process.

Direct quotes from thematic descriptions for Theme 2

- PA108: “They did not mention clinical trials.”
- PA104: “They were very unhelpful in that at the end and basically, you know, we were just told: no, you should just stick to the standard of care and which is doing the radiotherapy and eventually reirradiation, which we also did.”
- PA106: “All the clinical trials information that we got we got by ourselves because we spent hours literally reading, contacting, writing, and so on.”
- PA103: “So, um, we asked for clinical trials and we wanted to be part of them. But our oncologists seemed very hesitant and was dragging their feet. Um. And it turns out that we had to go and search for more information than they would even offer. So, but what we settled on was that we would start with chemotherapy. Against really against our oncologist advice that we would do a clinical trial.”
- PA109: “The doctor told us about the Stanford trial and one that I’m UCSF, but we chose to go with the Onc 201 trial at Stanford, and I’m so he was accepted into that. Our oncologist was very, very supportive.”
- PA105: “He gave us a spreadsheet that had all of the available clinical trials. What he thought would be the best option based on what our goals for our child was.”
- PA01: “No, you know what, I think they referred us to UCSF. I remember waiting a, really felt like a really long time, for that referral to go into UCSF, and yeah, I not, I think about it, I believe it was them that said that she could do radiation, and then

after that, we could talk about possible trials that she could get into, but she was nice and helpful and even got me gas cards to drive."

- PA104: "My oncologist said I'm gonna have one of the top experts visiting me randomly next week. And he set it up."
- PA111: "I remember the handwritten paper. It had listed three possible clinical trials."
- PA110: "They wanted us to do, I think it was the CED trial in New York, and they set it up. All I had to do was show up with my child."
- PA102: "Our oncologist provided me with great information on what was available and what he perceived as worthwhile."

These experiences were important because they are the building blocks for the application of decision-making through both the theoretical lenses of the hope and prospect theories. The participants all had to consume information to determine the intended outcomes. Ten of the 11 participants sought to enroll their child in clinical trials, and understanding what trials were available to them was important. Although they all eventually enrolled their children in clinical trials, they had different experiences based on the support or lack of support from their medical teams.

Theme 3: Treatment Selection and Goals

One core element of the research questions was understanding what treatment selections were made and then progressing to understanding why. The participants described what clinical choices they made for their children and what the goals were. The treatment selections could be similar while their goals varied. No participant elected to do symptom management only. Of the 11 participants, one chose to do radiation and

chemotherapy only. The other 10 chose to enroll in clinical trials while also taking symptom management treatments, radiation, or chemotherapies. The goals varied but fell into codes for cure, symptom management and quality of life, and more time with their child. However, the goals were not singular. As the parents described their treatment goals, more than one code emerged for individual participants. Three participants believed in the possibility that the clinical trial would cure their child and reverse the terminal diagnosis. Eight hoped to achieve more time with their child than the prognosis indicated. One of the three participants desired through their treatment selection a cure or more time. Seven participants' treatment selection was directed at improving symptom management and quality of life. One participant fell into all three codes for the desired outcomes of the treatment selection. The descriptions of their treatment selections and what they desired to achieve provided insight into how they understood the treatment and what they believed the possibilities were. The following summaries highlight their experiences:

- Participants described themselves as realists and did not hope to achieve a cure but did hope to reduce the suffering of their child and seek treatments that would improve or at least maintain their quality of life.
- Participants believed that their child could make a breakthrough in the clinical trial and be the first cure. They sought out the trials that they believed provided them with the greatest opportunity.

- All but one participant believed that clinical trials would be the best way to achieve their desired outcomes. Regardless of how they coded, they all chose this option.

Direct quotes from thematic descriptions for Theme 3

- PA105: “You know, at the minimum, we were hoping to have more, you know, quality time with our daughter, as much time as we could have.”
- PA111: “The idea that there was a clinical trial tells me that there is a chance that something can at least keep them alive longer.”
- PA101: “I was just thinking that I needed to keep him alive, and I would do anything to keep him alive. So, that meant looking at all options and, you know, I wanted to make sure that his symptoms were managed. He wasn’t in any pain. He was as high-functioning as possible, but I wanted to keep him stable and happy and functioning and alive as long as possible.”
- PA106: “But that did happen, but my hopes and expectations were that I would have more time with him, more quality time with him, where he was high-functioning.”
- PA104: “I was operating solely on hope for a miracle and the possible benefit of more time with my son.”
- PA103: “It like if we were given a certificate of incapacity to that we were not being realistic or something like this, and we were just saying: no, we hear you. You know, yes, this is not curable, you know, can also for a miracle or whatever.

But this, we understand that that is not what is going to happen, right. But we just need to keep on trying. I mean, you know, as a parent, you know."

- PA109: "They told us… me at the time radiotherapy, but it only prolongs the life."
- PA105: "CED. I was in the trial in New York, and, uh, we felt they had the best chance just listening to what options were and how the problem with the blood–brain barrier and being able to pass it. So it, um yeah, it was. It was definitely the best choice for us. And so yeah, we felt like he gave us the best shot of survival."
- PA108: "I chose this trial because it had success with tumor stability, improvement because some kids had improved with it, you know, at the time."

The participants were asked what their chosen treatment was and what brought them to that choice. The goals impacted the selection, even though eight of the 11 participants received adequate explanations about their child's disease and prognosis. Nine of the 11 chose to participate in a novel clinical trial. This theme began to lay the landscape for understanding the considerations that went into making a treatment selection, but future themes that emerged through the data analysis added equally important perspectives.

Theme 4: Financial Impacts

The financial impacts of a terminal disease can vary. The financial effects of the disease and any special considerations made as a result differed between participants based on several important factors. The participants varied in terms of their available resources. Based on the demographics shown in Table 1, all were insured, whereas their annual income ranged from unemployed with no income up to greater than $100,000.

Navigating the time needed to care for their terminal child impacted the employment status of the parents. Four of the 11 participants experienced no impact on their employment status, whereas the remaining seven experienced either unemployment or underemployment. Of these seven, four experienced underemployment, and three experienced unemployment. This was a direct impact of the need to provide primary caregiver support to their child.

Direct quotes from thematic descriptions of subthemes for Theme 4:

- PA101: "So I had to, you know, reduce the amount of hours I was working. So, that impacted us financially."
- PA103: "I mean, I lost income because I did stop or I started working less hours, and then I stopped working for some months."
- PA104: "I was able to reduce my hours at work, but my husband still needed to work because we have businesses that we own."
- PA107: "Not being able to be at work during his diagnosis and treatmenI. It impacted our family financially because we were not receiving the full amount of financial resources that we normally would."
- PA109: "I did not work after my child was diagnosed and neither did my wife."
- PA111: "But just as far as not working anymore. I wasn't working anymore."
- PA108: "Because I had to take off work to take care of my son"

The negative financial impacts that the families experienced fell into three sub-themes: negative financial impacts from costs associated with standard treatments, clinical trials, and making memories. All participants stated that they faced some form of

negative financial impact as a result of the terminal pediatric cancer diagnosis. Nine of the 11 participants experienced negative financial impacts due to the costs associated with participation in clinical trials. Two of the 11 stated that they experienced negative financial impacts as a result of costs associated with standard care modalities. Four of the 11 stated that they experienced negative financial impacts as a result of spending money on making memories. This included trips, experiences, and buying items. Three of the nine participants stated that they experienced negative impacts from participation in clinical trials. Travel costs for the child and family linked all these negative sub-themes. These costs included travel to the site, lodging, and food, enumerated in the direct quotes from the participants:

- PA102: "You know, we planned, you know, all these trips, camping, and anything that we could do. We had friends help support us and provide opportunities, but there was still always costs related to it."
- PA105: "We were awarded the Make-a-Wish from the Make-a-Wish Foundation, went to Disney in August, so it was very nice. We still tried to do things locally like just going out as a family, having supper at a restaurant, or going to a museum, parks, movies, experiences, and things of the like."
- PA103: "I'd have 16–17 kids sleeping all over the place and blow-up mattresses. But you're feeding them and you're doing all these things just to, just to make that time special."

- PA108: “Day-to-day expenses, gas, you know, getting to and from our appointments, going to call the clinical trial sites, there was some assistance provided, Ronald McDonald House, etc.”
- PA104: “So, the travel was the big thing for us.”
- PA109: “Um, we were eligible, like we weren’t coming from far enough to be able to stay at Family House again. So, we did have to pay for hotels a couple times.”
- PA106: “Yeah. So the MRI, the anesthesia, all those things we have paid for, yes, and then sought reimbursement once the insurance was in place.”
- PA105: “So’ we're 50 miles away, 55 miles away from Children’s. So, that’s where we did the treatment, and we got to live at Brant’s house at the time, which is like the… It was 6 weeks, 6 weeks, 5 days a week, and we’ve got to go home on the weekends. McDonald’s house was available some of the time.”
- PA111: “His is my priority and try to, you know, she couldn’t hold her head up, and it was really bad because, you know, and I was trying to get a wheelchair. And insurance doesn’t cover the wheelchair, and then they didn’t manufacture where, I mean, the whole process is too slow for this disease.”

The participants all had the opportunity to reflect on any negative financial impacts that they experienced and to what they could attribute those costs. Eight of the nine who experienced a negative financial impact from clinical trial participation reported that this was a result of travel-related expenses. The largest common source was the care selection of participation in clinical trials. The negative financial impacts were felt by all

participants, regardless of their income range. These explanations of the costs associated with having a child with terminal cancer provide context to the type of costs incurred and the magnitude of their impact. They also illuminate the financial impact of the treatment choices selected for the participants' children.

Theme 5: Hope (concept only, not as defined by Snyder's hope theory)

A theme that emerged during the interviews was hope. No questions were asked during the interview on hope, and the meaning of hope was not defined for the participants. The best definition based on the interpretation of the participants' statements was the desire for an outcome even in the face of improbability or uncertainty. Ten of the 11 participants described hope when recounting how and why they came to treatment decisions. Regardless of the treatment modality chosen, the participants noted that the possibility or hope of a miracle or improbable outcome was the deciding factor. They also discussed that the standard treatment did not provide hope because it was just designed to manage symptoms and slow progression, not to create the conditions or possibility for a cure and reversal of the terminal diagnosis of their child. A frequency word cloud revealed that hope was the most used word in the thematic coding (Figure 2). Ten of the 11 participants spoke of hope as the catalyst for their treatment choices. Snyder's (2002) hope theory describes hope as the agency and pathway toward a goal. Through each of the participants' descriptions, I identified the agency and pathway they used to pursue their goals, even if they were not ultimately achieved. The participants each described what they hoped for and what selections they made to pursue the goals.

Direct quotes from thematic descriptions of subthemes for Theme 5:

- PA101: “Try new things, and in the face of uncertainty, you know, at no point did I really think about really in depth the risk of any of the treatments that were happening, just because I knew that my child was sick and there was no cure. So I just hoped that it would be my child that was the exception.”
- A106: “And there was a different one as well. I did my own research on all of them. The plan was for her to complete radiation and she wouldn’t be able to start any of them until.”
- PA110: “I was hopeful that the radiation would shrink the tumor.”
- PA107: “I was feeling hopeful that I guess we had a plan of attack. It was 6 weeks of radiation and then I just, I remember the handwritten paper. It had listed three possible clinical trials. I remember the words possible.”
- PA105: “You know, yes, this is not curable, you know, can also for a miracle or whatever. But this, we understand that that is not what is going to happen, right. But we just need to keep on trying. I mean, you know, as a parent, you know.”
- PA104: “All we could do was do what was best for him, you know, to live some life. But the hope was always that he would be the one, the one that changes it all.”
- PA108: “The fact that there was clinical trials out there and experimental treatments gave us a possible way, hope, you know, to save our boy.”
- PA111: “We were hoping that, you know, that we would at least get more time or maybe a miracle and a complete cure.”

- PA103: “I was operating solely on hope for a miracle and the possible benefit of more time with my son.”

To avoid leading the discussion, the participants were never asked specifically about the concept of hope or asked if they were aware of Snyder’s hope theory. The participants were asked the what and why of their decision-making. Without prompting, they all described hope for an outcome. The hoped-for outcome varied, but all had a great impact on the treatment selection chosen. Notable was the strong connection to hope in decision-making but the underwhelming connection to the risks related to the treatment pathways selected. When looking for risk versus reward through the interviews, only a few mentioned risk being a consideration. Only one of the 11 participants mentioned risk outside the context of what the health care team explained to them about treatment plans, stating that they considered the risks when choosing a clinical trial: “We knew that there were the possibility of side effects, but we felt the possibility of more time was well worth it” (Participant A104).

Theme 6: Treatment Selection Regret

During the interviews, the participants were asked whether, knowing what they knew then, they would have changed their treatment choices. This question caused all participants to pause and think hard about their experiences. Through the responses to this question, the theme of regret emerged. After reflecting on their experiences and outcomes, the participants began to describe what they would have done differently and why. Of the 10 participants who chose a clinical trial, nine experienced no regret in their treatment selection, only in the outcome. They described that not trying to find a cure was

not a choice at all: if a semblance of hope and a pathway to get there existed, their duty as a parent was to try. The one participant who did not select the clinical trial had no regrets because it related to their treatment choice. They described that no path forward seemed that it would end well for their child: either basic treatment in the home or clinical trials far away without the comfort of home and loved ones. One participant showed regret due to feeling that they hastened their child's death as a result of the clinical trial medication's adverse effects.

Direct quotes from thematic descriptions of Theme 6:

- PA101: "Knowing what I know now, I would probably not participate in any radiation therapies or clinical trials."
- PA102: "No, I think I did the best I could with the resources that I had and knowing what I know, you know, knowing what I know now, there was no silver bullet, and there was nothing that was really going to work."
- PA104: "So, you know, I probably would have erred on the side of caution with the clinical trial, less invasive one, and we would have gone with that. But I still would have done a clinical trial because I was not OK, which is laying down and accepting it, and I don't think he would have been either, but I definitely don't regret what I, what we did, and how I went about it and letting him choose."
- PA108: "I am at peace with the choices we made. I just wish things could have happened more quickly for us in terms of getting into clinical trials."
- PA103: "And but no, we knew that there was. There was nothing right so. It wasn't like I was going to fight to say there must be something or go to Mexico or

do all these things that took away from the time that we got to share, right. And I think the more stress he would have been under, the worse it would have been. We just did our best with what we had."

- PA105: "I would not have changed a thing as far as treatment. We did our best."
- PA109: "I would only change how much information I had on the different trials… but I would have still chosen a trial regardless."
- PA110: "I would not have chosen a different clinical trial because they still believe this is the best one."
- PA106: "I can say we have no regrets."
- PA107: "You always make the best choice based on the info you have and what you want to see happen. So, with that in mind, I would not have done anything differently."

The participants described that even though they did not like the outcomes, they did not regret trying something to prolong their child's life while hoping for a cure. Understanding that the treatment choice was their only pathway to the possibility of their child living was the apparent motivator in this reflection of their treatment choices.

Summary

This chapter provided the study data based on the themes that emerged through the participant interviews and personal descriptions of their lived experience. It also described how the data was collected and analyzed. This data collection process led to six major themes emerging from the data, providing insight into the participants' experiences

and what impacted their financial and medical decision-making. The main research question for this study was "How are medical-based financial decisions made by the families of terminal pediatric cancer patients using the lens of hope and prospect?" The themes that emerged from the data were (1) explanation of disease and treatment, (2) medical team support in identifying novel treatments, (3) treatment selection and goals, (4) financial impacts, (5) hope, and (6) treatment selection regrets. These themes together provide clarity to the more specific research sub-questions regarding the impacts of the hope and prospect theories on decision-making individually. The evidence of the study's trustworthiness was validated through process descriptions. The following chapter discusses the study results, its value concerning social change, and recommendations for future studies to further close gaps in the literature surrounding this research topic. Chapter 5 describes the findings and their applicability to the research questions, as well as providing reflections and recommendations for future researchers.

Chapter 5: Discussion, Conclusions, and Recommendations

Medical decision making in cancer has been studied over the years with different focuses. Taylor and Doolittle (2019) reported that the act of medical decision making by caregivers of children with life-threatening illnesses can cause substantial psychological distress and have long-reaching impacts. Understanding what goes into this decision making and what factors influence the treatment selection may allow clinicians to better support establishing the care goals that the family desires versus the treatment path that they believe should be selected. Cortez and Halpin (2020) discussed how mere presence in a clinical trial may create uncertainty in those who have received a terminal diagnosis. This uncertainty is due to the perception of a possibility of a different outcome than what has been communicated.

Understanding the impact of hope and prospect on decision making is a method for the treatment team to learn how to better frame their goals of care conversations with the parents and guardians of terminal pediatric cancer patients. This population is one in which the outcome has been provided regardless of the forthcoming treatment options based on what current proven medicine can provide. Understanding the impact of the concepts of hope or risk versus reward in these scenarios can provide insight and allow treatment teams to frame expectations, imitations in the presence of such a powerful influencer.

Using a phenomenological approach, I examined through the lived experiences of the participants any impact of hope or prospect as they made treatment decisions that had both medical and financial consequences for their child and family. Tomaszewski et al.

(2020) described the usefulness of qualitative phenomenology in allowing the researcher to collect rich data based on the participants' explanations.

The semistructured interviews allowed the participants to share their experiences while extracting vital explanations describing their experiences and the presence or lack of concepts of hope and prospect. Through these interviews, I explored the medical and financial decision-making processes of parents with children with terminal cancer, with the clarifying subquestions of hope and prospect being catalysts for the selections made.

Key Findings

This study had one research question and two subquestions.

RQ: How are medical-based financial decisions made by the families of terminal pediatric cancer patients using the lens of hope and prospect?

Subquestion 1: Were the health care and financial decisions made based on the concepts of agency, pathway, and goal, as described by the hope theory?

Subquestion 2: Were the financial choices made in the care of terminal pediatric cancer patients representative of the concepts of risk versus reward, as described by the prospect theory?

Through the semistructured interviews and subsequent data and coding analysis, six themes emerged that provided clarity to the research question and subquestions:

- Theme 1: Explanation of disease and treatment
- Theme 2: Medical team support in identifying novel treatments
- Theme 3: Treatment selection and goals
- Theme 4: Financial impacts

- Theme 5: Hope
- Theme 6: Treatment selection regrets

These themes either confirmed or denied the presence of the components of the theoretical lenses through which this study was performed. The participants described, through their lived experiences and rationales behind medical decision making, what factors and considerations were considered when making medical decisions with financial implications for their child. The participants also described what was important to them in the decision-making process, from the input of the diagnosis through to the completion of the treatment and their thoughts regarding the process after their child had succumbed to the disease.

The data revealed several high-frequency words associated with the identified themes. All 11 interviews used high-frequency words related to the participants' experience such as clinical trial (187), time (159), hope (45), expenses (82), travel (26), and try (63). These high-frequency words helped to develop the themes that emerged. Of the 168 codes identified, hope was the theme that was present across all participant data but impacted by the other themes, as I demonstrate through the interpretation. The next high-frequency theme was financial impact. As the participants navigated their accounts of their experiences, consistency was clear in thought and action, with certain considerations being critical, while other aspects of decision-making were absent.

Interpretation of Findings

The studies on parents of pediatric cancer patients that have precceeded my study provide clairty as to what aspectes of the lived experience have answers and which

questions had yet to be asked.The literature review provided clarity to the exisiting gaps that needed to be addressed. Findings from within the data collected support concepts from previous studies and created a furtherence of understanding surronding the difficult choices that have to be made for their child and the why behind the selections made.The data collected during this study were from the lived experience of the participants. They described in detail how and why they made certain medical decisions for their child with terminal cancer. The participants' children had a variety of types of cancer diagnoses, but all were terminal. The participants described the day their child received the terminal diagnosis, how this information was communicated, and what they were thinking at that moment. The participants went on to describe what treatments their child was offered, what they selected, their goals, and to what extent the medical treatment teams supported their treatment decisions for their child. The participants then described the financial implications, both in the moment and after their child had died. They reflected on their choices and communicated either the presence or absence of regret. The data from these interviews were rich and insightful. To avoid leading the participants to describe their experience through the lenses of Snyder's hope theory or Tversky and Kahneman's prospect theory, the semistructured questions encouraged them to describe their thought process in the decision making; I reviewed that data for the presence of key tenets of each theory.

Research Question

The purpose of the research question for this study was to understand how medical and financial decisions were made by the families of terminal pediatric cancer

patients through the lens of their lived experience. The interview questions focused on bringing them back in their mind to the place and time in which the circumstances surrounding this would be clear. All the interview questions had the purpose of allowing the participants to examine the how and why of their choices and recount any challenges that were present and impactful. All six themes illuminate the answer to the research question but can be refined to describe the intersection or divergence with the research subquestions that refer to the theoretical application of the hope and prospect theories. When describing their lived experiences, the participants alluded to several key components that were considered when making medical treatment decisions for their child and the resulting financial implications. During the interviews, the participants described how they were educated on what the disease process was, what the treatment options available were, the financial costs of their decisions, how they felt about the decisions that they made during that time, and whether they would change their selections knowing what they knew then.

The alignment of the interview questions and research questions are demonstated in table 3. Interview Questions 1 and 2 provided context to what the parent knew about the disease and what treatment options were available to them based on personal research and education provided by the medical team. This demonstrated what information the parents had on which to base their medical and financial decisions. Theme 1 emerged from these two questions. This theme encompasses the quality of the explanations provided. The participants discussed how critical this time was for them and that it helped inform their decisions. Whether they felt the explanations were satisfactory or

unsatisfactory, this was when they all took information from the medical team and personal research to try to be informed about the disease and treatment options. The participants received information from their medical team, but all performed independent research on available clinical trials once it was determined that the standard treatment options available to them were not likely to change the prognosis.

Theme 2 describes the support or lack of support provided in the search for novel treatments. This emerged when the participants discussed the treatment options that they were aware of, how they became aware of them, and how they were connected to the medical teams running the novel clinical trials. The participants fell along a spectrum: those at one end received assistance with the process of locating a suitable clinical trial, and those at the other end felt alone and were forced to research, locate, and coordinate with clinical trial sites on their own to facilitate their child's participation. Through this theme, the landscape for the costs of the novel treatments became evident to the participants as they either were provided with the information or researched it on their own. Through this theme, parents described the novel treatment selections that were provided by the treatment team. When involved, oncologists provided their recommendations on which clinical trial to select, but those who were forced to identify their own relied on the opinions of message boards for children with similar diagnoses participating in the trials. This theme emerged and demonstrated the support that the participants received while trying to identify a suitable treatment plan for their child. This theme was consistent with the study performed by Eche et al. (2022) as they identified protectiver factors that had an impact on the concept of hope. The proecteive factors of

hope in this previous study were founded in the communication betwwen the medical providers and the parent. Eche et al. study detemined that the information provided by the medical team was valuable. But unlike the study by Eche et al. my resutls did not have an impact on agency, pathway or the goal Snyders definition of hope.

Theme 3 described the treatment selection and goals. This theme was key to answering the research question . Interview Questions 3, 4, and 5 combined allowed for this theme to emerge, providing clarity on the motives and considerations behind the treatment choices made. All but one participant chose to pursue a novel treatment for their child. Three sought this to achieve disease remission and a cure for their child. The remaining participants who chose clinical trials did so to provide them with more time with their children and extend their life beyond the expected prognosis. The larger portion of the group was accepting of the prognosis but sought a novel treatment to extend their child's life in not just quantity but quality. Sisk et al. (2021) examined what role uncertatinty played in determining paerent expectations for children with advance forms of cancer. Sisk et al. examined the uncertatiny of the clinical trials but found no true bearing on the treament selction. The parents' hope in the presence of a terminal diagnosis had the most significant impact on the treament selection. The agency and pathway that consituted the goal was dictated by the presence of the clinical trial and the measn for their child to participate and pursue the goal. The goal was not always the same, but the hope that was created throgh the pursuit of the goal was what was critical in this poplation.This study supported concepts identified by Kaye et al. (2020). The parents in my study and the one performed by Kaye et al. shared a common concept that hope

and realism are not mutually exclusive. The parents in both studies understood their child's condition and deteriroration, but still found hope in the little goals that they wanted to achieve for their child whether it be as robust as a cure or as simple as just a little more time.

Through the responses to Interview Questions 6 and 7, Theme 4 emerged through discussion surrounding the financial implications of the care treatment selections. The participants described the financial implications of the treatment selections chosen. These costs were from both direct care and the costs of travel, lodging, and uncovered medical costs resulting from participation in their selected clinical trials. Outside of the cost of care, a scarcity of resources was created through unemployment or underemployment for seven out of the 11 participants. The participants described the financial impact of participating in the trials. They discussed their awareness of the related expenses before accepting admittance into the clinical trials. Similar types of costs were experienced by all participants who chose a clinical trial as the treatment option, although one participant had their chosen clinical trial at a local health care facility.

Theme 5 was the concept of hope as it pertained to the treatment selections and the outcomes that the participants were seeking to achieve. It emerged organically without any specific prompting question, throughout the entirety of the interviews by all participants. What was being hoped for may have been different, but the presence of hope was indicated in the interviews of all 11 participants. Hope was not defined for the participants, nor was it part of any of the questions provided during the interviews. The mode to achieve the hoped-for outcome in 10 out of the 11 participants was the clinical

trial. The outcomes hoped for were a cure or more time. Although the participants had been given the terminal prognosis regardless of the treatment selection chosen, 10 out of 11 participants chose to try a novel treatment. For parents, the potential of achieving their goal was better than the option of doing nothing more than standard treatments that would not extend life or provide the possibility of a cure. The standard treatments were focused on quality of life and comfort for the child. The parents in this study, except for one, were willing to try novel treatments and potentially achieve their desired outcomes. The participants all either used the word hope or described agency and pathway, which are tenets of Snyder's hope theory. The pathway was the review and evaluation of treatment options and how they could help achieve the hoped-for outcomes. The agency was choosing to pursue novel therapies that would hopefully lead them to their desired outcomes of time or a cure for their child. Noted in this theme was the absence of the concepts of risk or reward when parents were making a significant clinical decision for their child. This reality seperated from what was found in previous studies like that of Pearson et al. (2022) in which parents weigh the risk and reward of novel cancer therapies.My study revealed that the traditional risk versus reward methodology was not considered in the pursuit of ahieving the goal for their child.

Theme 6 was reflective and connected to Interview Questions 8 and 9. This theme emerged when the participants reflected on the treatment choices they made, the ultimate outcomes, and everything that they experienced from the time of treatment selection until their child died. When reflecting on the treatment selections made, 10 of the 11 participants did not regret the treatment decisions they made or the financial impact that it

had on them and their families. They described that as a parent there was nothing that they would not do for their child. The cost did not matter, and the outcome did not matter because it was always going to be what it was unless a breakthrough or miracle happened, but the act of trying was their duty, and they could say unequivocally that they would do it again. Only one participant felt regret. Participant PA101 described that they would have not had treatment and just made each day that their child had left as special as possible. Their regret was related to the effects that their child experienced from the experimental treatments and the time it took to travel for them. The financial impact of the treatment was not the reason for their regret.

The themes collectively provide insight into the thought processes of these parents of terminal pediatric patients concerning treatment decisions and the corresponding financial impacts. The parents had many points of data input before making a treatment choice. Through the course of the identification and diagnosis of terminal cancer, they were provided with all of the standard and novel treatment options. The parents the clinical trials with the sites of care and evaluated the length of treatments, what was covered by insurance, and the costs they would need to incur. The parents identified what they needed to do to navigate their work obligations and for their children. This meant maintaining employment, reducing employment, or becoming unemployed. They then had to take the information in, weigh it against what they wanted to achieve for their child, and then make the treatment selection. When the parents described the treatment options they chose and why, the rationale had everything to do with the goals and had no consideration of the cost, impact on employment, or other

negative financial impacts. The parents only considered what treatment was the most promising, based on their understanding, considering cost as a prohibitive but not a determining factor. These medical decisions were made based on the hope for desired outcomes. The central research question used all the data from all nine interview questions, and the research sub-questions were answered through the presence or absence of data from the interviews.

Table 3

Alignment of Research and Interview Questions

Research question	Interview questions
RQ	1,2,3,4,5,6,7,8,9
SQ1	4,5,6
SQ2	4,5,6,9

Research Sub-Question 1

When examining whether financial and health care choices were made based on the concept of achieving a goal, several interview themes emerged that provide clarity. Themes 3, 4, and 5 directly addressed the goals, treatment decisions, and financial consequences of the selected treatment. The participants selected their treatment pathway to achieve their goals. The selection of the treatment that best aligned with their goals was what they believed was their best chance at progressing toward the goals. These

varied but largely fell into two categories. One category was focused on extending life for as long as possible. The other was much less significant but directed toward achieving a cure. The pursuit of the goal was the only determining factor in the choice. The interviews revealed no consideration of the cost of the care, only the treatment that provided the best chance to achieve their goals for their child. This aligns directly with Snyder's hope theory. This theory describes that a person's hope is determined by what their goal is and whether they have the agency and pathway to achieve it. Even though a terminal cancer diagnosis existed for the participant's child, hope governed their actions through their use of pathway and agency to pursue their goals for their child.

Research Sub-Question 2

Sub-question 2 asked whether health care and financial decisions made in the care of terminal pediatric patients were representative of the concept of risk versus reward. The participants did not demonstrate the application of this concept when making their treatment decisions. The participants did not describe any time when they considered the risk versus reward of the treatments that were provided to them as options. With the terminal diagnosis, the participants only described that there was nothing that they would not try to pursue the chance of having more time with their child or a cure. The possible side effects, costs, and unknown impacts of a novel treatment did not cause the participants to examine the risk versus reward balance present in Kahneman and Tversky's prospect theory. Participant A104 mentioned the concept of risk but also stated that the weighting of risk did not matter to them.

The data collected helped to clarify how hope and prospect played or did not play a role in the decision-making and resulting financial implications. Like Eche (2022) and Sisk (2021), viewing the lived experience through the lens of hope, this study provides a unique perspective on hope and the lived experience. The studies by Eche (2022) and Sisk (2021) focused on how hope is preserved and protected in the lived experience but not how hope determines what is next. The data demonstrates that the certainty of the diagnosis and the uncertainty of the unproven novel treatments provide the parents with the agency and pathway they need to pursue hope. The hope of a desired outcome, accompanied by a terminal diagnosis, dictated the treatment selection with little to no deference to the cost associated with the agency and pathway. The data demonstrated that the pathway created through the novel treatment directly impacted the desired outcome. The parent's socioeconomic class did not have any bearing on what the goal selected was or the associated cost. The goal that completes the triad of hope, as described by Snyder (2002), was the single indicator that influenced the treatment decision selection. One interesting observation from the data was that in the decision-making process, there was no consideration as to the risk of the treatment selection, even though it is known to be unproven. This dynamic of hope and prospect will warrant further investigation. The balance of risk and reward, as described by Kahneman and Tversky (1979), was noticeably absent in the decision-making process. Particulalry the editing phase was dampened due to the scope of possibilites created by known teatments that only manage symptoms and did not help the parents pursue the goals that they had for their child. The lack of prospect supported the abandonment of weighing risk in the tradiotnal sense.

Parents did not weigh the cost or novelty as a deterrent to their treatment selection. The fact that risk was not a consideration in deciding on using an unproven treatment demonstrates that the only crosswalk to this theory was that due to the diagnosis, only reward was considered. The data reveals the predictability of hope and the heavy weighting of reward versus risk in the treatment selection in this population.

Limitations of the Findings

This study had some limitations that were present at its inception and others that presented themselves during the data collection phase. The nature of this phenomenological study limits the ability to generalize the findings. This is due to its examining a very specific and limited lived experience that large segments of the population will never have and may find difficult to relate to. During the study, it became evident that participants whose children had died more recently tended to have a more robust and presumably accurate recount of their experiences, with few gaps in memory surrounding specific details. The financial cost to the parents generalized, but participants with more recent experiences gave more accurate details, and some came to the interview with records to refer to. This study was limited to participants located in the United States, and all were insured due to either employment or government assistance. No participants were employed and uninsured so the dynamic might have been different in that population.

Recommendations

Examining the presence of goal-oriented action closer to the time of the experience might be beneficial in trying to better understand the impact of hope in

clinical and financial decision-making as it relates to the parents of terminal pediatric patients. No current studies have sought to better understand the impact of hope in the presence of a terminal diagnosis. Studies have examined decision-making and the involvement of pediatric patients, as well as the level of hope of these families, but with no focus on the direct influence of hope in the decision-making process. These studies can build on each other and begin to close some of the gaps in understanding this phenomenon and its impact on parents and guardians of terminal pediatric cancer patients. Future studies are advisable to capture a more robust and timelier recount of the experiences. They may also connect the understanding of hope and decision-making to quantify the Likert Hope Scale to better support interventions for families in determining the appropriate care for their child. Future studies would help to better refine the interventions during the goals of care conversation and find ways to support families throughout the process. Another area to examine in the any correlation between hope and the reward aspect of the propsect theory and the data has revealed in this case some consitencies with the presence of hope and the absence of factoring in risk into decision making in this population. The editing phase of the prospect theory was noticeably not considered because the outcome possibilities were certain with no action, but unknown possibilites with the selection for novel treatments.

Implications

The pediatric terminal cancer patient population currently starkly contracts with adult terminal cancer patients regarding the disease-targeting therapies utilized (Kaye et al., 2019). Helping to change the way that we support these families will help to protect

them against the socioeconomic implications of making decisions that do not have positive outcomes for their child but have significant financial consequences for the parents and guardians after their child has died. Abrams et al. (2021) described the costs associated with cancer treatment and the financial toxicity caused by these direct and indirect costs. Their study revealed that regardless of the terminal diagnosis, the parents were hopeful to achieve specific goals such as more time or even a cure. These choices led to an increased financial burden from costs. Finding a way to better support these families, by finding ways to provide greater financial support or a different approach during the goals of care conversations, will better protect them from the financial implications of their treatment choices based on their goal-oriented treatment decisions. Grier, Koch, and Docherty (2023) described the benefit of improving the goals of care conversations for pediatric patients by ensuring that they are culturally sensitive and individualized to honor the experiences and goals that influence medical decision-making. These conversations should fill in knowledge gaps and provide tools and support to achieve the goals of care.

The current practice in the goals of care conversation is focused on what options are available to this population and how to connect them to what is avilable. Studies by Blazin et al. (2018), Sisk et al. (2020 and Hendricks and Haase (2019) describe this pivotal opporunity to impact the experience of what is to come for patients and their famlies. Taking what is now known and applying it to bolstering the conversation to help frame the choices to come, what others families that have been through with similar prognosis and how to develop protective factors both emotionally and finacially is

critical. Understanding the chocies and the propersity for treatment selections can help better prepare providers to frame the conversation, provide resources and support optimal outcomes based on the family wishes.

The application of the hope and prospect theories in understanding decision making in this population has illuminated certain tendencies. It is clear that in this instance, hope can better help parents and providers to undertand how treatment selections are made. The next step would to be able to quantify hope comparatively to this population. Being able to create a tool for screening and intervention purpouses would be expected to have positive impacts on this population. Applying this theory in this population opens up the possibility to expand the understanding of hope in this setting and leverage this understanding to improve goals of care conversations.

Understanding how to shift from a paternalistic view of care to patient-centered care involves improving the goals of care conversation from suggested care to what patients and families desire. Tonelli and Sullivan (2019) described that non-interference and support of autonomy in decision-making is the best way to shift from paternalism, which is often associated with dissatisfaction with the care experience. Using the information from the present study to change policies and procedures relating to supporting patients through the coordination of resources and improved goals of care conversations will ignite social change for them.

Conclusion

The findings from this study reveal that hope and goal-oriented treatment decisions represent a primary determinant of treatment selection and the ensuing financial

implications. Risk versus reward was not a consideration for the parents of terminal pediatric cancer patients. The medical treatment team must have effective goals of care conversations to support these families, even when their treatment selection goes against the recommendations of the team. This means determining how to better connect parents and guardians with resources that reduce the financial impacts related to the aggressive treatment choices they make based on their goals for the child. The study revealed that the parents largely chose aggressive novel treatments when their child had a terminal diagnosis. Treatment teams with this knowledge should better develop pathways to help parents achieve their goals while reducing their resulting financial burdens.

Providing awareness and context to the medical decision-making of this population will allow for positive change in the focus of goals of care conversations. Understanding that Snyder's hope theory concepts can contextualize the treatment choices made by this population is the first step toward improved goals of care conversations and resource strategies. The participants in this study communicated that they sought treatment pathways that they believed provided them with the best chance at achieving their goals of care. The impacts of financial costs related to the treatment selection were not considered by participants in any socioeconomic categories. The parents in this study communicated that only the desired outcome, or its potential, was the driving factor in the treatment decision-making. Understanding the pattern of decision-making in this population will help the treatment team to provide patient-centered care based on the needs and goals of parents versus a recommendation based on the likelihood of novel treatment success.

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Appendix A: Letter of Introduction

Dear **Participant name will be inserted here**,

My name is Timothy Campbell, and I am a doctoral student at Walden University working toward completing my studies in Health Services with a focus on Healthcare Administration. I invite you to participate in my research study to understand the financial-related healthcare choices parents of terminal pediatric patients make to provide care for their children. The purpose of this study is to better understand the lived experiences of parents of terminal pediatric patients and what influences their treatment decisions and the resulting financial impact to better inform future treatment goals conversations upon terminal diagnosis.

Participant eligibility for this study includes the following criteria: (a) the child of the participant must have succumbed to the terminal illness before participation in this study; (b) the participant is a resident of the United States, but citizenship status and/or legal status will not be exclusionary for this study; (c) the participant will need to be able to speak English and read at least at a fifth-grade level to be able to understand the consent form provided to them; (d) the child's cancer diagnosis must have been confirmed via diagnostic testing; (e) the participant must have access to a device supporting virtual video teleconference; and (f) the participant must have chosen one or a combination of three modes of care for the child:

a. Symptom management
b. Radiation and chemotherapy

c. Clinical trial

Based on these criteria, I am inviting you to participate in this research.

This study is important to the field of Health Services as the results could lead to improvement in goal of care conversations and the outcome-based utility of healthcare services and provide context for the decision-making of future parents of children with terminal cancers. Your participation would help give context to this topic in a meaningful way and has the potential to benefit others who encounter similar experiences and circumstances in the future.

If you are willing and have an interest in participating in this study, please review the attached consent form. If you have any questions or require clarification about the content of the consent form, please reach out to me, and I will respond with any needed clarification. Once you have reviewed, understood, and approved the consent form, please sign and return it to me at this email address.

Many thanks for considering my request.

Yours sincerely,

Timothy Campbell MSN, RN, CMSRN, CPHQ

Ph.D. Candidate, Walden University

Appendix B: Interview Protocol

Participant Code:

Interview Date:

Interview Time:

1. Consent Signed Y/N
2. Connectivity of MS Teams good Y/N
3. Consent reviewed and opportunity to ask questions provided Y/N
4. Participant informed of recording and transcribed Y/N
5. General introduction and small talk Y/N

Interview Questions

1. Tell me about the day your child was diagnosed and what conversations you had with the medical team.
2. Based on your initial conversations with your child's medical team, what treatment options were presented to you and what did they advise is the best pathway.
3. Tell me about what you were thinking when choosing what care to provide your child immediately after diagnosis.
4. What care did you choose for your child and why?
5. Based on the treatment choice, what were your expectations on the treatment outcomes for your child?
6. Tell me about the financial impact the treatment choices you made for your child had on you and your family.
7. What other costs not directly related to the care of your child did you incur because of the treatment choices made?
8. Did your child have any sudden changes in health status? If so, did it change your desired plan of care?
9. Is there any information that if you had on the day of diagnosis would have changed your treatment choice?

Closing explanation of transcription process and expectations. Y/N

Appendix C: Demographic Questionnaire

Participant number: _____

Date: _____

Location: _____

Email address: _____

1. What was the gender of your child?

Male _____

Female _____

Prefer not to answer_____

2. What was your employment status prior to your child's cancer diagnosis?

Employed_____

Unemployed_____

3. What was your employment status after your child passed away as result of the cancer?

Employed_____

Unemployed_____

4. What is your highest completed level of education?

Middle school _____

High school _____

Associate degree_____

Bachelor's degree_____

Graduate degree_____

5. What was your child's insurance status prior to their cancer diagnosis?

Insured _____

Uninsured _____

6. Did your child become uninsured while they were sick with cancer?

Yes ____

No _____

7. How old was your child when they were diagnosed?

0–5____

6–10____

11–15_____

16–20_____

8. What was your household income prior to your child's cancer diagnosis?

0–25,000 _____

26,000–50,000 _____

51,000–75,000_____

76,000–100,000_____

>100,000_____

Appendix D: Advertisement