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Post-decisional Conflict in Selecting Cancer Treatments: Perception of Information Disclosure may Influence Decisional Conflict, Decisional Regret, and Self-Acceptance in Bereaved Parents of Children with Cancer

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Post-decisional Conflict in Selecting Cancer Treatments: Perception of Information
Disclosure may Influence Decisional Conflict, Decisional Regret, and Self-Acceptance in
Bereaved Parents of Children with Cancer

by

Danielle De Santis Sperandeo

A Dissertation Presented to the
College of Arts, Humanities, and Social Sciences of Nova Southeastern University
in Partial Fulfillment of the Requirements for the Degree of
Doctor of Philosophy


Nova Southeastern University
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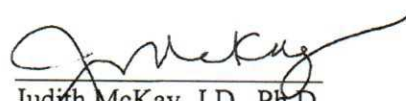
Nova Southeastern University
College of Arts, Humanities, and Social Sciences


This dissertation was submitted by Danielle De Santis Sperandeo under the direction of the chair of the dissertation committee listed below. It was submitted to the College of Arts, Humanities, and Social Sciences and approved in partial fulfillment for the degree of Doctor of Philosophy in Conflict Analysis and Resolution at Nova Southeastern University.

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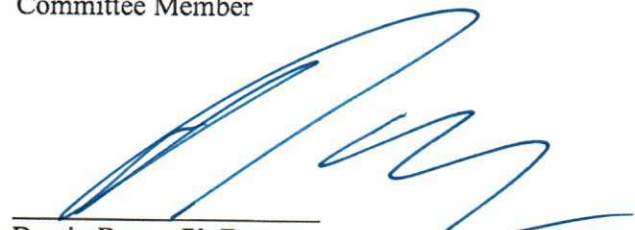


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Dedication

This research project is dedicated to my son, Hassan Nicholas Hammoud. The opportunity to parent Hassan was a gift unparalleled by any other life experience. His courageous battle with cancer spanned a period of 6 years. Together, we went on a quest for curative treatments, never abandoning faith in possibility over probability.

As Hassan's parent, I participated in hundreds of medical consultations with oncologists around the world. I navigated a complicated and often entangled web of medical decisions where information was sometimes unavailable, incomplete, or delivered at a pace that was slower than the disease progression. I lived through this experience with a nagging hunch that a decisional framework was needed to empower both parents and their sick children. My experience as medical decision maker is the inspiration for my research questions in this dissertation. My final recommendations in this study are presented to honor both the collective yet unique experiences of every child, mother, and father, whose lives have been jolted by a cancer diagnosis. I have a profound respect for their dignity in the desperate search for medical answers. The more beautiful and enduring quest involves faith, justice, and universal truth. I am especially grateful to Kathleen Adlard, a gifted clinical oncology nurse. At a time when I thought study recruitment might be impossible, Kathleen saw the value in my project and entrusted me with access to a vulnerable population.

In closing, I want to acknowledge my grandmother and lifetime source of strength, Josephine Miranda. My grandmother deeply desired the honor of watching me bring my doctoral studies to fruition. My every trial and conflict is graced by her wisdom.

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Abstract

This study aimed to establish a connection, if any, between perceptions of information disclosure about medical treatment and decisional conflict in bereaved parents of children with cancer. Decisional regret was an important theme in this exploration because decisional conflict strongly aligns with the propensity to mentally redo past events, thereby forming counterfactual alternatives to reality. People generate counterfactuals to hypothesize a more favorable outcome subsequent to a negative event or the death of a child as applicable to this study. A secondary objective was to investigate the potential influence of counterfactual processing and regret on the construct of self-acceptance: a phenomenon researchers have rarely studied in the population of interest. Study participants included parents who lost a child to cancer in the United States after participating in medical treatment prescribed by a licensed oncologist. Cluster and convenience sampling were employed to recruit 92 participants. Quantitative methods were used in obtaining data samples through validated instruments for each independent and dependent variable. The responses collected indicate that a perceived lack of information disclosure about treatment risks and efficacy, yield a positive influence on decisional conflict after the death of a child. Similarly, decisional conflict positively correlates with decisional regret, while the latter negatively correlates with self-acceptance in the bereavement process. The research implications call for additional studies that further isolate factors that contribute to decisional conflict. This study advocates for decision making tools and collaborative processes that ensure parents are well informed and involved in making medical decisions from diagnosis through palliative care, if a cure is not possible.

Chapter 1: Introduction

A pediatric cancer diagnosis is a recognized catastrophic experience. The parents or caregivers of a newly diagnosed child confront a host of complexities in their medical decisions (Feudtner, 2007). When a prognosis is uncertain or poor, as is often the case, parents make these decisions under tumultuous conditions. Time constraints, stress, incomplete or obscured information, and distraught emotions, can hamper the decision-making process, creating doubt, confusion, and, in the most unfortunate cases, long-term regret and life-adjustment difficulties. The healthy psychosocial adjustment of cancer patients and their families begins with self-agency for patients and caregivers, including a sense of personal satisfaction in the initial treatment decisions initiated. Self-agency characterizes the intentional ability to influence present and future decisions through personal motives and actions (Damon & Hart, 1991).

Physicians have long wrestled with how much patients need to know and in what manner they should share the information. Physicians hold concerns about a patient's ability to comprehend diagnostic and treatment details sufficiently, and do not want to overwhelm patients and caregivers who experience the stress and disorientation of receiving poor health news. Physicians must leverage their own discretion in these matters while observing ethical mandates that do not and cannot cover the wide range of variation in situational factors and patient needs.

Under the Nuremberg Code, medical practitioners have a legal and ethical responsibility to help families make well-informed decisions about the expected benefits and risks of medical treatment, the risks of foregoing the treatment, and the alternative therapies that may be available, if any. Informed-consent guidelines are often challenging

for physicians to interpret because they do not offer a specific quantity of information that needs to be revealed. As a general principle, doctors hold to community disclosure standards or best practices that other physicians in the local community would follow if presenting a similar diagnosis (Murray, 2012). The *Principles of Biomedical Ethics* (Beauchamp & Childress, 1979/2013) is a more recent publication that can supplement the physician-disclosure guidance that was more loosely constructed in the Nuremberg Code. Beauchamp and Childress (1979/2013), presented four moral constructs—respect for autonomy, beneficence; nonmaleficence, and respect for justice—intended to serve as ethical cornerstones for physician conduct.

An ongoing debate on how to reconcile ethical decision-making practices in a clinical environment that is fraught with continuously shifting variables and dynamics influences the literature on medical decision making. Theories may tend to oversimplify decision making as a uniform, homogenous, and linear process. Clinicians and patients in an oncology unit know well this is not the case. If society accepts that ethical decision making is an unattainable pursuit, the story would end here. Fortunately, from a patients'-rights perspective, this topic will not dissipate soon. The messy nature of treatment decision making is colorfully illustrated as follows:

Some decisions are straightforward, whereas others challenge even the most experienced clinician. Some decisions are rich in ethical and religious overtones, some have profound economic implications for other patients and for health care systems, some tax the clinician's negotiating skills, and some suggest multiple solutions, whereas for other decisions there is no good answer. (Whitney et al., 2006, para. 12)

The present study investigated the primary decisional factors and circumstances that contribute to decisional conflict and decisional regret. The focus was limited to the presentation of risks and negative treatment side effects associated with best available therapies for pediatric cancers. The central purpose of the study was to determine whether physician disclosure of treatment risks, including treatment inefficacy potential and quality-of-life compromisers, impacts decisional conflict, measured by validated and/field-tested instruments. Physicians have an ethical and humanistic need to heighten awareness and sensitivity to modifiable factors that can increase decisional satisfaction and avoid maladaptive consequences of poor decision making.

Background—The Phenomenon of Decisional Conflict

Research psychologist Janis (1959), who characterized problematic decision making as a result of competing counter forces within an individual. The incongruence of these forces impedes the acceptance and final execution of a decision. The emotional consequences of decisional conflict include anxiety, tension, avoidance, regret, and stress. Heretoforeward, we will subsume that decisional conflict encompasses these troublesome emotions. Janis (1959) further underscored the likelihood that decisional conflict could result in intrapersonal and intra-group conflict when decisional conflict led to faulty decision making with broad scale consequences.

Medical decision making involves a narrow scope of content and affected parties, but the ramifications of these decisions can impact longevity and overall quality of life. The North American Nursing Diagnosis Association (2014) expanded Janis' definition to include the loss factors at stake. The organization holistically adopted challenges, risks,

and regrets concerning the personal values of finances, health, career, and family relationships as central concerns when managing decisional conflict in clinical settings.

Physicians may be prone to view decisional satisfaction singularly in light of treatment efficacy, irrespective of personal-value congruency, and quality-of-life indicators. One study demonstrated that when patients refuse chemotherapy, oncologists rated this as a good or reasonable decision when patients could articulate the benefits and drawbacks of the treatment from a medical standpoint alone. Oncologists who were interviewed seldom spoke about subjective and individual preferences related to dying, personal values, or other psychological constructs (Huijer & Van Leeuwen, 2000).

A multitude of factors can produce decisional conflict: a patient's lack of resources (including support systems), unrealistic expectations, social pressures, skills and confidence, and a lack of knowledge (O'Connor & Jacobsen, 2004). Some of these are predetermined in a diagnosis and others result from the physician–patient communication that ensues following the diagnosis. General consensus is that the physician–patient relationship and communication patterns are important influencers of decisional satisfaction in patients (Fallowfield, Jenkins, & Beveridge, 2002). However, vast inconsistencies exist in the manner doctors and patients navigate treatment options.

Physicians typically present the oral presentation of treatment risks, not to be confused with written informed consent, in a postdiagnosis consultation. The format and framing of this discussion is standardized neither by the American Academy of Pediatrics, nor by the American Oncology Association. In the absence of formal and published guidance for physicians, two polarities are possible. On one end of the spectrum, well-intended physicians may act as the unilateral voice in employing a

treatment. In contrast, the patient's self-agency and rights are central to the process, with the physician acting as counselor or advisor rather than the final decision maker.

Some studies yielded evidence that two types of factors—socioeconomic and situational—have impacted patient involvement in decision making. Examples are the degree of distance between the social and socioeconomic status of doctor and patient, the number of cases the doctor is managing, and how much time the physician can allocate to each patient, (Edelmann, 2000).

If Western medicine strives to be a world-class provider of patient-centered and compassionate care, scholarly dialogue is needed about how the presentation of treatment risks and benefits may impact decisional conflict in the short term and years after treatment has concluded, successfully or unsuccessfully. Although guidance does exist concerning the presentation of “bad news,” one may wonder why no existing model or standardized best practice advocates cancer patients (or their surrogates) collaborate with oncologists to evaluate medical treatments. From a patient-centered standpoint, the decision-making process would ideally result in a mutually agreeable approach to treatment that honors the background and values of the patient, including the realistic consideration of the family's social and financial resources. Shared decision making and decisional aids are pillars of hope in the quest to improve decisional satisfaction. Research in support of these resources may serve as a catalyst to bolster further interest in the development and implementation of shared decision making through physician training and decisional support tools.

Shared Decision Making, Benefits, and Challenges

Over the last 2 decades, burgeoning research described treatment decision making. Extant literature has evolved from broad scope and overarching questions such as, “Do parents of sick children want to make medical decisions?” and, “Are parents of children with cancer satisfied with their current level of involvement in treatment related decisions?” (Mack et al., 2011) into more finely tuned research problems that do not presuppose a desired passivity on the part of the decision maker. Available studies have compositely investigated several factors that influence decision-making satisfaction that include family support systems, the role of stress and emotions in the decision-making process, time constraints, trust and rapport with the child’s oncologist, clarity and comprehensiveness of information received, and, to a lesser degree, the demographic characteristics of research participants. Superficially, health care practitioners collectively express a willingness to adopt shared decision-making models. Several studies affirmed the positive emotional adjustments that occur when patients develop a strong partnership with their physicians in the exploration, comparison, and pursuit of treatment options (Diefenbach et al., 2009; Gillam & Sullivan, 2011). Although the literature contains positive commentary on shared decision making as a general concept, several challenges may thwart shared decision making from gaining widespread support and implementation. First, no commonly understood definition exists for what constitutes shared decision making, despite considerable dialogue surrounding what the definition could involve. Elwyn and Miron-Shatz (2010) suggested that shared decision making should encompass a set of explicit objectives on which doctors and families agree. Feudtner (2007) asserted that consensus building would likely be a key component in a

shared decision-making model, but physicians and their patients should also plan a course of action for when they do not reach consensus. Second, the parties may perceive deviance when a patient's values run counter to societal values or otherwise limit the advancement of clinical research, or the cost efficacy associated with obtaining early intervention influences decision-making processes (Chin, 2013). Although not applicable to all cancers, a practical example may involve a patient who refuses treatment after an initial diagnosis but elects to participate in treatment after a relapse. It is plausible that this individual may require more invasive and expensive therapies than otherwise would have been employed.

The third obstacle is the tendency for some physicians to employ therapeutic communication strategies that frame treatments in an optimistic light, in the belief that families need to have cause for hope as a precursory condition for treatment compliance. Whitney et al. (2006) advocated for a pediatric decision-making model that attempts to resolve the problematic intersection of ethical concerns and clinical realities. The novelty of the model includes differentiation between two types of sovereignties: decisional priority and decisional authority. Decisional priority involves the identification of a preferred treatment based on conventional acceptance through research outcomes. Decisional authority describes the final ability to accept or reject a treatment when competing factors no longer point to a single or best-treatment option. To offer an analogy, the act of steering a ship in a storm in the direction that appears to be the safest and closest to the shore is an example of decisional priority. Decisional authority involves the act of pressing or releasing the gas pedal when no shoreline is in sight or when multiple directions offer comparably safe waters.

The model posits that decisional priority should rest with clinicians when a probable cure is statistically high or only one treatment options exists. Alternatively, when multiple treatments are available with similar degrees of efficacy and toxicity or death is imminent—a condition known as clinical equipoise—decisional priority is revested with the parents. The concept of decisional priority is likely more relevant for clinical diagnoses that have predictable prognoses and treatment protocols. The model does not have general applicability for the majority of pediatric cancers that have a modest potential of cure or life extension. In these more frequent situations, decisional priority would seldom reside with the clinician.

In a manual dedicated to the discussion of the communication and presentation of a life-altering diagnosis, a vignette describes a young doctor who casually speaks to an adolescent girl and her mother in a hospital ward about her newly discovered diabetes. The doctor is described as fatigued and hastily moving from one patient to another. The doctor smiles and advises the girl that she will still be able to accomplish all her dreams, irrespective of the disease symptoms and outcomes (Ahlzen, 2010). Although well intended, the physician may be downplaying the realities of diabetes to offer the family hope and an optimistic outlook.

In a positional paper, Edwin (2008) opined that physicians overestimate the role of emotion in their patients, believing that stress and sadness incapacitate people from understanding medical information and making informed decisions. Edwin encouraged physicians to disclose the risks associated with treatments, even when the risks may be discouraging and unpleasant. A study involving 56 parents of children who died in an intensive-care unit supported this position. Most participants interviewed expressed the

desire to receive a direct and honest account of their child's prognosis and treatment options. Some parents reported feeling betrayed when a prognosis was postponed or avoided. The study conclusion points to the importance of physician–patient communication processes when considering after-death adjustment needs (Meert et al., 2008).

The fourth and perhaps most relevant argument to this study involves the common belief among physicians that patients and their caregivers lack the intellectual aptitude or numeracy skills to fully understand the benefits and risks associated with best available-treatment protocols (Pieterse, Bass-Thijssen, Marijnen, & Stiggelbout, 2008). Reyna (2004) designed several activities that illuminate the type of numeracy errors made by patients when evaluating treatment risk. The most common processing errors involved difficulty understanding absolute risk rather than relative risk. Later research supported the findings that most patients do indeed struggle with understanding the drawbacks of treatment when numerically expressed as relative risk (Fagerlin, Zikmund-Fisher, & Ubel, 2011; Reyna, Nelson, Han, & Dieckmann, 2009;). Although difficulty with numeracy skills is a well-documented phenomenon in shared-decision processes between doctors and their patients, the existence of poor numeracy skills does not, by itself, abdicate physicians from their ethical imperative to inform patients about risk. Decisional aids can be useful tools in helping the lay decision maker align with their personal values, and balance the positive and negative aspects of treatments with similar purported risks and benefits.

Decisional Aids

A decisional aid is a pictorial or graphic representation of numbers that can be associated with treatment efficacy and risks (Fagerlin et al., 2011). Decisional aids are increasingly a subject of research and discussion in the medical decision-making research because they can supplement a patient's understanding of treatment options, thereby complimenting the shared decision-making model. In a study of adult patients with solid tumors, investigators found an improved ability for patients to organize and comprehend information related to their disease (Jones, Steeves, Ropka, & Hollen, 2013). A similar study demonstrated that in adult populations, the use of decisional aids improved short-term decisional satisfaction but did not significantly influence long-term decisional satisfaction (Wong & Szumacher, 2012). To date, researchers have more frequently researched decisional aids in adult populations and with mixed results. At present, decisional aids are not used in pediatric oncology with any degree of regularity or uniformity.

In summary, shared decision-making models rest on the assumption that most or all patients prefer an active voice in treatment decision making. Researchers rebutted this assumption in a large scale public survey summarized by Levinson, Kao, Kuby, and Thisted (2005). According to the survey outcome, more than 50% of the individuals surveyed stated a preference for their doctors to make the final decisions. Survey results require caution. First, what people report they prefer in a hypothetical situation (e.g., "if I needed medical care") can be quite different from what they would actually prefer in a real-life scenario. More importantly, survey participants were asked about decisions pertinent to their own health rather than the health of their child. Physicians use

considerable discretion, but are not equipped with decisional-support tools to best assess a patient's and caregiver's needs for information. The research surrounding decisional aids has been slowly progressing, but generally limited to adult populations. At present, more than 500 decision aids are circulating, although not all of them are fully developed. The International Patient Decision Aid Standards (2013), a conglomeration, governs decisional-aid standards.

Counterfactual Regret

Counterfactual thinking is the pondering of decisions that could or should have been made if the decision maker could revert to the time of making the decision. Counterfactual regret occurs in the aftermath of a poor outcome when the decision maker laments not selecting an alternative that hypothetically could have led to a preferable outcome, or in worst cases, prevented a tragic accident or disaster (Byrne, 2005). Counterfactual regret can be adaptive when an individual uses this thinking to observe patterns of faulty decision making so as not to repeat the same errors. In contrast, counterfactual regret can be maladaptive when the decision maker had relatively little or no control over the choices or if all choices presented would have realistically led to a poor outcome, as is typically the case when treating incurable diseases. Some researchers suggested that, due to the traumatic nature of losing a child, bereaved parents engage in a more sustained and complex form of counterfactual thinking that has not been sufficiently researched. This manuscript explores counterfactual regret in detail.

Problem Statement and Study Overview

The present study aimed to determine if parents of children with cancer (following death) experience greater degrees of counterfactual regret when parents self-

report that treatment options and risks, including unfavorable side-effects, were not disclosed in a satisfactory manner. A second objective is to better understand if and how counterfactual regret, once detected, influences parental adjustment outcomes in the domain of self-acceptance. The first null hypothesis is that physician disclosure of treatment risks does not result in greater decisional regret in the population of interest. The second null hypothesis is that the presence of decisional regret does not result in lower self-acceptance during the bereavement process.

This quantitative correlational study applied a correlational statistical test to determine the direction and magnitude of a relationship, should one exist. In the present study, the independent variable for the first null hypothesis was satisfactory risk disclosure from clinicians. The dependent variable was labeled decisional regret. In the second null hypothesis, decisional regret was the independent variable and self-acceptance was the dependent variable.

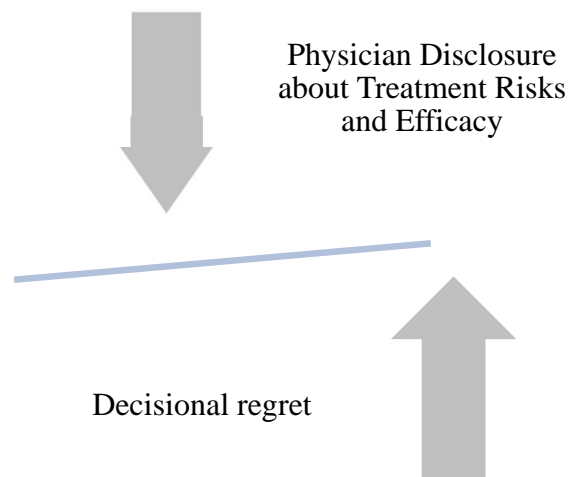


Figure 1. A diagram illustrating the potential relationship between the independent variable and the dependent variable in the primary hypothesis.

Theoretical Framework

Decision-making behaviors include three necessary components: actions, conditions, and outcomes (Eisenfurh, Weber, & Langer, 2010). A structural or process-related approach can characterize the study of decision making in general. In a structural or normative model, the empirical objective is to produce an ideal decision under circumstances that involve risk. Common assumptions underlying these theories follow: (a) the decision-making agent will reliably act out of self-interest, (b) the agent is informed and rational, (c) agents have consistent preferences that can be altered by reframing decisional factors. In structural models, a decision is viewed as the function of input parameters that are often manipulated by the investigator. Researchers develop statistical and mathematical models to control for parameters and account for changes in results (Abelson & Levi, 1985).

In the field of conflict studies, several foundational theories are structural in nature. Expected-utility theory and game theory, described in Chapter 2, are both structural and normative theories that explain the important influence of decision framing. By analyzing the volume and characteristics of decisional sets, these theories can offer transferable insight concerning why parents who make medical decisions on behalf of their children may tend to discount some types of decisions while overestimating the benefits of others. A weakness of structural theories is that they have difficult accounting for variations in decisional outcomes unrelated to set parameters. Moreover, some criticize these theories for failing to account for intertemporal choice: decisions that change across the continuum of time (Tversky, 1972.)

Process-related approaches to decision making borrow heavily from the field of psychology and are more interested in human variations in choice, irrespective of input. To provide a holistic literature review and a deeper discussion, this manuscript borrows from less linear psychological theories that similarly deduce decisional factors while acknowledging the complex cognitive and emotional factors that affect how people reach decisions. A growing body of literature under the umbrella of process theories use naturally occurring decisions and consequences. For example, fuzzy-trace theory views emotion and cognition as the nucleus of decision-making practices.

The constructs of these theories may substantiate or challenge the benefits of shared decision making and decision-support interventions. Some theories also concern how decision makers adapt to the consequences that accompany each decision. Counterfactual-regret research adds a novel dimension in understanding coping processes in the aftermath of a negative event, including traumatic loss.

Definition of Terms

Aspirational benefits. Include the advancement of research and quality of life associated with participation in Phase I clinical trials (Glannon, 2006).

Cognitive dissonance. Describes feelings of anxiety or regret for the loss of missed opportunities, once an individual commits to a specific course of action, particularly if the elected choice contradicts otherwise personal ideals or values (Jarcho, Berkman, & Lieberman, 2011).

Collaboration. An approach to resolving conflict intended to meet the needs of all parties. Scholars generally prefer this approach over other tactics such as avoidance or confrontation (Folger, Poole, & Stutman, 2009).

Counterfactual regret. Postdecision grievances that arise from evaluating or dwelling on poor outcomes associated with an irreversible decision (Byrne, 2005; Connolly & Zeelenberg, 2002).

Counterfactual thinking. An important term in this study, counterfactual thinking is precursory to the examination of counterfactual regret, a key variable in the study design. Counterfactual thinking is the postdecision musings over actions taken or not taken, often with the benefit of hindsight knowledge (Byrne, 2005).

Decisional aids. Visual depictions or animations of sequential questions designed to inform patients about treatment alternatives, efficacy, and risk, to better inform the decision-making practice (Fagerlin et al., 2011). Designers of some decisional aids aim to additionally help patients evaluate and integrate their own priorities, values, and preferences. A simple document can contain decisional aids, or they can be interactively supported by software programs or applications.

Decisional authority. Referenced here in the context of a study designed to mitigate the contradictions between ethical aspirations and clinical realities for chronic or terminal pediatric diagnoses, decisional authority refers to a parent's fundamental rights to accept or decline a treatment, even when clinician has taken a central role in navigating the decision-making process (Whitney, et al., 2006).

Decisional biases. Faulty thinking patterns that result in a decision maker overfocusing on limited information or deemphasizing information that may be nebulous or not fully present (Thaler & Sunstein, 2008).

Decisional conflict. A negative set of emotions—anxiety, tension, regrets, etc.—that result from competing counterforces in an individual concerning the acceptance and

execution of a decision (Janis, 1959). Decisional conflict is more probable when the decision maker has limited resources, information, and support.

Decisional Conflict Scale. First developed by O'Connor (1995) to better understand factors of uncertainty that face consumers when making health care decisions. The scale further evaluates modifiable factors associated with uncertainty, as well as the patient's perceived decisional effectiveness.

Decisional priority. A term developed by Whitney et al. (2006) refers to distinguish decisions that should be best determined by physicians on account of prevailing circumstances; for example, it is the only or best available treatment.

Decisional satisfaction. Characterized by positive feelings associated with making fully informed decisions with adequate support systems.

Direct benefits. Describe an enhanced quality of life or prolonged life as a result of participation in clinical trials, or most often a Phase I clinical trial (Glannon, 2006).

Emotions. Detectable neural changes in the status of feeling and mood (Starcke & Brand, 2012) leading to coordinated behaviors and responses (Keltner, Hiedt, & Shiota, 2006). As a layperson's term, it is not necessary to redundantly list types of emotions, but for this study, emotions influence and are in turn influenced by decisional factors and outcomes.

Framing effects. Well-documented phenomena that involve decisional errors made when the semantic components of information pertinent to the decision are manipulated to underscore potential gains or losses. In this study, discussion of framing effects will be limited to the context of medical decisions; thus, the term definition is extracted from a study on medical decision making (Peng, Li, Miao, & Xiao, 2013).

Gist and verbatim traces. Frequently mentioned in discussions of fuzzy-trace theory are essential to understanding the central premise of this theory as an alternative viewpoint of medical decision making than traditional economic theories. Gist traces are memories altered by the attachment of meaning and emotion, whereas verbatim traces are actual memories, untainted by emotional processing (Deretsky, 2008).

Heuristics. Guidelines that simplify complex decisions. The disadvantages of heuristics is that when they are applied inappropriately or to decisions of great consequence, they can lead to decisional biases that are fully explained in this manuscript (Dietrich, 2010).

Incidence rate. Physicians often make treatment-related decisions, partly based on what they know about incidence rate. Incidence rate is simply the number of new cases of an illness in the most recent year published divided by the number of people at risk for being affected by the disease.

Mortality rate. The number of deaths or conditions caused by a specific condition or disease divided by the total number of people, expressed as a ratio over 100 for ease of reference (New York State Department of Health, 1999).

Numeracy. A component of health literacy that involves an understanding of numbers to determine the statistical risk and efficacy associated with treatment options (Peters, Hibbard, Slovic, & Dieckmann, 2007).

Nocebo Effect. The phenomenon of experiencing psychosomatic symptoms in association with negative treatment side effects, with no biological cause for the symptoms. Some physicians have noted that patients may experience pain or other unpleasant symptoms, shortly after being cautioned about the possibility of this effect.

Prevalence rate. A mathematical quantification of the total number of disease cases divided by the total number of people. (New York State Department of Health, 1999).

Self-acceptance. Feelings of self-worth and a balanced awareness of personal strengths and weaknesses, in the aftermath of a traumatic event.

Self-agency. Used in the traditional or general sense of the word, paraphrasing a widely cited definition from Damon and Hart (1991), self-agency characterizes the intentional ability to influence present and future decisions through personal motives and actions.

Shared decision making. In health care consumption, as defined by Elwyn, Coulter, Walker, Watson, and Thomson (2010), paraphrased as follows: Shared decision making involves a bidirectional process whereby patients and their physicians mutually consider the best available treatment options in accordance with a patient's preferred route of action. This manuscript details the benefits and challenges of decision-making models.

Social functionism. The manner in which social functionism regards human emotions. Social functionism largely regards all emotions, negative and positive, as adaptive for survival (Heidt & Shiota, 2006). The focus of social functionism aligns with evolutionary theory.

Social hedonism. First associated with Bentham (1748–1832), defined here to promote a deeper understanding of the historical factors that influenced the genesis of utility theory. Very briefly, social hedonism aligns with the value for pleasure as one's

greatest source of good and therefore should be the cornerstone of public policy and moral principles (Driver, 2009).

Trace. A technical term that that refers to how one manages and archives memories in the brain.

Chapter 2: Literature Review

The objective of this study, in part, is to encourage a greater willingness for physicians to fully disclose cancer-treatment efficacy and risks, using methods and visual aids that will help the patient or caregiver evaluate the benefits and drawbacks of each treatment option while applying their own value system to quality-of-life concerns. Many or most patients with cancer face an array of treatment choices that do not hold curative possibilities. Even if the treatment goal is to extend life, parents of children with cancer must carefully consider the manageability of side effects. This cannot be accomplished without a well rounded understanding of how such side effects may compromise their son or daughter's quality of life when measured against the morbidity and mortality rates of children with a similar diagnosis who have underwent similar therapies. The stakes are high for these families.

TABLE 4.1 Causes of Death in the Childhood Cancer Survivor Study Cohort

Cause of death	Number of deaths	Percent of deaths
Total	1,848	100.0
Recurrence	1,246	67.4
Treatment-related consequences	394	21.3
Subsequent neoplasm	235	12.7
Cardiac	83	4.5
Pulmonary	33	1.8
Other sequelae	43	2.3
Non-treatment related	208	11.3
External causes	94	5.1
Medical conditions	114	6.2

Figure 2. A table comparing cause of death amongst children diagnosed with cancer.

Note. Childhood Cancer Survivorship: Improving Care and Quality of Life. Institute of Medicine (US) and National Research Council (US) National Cancer Policy Board; Hewitt M, Weiner SL, Simone JV, editors. Washington (DC): [National Academies Press \(US\)](#); 2003.

Physicians have a legal and ethical obligation to offer complete information, unrestrained by personal doubts or value judgments about patients' intellectual capacity, emotional propensities, or financial limitations. The literature review for this study concerns identifying those elements of decisional models and theories that may contribute to more satisfying parent and caregiver treatment-decision outcomes made on behalf of children with cancer. A realistic anticipation is that no singular theory will have pure or comprehensive applicability to a clinical setting and the complexity of a doctor-patient relationship. Despite this caveat, exploring theories that have sought to explain expected consistencies in human decision making and the framing effects that lead to decision-making variation between people and even within the same individual has value.

The totality of these theories should yield a better understanding of how adequate the visual and auditory presentation of treatment options can position a patient to make a decision that is reasonably in their best interest. The implication—*in their best interest*—touches on the cognitive and affective components of a decision maker's experience and encompasses the entire family system. A decision that is in the best interest of the patient and their family assumes the decision maker completely understands the applicability of risk, not only on a theoretical level, but as applicable to the specific health challenges that they or their loved one are facing. Researchers in the field of medical ethics succinctly wrote: "Understanding in the context of informed consent represents the ability to go beyond the recitation of facts in integrating knowledge into a treatment decision" (Flynn et al., 2008, para. 2).

The depth and diversity of decisional theories, combined with what is known about the construct of decisional regret, should synergistically expose influential factors

that account for decision-making satisfaction and, conversely, decision-making conflict. Medicine is on the horizon of hope for improved medical decision making as a collaborative and transparent process, ensuring social justice for patients of all cultural and socioeconomic backgrounds. Decision-making software and decisional aids hold promise in serving a broader and more diverse spectrum of patients who struggle with information literacy and numeracy.

The body of literature on decision-making theories, taken together, may have important insights about what type of information patients need to make balanced decisions whereby each can cope with the short- and long-term consequences. The improvement in technology combined with new paradigms and physician training will produce new possibilities for improved shared decision-making processes, especially in the area of pediatric oncology.

Decisional Dichotomies

In his work, Reflections on the Guillotine, Camus (1959) is known for his poignant but pragmatic declaration, “Life is the sum of our choices.” Chesterton (1908) offered these sage words: Life “is a trap for logisticians ... it’s wildness lies in its waiting.” Remarkable scholars from multiple disciplines have dedicated their life’s work to understanding how people arrive at decisions. Decision-making theories are compelling, yet daunting to investigate because they are eclectic and transdisciplinary in nature. Human decision making is complex and subject to change with internal, external, and temporal factors. In this sense, the theories under study present a palimpsest of rich topography. As new empirical findings come forth, some ideas can be refuted whereas

others are reevaluated and reintroduced. Each modification or expansion of a theory yields new insights into decision making in a medical context.

This literature review intends to explore the antecedents of decisional conflict, and to similarly analyze the components of decision making that can be successfully manipulated to produce more satisfying decisions. One can readily distinguish between traditional and contemporary theories. If psychological theories present a nature–nurture controversy, the amalgam of decisional theories comparatively debates the gut–brain dichotomy (Buchanan & O’Connell, 2006).

Traditional theories germinate from behavioral economics and are generally static, meaning they attempt to explain a single decision in a given point of time. Traditional theories are computation and capacity based (brain-work focused), often drawing from mathematical models and formulas. Recent theories quite differently rely on intuitive factors, borrowing from the psychology of risk, including theories of rationality, and encompassing recent work in the area of memory and perception or, in layperson terms, gut-level instincts. Here is a brief survey of the historical fascination with understanding how a global human society makes decisions, individually, as a group, under conditions of certainty, and—far more captivating—under conditions of uncertainty.

The Architecture of Decision Making: Heuristics and Biases

Human beings make decisions during every waking moment of their consciousness. Next to breathing, making decisions is one of the most natural and necessary activities in which people engage. Arguably, medical decision making after a cancer diagnosis is different in many ways. Patients and families may need to trade

quantity of life for quality of life (Chapman & Sonnenberg, 2000). The decision to undergo treatment entails a commitment to lengthy hospital stays or frequent trips to an outpatient clinic, the management of multiple unpleasant side effects, and a continuous array of diagnostic tests that must be repeated over time to gauge treatment efficacy.

Heuristics are guidelines designed to simplify decisions that would otherwise be complex if not overwhelming. Heuristics are especially useful in limiting the amount of thought and energy one must invest in making a simple or routine decision (Shah & Oppenheimer, 2008). An example of a heuristic often employed in daily life is the price heuristic or pattern of thinking that automatically associates a higher dollar amount with better quality. Commonplace heuristics are useful, adaptive, and seldom of great consequence. In contrast, overreliance on or incorrect application of heuristics can reduce one's ability to accurately assess risk and make decisions that are in their best interest.

Decisional biases are defective heuristics or faulty thinking patterns that involve overfocusing or underfocusing on limited pieces of information in a way that distorts reality (Thaler & Sunstein, 2008). Several types of decisional biases are well defined and researched. Decisional biases are most impactful when used to make a life-altering decision.

The reviewed literature suggested that medical-treatment decisions are vulnerable to decisional biases for three reasons: (a) fear consumes the thinking process, that is, fear of treatment complications and death; (b) one has limited memory or schema for the circumstances and contextual issues surrounding the decision itself, that is, parents are not accustomed to medical terminology and statistics; and (c) people apply a high degree of intuitive reasoning to the decision-making process. Physicians and patients can have

decisional biases and most research on biases focuses on errors made by doctors who overrelied on specific associations when selecting or deselecting treatment pathways.

Because the patient and their family is the population of interest in this study, the discussion centers on decisional biases that occur in populations impacted by a cancer diagnosis. Researchers suggested that patients with a poor prognosis are particularly vulnerable to decision biases (Lipstein, Brinko, and Britman, 2012). High-stakes decisions, such as the choice to undergo surgery, radiation, or chemotherapy involve estimating the likelihood of potential danger. When people have particularly vivid memories of a related scenario, they are more likely to make biased decisions because they internalize and magnify risks (Kensinger, 2009). For this reason, clinicians should strive to help patients identify decisional biases before or while they are occurring to mitigate the negative effects that may occur when such biases predominate important health decisions.

The following biases will be briefly discussed as a platform for theoretical explorations in the chapter: confirmation bias, hindsight bias, projection bias, omission bias, and framing effects, which are prominently considered in normative theories of decision-making processes. Confirmation bias can commonly occur when an individual has a strong prejudice toward or against a specific choice. The person will act in a manner designed to confirm the validity of their presupposed belief. In layperson's terms, confirmation bias may be referenced as wishful. When faced with a medical-treatment decision, a parent of a child with cancer may have strong attitudes in favor or against chemotherapy based on prior experience, positive or negative, when observing friends or family undergo this treatment. Consequently, the parent may discount the curative or

palliative value of chemotherapy, which may have a therapeutic benefit for their child's specific diagnosis. Similarly, a parent may prematurely select chemotherapy based on a positive orientation, even when chemotherapy is not the best available treatment for their child's condition.

When a patient or caretaker projects a strong disposition to a treatment before the facts are carefully juxtaposed, it is advisable for the physician to more closely explore the proposing or opposing viewpoints that preclude statistical information (Heshmat, 2015). Hindsight bias can be described as a feeling of having known it all along. Hindsight bias leads the decision maker into ascribing a higher probability to an event, after learning the associated outcome, than would have been estimated in the absence of such knowledge (Voss, Perkins, & Segal, 1991).

The present study is interested in the psychosocial adjustment of patients who have selected and participated in medical treatments without curative results. Parents of children who have died from cancer may later evaluate their decisional outcomes as being ominous from the start, due to having information that was yielded after the fact. Hindsight bias can be an intervening variable that explains why caretakers experience long-term regret, independently from dissatisfaction with limited physician disclosure. Although the present study is quantitatively focused, hindsight bias would be well detected through qualitative research methods in follow-up studies.

Projection bias, involves the tendency of people to assume that a decision made in the present will remain constant in the future. Decisions are highly subject to change over time, particularly when emotional states vary and options are reframed (Leavitt & Leavitt, 2011).

Projection bias can be avoided when physicians intentionally revisit and reevaluate treatment options with their patients, particularly after significant changes in health status, emotional status, or when quality-of-life factors measurably improve or decline.

Omission biases involve the preference for nonaction that may potentially cause harm, rather than action that poses less risk or an equitable risk of harm. Studies can creatively manipulate risk factors in both directions. These manipulations cause mixed interpretations of the results (Baron & Ritov, 2004). For example, participants are more prone to have omission bias when the harm or threat of taking action is immediate, such as in the case of shooting one person to save a group from being harmed (Baron, 1992).

In medical settings, omission studies have centered on consumer decisions about vaccinations. Groopman and Hartzband (2012) referred to the example of the influenza vaccine. Nearly 40% of adults eligible for the vaccine prefer not to accept the injection. They generally feel well and share the sentiment that it would be unfortunate to become sick after receiving the vaccination. Thus, they choose inaction as a way to avoid harm, understanding that the decision not to vaccinate may invariably result in a flu outbreak at a later date. In a pediatric oncology setting, patients and their families may elect not to undergo aggressive therapies with high mortality rates, such as a bone-marrow transplant, on account of loss-aversion tendencies.

Framing effects involve the influence of semantic factors on the decision-making process that results in choices that do not fully account for all available information. Prospect theory strongly supports framing effects, frequently replicated in Western studies. A few researchers found age and sex differences in framing effects. However, these nuances are unimportant for the exploration of a potential relationship between

physician disclosure and pediatric oncology treatments. When participants are presented with a risk that emphasizes potential gain, they repeatedly select this option over an identical option where the risk is characterized in terms of loss. This is true in medical as well as nonmedical environments.

In a recent study conducted by Peng, Li, Miao, and Xiao (2013), the researchers asked participants to evaluate a drug treatment used in 100 people where 70 people directly benefited. The alternate frame asked the same group to evaluate a drug treatment used in 100 people where 30 people did not improve. The mean response was in favor of the first frame, where the choice was ensconced in terms of gain. This tendency is the attribute framing effect. A similar proclivity, known as the goal-framing effect, involves the decision-making person's preference for selecting an option that invites them to engage in a behavior before a negative consequence occurs, rather than after the negative consequence has transpired. The risky framing effect findings assert that participants will more likely accept treatments presented in terms of survival rates rather than mortality rates. The presentation of risk factors is highly relevant to the problem statement outlined in Chapter 1 of this study.

Classical Theories

Expected utility theory. Physicians make decisions based on historical and evidentiary knowledge derived from research and experience. Commonly, medical practitioners refer to the concept of rate: incidence rate, prevalence rate, and mortality rate (Felder & Mayrhofer, 2011). Viewing the patient as a consumer, a considerable number of variables factor into the decision-making process.

Expected utility theory concerns individual preferences and values (assumed to be rational) when faced with a decision that includes at least two options. The evolution of utility theory dates back to an 18th-century moral philosopher, Jeremy Bentham, who believed hedonistic principles drive humans, the desire to obtain pleasure and avoid pain. Bentham was the first to propose the prospect of pleasure as quantifiable, and to similarly assert that ethical choices should be made to maximize pleasure. Bentham's concept of social hedonism would later prove to be a precursory influence on the fundamental definition of utility or an ordered degree of preference (Bentham, 1978).

Bernoulli (1738/1954) introduced the concept of utility as a subjective preference in trying to solve a famous gambling problem, the St. Petersburg paradox. In the St. Petersburg Paradox, a gambling game involves the random toss of a coin. Each time the coin lands on heads or tails for a predetermined time, players have an associated monetary pay-out. The mathematical dilemma involves accounting for precisely how much money is justifiable as an entrance fee into the game (Barbera, Hammond, & Seidl, 2004). In a mathematical-utility model, two options are symbolically characterized by x and y where x and y are cardinal values on an ordinal scale. The objective of the theory is to determine an individual's preference for x , relative to y , assigning mathematical representations to each choice, in order of preference. The subtraction symbol can indicate the strength of preference difference between pairs of choices ($v, w, -y, z$). At times x can be incomparable to y in that neither choice carries greater weight (Fishburn, 1968).

von Neumann and Morgenstern (1944) further developed expected utility to include the consideration of risk factors. The frequency of a choice preference leads to

the assignment of a probability captured across four axioms: transitivity, continuity, independence, and completeness (Shafrin, 2007). Initially, researchers employed expected-utility theory to examine preferences related to commodities with monetary values, such as in the case of the St. Petersburg paradox. Over time, the idea of a utility could be more universally applied to any decision that produces a desirable outcome. In health care decisions, utilities correspond to feelings of well-being and longevity. Utilities do not refer to the medical treatment in a direct or isolated sense. Rather, the utility is ascribed to an improvement in health status that directly results after the treatment is administered (Felder & Mayrhofer, 2011). In measurable terms, a utility of zero corresponds with death, whereas a utility of one corresponds with perfect health (Tolley, 2009).

Utility theory draws multidisciplinary interest from the fields of psychology, economics, statistics, and management science because it has versatile applications, offering predictive and prescriptive value in understanding how people arrive at specific decisions. Psychologists have interest in the predictive value of the theory, whereas economists, managers, and statisticians hope to develop prescriptive protocols for specific types of decisions, supported by the tenets of utility theory. Despite the breadth of its value, utility theory has significant limitations. First, the derived mathematical utilities build on average choices over time, providing little or no account of decisional anomalies influenced by framing effects or preexisting biases (Moskowitz, Kuipers, & Kassirer, 1988). Second, the theory rests on choices made in the present moment, altogether discounting future choices, and the persistence of a given choice in that a preference that someone has today will be the same preference they have 1 month from

today, and into the future. Future decisions are important in an oncology setting where treatment efficacy, in part, depends on a patient's and family's long-term commitment to treatment adherence.

In the past 3 decades, developments in health economics and, specifically, medical decision making, have revived interest in utility theory because the theory aims to help people explore their preferences when faced with choices that are uncertain or multidimensional (Moskowitz et al., 1988). A pediatric cancer diagnosis carries tremendous uncertainty because cancer types and cells behave unpredictably in each individual body. Treatments impose negative side effects with highly variable degrees of curative and palliative potential. Health utilities involve defining health states or conditions and then assigning a preference value for each condition. Physicians can better tailor treatments to the needs of individuals and subgroups when they have the ability to assess preferences (Blinman, King, Norman, Viney, & Stockler, 2012). However, some researchers refute the importance of patient preferences, claiming the benefits of monitoring preferences compel a more critical examination of how the patient stands to benefit from preference-driven decisions.

Patient preferences. Patient preferences situate on priorities and values concerning longevity of life rather than quality of life. Cancer treatments have not advanced enough to offer both, so patients and their families must be prepared to make compromises. Physicians who are knowledgeable about their patients' preferences can be better prepared to make clinical decisions that are acceptable to the patient in the near future and over time. Blinman et al. (2012) discussed the variability of treatment preferences in general society rather than the patient diagnosed with cancer. The cancer

patient places greater value on the accessibility of affordable treatments. Furthermore, a patient who has already received cancer therapy will have a different perspective of treatment from a patient who is evaluating it for the first time. Treatment preferences must derive with a standard scale that presupposes good health to be measurable.

Although several instruments are available with varying degrees of validity, this discussion includes two of the most commonly used methods of assessment: the standard gamble approach and the time-trade-off approach (Tolley, 2009). As stressed in this study, physician disclosure is paramount in helping patients achieve a sense of satisfaction in their decision-making process. The assessment of patient preference rests on physician disclosure about quality-of-life factors that, when not confronted directly, can be diminished or omitted altogether in the doctor–patient dialogue.

The standard-gamble approach. In the standard-gamble approach, a patient faces an adverse or unpleasant health status demarcated by the letter H, such as an inoperable malignant brain tumor. The probability of receiving a cure through a particular treatment is denoted by upper case P, and the statistical possibility of immediate death from the treatment is expressed as P-1 (Felder & Mayrhofer, 2011). The patient faces the option of short-term perfect health followed by certain death or the possibility of an intermediate state of health for an extended period of time. In this scenario, the probability gradually adjusts until the patient no longer has a strong preference for one option or the other. The standard-gamble approach closely follows the principles of expected utility theory and has the longest running record as the preferred standard method of preference assessment in the medical community. One noted shortfall is the ceiling effect it produces for patients who are risk averse. The ceiling effect can make it difficult to find measurable

or statistically significant nuances in gambles as probabilities gradually adjust (Blinman et al., 2012).

The time-trade-off approach. When a patient is not in immediate danger, the time-trade-off approach can be a feasible way to negotiate difficult decisions. This method requires the decision maker to consider how many years of good health would be equivalent to years in poor health or, conversely, how many years the patient would sacrifice in poor health to attain better health thereafter, assuming that treatment selections will have a reasonable chance of efficacy (Stiggelbout, 2000). Researchers suggested that comorbidities influence a patient's positive appraisal of a treatment prospect (other health conditions in addition to the primary diagnosis), and even nonhealth statuses such as income, social support, and insurance factors (Gaskin et al., 1998). The advantage of the time-trade-off from a disclosure standpoint is that it opens a dialogue concerning the quality of life that one will compromise while enduring chemotherapy, radiation, and other invasive cancer treatments. Patients have the latitude to consider very personal factors that will be impacted by the sacrifices treatment will demand.

A contrasting and perhaps controversial view about preferences maintains that people do not actually possess reliable notions about healthcare options. When facing treatment decisions, people process the available cues and make decisions that are subject to change over time, or when the cues are manipulated. Lichtenstein and Slovic (2006) asserted that trivial preferences, such as what flavor of ice cream one likes, are relatively constant over time. However, when faced with unfamiliarity or uncertainty, people tend to invent preferences that are highly variable and subject to external influences. The idea

of constructed preferences underpins a growing scrutiny about the perceived benefits of patient autonomy and collaborative decision making. More attention will be devoted to these criticisms in a later section of this manuscript subtitled, Decision Support Interventions.

Game theory. Game theory, credited largely to von Neumann and Morgenstern (1944), emerged as a mathematical model to determine how competing agents will make decisions in conflict situations. In most cases, players are assumed to be rational opponents, motivated to maximize their best possible outcome. The opponents are well informed about the choices available to reach a desired outcome.

The scenario has a fixed number of choices and outcomes, each of which are invariable, meaning that the choices are discrete and constant; for example, one choice does not alter or build on another. In game theory, decisions, referenced as *strategies* can be ranked in ordinal number from least to most preferred. The conflict presumably rests in the challenge to select from options that inherently involve risk (Osborne, 1995). Some study designs require players to cooperate to maximize outcomes. It is important to this study to underscore that game theory addresses extraneous conflicts that occur between an individual and their outside world as they attempt to optimize material rewards or exoneration from an unpleasant circumstance.

The prisoner's dilemma (Axelrod, 1984) introduces a fictitious scenario where two players have committed a known crime. They are being held in separate cells and are faced with the decision to either confess the crime or plead innocence. Their individual decisions will impact their own fate and that of the other player; however, they face the dilemma of not knowing how the other will decide. The players can cooperate with each

other through the loyalty of not disclosing the crime, or defect by disclosing evidence that will convict themselves and the other player. The maximum reward involves only one player defecting, followed by both players cooperating. The greatest pay-off, betraying the other, also contains the highest amount of risk. Findings suggest that in a single episode of the game, players tend to act exclusively out of self-interest, even if the risk is greater, simply because they mistrust the unknown actions of the player with whom they are not permitted to communicate with. Game theory has been used to inform military tactics, political strategies, and organizational decisions in the business world (Kohler & Leinfellner, 1998).

The present study has interest in surveying this multipurpose theory for its potential applicability to medical decision making, either as a conceptual manifestation in the physician's consultation, or respectively in the form of decision support aids. Intuitively, game theory would appear to be at odds with the objectives of communication between medical practitioners and their patients. Clearly, medical decisions are incredibly more complex and with greater loss potential than games played in a laboratory setting. Also, choices in game theory are predetermined; thus, the theory does not capture the intrapersonal conflict that may develop as an individual navigates a complex array of variable decisions, as would occur in real-life encounters. Moreover, patients and their families are not considered to be in an adversarial relationship with their health care providers, and some researchers have gone to great lengths to challenge the rationality of patients and their families when facing difficult medical decisions with torrential emotions. Yet in the medical and game-theory environment, decision making is social and interactive.

Tarrant, Stokes, and Colman (2004) closely considered other game-theory designs such as the centipede game, which may hold promise for improving communication and cooperation between doctors and their patients, ultimately reducing decisional conflict in the process. The centipede game involves a continuous series of moves and countermoves that equate to a quantifiable point system. Although cooperation over time results in more accrued points, at various junctures defecting will result in a moderate but larger personal point gain. Comparatively, in a physician–patient scenario, cooperation equates with patients following their doctor’s advice, for example, taking their medicine as prescribed.

A patient illustrates defecting by ignoring their doctor’s advice, failing to fully disclose symptoms, seeking second opinions, or switching doctors. Doctors can transfer patients or continue to see them on a rote basis without the inclusion of reciprocal trust and information sharing (Tarrant et al., 2004). In the centipede game cooperation is the central responsibility of the patient, when in life, physicians can cooperate by sharing risks, connecting patients to supplemental resources, or sharing other patients’ testimonials. Cooperative behaviors foster trust whereas defecting behaviors erode it.

Game theory holds enduring interest in the area of conflict analysis because it reveals the human tendency to want to cooperate and trust when a relationship is present, even when it is not strategically sound to do so based on an artificially constructed system of punishments and rewards. Although game theory is not primarily concerned with trust as a variable of measurement, trust is a determinant behind human behavior in game and in clinical settings. Newer theories such as behavioral game theory and psychological game theory are making strides in determining the contextual factors that

predicate whether trust develops or erodes. Once identified, these future findings may enhance trust-building communication techniques in the pediatric-oncology setting in a way that may ultimately mitigate long-term decisional regret.

Conclusion to Traditional Theories

This section attended strongly to economic theories. This classification of theories subsumes that good decisions build on the quality of available information used to accurately assess risk factors. Although traditional economic theories offer some predictive value for simple decisions that occur in a laboratory setting, these theories lack universality when applied to medical-decision settings with variables that are obscure, dynamic, and fleeting. Here, this manuscript departs from economic theories that evoke experimental designs that define decision-making risks in absolute terms.

To present a rounded analysis of the published literature, next is a comparative explication of modern theories that deemphasize decision making as a calculus or intersection of risk factors and desired outcomes. In contrast, modern theories envelop the role of emotions, perceptions, and memory in decisional outcomes; factors intentionally omitted in economic and behavioral theories. Researchers demonstrated that anxiety and depression positively correlate with decisional conflict (Leykin & DeRubeis, 2010). Other studies and theories magnify the inherent errors that occur in memory and perception and ultimately influence decisional processes (Kensinger, 2009).

Contemporary Theories and Concepts

The role of emotions. Emotions are feelings that arise from a class of stimuli, such as threats or joyful images, and ultimately result in detectable neural changes (Starcke & Brand, 2012), physiological responses, and coordinated behavior (Keltner,

Hiedt, & Shiota, 2006). Emotions, positive or negative, are central to decision making because they have a large influence on motivations (Consedine, Magai, Krivoshekova, Ryzewics, & Neugut, 2004). Until recent decades, very few investigators attempted to study the relationship between emotions and decision making. The challenge is trying to study emotions when it becomes necessary to isolate not only a particular emotion, but the object or situation that has evoked it.

Several emotions can impact decisional processes. It is possible, for example, that in a study attempting to isolate the correlation between depression and decisional conflict, discrete emotions like fear and embarrassment are inevitably present, even when not controlled for in the study. Such emotions may move together in a positive or negative direction in a plotted display referenced as a covariance (Kenny, 1979). Covariances are difficult to monitor and account for when many emotions intertwine.

Contemporary decisional theories, in contrast to behavioral and economic theories, aim to account for the role of emotion in the processing and evaluation of risk, including post-decision-making outcomes such as human adaptation and adjustment to decisional consequences. The parallel interplay of cognition and emotion is widely accepted as a real and adaptive phenomenon in recent literature. These findings lend insight to the research questions in this study because one variable under investigation is decisional regret.

In early literature, scientists who study decision making viewed emotions as superfluous and disruptive to the target action of making a rational decision (Reynolds, Lynn, Zhou, & Consedine, 2015). Medical providers have been socialized not to become emotionally involved with their patients. Western physicians have long favored

emotional distance and detachment as a way of adhering to the norm of clinical objectivity, a construct that cautions physicians not to allow emotions to interfere with clinical judgment, diagnostics, and the application of medical treatment (Yakeley, Hale, Johnston, Kirtchuk, & Shoenberg, 2014). The practice of clinical objectivity can lend understanding to why doctors view patients' expressed emotions as a hindrance to selecting and adhering to a course of treatment. This is especially true for cancer patients and their families who are experiencing fear and anxiety in association with multiple issues (anticipation of pain, prognosis, treatment options, loss of normal routines, and death).

Social functionalism, with roots in evolutionary theory, regards emotions as adaptive and necessary for survival. In this theoretical orientation, even emotions such as fear and anger are beneficial in helping an individual identify and assess threats in their environment (Keltner et al., 2006). In general, negative emotions can be health promoting when the emotions are situation specific or dispositional to a specific diagnosis or medical condition (Consedine & Moskowitz, 2007).

In a frequently cited study, researchers qualitatively assessed women with breast cancer concerning their fear in relation to three separate independent variables: the screening process and mechanisms themselves, screening outcomes, and general fear of cancer. Researchers concluded that the women who were more situationally fearful about breast cancer, rather than all three items, were more likely to make the decision to participate in early detection screenings (Consedine, Magai, Krivoshekova, Ryzewics, & Neugut, 2004). Similarly, the display of prideful emotions is often culturally and socially discouraged as unattractive, especially for women; yet fostering pride can serve the

purpose of helping women better comprehend and recall information about medical risks (Reed & Aspinwall, 1998).

Medical decision making is more complicated than ever before. As the global sophistication of medical science develops and grows, patients and their surrogates have a widening spectrum of choices to consider. Genetic screening and counseling offer the opportunity for willing participants to examine probabilities associated with their vulnerabilities and predispositions to certain hereditary diseases. Consequently, genetic screening is a useful testing ground for understanding how emotions impact risk assessment and decisional satisfaction. Researchers classified women who underwent genetic screenings for breast cancer according to their decisional status: early, intermediate, late, or non-decision maker. The researchers also considered self-reported depression, generalized anxiety, and situation-specific anxiety. Comparatively, women with depression 1 month after making the decision to undergo screening were also more likely to score high on decisional conflict (Rini et al., 2009). More studies are needed to understand the emotional factors that distort risk assessment; longitudinal studies need to determine if and how positive and negative emotions can mitigate or prevent decisional conflict.

Fuzzy-trace theory. Intuition is at the epicenter of reasoning in fuzzy-trace theory (Brainerd & Reyna, 1990), a reasoning model and false memory paradigm that gained popularity by offering an explanation for false eyewitness testimony in legal arenas. More recently, researchers have applied fuzzy-trace theory to the assessment of risk in medical decision-making scenarios (Reyna, 2004). Fuzzy-trace theory can be viewed as a contemporary alternative to behavioral economics or capacity-driven theories

in the analysis of decisional processes and outcomes. Fuzzy-trace theory focuses on the influence of working memory, assessing how adults qualitatively reason through the risks associated with available choices, such as the willful acceptance or avoidance of those risks. Trace, as a scientific construct, directly refers to the manner people manage memories, archived by the brain. Verbatim traces are memories recorded as they occurred in actuality, without any altering of actual reality.

Gist traces, in contrast, are memories altered by the primal attachment of meaning and emotion (Deretsky, 2008). Brainerd and Reyna (1990) posited that people process verbatim and gist-memory traces in a dual and parallel manner or milliseconds apart, although the frequency with which this results in memory impairments varies from one developmental stage to another. Human attach meaning to most memories. According to Reyna (2004), psychophysical errors that occur after people project meaning onto verbatim traces hamper rational decision making. Consequently, people evaluate risk in the context of gist traces, and either ignore or misunderstand pertinent information.

If this argument has merit, than it logically follows that patients and caregivers who evaluate medical treatment will employ faulty reasoning, no matter how much risk their physician accurately depicts when presenting a prognosis. In one study, Reyna and Hamilton (2001) discovered that patient participants could not reliably recall the specific probabilities, expressed numerically, about the risks of not having surgery versus the risk of the surgery itself; a task that is associated with verbatim trace memory. Surprisingly, the same patients could accurately rank levels of risk from high to low in the correct order. The same study presented the additional finding that study participants displayed the tendency to ignore the number of possibilities (base-rate neglect), and to ignore

overlapping classes of risk, indicated with the use of blue and red tokens that represented more than one risk category. Although most scientists agree that the human memory is fragile and unreliable, fuzzy-trace theory might be critiqued for approaching the influence of emotions as a singular proposition, without differentiating the effects of positive versus negative emotional experiences on the accurate recall and comprehension of risk factors.

Kensinger (2009) argued that positive and negative events result in more vibrant memories than neutral events; an outcome attributed to increased brain activity between the hippocampus and amygdala. A second component of Kensinger's hypothesis, supported by neuroimaging studies, demonstrated that emotionally charged events result in superior recall of intrinsic contextual features but a compromised recall of extrinsic contextual features. A practical illustration involves showing pictures of a threatening snake to a group of participants.

Although participants may later recall, in great detail, portions of the image that were frightening—fangs, shape of teeth, etc.—the same participants will likely have a dissipated memory of the items surrounding the snake such as trees, sky, and rocks. The same researchers suggested that the researcher has considerable influence over the strength of recall; researchers instruct participants to pay special attention to the details of an object or event, a type of guidance referred to as encoding instructions (Kensinger, 2009).

Fuzzy-trace theory does not consider the counteractive measures an oncologist might take in their patient communication and presentation of treatment choices, which might help patients recall risk factors well after the consultation has concluded.

Contemporary work on memory and emotions (Kensinger, 2009; Reyna & Hamilton, 2001) presents an important departure from economic and behavioral theories of decision making, allowing researchers to leap forward with an important premise: the notion that emotions as precursory influencers over the types of stimuli people remember and with what degree of accuracy. Hence, the improvement of decisional satisfaction does not rest alone on improving patient numeracy and making risk factors more visible and intelligible to the layperson. Rather, the oncologist must now view emotion as a natural rather than an irrational component of decision making.

Sadness, fear, and grief have their place in the decisional process, but because they can shadow the accurate recollection of risk, it will be important for people to revisit risk factors multiple times in the health care journey, albeit inconvenient and inefficient, but central to patient satisfaction through the reduction of decisional regret. The view of emotion in the framework of fuzzy-trace theory has meaningful relevance for patients considering Phase 1 clinical trials. Medical professionals reserve Phase 1 trials for populations of cancer patients who have disease progress that is unresponsive to traditional or conventional therapies. Patients who are eligible for these trials often experience more intense emotion than patients who are progressing well on traditional therapies, or who are in a temporary remission state or hiatus from treatment.

Although emotion and cognitive patterns are mutually interdependent and part of rational decision making, excessive emotion such as overoptimism may lead someone to participate in a clinical trial under unrealistic and false understanding. Similarly, intense fear and grief may cause a patient or caregiver to decline participation before they have received and fully evaluated the statistical facts. Patient information needs for these types

of trials are also unique because patients often confuse research with therapy. Another important distinction that can blur is the difference between direct benefits and aspirational benefits. Direct benefits have salutary effects in that they prolong the life of a patient or otherwise improve the quality of life they have remaining. Aspirational benefits are offered when the patient's participation in the trial will bring valuable data to benefit future patients with the same or similar type of disease (Glannon, 2006).

Finally, fuzzy-trace theory has implications for the design of decisional aids. Decisional aids factor in emotions and offer different decisional pathways for patients experiencing turbulent emotions rather than those whose fear and anxiety have leveled over the course of time. The influence of emotions on memory and decision-making processes compels medicolegal industries to consider offering patients, oncologists, and caregivers more flexibility in the timing that information is delivered, absorbed, and acted upon. For example, the practice of informed consent disallows patients from participating in clinical trials without full disclosure of risks. To ensure the employment of timely treatment, oncologists must divulge information readily. Patients or caregivers are expected to make prompt decisions accordingly.

In a study of communication practices and attitudes between oncologists and cancer patients, 61% of oncologists reported the wish and preference to deliver information in smaller increments because they were convinced patients were too grieved or too much in shock to comprehend the shared information (Taylor & Kelner, 1987). Fast decisions are not necessarily good decisions that incorporate patients' needs and value systems. A commitment to decisions as life altering as surgery or an intensive chemotherapy or radiation course should not be made in a time-pressured environment,

particularly when treatment outcomes are of great consequence and efficacy rates are low or uncertain.

Postdecisional Regret

Regret is a universal human experience with cognitive and affective components. (Altman, 2017). Sorrow and grief are emotions closely tied to regret, whereas remembrance, inward thinking, self-blame, and doubt characterize thinking and reasoning patterns that are characteristic of regret (Landman, 1993). Regret is an inherent part of living and developing, yet most seek to avoid the experience of regret whenever possible. An intriguing distinction and one not easily determined is whether regret occurs based on the decision itself, or as a result of the decision-making process itself; that is, lack of information, lack of support, lack of time, and limited options (Connolly & Zeelenberg, 2002).

Regret is a central theme of interest in this study, but also very broad in definition and application. Therefore, it is necessary to appropriately distinguish one type of regret from another to sufficiently isolate a specific type of regret as the independent variable. Regret is a transitive verb, meaning that the action of regret attaches to a person, event, or situation.

Although many studies focus exclusively on predecisional regret, this study targeted postdecisional regret or thoughts and feelings experienced after a treatment decision is made and followed in full, or until illness or death prohibited completion of the treatment. Types of regret are defined and exemplified in the context of cancer treatment rather than the general experience of regret. Outcome regret describes regret associated with illness or death that a patient or their surrogate believes is a direct result

or byproduct of a specific decision. Zeelenberg and Pieters (2007) introduced the idea of procedural regret. When experimentally manipulated, procedural regret can be coaxed when patients or caregivers are not permitted enough time to evaluate the benefits and drawbacks of a decision, or perhaps distractions are deliberately interjected to disallow focused concentration on the decision-making process itself.

In a clinical setting, procedural regret can be at play when treatment decisions need to be rapidly made following a diagnosis, or patients feel unsafe or uncomfortable asking a sufficient number of questions before committing to a course of treatment. Early regret studies often concerned determining regret as a consequence of action rather than inaction, stressing that people more intensely regretted poor outcomes aligned with inaction than those that transpired from action (Gilovich & Medvec, 1995). Inaction is rarely an option for consideration after the initial diagnosis of cancer, particularly in pediatric populations where legal systems compel parents to accept and comply with best available therapies. Contemporary research draws from psychology to accentuate emotional and cognitive factors as integral to understanding the variability and duration of regret.

Counterfactual Regret

Counterfactual thinking is a naturally occurring phenomenon that involves imaginative alternatives to reality or the mental reconstruction of a past event (Byrne, 2005). People generate counterfactual thinking when precipitating events or antecedents mentally mutate to produce a different outcome to the one experienced. In a linguistic sense, counterfactual thinking occurs when a person uses mental scripts that contain “If ... then” clauses (Roese & Olson, 2014). A simple example might be, “If I had not

injured my knee, I would have won the tennis match,” or “If I had not trained so hard, I may have lost the marathon.” Hence, one’s reality alters with the use of mutations that are additions, subtractions, or substitutions to any or all events leading to a specific outcome. The ease with which one can alter these events is referenced as mutability (Wells & Gavansky, 1989).

Counterfactual thinking can be upward, that is, directed to how an outcome may have been better, or it can be downward, that is, applied to how something would have made things worse (Mandel & Lehman, 1998). Kahnemann and Miller (1986) predicted that upward counterfactuals exacerbate negative emotions and increase the potential for inward associations of controllability. Upward counterfactual thinking is parallel to counterfactual regret on the basis of perceived preventability and self-implication. In contrast, downward counterfactuals intensify positive emotions. One can direct counterfactual thinking to the actions of others as well as oneself (Epstude & Roesce, 2008).

Early studies of counterfactual regret occurred in laboratory settings where participants were asked to imagine alternatives to observed outcomes. Study findings, in general, supported the notion that people are more likely to regret the things they do, acts of commission, versus what they do not do, or acts of omission (Landman, 1987). As counterfactual thinking sparked more scholarly interest, investigators held increasing concern with the factors that motivated people to think in counterfactual terms. Taylor and Schneider (1989) found that upward counterfactual thinking had positive functions in helping participants adjust to unfortunate occurrences. Participants who mentally simulated alternative outcomes could build confidence in preparing for future challenges.

They could also find meaning in unfortunate events, repair bruised self-images, prepare for future challenges, and develop a regained sense of life mastery, overall. Relevant to this study, counterfactual thinking occurs in the aftermath of an undesirable event (Rye, Berry, Ali, and Draftary, 2008). Some researchers suggested that counterfactual processing is maladaptive. For example, Davis and Lehman (1995) posited that for traumatic events, counterfactual regret perpetuated suffering and grief associated with the unexpected loss of a loved one.

Although findings on the functionality of counterfactual thinking have been heterogeneous, laboratory studies contain significant limitations. Often, empirical studies on this subject involved asking participants to read stories about victims who encountered misfortune. The duration, intensity, and consistency of counterfactual-regret content cannot be effectively measured with fictitious scenarios because they do not make an enduring impression on the participant. Moreover, the affective responses in a laboratory setting are significantly less vivid than with real-life happenings. Also, scant research exists on individual differences in counterfactual thinking.

Early inquiries made some implicit assumptions that personality factors such as self-esteem and optimism might accompany varying degrees of counterfactual propensities. The collective research lacks breadth and depth, but some preliminary findings offer more support for personality factors as a significant consideration when assessing tendencies to imagine alternatives to real outcomes. (Taylor & Brown, 1988).

Researchers have offered less support for linking intellectual and analytical abilities with the frequency or duration of counterfactual thinking (Roese & Olson, 2014). A well supported hypothesis is that exceptional events are more likely to be reimaged

in the minds of those who experience them. Wong and Weiner (1981) postulated that people are more likely to search for causal factors when something happens that violates their expectations. In their study, the researchers asked University of California, Los Angeles, students to imagine a scenario where their friend studied for a midterm examination but ultimately failed it. Participants were to generate questions about the event. Wong and Weiner categorized reactions according to content and the findings supported the tendency for people to ask more reevaluate questions when an event violates their expectations. Another factor that evokes counterfactual reasoning is the memorable nature of exceptional events. If the circumstances that preceded the event are also more accessible in memory, it is easier to rescript and recompose the event using counterfactual alternatives. This idea closely relates to the availability bias explored at length by Kahneman (2000).

An engaging area of research, central to the current investigation, is how people counterfactually process traumatic events. The literature reveals important differences that challenge foundational assumptions about the mutability and content of counterfactual antecedents. Parents cling to the natural expectation that they will effectively protect their child from danger. When an accident or disease strikes, revoking this expectation, it is more likely for this population to compulsively ask causational questions. In the case of an accident, the cause is much more easily identified than in the diagnosis of cancer; a disease that modern science has not effectively grasped. Two studies involving bereaved parents offer a compelling finding: Bereaved parents do not follow the same mutability rules that most people do. Specifically, in studies where parents have lost their children to vehicle accidents or to Sudden Infant Death Syndrome,

participants did not demonstrate a greater inclination to replay and reimagine their actions leading to the event. They spent as much attention focusing on what they did not do which, in their minds, may have prevented their child's death (Davis, Lehman, Silver, Wortman, & Ellard, 1996).

Although the parents in the Davis, et. al. study (1996) did not perceive themselves to be directly responsible for their child's death, their counterfactual thinking centered on what they could have controlled. In the study involving parents who lost their children to Sudden Infant Death Syndrome, the researchers conducted two interviews across an 18-month time interval. During the second interview, researchers discovered that although counterfactual thinking persisted, the content of the counterfactual antecedents differed considerably from the original source of focus. Future field studies are needed to better understand persistence and consistency in counterfactual regret for bereaved populations.

Counterfactual regret may help explain why parents of children with cancer experience regret as an additional layer of sorrow in their bereavement process. Two important constructs are made salient in the book, *The Rational Imagination*, by Byrne (2005). Chapter 5 vividly opens with an anecdotal reflection of media coverage immediately after the World Trade Center was destroyed by an act of terrorism. Remarkably, the thrust of every news channel involved a preoccupation with strengthened airport security as the central means by which the horrors of 911 could have been prevented. They provided much less emphasis on foreign relations between the United States and the Middle East or a root-cause analysis of terrorism in general. The question raised by the selectively narrow coverage follows: *Why did airport security as a preventive factor predominate concerns over more complex sociopolitical factors?* A post

hoc analysis of media content supported the hypothesis that in the aftermath of an unfortunate event, people focus on what is controllable, familiar, and easily defined.

The causal factors of terrorism are difficult to conceive of and articulate because they are convoluted and foreign to most citizens of this country. Consequently, counterfactual thinking supersedes causational thinking. The common focus will hover on how baggage personnel might have or could have checked the hijackers' luggage more carefully. Similarly, for parents of children with cancer, it is unfathomable to entertain the genetic or environmental influences that may have caused their precious offspring to become afflicted. Rather than focus on how or why the cancer occurred, de facto, parents will dwell on the treatments they should have or would have selected (including those they should have rejected or discontinued), while regret flourishes in the process of this counterfactual thinking. The shock and terror of 911 partially lies in the inexplicable randomness of the event. An occurrence of pediatric cancer is well described as follows:

Cancer among children is not distributed with fairness or with equality. To those families affected by a child with cancer, it is seen as a cruel, unjust, and random assault. Justice appears, then, not in relationship to the disease, but rather to the treatment options. (Hord, Rehman, Anderson-Shaw, Hannon, & Schmidt, 2006, p. 5556).

In summary, counterfactual thinking finds fertile ground when negative experiences occur and, in retrospect, causational factors are deeply burrowed and not within cognitive reach. In tandem, the context in which the negative outcome transpires and the intensity of emotions experienced influence counterfactual regret.

One study emphasized context as a more reliable predictor of counterfactual regret (Mandel, 2003), whereas others asserted that the degree of negative emotions is the more dominant antecedent (Kahnemann & Miller, 1986). The current study aimed to corroborate the importance of situational context and emotional valence in counterfactual thinking, rather than debate which is more influential.

Regret and Loss Adjustment

Stakeholders often use bereavement and grief interchangeably, but they have a distinct difference. Bereavement broadly refers to the condition of having lost someone significant, in a generic sense. Grief encompasses the many cognitions and emotions that surround the loss that alter in form and intensity over time (Weiss, 2008).

Parental grief has unique characteristics that researchers and writers alike have struggled to effectively characterize and capture. Author Finkbeiner (1996), after losing a 20-year-old son in a train accident, dedicated study to better understanding the grief process in parents who lose their children. After a multitude of interviews with bereaved parents young and old, Finkbeiner (1996) shared the following reflection:

The human mind is wired to find patterns and attach meanings, to associate things that are alike, to generalize from one example to another in short, to make sense of things ... but children's deaths make no sense, have no precedents, are part of no pattern; their deaths are unnatural and wrong. So parents fight their wiring, change their perspectives, and adjust to a reality that makes little sense (p. 5556).

In many respects, the experience of bereaved parents have defied the foundational assumptions of earlier grief theories, particularly in the sequencing of assumed grief "stages," as well as the time associated with the completion of grief. Early studies

perceived grief to be an acute but temporary condition followed by normal functioning (Lindemann, 1944). Popular stage-based theories (Kubler-Ross, 1969; Rando, 1984) depict grief processes as linear and predictable. More recent work in this area with middle-aged participants led to common acceptance that for bereaved parents, grief is not only highly individualistic but also an indefinite experience with indelible and long-lasting social, psychological, and physiological consequences (Rogers, Floyd, Seltzer, Greenburg, & Hong, 2008; Sanders, 1998).

Researchers have been unclear about how the distinct cancer experience impacts the grief process for bereaved parents. Unlike a sudden or accidental death, the death of a child to cancer is preceded with potentially long intermittent periods of hope, followed by fear and despair in an alternating rhythm. As the child moves in and out of remission and relapse phases, the parents must repeatedly adjust their expectations and coping mechanisms accordingly. These parents experience a dual morbidity that is unique to any other parental grief experience (Rosenberg, Baker, Syrjala, & Wolf, 2012).

Counterfactual regret may be a magnifying glass in enlarging the complicated grief experience of parents of children with cancer. Parents of children with cancer will meet other families throughout prolonged stays in the hospital and frequent visits for outpatient services. In these exchanges, they will witness the recovery and survival of some children, and just as surely, the death and decline of others. When parents lose their own precious child, with whom they have a lifelong bond, they experience almost a gravitational pull to understand how and why their child died when other children with similar diagnoses went into a longer remission or were even pronounced cured. The inexplicable nature of this harsh truth can be self-occupying in a way that competes for

mental and spiritual space that might otherwise be used to rebuild one's identity and future sense of purpose.

A potential healthy outcome of the bereavement process is the gradual self-acceptance of the parent who has lost their child to a devastating and incurable disease. Self-acceptance is a broad but foundational element in humanistic psychology that is essential to self-actualization and grief work (Bernard, 2013). On a very basic level, self-acceptance involves the ongoing pursuit of self-love and understanding, despite deficiencies. Self-acceptance includes the desire and ability to become introspective on the totality of one's life, with an honest inventory of personal strengths and shortcomings. Self-acceptance further encompasses a willingness to accept negative life events while preserving self-esteem and hope of a better future (Ryff & Singer 2001). Few studies on the bereavement process have isolated counterfactual regret as a predicate of a more difficult grief process. Grief researchers have broadly examined guilt by comparing the effects of self-blame and regret as central facets of guilt.

For example, in one study of bereaved spouses with a mean age of 50, self-blame but not regret was a significant factor in grief complication, measured by higher levels of grief following loss, and prolonged grief symptoms over time (Stroebe et al., 2014). Although the centrality of regret in the Stroebe et al. (2014) study is of interest to the current investigation, the participants of interest are not comparable to the referenced study in their phase of life development or in familial relation to the deceased. To accentuate this point, the grieving spouse has likely anticipated the eventual separation as part of a normal life cycle. Further, they have not predictably functioned as the surrogate

decision maker for medical treatments that preceded their beloved one's death, a reality that can fuel guilt and regret.

Although death researchers prominently explored guilt, including child death, a great void exists in the literature on regret and parental bereavement. Researchers have rarely systematically studied sustained counterfactual regret in the bereavement process for parents who have lost children to cancer. Therefore, the avoidable tragedy of impaired self-acceptance compounded with the pain of losing a child, undergirds the importance of this study.

Preventing and mitigating decisional conflict and its long-term companion, decisional regret, can facilitate the bereavement process: a lifelong reality in the aftermath of a significant loss. The subhypothesis of this study asserts the possibility that decisional regret may damage lower self-acceptance, reported on scales of well-being that incorporate measurements of self-acceptance, as captured by Ryff and Keys (1995). If the null hypothesis is rejected, efforts to dissipate decisional regret can open new pathways to spark and advance self-acceptance, thereby abetting the progression of healing after traumatic loss.

Chapter 3: Methodological Design/Data Collection and Analysis

The present study attempted to evaluate whether bereaved parents of children with cancer experience statistically significant degrees of decisional regret when treatment options and risks, including unfavorable side effects, were not disclosed in a satisfactory manner. For the context of this investigation, perceived disclosure was self-reported in selected surveys described in this section. In the first draft of the problem statement, it was subsumed that the oncologist assigned to care for the parent's child would logically provide risk disclosure. The research question was revised to include more general disclosure, understanding that the continuum of oncology care would place the parents in contact with multiple clinicians over a length of time. The literature review process elucidated the complexity and fluidity of the clinical experience encountered by families navigating inpatient cancer treatments. Realistically, disclosure about treatment risks and side effects does not occur exclusively during a single conversation with a single point of contact. A second objective was to better understand if decisional regret, once detected, influenced parental-adjustment outcomes in the domain of self-acceptance, previously defined.

The long-term and overarching aspiration of this work was to generate dialogue about patient-centered and progressive ways medical professionals can willingly share information, even very negative information, to improve decision-making satisfaction for parents of children who suffer from chronic diseases who are often treated experimentally or with treatments that have a concomitantly high morbidity rate. If decisional satisfaction can intentionally improve, parental bereavement will be characterized by higher rates of self-acceptance.

A quantitative approach was selected for three reasons. First, the social constructs of interest are perceived information disclosure, self-reported decisional regret, and self-reported self-acceptance. These concepts are cognitive and psychological states of being, experienced internally, rather than observable or demonstrable behaviors. Second, the independent variables in this study are open to a wide spectrum of interpretation. These variables can be easily misconstrued and misapplied in an open-interview setting. This is especially true because published coding systems do not exist to examine potential correlations between these manifested psychological states. A quantitative inquiry is proposed as the first step in this exploration because the design, by nature, offers a parametric structure to the examination of these states, guided by instrumentation that is well validated in the scientific community. The validation of the selected instruments suggests that operational definitions have been well tested over time among larger populations than this study can feasibly recruit. Third, this topic is sensitive and addresses the potential vulnerability of the population affected by cancer in a general sense.

Quantitative studies present questions that permit participants to respond to questions in a liberal window of time and without being exposed to a face-to-face inquiry on topics that could evoke strong emotions.

Sample Selection—Rationale and Procedure

The population of interest in this study is bereaved parents of children with cancer who are between 30 days and 7,200 days post loss. In 2014, 1,960 U.S. children died from cancer (National Cancer Institute, 2018). Thus, about 4,000 parents who reside in

the United States are impacted by the death of their child in a given year. To derive an appropriate sample size, the following were considerations:

1. Total number of parents impacted with childhood cancer in a single year
2. The average sample size of previously conducted studies with similar research questions
3. An a priori power analysis using a 95% confidence level and an interval margin of 11.

In the majority of studies reviewed, participants' children were still living and actively receiving treatment. Consequently, the total available population of parents with children receiving treatment was much larger than the available population of bereaved parents in a single year. More than 12,000 new pediatric cancer cases were reported in 2014 (National Cancer Institute, 2018).

To determine the sample size appropriate to the present study, relative to similar research designs, the study entailed extracting a sample of six quantitative study protocols conducted in the United States. The sample size ranged from 56 to 193 with a mean sample size of 125.33 (see Table 1). However, in many cases, participants were all being treated in the same inpatient or outpatient hospital. Although using a smaller sample size of 92, the present study made efforts to expand the selection geographically, using electronic media as a method to publicize the study.

Table 1

Study Quantitative Protocols

Research setting	<i>N</i>	Citation
Outpatient clinics at two cancer centers	160	Jones et al. (2013)
Acute hospital	118	Gagnon & Recklitis (2003).
University of Florida Palliative care program	140	Knapp et al., 2010
Harvard Medical School	85	Lown, Clark, & Hanson (2009).
Dana Farber Medical School	193	Mack et al. (2011)
Children's cancer clinic	56	Meert et al. (2008).

An a priori power analysis was conducted for the present study using a widely available online tool (Creative Research Systems, 2012). The calculation determined that a minimum sample size of 85 events would be necessary to maintain a 95% confidence level and a confidence interval of 10.5. Study-recruitment efforts yielded a total of 92 cases.

The present study was granted approval by the Institutional Research Board of Nova Southeastern University. Convenience and snowball sampling were used to recruit prospective participants from a high-volume acute oncology clinic, as well as the online community. Participants were recruited from a children's hospital in the southwestern United States after obtaining consent from the hospital's institutional review board. The hospital is a prominent provider of oncology care in an urban area. Participants who consented to join the study were asked to voluntarily post the study flyer on their Facebook and Instagram pages (see Appendix A).

Parents who participated in the study received a \$35.00 Amazon gift card to compensate them for their time. Participants signed a consent form (see Appendices B

and C) describing the general nature of the study and associated risks. All participants were advised that they could terminate the study at any time. In advance of completing a battery of four surveys, all participants were asked to identify the date of their child's death, the age of their child at the time of death, and to select, from a drop-down menu, the types of treatments their child participated in, such as surgery, chemotherapy, radiation, and other (see Appendix D).

Data Collection, Management and Analysis Plan

Quantitative data collection. Biographical data accrued to determine if demographic factors such as age, gender, or level of completed education would influence results. Survey data accrued for each independent and dependent variable in the study. All of the surveys were administered through a confidential software identified as questionpro.com. Each participant was identified by a random number in the software platform and the collected biographical and survey data were retained in the same environment. The following validated instruments were employed: The Decision Conflict Scale (see Appendix E), The Picker Patient Satisfaction Inventory (see Appendix F), The Decision Regret Scale (see Appendix G), and the Ryff Scale of Psychological Well Being (see Appendix H). Each of the instruments was accompanied by a coding and scoring manual followed by the investigator in the interpretation of results. The author's consent was obtained to use the instruments to completed the dissertation study.

Decisional conflict in association with medical treatment decisions was measured with the Decisional Conflict Scale (see Appendix D; O'Connor, 2010). Parent perception of adequate information disclosure about medical treatment was measured with the Picker Patient Satisfaction Inventory (see Appendix F). High degrees of dissatisfaction

overall were calibrated with low satisfaction for information disclosure, as the majority of questions on the survey (seven of 15) are designed to gauge satisfaction with information sharing. Decisional regret was measured with the Decision Regret Scale (see Appendix G; O'Connor, 1995) and self-acceptance was measured with the Ryff Scale (see Appendix H; Ryff & Keyes, 1995; Ryff & Singer, 2001). The Decisional Conflict and Decision Regret scales both use a 100-point continuum. The upper and lower 25th percentiles reflect high conflict or high regret, respectively. The Ryff Scale uses six dimensions with a 6-point Likert-type scale. Higher scores on the dimension of self-acceptance equate to higher well-being on this construct.

Data interpretation and analysis. The variables in this study are continuous, nonextreme, and numerically quantifiable. A correlational study was employed because the goal of the statistical analysis was to compare the variables to identify any potential direction and magnitude of a linear relationship, negative or positive.

Chapter 4: Results

The purpose of this chapter is to review the research questions that guided this study, share the rationale behind the elected statistical tests that were employed, and report the results produced from these tests, including how they may support or refute the hypotheses. This chapter opens with a description of participant-recruitment approaches and data-collection methods. The frequencies of demographic variables involved in the study are presented to illustrate the data dispersion of participant gender, education, and race, while elucidating influences on results.

This study was quantitative, using a battery of validated surveys to obtain information from bereaved parents of children with cancer who died at least 1 year prior to the study invitation. All surveys employed in this research project were previously used in clinical acute settings and referenced in similar studies that aspire to better understand patient satisfaction and medical decision making.

Research Questions

1. Do bereaved parents of children with cancer who report dissatisfaction with physician disclosure of information pertinent to medical-treatment risks and options also report higher levels of decisional conflict? The null hypothesis associated with this question is that no significant relationship will emerge between patient satisfaction and decisional conflict. The alternative hypothesis states that a significant relationship will emerge between problems with patient satisfaction and decisional conflict.
2. Is there a positive relationship between self-reported levels of decisional regret in bereaved parents of children with cancer and decisional conflict? The

null subhypothesis states that no relationship will emerge between decisional conflict and decisional regret. The alternative subhypothesis asserts that a positive relationship will emerge between decisional conflict and decisional regret.

3. Is there a negative correlation between levels of decisional regret and self-acceptance in bereaved parents of children with cancer? The null subhypothesis states that no relationship will emerge between decisional regret and self-acceptance. The alternative hypothesis posits that higher levels of decisional regret will correlate with lower levels of self-reported self-acceptance.

Descriptive Statistics

The investigator obtained consent from the institutional review board at a children's hospital in a large urban area in the southwest United States. The consent permitted the investigator to send study-invitation letters to the parents of former deceased patients in the oncology unit. The collaborating institution is one of the largest providers of pediatric inpatient and outpatient oncology treatment in the region with 28 inpatient beds and 20 outpatient infusion centers. Study invitation letters were sent in English and Spanish, as the study was open to participants who speak either language. All Spanish content was provided by a professional and licensed translation company.

A total of 410 letters were mailed across a period of 1 month. Responding were 28 English-speaking parents with inquiries and three Spanish-speaking parents, by e-mail or telephonically. From November through February of 2017–2018, 28 English-speaking parents completed and returned the consent form and the electronic surveys. Spanish

speaking parents did not respond to the study invitation. The survey responses were collected and routinely updated in a confidential software environment known as questionpro.com.

Due to the quantitative nature of the study and the importance of having a sufficient sample size, the recruitment period extended past the initial anticipated time frame of three months. An additional nine parents agreed to post the study on their social-media pages, primarily through their Facebook accounts, online chat rooms, and support-group blogs. Hence, snowball sampling was incorporated to acquire a sample size sufficient to obtain statistical significance. From March through June, 64 referral parents completed all required survey instruments, resulting in a total of 92 English-speaking participants across a 6-month recruiting period. The study originally included responses from two married couples who referenced the same deceased child in their responses. Probability theory assumes that observations must be independent to ensure statistically accurate results. Therefore, only two of the four participants among the married couples were randomly elected to participate. This reduced the study sample size to a final total of 92 participants.

Study participants were asked to disclose personal demographic information that included their parental role (mother/father), race, and education level. Participants were also asked to identify the age of their child at diagnosis and at the time of death. The type of medical treatment employed, such as radiation or chemotherapy was also disclosed on the survey.

Parental gender. The study was open to mothers and fathers of deceased children with cancer. Prior to death, all of the parents' offspring were treated by a licensed

psychologist in the United States. The parents were the caregivers and primary decision makers in the medical-treatment process.

The majority of participants were mothers at a rate of 70.7%, whereby fathers participated at a rate of 29.3%. The research questions do not specifically examine potential comparative differences in the responses between mothers and fathers, but an intentional effort was made to include a balanced composition of parent roles to better support the generalization of outcomes in support of the hypotheses (see Table 2).

Table 2

Parental Gender

	Frequency	Percent	Valid percent	Cumulative percent
Mother	65	70.7	70.7	70.7
Father	27	29.3	29.3	100.0
Total	92	100.0	100.0	

Race. Although study participants represented multiple races collectively, the frequency data demonstrates that White and Latino parents were the predominant respondents. These two categories, combined, represented 68.4% of total participants (see Table 3). White parents participated at a rate of 7.6% higher than Latino parents, even though the participating hospital is geographically located in a community that has a large concentration of Latino populations. The third largest racial group included the self-identification of “other,” at a response rate of 9.8%, followed by those who identify with multiple racial categories at a rate of 8.7%. Those who reported they are of Asian, African, and Hawaiian or Pacific Islander ancestry, individually, accounted for less than 7% of all study participants (see Table 3).

Table 3

Race

	Frequency	Percent	Valid percent	Cumulative percent
Latino	28	30.4	30.4	30.4
Asian	4	4.3	4.3	34.8
Hawaiian or Pacific Islander	2	2.2	2.2	37.0
Black	6	6.5	6.5	43.5
White	35	38.0	38.0	81.5
Other	9	9.8	9.8	91.3
More than 1	8	8.7	8.7	100.0
Total	92	100.0	100.0	

Education. The educational attainment of study participants was almost equally distributed between the categories of high school, some college, and bachelor's degree, with nearly a third of the participants self-identifying in these categories, respectively. Close to 11% of participants reported having a graduate degree and they were grouped with the bachelor's-degree group (see Table 4).

Table 4

Highest Level of Education Achieved

	Frequency	Percent	Valid Percent	Cumulative Percent
High school	30	32.6	32.6	32.6
Some college	27	29.3	29.3	62.0
Bachelor's degree	25	27.2	27.2	89.1
Graduate degree	10	10.9	10.9	100.0
Total	92	100.0	100.0	

Age at diagnosis and death. The study included parents of children from age zero to 25 years old. The actual respondents included parents of children between zero to

17 years of age at the time of diagnosis, and between zero and 24 years of age at death. The average age of diagnosis for the children of parents in the study was calculated to be 7.05 years with a standard deviation of 4.97. The mean age of death was 9.22 with a standard deviation of 5.34. The Childhood Cancer Fact Library (2018), reported that the average age of onset for a pediatric cancer diagnosis is 8 years old. Study findings are consistent with this trend (see Tables 5).

Table 5

Child Age at Diagnosis and Death in Years

	Standard		Median	N	Minimum/Maximum
	Mean	Deviation			
Age at Diagnosis	7.05	4.97	6.50	92	< 1year /17 years
Age at Death	9.22	5.34	9.00	92	< 1year /24 years

Demographic Factors

The descriptive statistics did not yield any significant correlations for the categories of parent gender, race, or education levels. Although gender and race were skewed toward White female, the dispersion was sufficient, in relation to the sample size. Overall, demographic data did not influence the findings in a statistically significant manner. In the absence of identified covariates presented by the continuous variable of time, measured by age of death or diagnosis, no multiple regression study was performed. Equivocally, the group variables of age, race, and gender were not further analyzed.

Data Analysis and Results

SPSS, version 24, was used to perform all statistical analyses for this study with Pearson product-moment correlations conducted between all variables. A correlation test

was selected because most of the variables in the study were continuous. The first hypothesis was tested by calculating a correlation coefficient for the relationship between parent satisfaction with physician disclosure of information (measured by the Picker Inventory, with higher scores reflecting more problems; see Appendix F) and reported decisional conflict (measured by the Decision Conflict Scale, with higher scores connoting more decisional conflict; see Appendix E). The resulting correlation was significant. A positive relationship emerged between these two variables whereby $r(92) = .866$, and $p < .0005$ (see Table 7). This outcome is consistent with the primary hypothesis; more problems with physicians' disclosures aligned with greater decisional conflict. This finding supports the inference that bereaved parents of children with cancer experience higher levels of decisional conflict when they report higher levels of dissatisfaction with physicians' disclosure of information.

The second hypothesis (2a) statistical test assessed a potential relationship between decisional conflict and decisional regret, also using the Pearson product-moment-correlation coefficient. A positive correlation also emerged. Although not part of the original hypotheses, problems with physician disclosure of information also had a significant relationship to decisional regret, $r = .693$, $n = 92$, and $p = .01$. For Hypothesis 2a, the results suggested that participants who reported high levels of decisional conflict were more likely to equivocally report higher levels of decisional regret (see Table 8).

To test Hypothesis 2b, a Pearson correlation was employed to determine the possible association between decisional regret and self-acceptance. Once more, a statistically significant result was produced with a negative correlation of $r(90) = -.666$, and $p < .0005$. These results align with Hypothesis 2b, which predicted that decisional

regret would result in lower self-acceptance. Decisional conflict correlated with self-acceptance whereby $r(90) = -.837$, $n = 02$, and $p < .0005$.

Conclusion

The research questions for this study were addressed using correlational statistical analyses for each hypothesis. Findings indicated a statistically positive correlation between problems of satisfaction with physician disclosure and high degrees of decisional conflict.

Similarly, a demonstrated positive correlation emerged between decisional conflict and decisional regret, as expected. A negative correlation arose between decisional conflict and self-acceptance as well as between decisional regret and self-acceptance. The next chapter of this manuscript will address the implications of the findings in the context of the research questions, as well as recommendations for further inquiry.

Chapter 5: Discussion

Preface

The study under discussion was designed and executed to fulfill the requirements towards the completion of a doctoral degree in Conflict Analysis and Resolution.

Scholars have asserted that conflict studies, in broad and universal sense, are most often limited to conflict between social groups, social categories, or entire nations, versus conflicts between individuals or within the mind of individuals (Schellenberg, 1996).

The variables in the present study examine micro-conflict in the communication between oncologists and parents of children with cancer, e.g., information disclosure from the oncologist to the parent as surrogate decision maker. Oncologists are very much part of a social group of health care practitioners with established beliefs, values, and normative behaviors. Oncologists exist in significant numbers. A recent census in 2016, counted 14,639 licensed oncologists in the United States (www.statistica.com). Oncologists present a social group that routinely interact with each other in conference venues, through scholarly review of publications, and via continuous professional development.

The social cohesion model is comprehensively addressed by Turner in Tajfel's revisitation of intergroup theories (2010). In this work, the distinction between social group and social category rests on whether individual with common characteristics have routine interaction with each other in a way that promotes an attraction and common bond. In the same publication, the social identity model is depicted as a more loosely constructed definition of social group, in that the group need not be interdependent so long as a continuous attraction mutually exists. This latter point compatibly supports this investigator's orientation to parents of children with cancer as a social group with a well-

shaped identity and not merely a social category. Social networks serve to solidify this common identity by providing emotional support and the constant archiving of a shared experience.

In understanding how social media reduces social distance, it may be argued that parents of children with cancer represent a larger group of health consumers that feel interdependent in their quest for affirmation. (Henderson, Churchill, King, Rothschild, Lohser, et al., 2009). This group, in facing their vulnerable state and circumstances, repeatedly turn to online platforms to help navigate the best care for their child.

Parents of children with cancer negotiate the best available medical treatment throughout the duration and persistence of a condition requiring the care of a physician. Studies on negotiation and particularly compromise, identify factors that are strongly relevant to the practice of making medical decisions (Chapman & Sonnenberg, 2000).

Consequently, the problem of making satisfactory medical decisions is only an intrapersonal conflict absent the identification of participant as member of a group. The detection of patterns and themes across the spectrum of this social group strengthen the assertion that decisional conflict in medical decision making is a larger social phenomenon that has received insufficient attention in all disciplines concerned with decisional satisfaction and ethical practices in health care. This studies' results, outlined in the previous chapter, suggest that correlations between physician disclosure and decisional conflict in parents of children with cancer, may be replicated beyond the realm of cancer treatment and the negotiations that transpire in the treatment process. While this dissertation was in an early draft form, a study with nearly identical variables, albeit

different instruments of measurement, was being finalized. The results will be discussed in depth.

The present chapter provides an overview of the results of each hypothesis test followed by a discussion of the connection of those results to the empirical literature and of the clinical implications. In a scholarly spirit, there is a commitment to providing attention not only to studies that support the current results, but also to those that may refute or contradict the correlations that were determined. Finally, the chapter will conclude with limitations and recommendations for future exploration.

Primary Hypothesis - Overview

The primary research question in this study was the result of the following line of inquiry: Does decisional conflict about medical treatment occur at greater rates when bereaved parents of children report higher levels of dissatisfaction with physician disclosure of treatment risks and side effects. The study results yielded a positive correlation between these two variables whereby $r(90) = .866$, and $p < .0005$.

Studies that support the primary alternative hypothesis

At core, the present study has been concerned with the patient or parents' perspective on information disclosure in relation to their psychological adjustment and response. The focus is on the parents' experience versus the physicians' account of the communication surrounding treatment process and decisions. The majority of studies looking at medical decision making in pediatric cancer, have more broadly measured the concept of shared decision making and all this may entail, without isolating specific communication elements embedded within that construct. In contrast, the investigator and author of this manuscript has elected to magnify the influence of information

disclosure, apart from active or inactive involvement in decisional process. With that fundamental difference in mind, there is still an arguable amount of support for the results yielded in the current study.

After sifting through two decades of research that altogether omitted the phenomena of regret and decisional conflict in parents of children with cancer, the investigator was delighted to encounter a recent examination by Hong et al. (2016) that included both regret and decisional conflict in a different population – children with significant ear defects.

In this study, parents were undergoing surgical consultations for cosmetic ear surgery for their children. Decisional conflict was negatively correlated with reported parental involvement in the decision making process. Regret was also negatively correlated, but at a lower level of statistical significance. These dependent variable outcomes are consistent with the present study where both decisional conflict and regret were influenced by interactions between physician and parent with decisional conflict having a stronger influence than regret $r=.866$ and $r=.693$, respectively. The retrieved study included the administration of a survey to the surgeons where there was no reported significance between parental involvement and decisional conflict. The latter result suggests a lack of calibration in how parents view their decisional satisfaction in comparison to how physicians perceive the same construct (Hong, Gorodzinsky, Taylor, & Chorney, 2016).

In a larger study with 429 participants, the parents' perception of presented treatment "options" was negatively correlated with decisional conflict. Parents who reported being provided with clear treatment options reported less decisional conflict

(Bowland, Kryworuchko, Saarimake, & Lawson, 2017). These collective findings promote the value of collaborative decision making practices where treatment information is salient and communication objectives are established early in the prognosis.

Studies that challenge current findings

An underline assumption of the current study design and political inspiration is that physicians have an ethical obligation to provide the full disclosure of treatment risks and side effects in the spirit of *do no harm*.

A counterpoint to this discussion may be that physicians use their best discretion to balance when unfavorable information may be harmful in itself, if not disseminated incrementally or at a slower pace. Wells (2012) acknowledges that physicians may elect not to address the full gauntlet of medication side effects out of concern that it may produce a nocebo effect. A nocebo effect is associated with negative symptoms that result when a patient develops anxieties and expectancies in association with something unpleasant such as nausea, pain, dizziness, etc.

One of the strongest contenders to the primary alternative hypothesis results in this study, was a protocol authored by Stewart, Grim, & Kelly (2012). In this mixed method investigation using semi-structured interviews, researchers looked at decision making strategies employed by parents of children undergoing cancer treatment. They took into account family and clinician support systems as independent variables. Dependent variables involved a parents' overall satisfaction with their decision. The study findings indicate that parents were vigilantly concerned with making the right decision and were profoundly aware of the trust their children placed in them.

Ultimately, they were strongly convicted that they made the right choice about their child's treatment. Several quotes from the interview transcripts were included to illustrate this sense of self-trust, a finding that is disparate with the current study.

The attributional factors in this study were global in nature and closely linked to the parents support network. A few caveats should be considered when comparing the result variances.

First, self-selected participation in any study can incidentally solicit a study sample that naturally has a stronger support network, hence the available time comfort level for participation. Second, the study design examined the independent variables using open ended questions versus a quantitative survey. The transcript coding may have been indifferent to themes that were illuminated in the present study. Third, all children of the parents interviewed were still living and an element of hope and faith was strongly at play. There may not have been sufficient time for parental reflection on potential negative health outcomes.

Finally, the study authors admittedly confront the importance of treatment uncertainty. "Uncertainty made the decision making more difficult and intensified its impact". (page 422).

Treatment uncertainty is a variable that was not addressed in the current study, but it may prove to be very powerful in its own right, possibly strengthening the argument for more physician disclosure to mitigate uncertainty. Conversely, some diagnoses and prognoses accompany more uncertainty concerning disease behavior and progression. When the uncertainty threshold is high, it is possible that physician disclosure or lack thereof, may be comparatively inconsequential.

While re-reading my literature review, a close colleague entertained the notion that some parents may be so emotionally distraught over their child's cancer prognosis, with limited ability to cope, they will experience decisional conflict no matter what the oncologist communicates or how. This evoked my further consideration of coping skills as a potential covariate.

The present study design documented significant pre-existing mental health conditions in the pre-screening phase. The purpose of this data gathering was to have an awareness of the prevalence of such conditions from a participant protection standpoint and to obtain a reasonable confidence that the population was not unduly afflicted by mental health issues. The presence or absence of such conditions was generally balanced in relation to the general population. Although the literature review in this study was not concerned with polarities or deficiencies in coping skills in the sample examined, this may be a reasonable assertion to consider in future studies.

Research Implications

Moving toward stronger collaboration

The aggregate literature and study findings overall, serve to remind the principal investigator that effective communication, including information disclosure, between parents and doctors requires a two way commitment and responsibility. Parents who know what questions to ask and how to present them, may more effectively solicit information, even from a physician who is reluctant to disclose the summative risks. When this study initially commenced, the investigator admittedly was more heavily concerned with the physician's neglect of initiating such disclosure.

In retrospect, there lies the greatest promise in making communication a shared responsibility. This includes the teaching of communication skills, specific to medical treatments, to both oncologists and parents of sick children. Conversations about treatment pros and cons must be re-evaluated and checked for clarity, numerous times over the course of treatment protocols.

Newer studies, within the last 5 years, are discovering that most communication gaps occur during the early treatment phase period when parents may be too emotional to fully comprehend treatment guidance while oncologists are simultaneously avoiding the release of Pandora's Box. The development of a "100 day talk" in accompaniment with a conversation tool, may be a practical checkpoint for ensuring that parents have the needed time and space to vocalize any emergent dissatisfaction with the quantity and quality of information shared (Feraco, Gagne, Brand, & Sullivan, 2018).

In the field of conflict analysis and resolution, collaboration is heralded as a form of conflict prevention and mitigation that is preferable to negotiation. Moreover, effective collaboration contains pre-set list of premises required to set the stage for meaningful collaboration. It is imperative to make room for divergent viewpoints and values while incorporating acknowledgment of each parties' strengths. (Folger, Poole, & Stutman, 2009). Although parents may struggle with numeracy as previously discussed, they carry the strength of knowing their child and family dynamics in a way that the oncologist cannot. In sum, the clinical implications discussed here are buttressed by principles of sound collaboration borrowed from conflict studies.

Clinical Implications and Recommendations

The finding of this study and those that preceded it, point to the necessity of improving both the process and associated resources for relaying unfavorable treatment information to parents of children with cancer.

The importance of bilateral communication cannot be overstated in this endeavor in that parents need to be educated on how to communicate concerns with their oncologist just as much as oncologists need to be trained on approaches for sharing bad news. The composite literature findings, combined with the results of the current study, suggest that future communication practices should have a three pronged mission. First the presence of intense emotions in both patients and physicians should be accepted and normalized in the collaborative process. Several theorists have described the benefit of incorporating the acknowledgement of patient emotions as part of the communication and decision making process (Marshall, A. & Smith, R., 2005; Yakely, Hale, Johnston, Kirtchuk, & Shoenberg, 2014). Second, communication plans must be crafted differently for the needs of patients and families in acute pediatric settings versus adult oriented environments (Wolf and Frierdich et. al., 2014). Thirdly, communication training programs for both physician and patient (or caregivers) should include a framework for integrated decision making. In brief, integrated decision making includes the incorporation of patient values for quantity versus quality of life, as well as predetermined expectations and agreements for who will hold the final authority over a decision based on the nature and timing of the treatment factors (Chapman & Sonnenberg, 2000; Flynn & Wienfurt, et al., 2008).

Secondary Hypothesis- Overview

The secondary research question in this study introduced the following line of inquiry: Does the presence of decisional conflict positively correlate with decisional regret in bereaved parents of children with cancer?

The results demonstrated support for the secondary alternative hypothesis (H2). Increased level of decisional regret was related to measured levels of decisional conflict in the context of medical treatment elections.

Studies that support the alternative sub-hypothesis

In the absence of any formal statistical analysis, it can be intuitively inferred that multiple and diverse factors may contribute to decisional regret in parents of children with cancer. The present study design did not measure individual coping and cognitive skills that may increase resiliency to regret. An enduring curiosity, therefore, is whether other regret factors may outweigh or supersede the importance of physician disclosure of information and decisional conflict.

The answer to this question is yielded by a recent study involving two prominent cancer treatment centers that specialize in pediatric populations. Investigators conducted a multivariate regression analysis on quality of treatment information, parent education, parent race, desired involvement in treatment decisions, level of acceptance of child's diagnosis, parents' communication skills, and time between diagnosis and survey dissemination (Mack, Cronin, & Kang, 2016). The findings are consistent with the present study in that parent education did not influence decisional regret. In addition, quality of treatment information had a significant impact on decisional regret. Race was

also found to positively correlate with decisional regret, a factor that was not detected in the study at hand.

Studies that challenge current findings

Decision regret has become an increasingly common construct in study protocols involving pediatric populations and their parents or caregivers. Consequently, studies that challenge the present results would optimally do so by introducing other factors leading to the experience of regret in the same demographic when placed in similar situations and circumstances.

In a metacognitive analysis of studies using the Decision Regret Scale (the main instrument used in the present study design), factors such as adverse physical symptoms were cited as contributing to higher reported scores of decisional regret (Perez, Menear, Brehaut, & Legare, 2016). The research questions in the present study exclude consideration of the child's emotional and physical state near the end of life, which reflect the presence or absence of suffering to a subjective degree. A possible consideration is that the parents' witnessing of suffering is the more profound influencer of decision regret, in comparison to decision conflict alone.

In an experimental study of parents with children who suffer from inflammatory bowel disease, or juvenile idiopathic arthritis, parents rated their decisional experience as either self-led, physician-led, or shared. There were no differences in reported decisional conflict nor decisional regret among these three groups, a finding that appears counterintuitive to the majority of studies outlined throughout this manuscript.

The surprising result is what occurred when the parents were surveyed again, based on perceptions of physician 'engagement' which differs from decisional

involvement. When the same group of participants considered whether the physician used language they could understand, was available for their questions, and so forth, there were statistically significant differences in both decisional conflict and decisional regret. Low physician engagement negatively correlated with high decisional conflict and regret. Investigators concluded that being able to place trust in the physician managing care, was more predictive of decisional satisfaction than level of involvement in the decision process itself (Lipstein, et.al., 2016). The results, if replicated in an oncology setting, suggest that it's not how much information doctors comprehensively divulge to parents, but more so whether the information is presented intelligibly and compassionately. The stylistics become the dominant factor in decisional satisfaction. When reflecting on the questions used in the Picker Patient Experience Questionnaire (PPE), it may be important to critically re-evaluate some of the questions from a physician engagement standpoint. Moreover, the study design included adjustments for parents' stress level, an added level of analysis that has not been employed in other studies. From a methodology standpoint, it is good to know more about the rationale behind controlling for stress and the reliability and validity associated with doing so.

A final concept of interest, comparative to the influence of decisional conflict- generically speaking, is whether the parent's treatment decisions fit into the framework of how they may define good parenting. The parent's emphasis on the role of *good parent* is consistent with the importance of role identity in understanding what may be valid objectives and aspirations in the face of conflict (Sandole, Byrne, Standole-Saroste, & Senehi, 2008). Good parenting was not discussed or analyzed in the present study protocol, but at least one study has sought to define what this means for parents who elect

to complete a do not resuscitate agreement (DNR) or alternatively, enroll their children in a phase one experimental trial. Both groups define good parenting to include an attempt to alleviate their child's suffering. The commitment to bringing a sense of comfort to their children was a significant theme in how parents viewed their own decision making process (Maurer, et.al, 2010).

It may be narrow sighted, therefore, to discuss decisional regret in parents without first acknowledging the overwhelming and perhaps universal instinct to maintain good parenting, despite the grim possibility of losing your child.

Research Implications

When the current research question: Does decisional conflict influence decisional regret(?) is juxtaposed with the question; What are the myriad factors that influence decisional regret (?), the former question may prove to be over-simplistic within the scheme of medical decision making and its infinite complexity. Future research protocols should view decisional regret as a viable factor to be measured along a gradient of other factors such as preexisting anxiety. The end result is to determine the strength of decisional conflict in relation to competing contributors of regret, as there may be considerable interplay between all factors.

Clinical Implications and Recommendations

The clinical implications of decisional regret rest on future research findings that can parse out which factors leading to decisional regret are most significant and thus deserving of the most attention and resources. Learning that physician engagement is a more powerful predictor of decisional regret than physician led decision making, suggests

that communication training for oncologists needs to center more around the effective delivery of information versus who is leading the flow of information.

Tertiary Hypothesis – Overview

The third alternative hypothesis in this study asserts that decisional regret negatively influences self-acceptance. The study results yielded a negative correlation of $r(90) = -.666$, and $p < .0005$. Although not part of the original research question, decisional conflict correlated with self-acceptance whereby $r(90) = -.837$, $n = 02$, and $p < .0005$.

Pillay (2016) describes self-acceptance as embracing our total capacities, both good and bad, in such a way that we are more resilient to criticism whether internal or external. Self-acceptance was further developed by Carol Ryff as one of the primary elements of social well-being. Self-acceptance is not synonymous with self-esteem. The negative influence of decisional regret on self-acceptance should be considered with caution because self-acceptance is well formed in early adulthood and is negatively impacted by depression and other mental disorders that may preclude a pediatric cancer diagnosis, or otherwise be precipitated by it.

Parents of children with cancer, the participants in this study, do not present a blank slate when confronted with medical decisions. Support networks, emotional and intellectual capacities, and overall coping mechanisms can dominate the experience of decisional conflict and regret more so than physician communication as the former resources are aggregately developed over a lifespan.

Studies that support the alternative sub-hypothesis

There is a general consensus that people with strong self-acceptance can better modulate their emotions by suppressing negative beliefs and bouncing back more quickly from disappointment and failures.

Studies that challenge current findings

Study participants who had a low degree of self-acceptance in advance of their child's diagnosis, may have been more influenced by decisional conflict and regret than those who had a high degree of self-acceptance before managing their child's illness and associated treatment. There is no way to capture this information for comparative purposes, as one cannot predict the future state of health. It suffices to underscore that not all study participants entered the survey with the same coping strengths and abilities that are tied to strong self-acceptance. Studies that correlate mild depression or other mental illnesses to decisional regret, may diminish the importance of the present study's findings. One study found a significant relationship between mild depression, self-blame and decisional regret. A weakness of the study is that the decisional process was based on hypothetical considerations versus real life choices (Kraines, Krug, & Wells, 2017). Another study found a significant relationship between major depressive disorder and counterfactual thinking- a significant factor in the experience of regret (Howlett & Paulus, 2013). The biographical data collected in the present research design, included a pool of self-identified depressed parents. A person's general state of psychological health is a stronger determinant of self-acceptance than a single event, decision, or season of calamity. Consequently, decisional regret may not be the primary culprit behind low

self-acceptance. The real answer may lie behind the depression that is accompanied by decisional regret.

Research Implications

Future studies on regret and self-acceptance may have stronger statistical sensitivity if persons with mental disorders are excluded or if the presence of such disorders is adjusted for in the final analyses. In a relatively small sample size of 92, even a few depressed participants may potentially inflate the mean variance.

Clinical Implications and Recommendations

The Ryff Scale of Well Being may be a useful instrument in informing clinicians about the depth and type of resources parents will need to make satisfactory medical decisions. Parents with low self-acceptance may be prone to procrastinate or over ruminate on decisions pertaining to their child's treatment. The medical team can mitigate this possibility by offering more frequent emotional support and intervention.

Applications in the Field of Conflict Resolution

The results of the present study demonstrate support for improved communication training that will lead to shared decision making between pediatric oncologists and the parents they interact with. The research data has been collected from a narrowly defined population within the parameters of recalling what occurred in an acute medical setting. However, the phenomena of self-acceptance, counterfactual regret, and post-decisional conflict has broader implications for improved training in multiple professions-particularly roles that involve crisis response and intervention. In the introductory chapter of this paper, it was noted that a diagnosis of pediatric cancer is a catastrophic event. Similarly, police officers, paramedics, and firefighters, and military personnel are

called upon to manage catastrophic events for which they have limited control over.

These agents of community service are faced with life altering decisions made under stressful and less than optimal time constraints. The decision to end or save someone's life is often made in a fraction of a second, with a lifetime of emotional consequences.

Klein, Zapotosky, and White (2012), assert that police officers who kill in the line of duty are faced with years of grief, guilt, and alienation that are exacerbated by public scrutiny and investigations concerning their potential culpability. The presence of guilt and social alienation are elements associated with compromised self-acceptance, as examined in bereaved parents who are no less haunted by the difficult decisions they had to make. Future work in conflict resolution should be directed towards re-writing the script for training so that individuals in high stress roles can do some of the mental work necessary to normalize emotional responses to difficult decisions.

The implementation of such training may hold some promise in mitigating the painful regret that arises when difficult decisions lead to unfortunate outcomes.

Limitations

The current study is characterized by multiple limitations. Generalizability of results is reduced due to the small sample size and the limited diversity in the study recruits, both ethnically and in terms of gender. Due to the potential vulnerability of the population under study and the observance of the Health Insurance Portability and Accountability Act of 1992 (HIPAA) which governs privacy laws for patients, it was logistically challenging and time intensive to gain access to multiple pools of bereaved parents beyond the southwestern United States.

Chapter 3 outlines the difficulty of this process in greater detail. This study also did not require information about socioeconomic status nor religious faith.

These are demographics that may have added depth of insight into behavioral patterns and variances. For example, parents who identified themselves religious as opposed to non-religious might score differently on decisional conflict and decisional regret in line with a particular life perspective.

Another study limitation is the potential external factors, aside from satisfaction with the quality of medical information shared, that may influence satisfaction with treatment choices. For example, the quality of medical insurance and benefits accessible to the parent of a child with cancer may limit the range of treatment choices available, thus introducing an external source of stress that is not visible or detected with the instruments used in the current study design.

Social support outside of the hospital setting may also play a significant role in improving decisional satisfaction, in a way that confounds with attributing decisional dissatisfaction as an exclusive byproduct of the patient-physician communication dynamic.

On a final note, the current study is limited in the depth of information that can be elicited in a survey alone. One study on patient-physician conflict made use of videography to code and measure non-verbal communication that was associated with conflict (Leblanc & Kenny, et.al, 2009). The video capture of this information made it possible to measure important nuances in the discord such as proportional talk time, volume of voice, abruptness of explanations, etc. This presents a richer and more layered form of communication analyses than the current study aspired to within the parameters of available time and funds.

It would be interesting to re-test the first null hypothesis in this study using videotaped narratives from the population of interest, as a form of qualitative research. The presence or absence of conflict could be coded based on non-verbal gestures, tonality of oral communication, and other more multi-dimensional aspects of communication that are easily missed within the context of survey questions alone.

As with any study, there may be considerable variations in the way that investigators define, operationalize, and measure very similar constructs. A lack of standard vernacular in decision theory may complicate or thwart the opportunity for making meaningful comparisons in research findings, and replicating positive effects with newer populations or expanded samples. As previously emphasized, regret can be categorized and explained in relation to both outcome and process, and in relation to other or self. Therefore, understanding the influence of regret on other cognitive and behavioral functions is potentially impaired when terms and measurements are not effectively determined.

Final Reflections

The work in conflict resolution, past, present, and future, remains challenging in its vastness and diversity. When selecting this dissertation topic and advocating for its importance in the year 2014, I was preoccupied with the concern that due to its low visibility in the media and the social sciences, medical decision making would receive mild if any interest from academic and medical audiences. Conflict related topics are so often spurred by world events and the media attention appropriated to such events. I nearly departed from the topic in favor of something underscored in my courses and well discoursed by scholars in the field. The narrowness of my study paled in comparison to

conflicts surrounding wars, genocide, violence, ethnic tensions, and police brutality, when evaluating the importance of a topic with metrics of broad and longitudinal world impact. The difficulty in recruiting participants further led to me to question the direction of my studies and the feasibility of my undertaking. Yet, it was fascinating to see the slow emergence of studies on medical decision making, rise between 2016 and 2018 on this widely muted topic. The compass behind my continuance was anchored in my belief that conflict resolution, as both art and science, should fundamentally improve quality of life, for the individual, the family, the community, the state, the nation, and the world. While relatively few will experience a catastrophic illness, nobody is immune to failing health nor the anticipation of death.

Successfully defending my dissertation served as the final affirmation that my studies took me down a path that I believe will open more widely for future travelers, whether they be academics, practitioners, or just a person trying to make sense out of human suffering.

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Appendix A: Study Recruitment Flyer

Are you a parent who has suffered the loss of a child from cancer?

You may be a qualified participant if you meet the following criteria:

- 1) You have lost a child to cancer more than one year ago.
- 2) Your child's cancer was treated by a licensed oncologist in the U.S.
- 3) You are 21 years of age or older
- 4) You currently reside in the U.S.
- 5) You have regular access to the internet
- 6) You have current access to health insurance

A dissertation research study is recruiting voluntary participants.

The study is focused on understanding **how parents make treatment decisions, and how communication between parents and doctors can be improved.**

If selected to participate, you will complete 4 brief multiple choice surveys about your experience with cancer treatment, and one brief open-ended response. Your time commitment is approximately 1 hour and 15 minutes.

You can complete the surveys using your home computer, laptop, or tablet.

Your responses are strictly confidential.

You will receive a \$35.00 Amazon gift card for your participation.

Principal investigator: Danielle Sperandeo

Please contact dsperandeo@yahoo.com for more information or to join the study, call **909-286-0002.**

Appendix B: Invitation Letter and Consent Form—English



Consent Form for Participation in the Research Study Entitled “““

Funding Source: None.

IRB protocol #:

Principal investigator

Danielle De Santis Sperandeo, Master of Education

10751 Spyglass Dr.

Rancho Cucamonga, CA 91730

909-286-0002

For questions/concerns about your research rights, contact:

Human Research Oversight Board (Institutional Review Board or IRB)

Nova Southeastern University

(954) 262-5369/Toll Free: 866-499-0790

IRB@nsu.nova.edu

Site Information Address

Introduction

You are invited to participate in a research study being conducted for a dissertation at Nova Southeastern University in Fort Lauderdale, Florida. Before agreeing to participate in this research study, it is important that you read the following explanation of this study. This document describes the purpose, procedures, benefits, risks, discomforts, and precautions of the program. Also described is your right to withdraw from the study at any time. No guarantees or assurances can be made as to the results of the study.

What is the study about?

Why are you asking me?

What will I be doing if I agree to be in the study?

The length and depth of the potential interview depends on the degree to which you wish to participate. You have the right to refuse or prematurely terminate your involvement in this study at any time. I will only terminate your participation if I determine that you are in danger or pose a threat to another.

Is there any audio or video recording?

What are the dangers to me?

Possible risks and discomforts may include:

“If you have any questions or concerns about the research, your research rights, or have a research-related injury or problem, please contact Danielle Sperandio at the number above. You may also contact the IRB at the numbers indicated above with questions as to your research rights.

Are there any benefits for taking part in this research study?

There are no direct benefits by participating in this study.

Will I get paid for being in the study? Will it cost me anything?

There are no costs to you or payments made for participating in this study.

How will you keep my information private?

All information obtained in this study is strictly confidential unless the law requires disclosure. Your identity as a participant will not be disclosed to any unauthorized persons; only the researchers and the Nova Southeastern University Institutional Review Board (the committee that approved this research project) will have access to the research materials, which will be kept in a locked safe for a period of 60 months. Any references to your identity that would compromise your anonymity will be removed or disguised prior to the preparation of the research reports and publications.

What if I do not want to participate or I want to leave the study?

Participation in this study is voluntary; refusal to participate will involve no penalty. You are free to withdraw consent and discontinue participation in this project at any time and for any reason. Questions concerning this research will be answered by the researcher before, during, and after the study. Any information or contribution you make to the study will be kept for 60 months, but will be excluded at your request.

Other Considerations:

If significant new information relating to the study becomes available, which may relate to your willingness to continue to participate, I will provide you with this information.

Voluntary Consent by Participant:

By signing below, you indicate that

- this study has been explained to you
- you are at least 18 years of age
- you understand written English and have read this document or it has been read to you
- your questions about this research study have been answered
- you have been told that you may ask the researchers any study related questions in the future or contact them in the event of a research-related injury
- you have been told that you may ask Institutional Review Board (IRB) personnel questions about your study rights
- you are entitled to a copy of this form after you have read and signed it
- you voluntarily agree to participate in the study entitled “The inter and intra departmental conflict among Black police officers, their agencies, and the community in which they work regarding critical police incidents and police use

of force perception by Black Americans.”

Participant’s Signature: _____ Date: _____

Participant’s Name: _____ Date: _____

Signature of Person Obtaining Consent: _____

Date: _____

Graduate School of Humanities and Social Sciences
3301 College Avenue. Fort Lauderdale, Florida 33314-7796
(954) 262-3000. 800-262-7978. Fax: (954) 262-3968
Email shss@nsu.nova.edu. <http://shss.nova.edu>

Appendix C: Invitation Letter and Consent Form—Spanish

Formulario de Consentimiento/Adultos/General

del protocolo del IRB: 2017-134

Investigadora Principal

Danielle De Santis Sperandeo, Maestría en Educación

635 S. Mentor Ave.

Pasadena, CA 91106

909-286-0002

Para preguntas/pendientes acerca de sus derechos en una investigación, comuníquese con:

Human Research Oversight Board (Institutional Review Board o IRB)

(Consejo de Vigilancia sobre Investigaciones Humanas [Consejo Institucional de Revisión o IRB])

Nova Southeastern University

(954) 262-5369/Llamada sin cobro: 866-499-0790

IRB@nsu.nova.edu

Información de la Dirección del Centro

Introducción

Se le invita a participar en un estudio de investigación que se realiza para una disertación en Nova Southeastern University en Fort Lauderdale, Florida. Antes de consentir en participar en este estudio de investigación, es importante que usted lea la siguiente explicación de este estudio. Este documento detalla el propósito, procedimientos, beneficios, riesgos, molestias y precauciones del programa. También detalla su derecho a retirarse del estudio en cualquier momento. No se pueden hacer garantías o asegurar los resultados del estudio.

¿De qué se trata el estudio?

El estudio trata de tener un mejor entendimiento acerca de cómo los padres de niños con cáncer deciden acerca del tratamiento a nombre de su hijo. Parte de este estudio incluye un interés en los factores de comunicación entre proveedores de servicios de salud y padres. Otro interés incluye cómo los padres manejan el proceso de duelo después de la pérdida de su hijo a resultado del cáncer.

¿Por qué me pregunta?

La investigadora principal de este estudio le invita a participar debido a que tiene experiencia directa en la toma de decisiones sobre el tratamiento del cáncer y ha sufrido la muerte de un hijo debido a complicaciones del cáncer o evolución de la enfermedad. Su participación es voluntaria y puede dejar de participar en cualquier momento.

¿Qué estaré haciendo si acepto participar en el estudio?

La duración y profundidad de la posible entrevista dependen del grado en que usted quiera participar. Usted tiene derecho a rechazar o cancelar prematuramente su participación en este estudio en cualquier momento sin dar razón alguna. Únicamente terminaré su participación si determino que está en peligro o representa una amenaza para otros.

Si acepta participar en el estudio, recibirá un vínculo electrónico para cuatro encuestas y una pregunta abierta. Se le presentará una serie de declaraciones sobre su satisfacción con la comunicación con los médicos y las decisiones que usted tomó a nombre de su niño. Habrá algunas preguntas adicionales sobre cómo se encuentra ahora su propia vida. En cada caso, le darán cinco alternativas para responder. Cada encuesta debe tomar más o menos 5 a 10 minutos para completar. La última pregunta requerirá que comparta una breve historia por escrito. Esta parte de la encuesta debería tomar entre 15 y 20 minutos.

¿Se grabará algo en audio o video?

No habrá grabación de audio o video en el estudio. Las respuestas de sus encuestas se recopilarán e identificarán con un número aleatorio de 4 dígitos. Cualquier información recopilada de usted será ingresada, encriptada y almacenada en una unidad de memoria basada en la nube, también conocida como DropBox.

¿Cuáles son los peligros para mí?

No se percibe que haya peligros para usted.

Los posibles riesgos y molestias podrían incluir:

- Sentimientos de tristeza o enojo al recordar eventos pasados sobre sus experiencias en un ambiente de servicios de salud. La investigadora tomará todas las precauciones para asegurarse de que usted se sienta con la mayor comodidad posible en todas las actividades.

Si usted fuese a tener la necesidad de recibir asesoramiento individual durante o después de su participación en el estudio, usted se debe comunicar con su médico de cabecera para obtener una lista de proveedores de salud mental con cobertura por parte de su compañía de seguro de servicios de salud.

Si desea conectarse en línea con un grupo de apoyo para el duelo, consulte la siguiente lista de recursos que se encuentra en el sitio web de la American Association of Marriage and Family Therapists (Asociación Estadounidense de Terapeutas de Matrimonio y Familias): http://www.aamft.org/iMIS15/AAMFT/Content/Consumer_Updates/Grieving_the_Loss_of_A_Child.aspx

Recursos

- Bereaved Parents of the U.S.A. Un grupo de auto-ayuda que ofrece apoyo, entendimiento, compasión y esperanza para padres, abuelos y hermanos/as en luto.
- Candlelighters Childhood Cancer Foundation: Fundada por padres de niños con cáncer, este grupo ofrece apoyo para padres que tienen un niño diagnosticado con cáncer y aquellos cuyo niño ha muerto a resultado de cáncer.
- Compassionate Friends: Una organización para padres en luto, asistiendo a familias después de la muerte de un niño.

Si usted tiene cualquier pregunta o inquietud sobre la investigación, sus derechos en una investigación o si tiene una lesión o problema relacionado con la investigación, comuníquese con Danielle Sperandeo al número de teléfono anotado en la primera página de este documento. También puede comunicarse con el Consejo Institucional de Revisión

llamando a los números indicados si tiene preguntas relacionadas con sus derechos en una investigación.

¿Hay algún beneficio al participar en este estudio de investigación?

No hay beneficios directos al participar en este estudio.

¿Recibiré pago por participar? ¿Me costará algo?

No hay gastos para usted por participar en este estudio.

Usted no recibirá compensación monetaria por su participación. Sin embargo, en agradecimiento por su ayuda, usted recibirá una tarjeta de regalo de Amazon con un valor de \$ 35.00, que se enviará directamente a su cuenta de correo electrónico.

¿Cómo mantendrá usted mi información privada?

Toda la información que se obtiene en este estudio es estrictamente confidencial a menos que la ley exija una divulgación. Su identidad como participante no será divulgada a ninguna persona que no está autorizada; solo los investigadores y el Consejo Institucional de Revisión Nova Southeastern University (el comité que aprobó este proyecto de investigación) tendrán acceso a los materiales de la investigación, los cuales se mantendrán en una caja fuerte con llave por un período de 60 meses. Cualquier referencia a su identidad que pudiese comprometer su anonimato será eliminada o disfrazada antes de preparar los informes y publicaciones de la investigación.

¿Qué pasa si no quiero participar o si me quiero retirar del estudio?

La participación en este estudio es voluntaria; negarse a participar no implicará ninguna sanción. Usted es libre de retirar su consentimiento y suspender la participación en este proyecto en cualquier momento y por cualquier razón. La investigadora contestará las preguntas relacionadas con esta investigación antes, durante y después del estudio. Cualquier información o contribución que usted haga al estudio se mantendrá durante 60 meses, pero se excluirá si usted lo solicita

Otras Consideraciones:

Si hay disponible nueva información de importancia relacionada con el estudio la cual pudiese estar relacionada con su deseo de seguir participando, yo se la proporcionaré.

Consentimiento Voluntario del Participante:

Al firmar a continuación, usted indica que

- le han explicado este estudio
- usted tiene por lo menos 21 años de edad
- usted entiende el idioma español escrito y ha leído este documento o se lo han leído
- usted tiene acceso regular al Internet
- le han contestado sus preguntas acerca de este estudio de investigación
- le han dicho que en el futuro usted puede hacerles a los investigadores cualquier pregunta relacionada con el estudio o comunicarse con ellos en caso de una lesión relacionada con la investigación
- le han dicho que puede hacerle preguntas al personal del Consejo Institucional de Revisión (IRB) acerca de los derechos que usted tiene como participante en una

investigación

- usted tiene el derecho a una copia de este formulario después de haberla leído y firmado, usted consiente voluntariamente a participar en el estudio titulado “Conflicto Después de Seleccionar Tratamientos para el Cáncer: Divulgación de Información Podría Influir Arrepentimiento Contra-Factual y Auto-Aceptación en Padres de Niños con Cáncer que Están en Luto”.

Firma del Participante: _____ Fecha: _____

Nombre del Participante: _____ Fecha: _____

Firma de la Persona que Obtiene Consentimiento: _____

Fecha: _____

Por favor entregue este formulario a dsperandeo@yahoo.com

Graduate School of Humanities and Social Sciences
3301 College Avenue. Fort Lauderdale, Florida 33314-7796
(954) 262-3000. 800-262-7978. Fax: (954) 262-3968
Email shss@nsu.nova.edu. <http://shss.nova.edu>

Appendix D: Participant Biographical Data—Questionnaire

- 1) Select your preferred language:
 - a) English
 - b) Spanish
- 2) Select which of the following identify you:
 - a) I am the mother of a deceased child with cancer
 - b) I am the father of a deceased child with cancer
- 3) Select your race:
 - a) Latino
 - b) Asian
 - c) Hawaiian or Pacific Islander
 - d) White
 - e) Black
 - f) Other
 - g) More than one apply
- 4) Select the highest education you have completed:
 - a) High School diploma or GED
 - b) Some college
 - c) Bachelor's degree
 - d) Master's degree
 - e) Doctoral degree
- 5) Select any conditions you have been diagnosed with:
 - a) Depression
 - b) Anxiety
 - c) Bipolar depression
 - d) Other mental illness
 - e) None of the above
- 6) Which of the following treatments did your child receive:
 - a) Chemotherapy
 - b) Radiation
 - c) Surgery
 - d) Bone Marrow transplant
 - e) Alternative treatment
 - f) More than one
 - g) None of the above
- 7) How old was your child at the time of diagnosis? _____
- 8) How old was your child at the time of death? _____

Appendix E: Decisional Conflict Scale

Response options:

strongly agree, agree, neither agree nor disagree, disagree, strongly disagree

- 1) I knew which options are available to me
- 2) I know the benefits of each option
- 3) I know the risks and side effects of each option
- 4) I am clear about which benefits matter most to me
- 5) I am clear about which risks and side effects matter most to me
- 6) I am clear about which is more important to me, benefits or risks
- 7) I have enough support from others to make a choice
- 8) I am choosing without pressure from others
- 9) I have enough advice to make a choice
- 10) I am clear about the best choice for me
- 11) I feel sure about what to choose
- 12) This decision is easy for me to make
- 13) I feel that I have made an informed choice
- 14) My decision shows what is important to me
- 15) I expect to stick with my decision
- 16) I'm satisfied with my decision

Appendix F: The Picker Patient Experience—Content

Item	Item content
1.	Doctors' answers to questions not clear
2.	Nurses' answers to questions not clear
3.	Staff gave conflicting information
4.	Doctor didn't discuss anxieties or fears
5.	Doctors sometimes talked as if I wasn't there
6.	Not sufficiently involved in decisions about treatment and care
7.	Not always treated with respect and dignity
8.	Nurses didn't discuss anxieties and fears
9.	Not easy to find someone to talk to about concerns
10.	Staff did not do enough to control pain
11.	Family didn't get opportunity to talk to doctor
12.	Family not given information needed to help recovery
13.	Purpose of medicines not explained
14.	Not told about medication side effects
15.	Not told about danger signals to look for at home

Appendix G: Decision Regret Scale

Response options:

strongly agree, agree, neither agree nor disagree, disagree, strongly disagree

- 1) It was the right decision
- 2) I regret the choice that was made
- 3) I would go for the same choice if I had to do it over again
- 4) The choice did me a lot of harm
- 5) The decision was a wise one

Appendix H: Ryff's Psychological Well Being Scale/ Self -Acceptance Dimension

1= Strongly agree and 6 = Strongly disagree		
	I am not afraid to voice my opinions, even when they are in opposition to the opinions of most people.	1 2 3 4 5 6
2	In general, I feel I am in charge of the situation in which I live.	1 2 3 4 5 6
3	I am not interested in activities that will expand my horizons.	1 2 3 4 5 6
4	Most people see me as loving and affectionate.	1 2 3 4 5 6
5	I live life one day at a time and don't really think about the future.	1 2 3 4 5 6
6	When I look at the story of my life, I am pleased with how things have turned out.	1 2 3 4 5 6
7	My decisions are not usually influenced by what everyone else is doing.	1 2 3 4 5 6
8	The demands of everyday life often get me down.	1 2 3 4 5 6
9	I think it is important to have new experiences that challenge how you think about yourself and the world.	1 2 3 4 5 6
10	Maintaining close relationships has been difficult and frustrating for me.	1 2 3 4 5 6
11	I have a sense of direction and purpose in life.	1 2 3 4 5 6
12	In general, I feel confident and positive about myself.	1 2 3 4 5 6
13	I tend to worry about what other people think of me.	1 2 3 4 5 6
14	I do not fit very well with the people and the community around me.	1 2 3 4 5 6
15	When I think about it, I haven't really improved much as a person over the years.	1 2 3 4 5 6
16	I often feel lonely because I have few close friends with whom to share my concerns.	1 2 3 4 5 6
17	My daily activities often seem trivial and unimportant to me.	1 2 3 4 5 6
18	I feel like many of the people I know have gotten more out of life than I have.	1 2 3 4 5 6
19	I tend to be influenced by people with strong opinions.	1 2 3 4 5 6
20	I am quite good at managing the many responsibilities of my daily life.	1 2 3 4 5 6
21	I have the sense that I have developed a lot as a person over time.	1 2 3 4 5 6
22	I enjoy personal and mutual conversations with family members or friends.	1 2 3 4 5 6
23	I don't have a good sense of what it is I'm trying to accomplish in life.	1 2 3 4 5 6
24	I like most aspects of my personality.	1 2 3 4 5 6
25	I have confidence in my opinions, even if they are contrary to the general consensus.	1 2 3 4 5 6
26	I often feel overwhelmed by my responsibilities.	1 2 3 4 5 6
27	I do not enjoy being in new situations that require me to change my old familiar ways of doing things.	1 2 3 4 5 6
28	People would describe me as a giving person, willing to share my time with others.	1 2 3 4 5 6

- 29 I enjoy making plans for the future and working to make them a reality. 1 2 3 4 5 6
- 30 In many ways, I feel disappointed about my achievements in life. 1 2 3 4 5 6
- 31 It's difficult for me to voice my own opinions on controversial matters. 1 2 3 4 5 6
- 32 I have difficulty arranging my life in a way that is satisfying to me. 1 2 3 4 5 6
- 33 For me, life has been a continuous process of learning, changing, and growth. 1 2 3 4 5 6
- 34 I have not experienced many warm and trusting relationships with others. 1 2 3 4 5 6
- 35 Some people wander aimlessly through life, but I am not one of them. 1 2 3 4 5 6
- 36 My attitude about myself is probably not as positive as most people feel about themselves. 1 2 3 4 5 6
- 37 I judge myself by what I think is important, not by the values of what others think is important. 1 2 3 4 5 6
- 38 I have been able to build a home and a lifestyle for myself that is much to my liking. 1 2 3 4 5 6
- 39 I gave up trying to make big improvements or changes in my life a long time ago. 1 2 3 4 5 6
- 40 I know that I can trust my friends, and they know they can trust me. 1 2 3 4 5 6
- 41 I sometimes feel as if I've done all there is to do in life. 1 2 3 4 5 6
- 42 When I compare myself to friends and acquaintances, it makes me feel good about who I am. 1 2 3 4 5 6

Appendix I: Statement of Original Work

Statement of Original Work

I declare the following:

I have read the Code of Student Conduct and Academic Responsibility as described in the *Student Handbook* of Nova Southeastern University. This proposal represents my original work, except where I have acknowledged the ideas, words, or material of other authors.

Where another author's ideas have been presented in the applied dissertation, I have acknowledged the author's ideas by citing them in the required style.

Where another author's words have been presented in this applied dissertation, I have acknowledged the author's words by using appropriate quotation devices and citations in the required style.

I have obtained permission from the author or publisher—in accordance with the required guidelines—to include any copyrighted material (e.g., tables, figures, survey instruments, large portions of text) in this applied dissertation manuscript.

Signature
Danielle De Santis Sperandeo

April 9, 2019