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Influence of Dual Process Decision-Making Theory in Patients Diagnosed With Cancer

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Abstract

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Dissertation Submitted in Partial Fulfillment

of the Requirements for the Degree of

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Abstract

Each year millions of people face the medical decision-making cycle that comes with a diagnosis of cancer. For patients and their families, this can be a rollercoaster of confusion and fear. Researchers have indicated that the complexity of the decision-making process is underrepresented in the current approach of informed decision-making. The purpose of this study was to add to scientifically-validated research expanding the identification of factors that influence decision-making for individuals diagnosed with cancer. Fuzzy trace theory (FTT) is the dual process memory theory used as the framework for this study. Qualitative data were collected using semistructured interviews with 10 participants. The sampling strategy included purposeful sampling and snowball or chain sampling. The audio-recorded interviews were transcribed and analyzed. Software tools were used to aid in the creation of word mapping and clusters and a naming structure emerged. A comprehensive thematic analysis was completed. Participants detailed experiences with family and social dynamics, psychological or emotional stress, external influencing factors to the decision-making process, and experiences with cancer advertising. This research can create positive social change through the advancement of scientifically-validated research to support patients during the decision-making process.

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Dedication

Many physicians, nurses, ancillary health care providers, and cancer service groups contributed to my passion for understanding the patient decision-making process. Having served in the field of oncology for over 25 years, many collegial relationships were forged. When I began this journey, many of those colleagues came to my assistance in the completion of my doctoral research. It would be my honor to name each of the healthcare colleagues who contributed to the completion of this research. However, divulging specific information might compromise the confidentiality of study participants. For this reason, I will need to use this section to say thank you in a more confidential fashion. To the many talented oncologists, dedicated leaders, and allied health professionals I have had the pleasure to know, please accept my heartfelt gratitude. I would also like to say thank you to mentors who never let me give up this dream, even when I felt overwhelmed. To Mitesh Patel, MD, Jacque Engstrand, RN, Donna Dahlin-Parent, RN, Adrienne McReynolds, and Lori Muir, your support and friendship means more to me than you will ever know. Lastly, thank you to Dr. Aagard, my committee chair. There were moments of complete mental and emotional exhaustion that you helped me process. I am eternally grateful for this experience.

Acknowledgments

Completing this incredible journey of doctoral studies would not have been possible without the support of my loved ones. The encouragement and understanding from my family and friends sustained me during moments of doubt and exhaustion. My family demonstrated considerable patience with the constant deadlines and redundant absenteeism. My close friends vowed to not forget me, and patiently waited for the fleeting moments of availability for long overdue visits. My wonderful family and friends also celebrated the many accomplishments and milestones. Forever my champions, they encouraged me to reach further. I look forward to smothering them with my love and attention for many months to come as I make up for lost time. To my husband of 30 years, a special thank you for hanging on even my goals seem to lofty. To the rest of my family, each of you helped me in unique and special ways. Please accept my love and humble appreciation.

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Chapter 1: Introduction to the Study

According to the National Cancer Institute (NCI, 2017), 14.5 million individuals in the United States live beyond a diagnosis of a cancer. Cancer survivors face multiple medical decisions throughout their journey. Treatment options continue to change with advances in scientific discoveries and technology (American Society of Clinical Oncology [ASCO], 2015). Examples of advances in the treatment of cancer include improvements and developments in surgical technique, increased systemic drug regimens, expansion of genetic testing, and greater applications of radiation therapy in all stages of disease (Masters et al., 2015). With numerous treatment advances, individuals face increasingly complex treatment decision-making (ASCO, 2015; Croyle, 2015; Reyna, Nelson, Han, & Pignone, 2015).

Continued expansion and complexity in medical options can influence patient informed decision-making (Reyna et al., 2015). Wolfe et al. (2015) suggested complex treatment options and limited time between diagnosis and treatment could result in poor decision-making practices by patients. Informed decision-making requires the ability to ascertain "benefits, risks, and uncertainties," in addition to incorporating personal preference and desired control (Reyna et al., 2015, p. 105). The emotional and cognitive environment that exists parallel to personal preference and desired control is equally complex, and the influence is less tested with scientific rigor (Aning, Wassersug, & Goldenberg, 2012; Bodie et al., 2011; Epstein & Gramling, 2013; Reyna et al., 2015). Numerous internal and external influencers further complicate patient decision-making at a time when stress and fear levels have increased.

In the next section, I provide the study background based on literature review findings, followed by the problem statement, purpose, and framework. Study details including methodology, sources of data, limitations, and assumptions, are also provided. I provide the study significance and summary in the final portions of this chapter.

Background

I reviewed many articles specific to shared decision-making (SDM), provider communication, messaging, and patient-directed care. I identified degrees of discordance in the research conclusions in each area in the literature review. However, the influence of provider messaging in the decision-making process was underrepresented in the literature. Researchers have also found variations between patients deferring all decision-making to their providers to examples of patients preferring to make all treatment decisions and areas in-between (Back, Trinidad, Hopley, & Edwards, 2014; Epstein & Gramling, 2013; Livaudais, Franco, Fei, & Bickell, 2013; Pass, Belkora, Moore, Volz, & Sepucha, 2012, Singh et al., 2010).

I could not identify scholarly publications that showed causation of compliance or nonadherence with treatment. Perceived confidence by patients in decision-making was identified as represented in the literature (Aneja & Yu, 2012; Epstein & Gramling, 2013; Forsythe et al., 2014; Glass et al., 2012; Reyna et al., 2015). Understanding the role of patient specific exposures to variables that influenced decision-making was considered important to support healthcare providers in meeting the expectations for informed consent and SDM.

I also reviewed reports from leading organizations in healthcare and reports of cancer care practice trends in the United States. The criteria I reviewed, in the annual reports by ASCO (2015) and Institute of Medicine (IOM, 2013), were broad and included areas beyond the scope of this research. The ASCO (2015) and IOM (2013) reports indicated rich details about industry shortcomings and the need for improvements in patient/provider communication. The reports oversimplified the healthcare delivery environment and lacked a direct correlation or causal factors for the identified gaps in this research. The ASCO (2015) and IOM (2013) reports supported this research study in at least two distinct ways. First, many references to cancer treatment decision-making and disruptions in cohesive care were cited. Second, the ASCO (2015) and IOM (2013) reports highlighted the need to identify and define causal factors and opportunities for improving the patient decision-making experience.

Next, I observed limited research regarding the influence of messaging by members within the patients' support circles or other external influences. Some researchers mentioned various external influences and suggested additional study in this area (Epstein & Gramling, 2013; Forsythe et al., 2014; Imber-Black, 2014). The lack of in-depth study, regarding the influence of external influencing factors on decision-making, was important for this study.

In addition, the role of psychological distance was found as very new in the literature and should be further reviewed in the setting of cancer decision-making (Fukukura, Ferguson, & Fujita, 2013; Reyna et al., 2015). Fukukura et al. (2013) suggested that the decision-making process was improved when sufficient time could

elapse during situations where a great deal of information was presented. I identified no researchers who addressed psychological distance related to cancer treatment decision-making.

The use of decision-making aids for patients diagnosed with cancer was inconsistent in the many examples of literature I reviewed (IOM, 2013; Joseph-Williams, Elwyn, & Edwards, 2014; Reyna et al., 2015; Thorne, Oliffe, Stajduhar, Oglov et al., 2013). In addition, the influence of expanded Internet-based education tools was introduced but not in depth (Wolfe et al., 2015). Wolfe et al. (2015) suggested decision-making tools or aides were not based on medical decision-making theories; as such, these were not as effective as possible. For this reason, I believed this represented an area that warranted further study.

I found limited research on the influence of marketing techniques from direct to consumer advertising (DTCA) during treatment decision-making (Abel, Burstein, Hevelone, & Weeks, 2009; Tan, 2015; Vater et al., 2014). Increased competition between healthcare organizations and continued changes in reimbursement have escalated the need for organizations to solicit patients to seek services at their facilities. The gaps in the current literature on DTCA was suggested as an important area for additional research specific to influence on the decision-making process.

Researchers have identified the role of dual process decision-making in health care and noted it as an area in need of additional study attention (Reyna et al., 2015; Wolfe et al., 2015). The literature included descriptions of the confused mental state that could accompany a diagnosis of cancer (Wolfe et al., 2015). Reyna et al. (2015) also

recommended future research aimed at understanding ways in which individuals

organize, synthesize, and recall information for cancer treatment decision-making. In

addition, I evaluated how to ensure providers addressed personal values, external

messaging, and other factors that influenced decision-making.

Problem Statement

Researchers have identified needs for greater understanding of the relationship

between emotion and cognition, as well as ways in which the dual process theory have

influenced decision-making (Fukukura et al., 2013; Reyna et al., 2015). Cleary defined

variables, related to emotion and cognition for patients faced with a diagnosis of cancer,

were limited in the literature and have potential implications on informed decision-

making (Livaudais et al., 2013; Reyna, 2012; Reyna et al., 2015). I reviewed literature

that indicated discordance in study conclusions about informational needs for patients

during decision-making. Based on gaps in the literature review findings, further

evaluation was needed to understand the influence of emotionally-based appeals used in

DTCA on cancer treatment decision-making (Abel et al., 2009; Tan, 2015; Vater et al.,

2014).

Purpose

The purpose of this study was to gather detailed interview responses, analyze and

interpret the data, and develop recommendations for understanding the treatment

decision-making process. In this study, I focused on understanding the influence of the

identified variables on gist and verbatim recall, as well as the influence on patients during

dual process decision-making. Verbatim recall refers to detailed and "precise

information," while gist recall refers to "meanings" that are unique to individuals (Smith et al., 2013, p. 6189). Verbatim and gist are discussed in greater detail in subsequent sections.

Research Questions

Research Question 1: What are the information-based (verbatim) factors influencing cancer treatment decision-making for patients diagnosed with cancer?

Research Question 2: What are the emotional-based (gist) factors influencing cancer treatment decision-making for patients diagnosed with cancer?

Research Question 3: Are there factors outside of verbatim or gist examples that are reported as influential in the cancer treatment decision-making process in the study population?

Theoretical Framework

Health care decision-making literature included the theoretical framework of dual process, cognition, and emotion. According to Reyna et al. (2015), FTT includes verbatim and gist recall. Verbatim recall, relating to cancer treatment decision-making, consists of complex concepts (e.g., survival or risk ratios and efficacy percentages; Reyna et al., 2015; Wolfe et al., 2015). Gist recall includes the "fuzzy" portion of decision-making based on unconscious awareness or individual perception (Reyna et al., 2015). The focus of this study was on the relationship between factual and emotional navigation through the decision-making process and understanding how each category influences decision-making.

Nature of the Study

I chose case study design for my qualitative research, and I focused on developing answers to explain the defined research questions, as suggested by researchers (Center for Research Quality, 2015; Maxwell, 2013; Patton, 2015). The key phenomenon was the decision-making experience for patients newly diagnosed with cancer. I selected case study for the unique properties of this method. According to Creswell (2013), case study seeks to gather in-depth understanding about real-life cases being studied. Merriam (1998) described case study as a "holistic description" (p. 20). Case study is also useful for the development of themes (Creswell, 2013). In this research, I included the multiple case study approach and employed replicated interviews to assist in generalizing the findings (see Creswell, 2013).

Two sources of data collection were used in the completion of this research. Participant data were collected using (a) semistructured in-depth interviews and (b) follow-up calls. Participant data were transcribed and hand coded with the creation of a naming structure for thematic analysis. The second data source included cancer center advertising materials. I reviewed website data advertisements for facilities in California. The secondary data were evaluated using some of the key terms identified during the literature on DTCA (Abel et al., 2009; Tan, 2015; Vater et al., 2014).

Definition of Terms

Cancer: Cancer is the uncontrolled growth of abnormal cells (National Institutes of Health, 2015b).

Diagnosis: Diagnosis is the clinicians statement of disease or condition after evaluating the symptoms, physical exam, and findings from testing (National Institutes of Health, 2015b).

Direct-to-consumer-advertising (DTCA): DTCA refers to patient directed advertising is usually associated with pharmaceuticals but is also used to describe other to include direct advertising for medical treatment to specific populations (Tan, 2015).

Gist recall: As used in FTT, gist recall refers to the substance, essence, or meaning of an encounter or experience (Reyna & Brainerd, 1995).

Primary site: The primary site is the location where the cancer started, which is usually named after the organ where the cancer originated or started (National Institutes of Health, 2015b).

Stage: Stage refers to the schema used to detail how far the cancer has spread and is based on defined criteria (National Institutes of Health, 2015a).

Verbatim recall: As used in FTT, verbatim recall refers to the recollection of detail that includes literal fact or very specific details (Reyna, Nelson, Han, & Dieckmann, 2009).

Assumptions

The assumptions that guided this study included that (a) the patient/provider relationships are more complex than reflected in the literature; (b) DTCA provides a greater influence on patient decision-making compared to what is currently understood; (c) the patient support circle provides greater influence on decision-making compared to what is currently understood; (d) semistructured in-depth interviews, completed as close

to the first date of diagnosis as possible, provided the best opportunity for accurate memory recall; and (e) participant enrollment could be challenging close to the delivery of a diagnosis due to the life changes associated with a life threating illness.

Scope and Delimitations

The scope of the study included patients facing a first diagnosis of cancer with no limitations from stage of disease or primary site. I did not include participants with a previous diagnosis of cancer. Additional eligibility requirements included being between the ages 25 to 80, being without cognitive impairment, and living in California at the time of diagnosis. I used a qualitative approach to evaluate the influence of emotion and cognition for patients during the decision-making process. I identified the variables specific to decision-making in this population in the literature review and integrated these into the research design and interview questions. I combined participant data and data from the literature and document review. I conducted interviews in person, without the use of external interviewers. Telephone interviews were used for participants who could not keep an in-person interview.

Limitations

The study included only individuals living in the state of California at the time of diagnosis. The focus on participants from a specific state could limit the ability to generalize the analysis findings to the broader public. The accuracy of self-reported information from interviewees might also represent a limitation due to recall bias or confirmation bias. Another limitation was the criteria of English speaking only participants. According to the U.S. Census Bureau, several cities within California have

large populations where languages other than English are spoken at home (http://www.census.gov). Due to limited resources for interpretation of materials and transcribing, I only enrolled English-speaking participants. Interviewers can also be a limitation if interviewer bias or emotions are not separated from the study process (Patton, 2015). Staying mindful development and review of all study and interviewing materials helped limit interviewer bias. Understanding potential pitfalls and incorporating stop gaps into the study design was met. For instance, confirmation bias was noted to effect memory impacting recall of information, as suggested by researchers (Frost et al., 2015). The use of vocal recording and verbatim transcription reduced the potential for confirmation bias in the capture and analysis of interview content.

Significance of Study

This research could expand theory-based findings regarding patient/provider communication and shared decision-making. The study findings were significant for provider practices by offering a better understanding of the variables that have the potential to influence patients during cancer treatment decision-making. This study showed practitioners opportunities for a deeper understanding of patients' needs during the decision-making process. In addition, this study could allow for the development of best practices for shared decision-making focused on patients' reported needs.

This research was also important to understand further the theoretical constructs of dual process cognition and emotion during the decision-making process for patients confronted with a diagnosis of cancer. Specifically, this study indicated a better understanding of the roles of verbatim and gist recall in situations of life threatening

illness. Study findings would allow for continued growth in the fields associated with decision-making and health behavior.

The positive social change influence of this research included developing processes to support individual patient preferences for cancer treatment. Cancer patients, the oncology health care community, and health care leaders could use the research findings for clinical and programmatic strategies that focused on blending scientific advancements and patient preference.

Summary and Transition

Specialty providers have faced delivering the diagnosis of cancer to vast numbers of patients every year. The study purpose focused on understanding internal and external variables that influenced decision-making for patients diagnosed with cancer. I considered comprehensive theory-based research analysis of the patient decision-making process lacking. In addition, conflicting literature findings on components of this research added to the support for further study. The journey of patients diagnosed with cancer and their support system could involve fear, anxiety, and unknown outcomes. Patients face influencing variables from many directions. The theoretical framework of FTT and dual process decision-making provided the correct approach for this research.

Chapter 2 details the findings of the literature and various research elements. Chapter 3 follows with detailed research methods. Chapter 4 presents the findings from this research. Finally, Chapter 5 concludes the study with implications, recommendations, and a final summary.

Chapter 2: Literature Review

Introduction

The IOM (2013) stated, "Patient-centered communication and shared decision-making" (p. 20) was lacking in the United States. The IOM (2013) suggested treatment of decision-making was often not evidence based and that physician practices lacked standardized methods to address this challenge. Several researchers have indicated other variables or influencing factors could be responsible for challenges in the shared decision-making process for patients diagnosed with cancer (Epstein & Gramling, 2013; Forsythe et al., 2014; Imber-Black, 2014). The assessment of patient/provider relationships, shared decision-making, and identification of patient preferences was warranted to ensure clinicians met the needs of patients and their support systems.

In addition, I identified the emerging field of psycho-oncology and the challenges in sharing complex medical information with patients. Research in understanding effective approaches to presenting complex medical information provided opportunities to clarify the needs of patients during the decision-making processes. Progressive research on dual-process decision-making theories would provide explanations for use in patient/provider relationships. Identifying and understanding factors that influenced decision-making was suggested as important for the adequate evaluation of this topic. Family influence and consumer advertising represented examples of potential influencing factors that researchers did not explain with great depth in the literature.

This chapter includes an introduction to FTT, the theoretical framework of this study. The next section includes an outline of multiple variables or influencers identified

in the literature. Variables/influencing factors included (a) decision-making elements; (b) provider specific variables; (c) the patient/provider relationship; (d) provider communication and shared decision-making; (e) patient specific variables; (f) patient preference; (g) family and social direction; (h) faith, spirituality, or personal belief variables; (i) ethnic, cultural, and individual views; (j) other individual characteristic variables; (k) and DTCA. In the next section, I detail dual process cognition and emotion, verbatim and gist memory, and psychological distance.

Literature Search Strategy

Search Strategy

I conducted the literature review by searching multiple databases. I used MEDLINE and CINAHL as the primary databases. I used SocINDEX, ProQuest, PubMed, and SAGE for literature searches. Additional industry specific databases searched included the American Cancer Society (ACS, 2016) and the NCI (2017) division of the National Institutes of Health (2015a, 2015b).

Search Terms

Primary search terms included *cancer*, *dual cognition, dual-process, emotion*, *decision-making*, *cancer treatment*, *patient/physician relationship*, and *fuzzy trace theory*. I used additional terms in combination with the primary search terms that included *literacy*, *numeracy*, *informed consent*, and *quality*.

Theoretical Framework

I used FTT as the theoretical framework in this study. According to Reyna and Brainerd (1995), the development of FTT began in the early 1990s, detailing human

reasoning, memory, and disassociation. FTT evolved based on continued research findings in the field of memory and logic (Reyna & Brainerd, 1991). Psycholinguistics was also referenced for the associations with FTT (Reyna, 2012). According to Reyna (2012), FTT has undergone many phases of research testing.

Verbatim and gist recall are the dual processes associated with FTT and were the focus in this literature review. Verbatim recall is based primarily on detailed information or complex facts, and gist recall is based primarily on emotion (Reyna, 2012; Reyna et al., 2015). The processes of emotion and cognition occur in many possible sequences, in tandem, separate, interrupted, or dependent, and these are unique to each cancer patient's journey. Reyna (2012) added a third FTT theme, intuition, and suggested an overlapping of decision-making. This theme is covered in greater detail in the section on dual-process cognition and emotion. FTT is used in most of the remainder of this study. Occasionally, dual process is used when speaking of decision-making theories in general. When referring to a specific memory recall, verbatim or gist is used.

According to Reyna (2008), distraction occurs more often in verbatim memory compared to with gist memory. An increase in distraction during verbatim recall can influence decrease decision-making based on science and shift greater emphasis on emotional recall. I will explain the influence of verbatim and gist recall in greater detail later in this chapter.

The selection of FTT as the theoretical framework was based on the culmination of advances in the development of FTT. The 2015 publication in American Psychologist highlighted many components of decision-making that occurred throughout the cancer

journey (Reyna et al., 2015). Reyna et al. (2015) presented multiple components of memory recall involved during decision-making. The authors also detailed the expansion of FTT, applicability of FTT, and specificity to cancer decision-making. After conducting research in FTT from the early literature through current writings, the use of FTT as the theoretical approach was solidified.

Literature Review

Decision-Making Elements and Variables

Decisions, made in response to a diagnosis of cancer, can be complex and overwhelming (Epstein & Gramling, 2013; Gibbins, Bhatia, Forbes, & Reid, 2014). Epstein and Gramling (2013) defined cancer decision-making as an iterative process, an excellent description for a period often rife with emotion and decision-making starts and stops. In this research, I focused on provider specific, patient specific, and other external variables or influencing factors related to decision-making after a diagnosis of cancer.

Decision-making elements for patients diagnosed with cancer vary based on their individual cancer types and the extent of disease. The completion of additional testing may occur to establish a clearer understanding of the extent of disease before forming a treatment plan (IOM, 2013). The current health status of the patient is also an element one must consider (IOM, 2013). Surgery, chemotherapy, radiation therapy, immunotherapy, targeted therapies, and hormone therapy entail the most common modalities of treatment for cancer (National Institutes of Health, 2015a). Types of treatment are also unique to each person's journey. The elements detailed play only a

minor role in this research. In the next section, I provide greater detail of the focus of this research.

Variables support, change, or otherwise can influence patient decisions and exist in combination with the elements of their diagnosis (Bodie et al., 2011). Variables are unique to each patient and occur at multiple points throughout the journey. The subsequent sections include the literature review findings, as outlined in the following categories: (a) provider specific variables, (b) patient specific variables, and (c) other external influences. Each category has prominent subcategories that I identified during the literature review.

Provider Specific Variables

I identified key provider specific variable terms in the literature that showed support for an evolution toward care models that focused on partnerships between providers and patients. Terms, such as *patient-centered*, *shared decision-making*, and *patient-driven care models*, were prominent. Researchers have noted important factors about the patient/provider relationship and provider communication, which indicated a need for greater study (ACS, 2016; ASCO, 2015; Epstein & Gramling, 2013).

Patient/provider relationship. The development of the patient-provider relationship can influence the decision-making process (Epstein & Gramling, 2013). In the management and treatment of life-threatening chronic illness, as in the instance of cancer, emotions, and external influences, can also influence the patient-provider relationship (Epstein & Gramling, 2013). All patients, diagnosed with cancer, and their support systems have a unique set of needs and expectations of their providers (Dy et al.,

2014). Specialty oncology physicians often meet patients for the first time at the initial

diagnosis or shortly after. Only a small window of time is left to quickly understand the

"unique characteristics of each clinical situation" (Epstein & Gramling, 2013, p. 97S).

A medical oncologist often manages the cancer care plan. With continued changes

in health care environments and reimbursement, medical management can vary

(Friedman et al., 2014). Patients may have relationships with many specialty physicians,

at multiple facilities, and in some instances, in different geographic areas, increasing the

potential for missed communication during the continuum of care (ASCO, 2015). The

IOM (2013) and the ASCO (2014, 2015) published articles in support of team-based

models and multidisciplinary teams, as methods to ensure comprehensive input for

treatment considerations (Friedman et al., 2014).

Providers must deliver the information needed during decision-making in a

situation that is often complex and ambiguous (Epstein & Gramling, 2013; Joseph-

Williams et al., 2014). How the information is delivered and by whom are important to

consider (Epstein & Gramling, 2013; Joseph-Williams et al., 2014). Joseph-Williams et

al. (2014) offered a systematic analysis of nearly 300 articles, detailing the complexity of

the exchange of information during the decision-making process. The provider skill in

messaging was an important factor in the patient-provider relationship (Joseph-Williams

et al., 2014). Joseph-Williams et al. (2014) pointed out that finding a balance in

messaging and fostering an effective patient/provider relationship was complicated but

not insurmountable (Thorne, Oliffe, Stajduhar, Oglov et al., 2013).

Provider communication and shared decision-making. SDM is an approach focused on defining patient preference and incorporating that preference into the treatment decisions (Clayman, Makoul, Harper, Koby, & Williams, 2012; Glass et al., 2012; Pass et al., 2012). Specifics about the benefits of SDM varied in the literature. Transparency, open discussions, and sharing of all treatment options is the gold standard in cancer care (Housri, Coombs, Orandi, Pawlik, & Koniaris, 2011).

Glass et al. (2012) surveyed 488 individuals, aged 21 to 70, with various health decision-making interactions. Glass et al. focused on understanding the relationship between SDM and patient satisfaction. Glass et al. provided specific areas of focus that complemented my research. For instance, the SDM-Q-9 questions were specific to defining the interaction between the patient and the provider, representing the basis of SDM (Glass et al., 2012). In this study, I identified the presence of SDM for participants and expanded the understanding of variables that influenced SDM for participants.

Patients and their families need provider, as it can influence patient decision-making behaviors. Some researchers have suggested that communication needs differed when patients were newly diagnosed or further along in their cancer journeys (Back et al., 2014; Thorne, Oliffe, & Stajduhar, 2013). Knowing what the patient needs to or wants to hear is complex. Whether using SDM, meaningful participation, or another communication technique, each patient has a distinctive set of needs and expectations (Epstein & Gramling, 2013).

I also identified research that addressed provider skills in the delivery of diagnoses and decision-making information in an SDM format (Joseph-Williams et al.,

2014; Pass et al., 2012). Some researchers have suggested physicians lacked training in the technique of SDM or had limited skills in tailoring messaging for patients (Livaudais et al., 2013; Pass et al., 2012). Epstein and Gramling (2013) claimed that the complexity of messaging compounded the other challenges in communication. Glouberman and Zimmerman (as cited by Epstein & Gramling, 2013, p. 96S) asserted that problems arose when providers addressed complex situations with simplistic approaches. Some researchers have suggested providers should use less complicated messaging to help patients better understand the diagnosis and treatment, which would lead to better patient compliance (daCosta DiBonaventura, Copher, Basutro, Faria, & Lorenzo, 2014).

Researchers have noted the potential for providers to persuade or otherwise influence patients due to framing during the process of messaging (Broniatowski & Reyna, 2013; Epstein & Gramling, 2013; Reyna & Brainerd, 1991). For the purposes of provider messaging, review of the literature indicated framing influenced patient decision-making, even to the point of going against their own preferences (Back et al., 2014; Epstein & Gramling, 2013). Framing by providers is composed of all portions of the messaging, such as scientific data, recommendations, biases, or past experiences.

Pass et al. (2012) recorded SDM exchanges between patients and providers. The study consisted of medical record review, surveys, and observations. A total of 178 patients participated in the study. Pass et al. stated participants reported they used all SDM activities. Pass et al. also suggested that patient ratings, compared to observer ratings, indicated patients gave providers higher ratings for exhibiting SDM behaviors. According to Pass et al., patients scored physicians high for making them feel involved in

the decision-making process but not as high for seeking their preferences. Conversely, the nonpatient observers gave the physicians high marks for preference seeking (Pass et al., 2012). The difference in perception, presented in this study, underscored the complexity that providers and patients faced in the delivery and receiving of a diagnosis of cancer in a format that they could use.

There is no defined time when patients are most open to receiving a diagnosis of cancer (Epstein & Gramling, 2013; Thorne, Oliffe, & Stajduhar, 2013). Patients are not always adequately prepared to receive, process, and make decisions related to a cancer diagnosis, at least in the early stages (Back et al., 2014; Livaudais et al., 2013; Thorne, Oliffe, Stajduhar, Oglov et al., 2013). In addition, not all patients are comfortable with the responsibility of decision-making and may feel overwhelmed or burdened by the responsibility (Back et al., 2014; Livaudais et al., 2013; Pass et al., 2012). Back et al. (2014) suggested patients did not want to define personal treatment goals, as suggested in other literature. There are varying levels of desired participation by patients in treatment decision-making, requiring physicians to identify this issue, as well as other characteristics early in the patient/provider relationship (Epstein & Gramling, 2013; Hauer, Fernandez, Teherani, Boscardin, & Saba, 2010; Livaudais et al., 2013; Pass et al., 2012; Singh et al., 2010). Delivering the diagnosis and treatment information in an SDM format may provide patients with the peace of mind of having heard everything, even if they defer to the provider for final decision-making (Shay & Lafata, 2015).

Patient Specific Variables

In this section, I detail patient specific variables, identified in the literature review, that exist in combinations with the patient/provider relationship. Many nonclinical influencing factors are identified that patients must navigate throughout their journey. The influence of each of these variables on decision-making is important to understand.

Patient preference. A new diagnosis of cancer presents patients with an unfamiliar situation (Epstein & Gramling, 2013). Patients may not easily express their preferences due to the confusion, anxiety, and emotions that accompany a diagnosis of cancer (Epstein & Gramling, 2013; Jager, 2012). Glass et al. (2012) suggested patients reported higher levels of satisfaction when their preferences were discussed with provider recommendations in an SDM format. People are not good at identifying their own preferences when faced with areas of unknown information (Reyna et al., 2015). Reyna et al. (2015) claimed the ambiguity of treatment information, such as statistical values associated with the complexity of treatment efficacy rates, was an example where patients could face difficulty in identifying their own preferences. In the section on verbatim and gist, I provide important factors of the decision-making process found in the literature, along with further correlation between patient preference and SDM.

In addition, the results in the literature have shown patients would accept potential side-effects or long-term post-surgical effects of treatment if their perception included the belief that all risks were acceptable (daCosta DiBonaventura et al., 2014; Gibbins et al., 2014). Gibbins et al. (2014) produced findings that patients used criteria related to ways

in which treatment would influence their daily living as a deciding factor for accepting or declining treatment. Other research findings have shown patients are willing to endure extensive side-effects and high costs in the hopes for a cure (daCosta DiBonaventura et al., 2014). Conversely, as mentioned in the previous section, many patients prefer not to have the responsibility of treatment decisions (Back et al., 2014; Livaudais et al., 2013; Pass et al., 2012)

Family and social direction. Imber-Black (2014) highlighted influence from family and social relationships during the treatment decision-making process. They furthered that families could be ill-equipped to have discussions related to chronic life-threatening illness; in some instances, the family discussions could cause more harm (Imber-Black, 2014). Imber-Black (2014) provided clinical exemplars (real patient stories) to demonstrate the complexity and influence of families on patients faced with chronic illness. In addition, Imber-Black indicated that the delivery of a diagnosis of cancer could bring to the surface old and hidden away memories.

I observed examples of the social influence from mainstream publications on decision-making. For instance, on a large scale, the "Angelina Jolie effect" is a prime example of mass media and fame influencing public awareness and medical decision-making (Lebo, Quehenberger, Kamolz, & Lumenta, 2015). Several editorials were written after Ms. Jolie went public with her decision to have a prophylactic double mastectomy in response to a positive BRCA genetic test. Spikes in genetic screening and mastectomies were reported, with decreases in both after time passed.

On a smaller scale, some research findings have indicated social influence could occur from interactions with friends, groups, and other social circles (Bodie et al., 2011). Bodie et al. (2011) suggested individuals under great stress would seek social support. Framing, as explained in the previous section, can also occur in family and social interactions. Bodie et al. (2011) and Imber-Black (2014) suggested "supportive communication" was not always pertinent to the individual's diagnosis, and it might even be harmful. Imber-Black (2014) detailed the influence of the patient's past experiences with cancer in others and of those experiences on the patient's decisions. From another perspective, Epstein and Gramling (2013) indicated that social influence could help the patient feel a greater sense of "autonomy."

Faith, spirituality, or personal belief variables. Newfound spirituality or strengthening of current faith and spirituality after a diagnosis of cancer were well established in the literature (Burg et al., 2015; Lagman, Yoo, Levine, Donnell, & Lim, 2012; Stanton, Rowland, & Ganz, 2015; Tallman, 2013). I identified limited research regarding the influence of faith and spirituality on cancer treatment decisions. Faith, words of hope, and other spiritually-charged experiences were prominent in the literature for patients facing a diagnosis of cancer (Back et al., 2014; Schapmire, Head, & Faul, 2012). Patients who have strong faith or spiritual beliefs were described as having a sense that things would work out as planned (Drew & Schoenberg, 2011; Schapmire et al., 2012). Researchers have also noted faith and spirituality in treatment decision-making could extend to alternative options, such as faith healers (Lagman et al., 2012).

Ethnic, cultural, and individual views. The influence of ethnicity on cancer treatment decision-making was not clearly defined during the literature review. I identified research that reflected higher rates of disease, more advanced disease at diagnosis, and decreased use of screening methods within certain ethnic groups (IOM, 2013). Livaudais et al. (2013) included a longitudinal review of 368 women, ages 28 to 89, who were treated for breast cancer. Livaudais et al. suggested ethnicity influenced decision-making in two ways: increased mistrust of the medical profession and decreased desire to make then medical decisions. Livaudais et al. suggested underlying cultural differences as the reason for variations in the patient report decision-making roles

Huang, Ma, Ngo, and Rhoads (2013) researched the use of NCI (2017) designated facilities with defined populations. Huang et al. (2013) suggested there were variances in the use of NCI (2012) facilities by minority groups. Huang et al. included the review of 79,231 records from the California Cancer Registry of patients diagnosed and treated 1996 through 2006. The interpreted findings showed monitories were less likely to use NCI (2012) facilities; researchers have noted the living distance from and NCI (2012) facility as a key predictor to limiting use (Huang et al., 2013).

Joseph-Williams et al. (2014) indicated higher rates of deferring to authority by at least one minority group. Singh et al. (2010) stated non-White minority populations in the study were younger in age compared to Whites. In addition, Joseph-Williams et al. (2014) suggested that younger participants wanted to take a more active role in medical decision-making. It was yet to be seen if younger ethnically diverse people would take the role of active shared decision maker.

Other Individual Characteristic Variables

What patients received from message exchanges varied based on the individual receiving the information (Thorne, Oliffe, & Stajduhar, 2013). Researchers have noted characteristics, such as age, language, economic factors, or literacy and education, as influencing medical decision-making. Literature findings, specific to the aforementioned characteristics, were sparsely represented and presented in the subsequent paragraphs.

Cohen, Jenkins, Holston, and Carlson (2013) identified factors, such as age, geography, and socio-economic status, played a role in medical decision-making. Researchers have associated age with desiring a more active role in decision-making (Singh et al., 2010). Aneja and Yu (2012) and Lin et al. (2016) suggested geography represented an influencing factor for deciding to leave a community to receive specialty care or to forgo treatment due to the distance. Huang et al. (2014) suggested higher education rates were equivalent to higher rates of NCI (2012) facility use. Huang et al. noted socioeconomic factors as associated with influencing the selection of where to receive treatment.

Researchers have suggested numeracy as relational to the understanding of numerical data, which was not an effective method of communication in medical decision-making (Rabin & Glasgow, 2015; Reyna et al., 2015). The cancer stage is a numerical schema that details how far the cancer has spread at the time of diagnosis (http://www.cancerstaging.org). Treatment efficacy and survival rates are also numeric values, reflected most often in percentages (Reyna et al., 2009). Reyna et al. (2009) suggested challenges with numerical data existed even for individuals in the health field

with an extensive education. Reyna et al. (2015) indicated increases in decision-making fluctuation when low numeracy was present. Given the prevalence of numerical data associated with cancer decision-making and the suggestions that patients struggle with complete understanding, it is probable that challenges will arise during decision-making.

I observed indications in literature review findings that suggested the timing of serious illness can influence decision-making (Imber-Black, 2014). For instance, patients might be experiencing the anniversary of the death of a loved one at the time of their diagnosis and have an emotional response to their own decision-making. A discussion on timing is also included in the later section on psychological distance.

Researchers have mentioned the use of decision-making aids as both effective and ineffective in the literature (IOM, 2013; Joseph-Williams et al., 2014; Reyna et al., 2015; Thorne, Oliffe, Stajduhar, Oglov et al., 2013). The IOM (2013) suggested decision-making aids were beneficial for providing decision-making education to patients, but these fell short in some areas, such as how to navigate an SDM encounter with a provider (Epstein & Gramling, 2013; Joseph-Williams et al., 2014). Rabin and Glasgow (2015) provided a review of the literature that assessed gaps related to the development and use of cancer specific noncomplex information for patients. In addition, daCosta DiBonaventura et al. (2014) supported previous research and suggested benefits in using less complicated treatment regimen information. Finally, Lillie et al. (2014) suggested decision-making aids were less effective when used only with the patient, without their support member or members present.

Direct-To-Consumer-Advertising (DTCA)

The final external variable I included as pertinent to the current research was Direct-To-Consumer-Advertising (DCTA). The literature review on DTCA was limited. I reviewed and included Abel et al.'s (2009) older study in the literature review to understand the influence of DTCA, which involved reviewing the advertising method, exposure, and messaging. Each study, published on this topic, approached DTCA in a different fashion; these are detailed in the following paragraphs.

According to Tan (2015), DTCA is controversial primarily due to the complexity of cancer treatments and the cost associated with care. Researchers have noted advertising for health care services as lacking the heavy regulatory oversights placed on pharmaceuticals ads (Schenker, Arnold, & London, 2014). Schenker et al. (2014), suggested the lack of regulatory oversight allowed companies to advertise without accountability.

Tan (2015) focused on DTCA from the population level for breast, prostate, and colorectal cancers. Tan also suggested that age and ethnicity played a factor in the number of reported exposures to DTCA. Participants in the Tan research reported less frequency in exposure to DTCA with increased age. The exposure to DTCA, based on ethnicity, included African Americans reporting higher exposure to DTCA for prostate cancer, and Hispanics reporting higher rates of colorectal cancer DTCA over their White counterparts (Tan, 2015). Tan (2015) stated the highest reporting of DTCA was in breast cancer patients.

The systematic content analysis, conducted by Vater et al. (2014), included a review of 409 messages from 102 cancer centers. Vater et al. suggested advertising content included emotional messaging to influence the decision-making of patients. Researcher have also used framing in DTCA to prime recipients to receive specific messaging (Broniatowski & Reyna, 2013; Epstein & Gramling, 2013; Reyna & Brainerd, 1991). In addition, limited information, regarding risk or treatment efficacy, appeared in the advertising, and researchers reported the use of emotional messaging and phrases of hope as the centerpiece of DTCA (Vater et al., 2014).

Abel et al. (2009) included surveys from 348 individuals with a diagnosis of breast or blood cancers and under treatment at the Dana-Farber Cancer Center in Boston, MA. A high number of the participants responded that they were aware of and exposed to DTCA within the preceding 12 months (Abel et al., 2009). Television was the primary source of DTCA exposure, and most participants stated they became aware of treatments they did not previously know about (Abel et al., 2009). Most participants agreed the messaging used was easy to understand, and participants reported feeling positive about the impact of the messaging (Abel et al., 2009). A small portion of the participants reported being less confident with their providers after exposure to DTCA (Abel et al., 2009).

The three research articles about DTCA showed varied approaches to assessing the impact of marketing on decision-making. The literature review indicated that patients looked for any sign of hope and that patients would search for any opportunity to change the odds (Reyna et al., 2015; Schildmann, Ritter, Salloch, Uhl, & Vollmann, 2013). This

research incorporated a review of web based DTCA currently in use and accessible on the web. I focused on developing an understanding of the types of messaging used in the advertising of cancer related services and the potential framing effects on future cancer patients. In addition, understanding the "perceived credibility" by consumers toward the organizations using DTCA and the potential influence on decision-making was relevant (Epstein & Gramling, 2013).

Fuzzy Trace Theory

In this section, I provide input from researchers in the field of psycho-oncology. Researchers have suggested various theoretical approaches to describe the elements of oncology specific decisions (Bodie et al., 2011). I reviewed dual process theories, such as FTT, to explain the connection and divisions of multiple influences (i.e., logic and emotion) in decision-making.

Reyna et al. (2015) referred to the "conflict" that occurred during dual process decision-making and the influence of individual characteristics on ways in which the conflict was addressed. Epstein and Gramling (2013) wrote about dual process decision-making and suggested patients lacking all disease information at the initial encounter endured additional stress or confusion. The terms, used by Epstein and Gramling (2013), differed from what Reyna et al. (2015) used; however, there were similarities in the meanings. For instance, Epstein and Gramling (2013) condensed cancer decision-making into three categories: "simple, complicated, and complex" (p. 95S), which included the terms "intuition" and "deliberation" as primary decision-making elements (p. 98S). Deliberation is similar to verbatim recall and intuition to gist recall. In addition, Epstein

and Gramling (2013) suggested concurrent movement between intuition and deliberation in decision-making.

According to FTT, verbatim and gist memory are formed together, with gist memory consisting of a simplified residual recall after the verbatim process occurs (Reyna et al., 2015; Wolfe et al., 2015). Another way to think of the differences between verbatim and gist is specificity and generality, respectively. Reyna (2012) suggested the development of gist memory recall increased as people aged and became more reliable or accurate with experience.

Researchers have suggested interference occurred more often with verbatim memory recall and was less reliable (Broniatowski & Reyna, 2013; Reyna et al., 2015). People develop verbatim memory from factual information (Reyna, 2008; Reyna et al., 2015). This information would be reflected in the understanding of testing, staging, and statistics, as related to treatment efficacy, survival data, and risk models (Reyna et al., 2015).

The category of gist memory consists of the fuzzy portions of memory (Reyna, 2008). Reyna (2008) reported that the essence of the experience was what was included in gist memory recall. Over time, gist memories will progress into categorical memory recall with decreasing specificity (Reyna, 2008). The practice of patients reaching out to others for support during their journeys could impact gist memory (Epstein & Gramling, 2013). In addition, patients who have been caregivers to patients with cancer will have gist memories of the experience (Epstein & Gramling, 2013). Fukukura et al. (2013) cited prior research by Miller that included the concept of *chunks*. The concept of chunking

information is like gist memory, as it refers to a categorizing of information into more manageable pieces (Fukukura et al., 2013).

Psychological Distance

Economic theorists attempted to understand when consumers have the right amount of information and when too much information was given, thereby influencing decision-making (Fukukura et al., 2013). Psychological theorists have suggested decision-making was improved when sufficient time could elapse between an event, allowing for a decrease in "information overload" (Fukukura et al., 2013). By redirecting attention, patients can make better decisions with psychological distance, giving people the opportunity to take a step away from the situation (Fukukura et al., 2013). The study findings indicated that large amounts of information hindered the ability to receive and consider all elements, which could lead to confusion, decision delays, and dissatisfaction (Fukukura et al., 2013).

Fukukura et al. (2013) also cautioned that in some instances, distance did not prove beneficial, and participants could not recall specific detail. Following FTT, detailed memory is more consistent with verbatim memory and is recognized by researchers immersed in work with dual process theories (Reyna et al., 2015). Understanding the amount of time that elapsed between the diagnosis and commencing treatment could be beneficial.

Summary and Conclusions

Significant research findings substantiated the need for further study regarding the relationship between dual cognition and decision-making for patients diagnosed with

cancer. Multiple unique patient variables were presented in the literature that influenced decision-making beyond what provider communication provided. Patient variables, combined with provider variables, in addition to the complexity of a diagnosis of cancer, would create opportunities for researchers in the development of communication tools.

The influence of external variables on decision-making by patients diagnosed with cancer was well established in recent literature reviews, as cited in this document. Researchers have recently recognized the influence of external variables on the decision-making process of patients. Therefore, this study would help build knowledge in the areas of FTT, dual process decision-making, and DTCA, and these could influence the decision-making process for individuals diagnosed with cancer.

Chapter 3: Research Method

Introduction

I intended for this study to collect data that would help develop a deeper understanding of the decision-making experience for patients newly diagnosed with cancer. According to Jacobsen and Andrykowski (2015), it was only as recent as the 1980s that the stigma of a cancer diagnosis began to fade. From that same period, according to Jacobsen and Andrykowski, psychology and health behavior theories started to take strong shape, and the field of psycho-oncology started to form. The relationship between emotion and cognition, in the scenario of a diagnosis of cancer specific to verbatim and gist recall, had limited representation in the literature and merited further study.

In Chapter 1, the study background, problem statement, study purpose, and research questions were presented. Chapter 2 included the outline of the variables or influencers identified in the literature as potentially influential to the decision-making process. Chapter 2 also included greater detail of FTT, verbatim and gist memory, and psychological distance. In Chapter 3, I outline this research design. The components included in Chapter 3 also show support for the selected approach.

Research Design

I chose qualitative research and case study design as the methodological framework for this research. Qualitative research focuses on developing answers to defined research questions (Center for Research Quality, 2015; Maxwell, 2013; Patton, 2015). I selected case study design for the unique properties of this method. Researchers

can use case study, according to Creswell (2013), to gather an in-depth understanding about real-life cases studied. Case study is also useful for the development of themes from detailed field work research (Creswell, 2013). This research included the multiple case study approach with replicated interviews to assist in generalizing the findings.

According to the ACS (2016), over 173,000 Californians faced a new diagnosis of cancer during 2016. The central phenomenon of this research was the decision-making process for patients newly diagnosed with cancer. After an extensive literature review, factors, suspected of influencing the decision-making process, were included in this study.

I chose case study for the valuable development of themes from detailed field work research. Researchers can use case study to gather in-depth understanding about real-life cases being studied (Creswell, 2013). This research included the multiple case study approach with replicated interviews to assist in generating themes and generalizing findings.

I considered other qualitative research traditions, such as ethnography, grounded theory, phenomenology, and narrative. I did not select ethnography due to the reliance on greater levels of field work. I did not focus on culture, as seen in ethnography. Grounded theory did not include enough specificity of data needed for this study, and I did not seek to develop a new theory. In addition, I did not select phenomenology; however, it was closely related to case study. The decision-making process studied was not focused on the lived experiences, as would be consistent with phenomenology, rather the influence of defined variables. The higher level of data specificity and participant exposure made case

study a better method for this study. Finally, narrative research was not the ideal approach to meet the broad data collection needs of this research and was not the story of patients' lives.

Role of the Researcher

Almost all participants were new introductions to me. I knew one participant through an established relationship. I did not work with any participants. I decided to avoid any suggestions of pressure or coercion and did not interview individuals I worked with even if they met inclusion criteria.

I considered potential areas for bias during the development of this research. Potential bias did not stop at study design, and I considered bias during each phase of the study execution, analysis, and final publication. I offered a journal as the only item available to participants.

Methodology

Sampling and Sample Size

I used purposeful sampling and snowball or chain sampling for this research. Purposeful sampling provided the most effective method for identifying information-rich participants from the study population (Maxwell, 2013; Patton, 2015). This sampling approach included research participants in the process of recruitment (Sansour, Tong, Jaber, Talbi, & Julliard, 2010).

I evaluated each individual interested in participating using the study criteria. Participants enrolled were between the ages of 25 to 80, without cognitive impairment,

with a first diagnosis of cancer, and lived in California at the time of diagnosis. I did not

include the stage of disease or primary site in the participant inclusion criteria.

The sample size in qualitative research is not based on statistical or mathematic

formulas (Dworkin, 2012; Miles, Huberman, & Saldana, 2014; Patton, 2015).

Consideration of the study sample size was important during the selection process, as

well as during analysis. According to Miles et al. (2013), the number of cases sampled

can impact the analysis portion if the number is too large number or if the interviews are

complex and lengthy. Attempting to complete qualitative analysis with excessive

amounts of participants or data can lead to difficulty keeping data structured and may

extend study completion. In consultation with the committee, we agreed on a research

sample size of 10 participants.

Saturation, as it relates to sampling, is a hallmark point that characterizes

comprehensive qualitative research. Saturation in data collection occurs when the process

of collecting and analyzing additional data does not produce concepts that are new

(Rothman et al., 2009). Another way to explain saturation is a point in the research where

concepts are repeating, and new content is not added. Saturation is also discussed in the

section on data trustworthiness.

Participant Selection

I employed multiple strategies for study participant recruitment. The categories

for recruitment strategy included (a) community engagement, (b) social media, and (c)

daily personal interactions. I provide details for each approach in the following

paragraphs.

Community engagement opportunities provided several venues to advertise and recruit participants. Patient support groups were one example of an opportunity for researcher interaction with individuals diagnosed with cancer. There were many support group members who did not meet participant inclusion criteria. Those who did not meet the inclusion criteria forwarded information to support group members who might be eligible, according to the snowball or chain sampling strategy. I used the ACS website to obtain a list of support group resources for locations throughout California (https://www.acs.org/). I completed web searches focused on supports groups in both inpatient and outpatient cancer centers.

A Google search of the term *churches supporting cancer patients in California* resulted in over 83 million hits, with many duplicates. To reduce the total number of web results, the strategy I used included (a) removing duplicates, (b) removing websites in languages other than English, and (c) identifying church systems or affiliations. I contacted churches from all denominations and requested to post and distribute research flyers (Appendix A) within their congregations.

Social media also provided an opportunity to reach individuals throughout the state. I reviewed organizational social media guidelines from oncology related sites. Some professional organizations developed guidelines for social media use. For instance, the Journal of Clinical Oncology published rules for social media use (as cited in Brophy Marcus, 2014). I also used Facebook, Twitter, and LinkedIn for the social media advertisement strategy. Brophy Marcus (2014) noted the three social media tools as useful in other research advertising. I included a study-specific Facebook page that

included the recruitment and supplemental paperwork approved by the IRB. I monitored the Facebook page regularly, which I set to the maximum level of confidentiality. The use of social media in study advertisement and recruitment has expanded, and researchers have proven it as an efficient and cost-effective strategy (Valdez et al., 2014). The materials, posted on the social media websites, included the same advertising materials approved by the Internal Review Board (IRB); one may find these in the appendices.

I screened individuals who expressed an interest in becoming a study participant for meeting enrollment criteria, and then scheduled them for an interview. I obtained consent before proceeding with the audio recorded interview. I did not conduct interviews on the same day as initial contact.

I merged the social media venue with the academic environment through university-based posting. I posted research advertisements on the California State University Bakersfield LinkedIn site. I also used the Walden online research participation system as the second academic advertisement strategy.

Examples of daily interactions included personal introductions made in nonwork environments. During the recruitment phase of this study, I traveled a significant amount and held a position of project director and consultant. I carried copies of the IRB approved flyer and distributed these to individuals, as appropriate, who I met in organic settings.

Research Questions

Research Question 1: What are the information based (verbatim) factors influencing cancer treatment decision-making for patients diagnosed with cancer?

Research Question 2: What are the emotional based (gist) factors influencing cancer treatment decision-making for patients diagnosed with cancer?

Research Question 3: Are there factors outside of verbatim or gist examples that are reported as influential in the cancer treatment decision-making process in the study population?

Data Collection Instrumentation

Consent

I obtained signed consents after the participant reviewed the research flyer, which was prescreened with the IRB approved screening tool. The consent template included the study background, procedures, volunteer rights, risks and benefits, and other crucial elements. Before participants signed the consent, the participant received the opportunity to ask any additional questions. The consent included the agreement to allow for audio recording of the interview session.

Interview Protocol

I developed an interview protocol for this study. The document included specifics about the interview process, and I used the document to facilitate the interview process and meet the IRB requirements. The protocol included a scripted opening, interview questions, and follow-up notes. The interview protocol for this research is provided in Appendix B.

Expert Panel Review

I assembled an expert panel to conduct a review of the interview protocol. Expert panels are widely accepted for use in assembling experts in the field to provide

knowledge on a given subject (Renn, 2015). In this study, assembling members in various capacities of healthcare provided an opportunity for in-depth and constructive feedback. The focus of the expert panel review was to test researcher-developed questions and the approach to interviewing. The panel members for this study occurred in different geographic areas of the United States. To accommodate the geographic separation of the panel members, each panel member received the study parameters, and I then contacted them by phone for discussion. I collected and considered all discussion points from the panel review.

Five individuals from various healthcare and oncology roles served on the expert panel. The panel members consisted of two men and three women. The professional roles of the panel members, at the time of the study review, included (a) executive in healthcare administration, (b) oncology surgeon, (c) research nurse, and (d) oncology program directors. The panel members were selected for their experience in current and past roles. The healthcare executive panel member also had IRB experience. All panel members had broad experience with research and patient relationships. One of the oncology service line directors also had substantial experience in behavioral health and outreach programs. The second oncology service line director had clinical nursing experience and experience with patient assistance programs. Finally, the research nurse panel member had a long history in writing and conducting research related to life threating diagnoses.

Procedures for Participation and Data Collection

In this section, I provide the procedures for participation and data collection detail. Data were collected through in-person in-depth interviews. I collected all data as the primary researcher. Data collection occurred in three segments, described in the next paragraph.

The first step of data collection included the audio-recorded interview. I used the research protocol during the interview to stay track with the interview questions. I conducted audio recordings of all participant interviews, and all audio recordings met the same levels of confidentiality as other forms of data. I also made notes during the interviews to ask clarifying questions. The notes were shredded immediately following the interview because the responses were within the audio recording.

Next, I offered each participant a journal at the end of the interview. A sticker was placed in the inside of the journal for participant reference. The language on the sticker read, "Please journal any and all experiences related to your treatment decision-making. There are no directions or rules given for journaling. Include anything you wish to share." Four participants accepted the journals, but no participants recorded notes in the journals.

Third, I attempted a follow-up telephone call 45 to 60 days after the in-person interview. The purpose of the telephone call was threefold. First, I used the telephone call to confirm any outstanding questions that came up during the transcription process of the initial interview. Second, I used it to request participant feedback of any additional decision-making experiences that had not been covered during the interview. Third, I used it to let the participant know that they were exiting the study.

I completed a web based review of cancer center advertisement occurring in California. I included website advertisements for cancer services within California in my review. I removed the previously planned public or community based newspapers, magazines, or other publications. I evaluated the information gathered in combination with literature specific to influence from advertising.

Data Management and Analysis Plan

I was the primary tool for data management and analysis. I conducted the initial thematic analysis using hand coding. In addition, I prepared in-person interviews, journal notes, and follow-up call notes in transcription form. I only used software tools to aid in creating word mapping and clusters for analysis and identification of themes in the data. A naming structure was created using hand coding and excel tables. I developed themes and re-evaluated these as the naming structure emerged. Computer-assisted quality data analysis software (CAQDAS) was considered but not used.

<p align="center">**Methods to Ensure Data Trustworthiness**</p>

I completed ensuring data trustworthiness through several methods. In this section, I provide credibility, transferability, dependability, confirmability, and ethical procedures. Each category of data trustworthiness added value to this research, including the combination of methods that provided trustworthy data.

Credibility

Strategies for establishing *credibility* included triangulation, member checking, prolonged contact, and saturation. The potential influence to credibility of participant responses, as based on the types of interactions, locations, and other fieldwork specifics,

were recognized, as based on researchers' suggestions (Creswell, 2013; Patton, 2015). I held in-person interviews in neutral locations at the preference of the participant.

Patton (2015) referred to triangulation as a "test for consistency" (p. 20). According to Maxwell (2013), researchers cannot assume triangulation ensures increased validity. For example, if three methods are used to triangulate, but each of the methods are at high risk for bias, triangulation may not be successful (Maxwell, 2013). One must evaluate the credibility of each method needs prior to establishing a strategy for triangulation. According to Patton (2015), triangulation can be applied to data, investigator, theory, and methodology.

For this study, I focused on "data triangulation" (Patton, 2015, p. 20). The triangulation methods included participant interviews, follow-up calls, and literature. I developed the in-person interviews to elicit "episodic-memory" (Patton, 2015, p. 20). Using episodic-memory indicated a better data opportunity for gathering rich participant responses.

I modified the strategy of member checking from the earlier plan, as detailed in Chapter 4. I prepared the audio recording of interviews in transcription form for data analysis. I offered journals to participants. Modifications to the plan for journal notes are also provided in Chapter 4.

This study included prolonged contact with participants. Three planned contact points with the participants were used, interview, follow-up call, and data analysis. This prolonged contact with the data allowed for greater opportunities to validate the data and

ensure accuracy. Prolonged contact strengthens the trustworthiness of the data and reduces self-report bias (Maxwell, 2013).

I defined saturation earlier in this document. The strategy for sampling, advertising, and recruitment in this study was strong. I planned many methods for identifying study participants and believed that meeting saturation would not represent a problem. If recruitment occurred slowly, I planned to use additional connections and social media postings in the approved IRB materials.

Transferability

According to Patton (2015), transferability refers to extending the findings to other situations. Generalizability is another term used for transferability. In this study, I met transferability by focusing on the relationship between emotion and cognition in decision-making. Other factors existed that influenced decision-making for patients in the study populations, but these were not the focus of this research.

Dependability

Dependability is important to ensure that other researchers can recreate and build on a study using the path the initial researcher has prepared (Thomas & Magilvy, 2011). Thomas and Magilvy (2011) referred to the development of an audit trails for dependability. I prepared a study so other researchers could easily audit for the study's purpose, participant selection process, data collection, length of study, and detailed analysis.

Confirmability

Confirmability focuses on the entire study, with special attention on the findings of the study. Thomas and Magilvy (2011) reminded researchers to consider if other researchers would come to the same conclusion after reading their research. Examples of confirmability included audit trails of the data analysis process. I created and saved classification structures and all processes or materials used in my data analysis steps, as suggested by researchers (Creswell, 2013; Thomas & Magilvy, 2011).

I also completed research by considering reflexivity. According to Patton (2015), this term revolves around "self-awareness" (p. 20). Researchers must always be aware that when left unchecked, they could allow personal biases to enter the work. Working with the expert panel of advisors, I reflected on many of the steps taken during the dissertation process. Reflexivity is easily applicable to every section about trustworthiness, and when used properly, it exhibits a commitment to academic and scholarly rigor.

For this study, I used the following: (a) database of all raw data, including interview transcripts, journal notes, and follow-up call notes; (b) all notes developed during the thematic analysis, including coding approach, word trees, tables, and other items developed and used during data analysis; and (c) a comprehensive list of all peripheral materials, cited or not, that was used during data analysis.

Ethical Procedures

I considered ethical procedures in all research paramount. The IRB approved and granted the study approval, with the number of 11-28-16-0508681. All recruitment

materials were also IRB approved. All methods of data collection, detailed in this document, were approved by the IRB, and these were followed. Rigorous steps were taken to follow all data confidentiality methods detailed in this chapter.

I did not conduct the study within my work environment to mitigate potential ethical issues due to work place influence. There was also no sponsorship of the study, removing potential bias in the findings. I held no position of power, and there were no incentives offered to participants.

Summary

The details of all aspects of the research methods for this qualitative case study were provided in this chapter. Support for the selected approach and details of the sampling and recruitment strategies were defined. I also provided the steps taken for adhering to the stringent goals for scientific rigor and dependability. I concluded the chapter by providing the detailed plans to ensure data trustworthiness. In the next section, I provide data findings and analysis.

Chapter 4: Results

The objective for this study was to collect treatment decision-making stories directly from patients who were recently diagnosed with cancer. The stories were coded, themed, and interpreted to develop an understanding of decision-making using FTT. The research questions were as follows:

Research Question 1: What are the information based (verbatim) factors influencing cancer treatment decision-making for patients diagnosed with cancer?

Research Question 2: What are the emotional based (gist) factors influencing cancer treatment decision-making for patients diagnosed with cancer?

Research Question 3: Are there factors outside of verbatim or gist examples that are reported as influential in the cancer treatment decision-making process in the study population?

I developed the research questions using literature review findings and FTT, with a focus on verbatim and gist recall. Interview questions were developed in accordance with the research questions above. I developed 16 interview questions and mapped these to the associated research question (see Appendix B).

Expert Panel Review

I assembled an expert panel for study review. The emphasis of the expert panel review included an evaluation of multiple study design components. The expert panel provided insights and recommendations on the researcher-developed questions, approach for interviewing, and process for data collection. The expert panel members resided in different geographic areas of the United States. To facilitate the communication process

with members, I prepared a PowerPoint document that included study components for review by expert panel member. I emailed the document to each panel member and obtained feedback from the panel members using phone calls, in-person reviews, and emails. Panel members suggested changes to the interview question order and noted their concerns with participant compliance with the earlier plan for member checking and journaling activities.

Based on the expert panel review, I modified the existing study parameters, as detailed in the following paragraphs. I compiled all recommendations and reviewed these with the committee chair before I made changes. I modified the order of interview questions. Questions that seemed similar were spread out within the interview protocol (Appendix B). The final version of the interview protocol reflected the weaving of questions that facilitated the natural story telling process without inadvertently influencing participant responses.

I accepted the recommendation by panel members to modify the member checking process in two ways. First, I re-asked interview questions during the interview if a lack of clarity existed with the response. This process resulted in the process of asking clarifying questions or reading responses back to the participant to ensure accuracy and credibility of the data. In addition, if a portion of the transcribed interview was unclear, I planned to discuss the question with the participant during the follow-up call.

The expert panel also suggested few, if any, participants would agree to journaling. I decided to offer journals to each participant to be used if they wanted to

journal. Four journals were distributed, and no journals were returned. This aspect showed the panel suggestion was accurate.

The panel members also expressed concern that recruiting would be difficult if attempted too close to the date of diagnoses. The panel recommended defining eligibility from the date of diagnosis through the first course of treatment. Recruitment did prove challenging when patients were newly diagnosed. Recruiting became easier a few weeks out from the date of diagnosis.

The final adjustment to the study came from committee review. The original study included this statement: "It is pertinent to the proposed research to include inquiry into the amount of time between the diagnosis and commencing treatment." I later determined that this piece of information would be difficult to use. I removed any focus on questions related to the number of days that transpired between diagnosis and the start of treatment from the interview design.

Research Setting

I collected data using interviews that consisted of open-ended questions. I developed subquestions for some of the interview questions to help facilitate the interview process or provide clarification if participants did not understand the questions. The primary setting for the completion of interviews included neutral locations selected by participants. Three participants were in the process of receiving chemotherapy and under physician direction to follow strict infection control measures. For this reason, I accommodated the request for these participants to complete phone interviews. In

addition, due to geography and transportation issues, I conducted a phone interview for a fourth participant.

I completed follow-up telephone calls, as well. I asked participants if they had any additional experiences they would like to share that were not covered during the interview. The notes, obtained from follow-up calls, were added to the transcript data and part of the analysis process. I released participants from the study at the end of the follow-up call and reminded them of the confidentiality practices for this study.

For the secondary data analysis, I completed a review of California web-based cancer advertisements. I restricted the review of cancer advertising to the advertisements found during the web search. The findings from the cancer advertising are provided in this chapter, under the cancer advertising and DTCA section.

Demographics

At the time of diagnosis, all participants lived in California. To ensure confidentiality of participants, the geographic distribution presented was separated by regions. According to the California Travel & Tourism Commission website, California consists of 12 regions (http://www.visitcalifornia.com). At the time of the interview, study participants lived in California's North Coast, San Francisco Bay Area, and the Central Valley.

All inclusion criteria were met. As previously stated, no criteria existed for the type of cancer. The goal was to obtain participants who were diagnosed with different types of cancer. Participants in this study included individuals diagnosed with cancers of the breast, thyroid, prostate, head and neck, lymph nodes, and lung.

Data Collection

I obtained IRB approval November 28, 2016. I completed this study as the primary researcher, with no research assistants. Using a random number process, I separated the 481 cities within California into numeric segments of 25 cities each. I completed recruitment efforts per segment until I reached the required recruitment.

The recruitment efforts I followed included searching each city using matching steps. First, the ACS page for support groups was searched by city name. I attempted to contact each support group listed in the ACS city search. Contact with support group leaders was attempted through telephone calls, emails, or U.S. postal mail service. Next, I searched cities on the web for cancer support services within that area. I identified web-based support groups by typing "cancer support," followed by the city being searched. I then attempted to contact any support resources not already identified using the ACS website. I included nearly 100 California cities in recruitment efforts, at the time recruitment was closed.

I enrolled, interviewed, and discharged a total of 10 participants for this case study and found recruitment difficult. Many individuals expressed an initial interest in participating and later declined. Recruitment of participants included individuals with a first diagnosis of cancer. I attempted to recruit and interview participants as close to the date of diagnosis as possible. Staying as close to the original date of diagnosis was preferable to avoid confirmation bias. However, patients, early in their journey and in the throes of adjusting to a diagnosis of cancer, were difficult to recruit.

I created data collection instruments approved by the IRB. The approved data collection instruments included two versions of the invitation to participate, an informed consent, screening questions, and an interview protocol. The invitation to participate and consent were provided for each contact made during the recruitment process. I did not send out the screening questions, but I used these to screen for eligibility when contacting a potential participant. I used the interview protocol during the interview process. A study protocol was developed form the IRB application at the requests of oncology practices considering placement of invitation flyers in common areas approximately 2 months after recruitment was opened. The IRB confirmed that approval was not necessary for this information to be shared.

The three categories of recruitment included (a) community engagement, (b) social media, and (c) daily personal interactions. The recruitment activities used for each category are detailed in the following section. Deviations to the original recruitment plan are also provided in this chapter.

The recruitment efforts within the category of community engagement included (a) in-person support groups, (b) web based support groups, and (c) church groups. It was immediately apparent from the first segment of cities that using church groups to recruit would yield limited, if any, participants. Church group recruitment was also extremely labor intensive. The use of church groups was stopped after the first segment of 25 cities.

The ACS website represented the primary source I used to identify locations for in-person support groups. I reviewed the list of support groups on the ACS web and found that the ACS most often supported these support groups. There were also instances

where the support groups listed on the ACS site were sponsored by the facility where the support group was held. I contacted support group sponsors listed on the page. Many contacts with support group sponsors produced an agreement to distribute invitations to participants during support group meetings or through other support group contacts.

Many examples of support groups existed that were led by the facility or organization and not the ACS. In those instances, the responses I received usually included the need to have the facility's IRB review the invitation to participate before distribution could occur. I often had to place several emails or calls to confirm facility IRB approval to distribute flyers during support group meetings. For example, IRB-approved study documents were submitted to the ACS, Cancer Survivors Network (CSN) on January 5, 2017. The CSN website provided another opportunity for recruitment through the ACS resources (https://csn.cancer.org/). I received approval to post on the ACS-CSN website, and I posted the invitation to participate on January 12, 2017.

As noted above, I only included local churches in the first random order segment of California cities. My initial attempt of using Google to search *churches supporting cancer patients in California* returned over 83 million results. I then used the website, http://www.ChurchFinder.com, to locate churches within each city. In most cities, I located more than 20 English speaking churches. In some larger cities, I identified 100 or more English speaking churches. For each church, I requested to speak with the individual in charge of support groups. It was a nearly unanimous response from church staff that the church secretary would review and post the flyer on the church bulletin

board. Only one church approved my request to post the invitation flyer in the church newsletter. No participants were located through church recruitment efforts.

For social media recruitment, I used Facebook, Twitter, and LinkedIn. I also used personal support group webpages linked to Facebook pages. As noted above, I searched web-based support groups by city, and located many social media links. This recruitment strategy also required multiple reposting's of the study advertisement, on numerous social media platforms, each week. The materials, posted on the social media sites, included the invitation to participate, informed consent, and study protocol. I developed a study-specific Facebook page, which I shared through Twitter and LinkedIn. I sent several Tweets that advertised the study. The process of tweeting did not produce substantial interest in the study.

I requested to add the study opportunity to the Walden online research participation system. Walden accepted the request. There were no participants identified from the Walden online system. My original plan included posting on the California State University Bakersfield (CSUB) academic site. After further review, I decided the post on the CSUB website would not be useful due to the primary age group in attendance.

Daily personal interaction included spontaneous introductions to individuals in nonwork environments. Travel, volunteer outings, and introductions through family or friends represented examples of nonwork related personal interactions. The personal interaction settings provided opportunities to hand out invitations to participants. If individuals were not eligible for the study, they were asked if they would be willing to share the information with anyone they knew as eligible. In addition to the recruitment

efforts above, four community-based oncology offices agreed to provide flyers. The practices provided the invitation to participate flyers in common patient areas. Participants were identified and enrolled through this partnership.

Individuals expressing interest in participation in any avenue were screened for eligibility. The questions on the IRB screening question tool were asked of each potential participant. When I identified a potential participant as eligible, I scheduled him or her for an interview. Moreover, each participant consented to an interview that included an audio recording. I used two audio recording devices in the event one recording device failed. I did not take field notes, only notes made during the interview as a reminder to ask a clarifying question. I attempted to contact each participant for a follow-up. I called participants 45 to 60 days after the initial interview. In some instances, I made contact later than 60 days. When participants provided additional interview feedback during the follow-up call, I added the new feedback to the interview transcription.

Several weeks passed with no participants coming forward, and revisions to the flyer were requested through IRB. Feedback from several of the support groups and social media sites provided suggestions for a more appealing flyer. The IRB approved the changes to the advertisement flyer language, and the new flyer language was used (Appendix C). I reevaluated the recruitment strategy several times during regularly scheduled calls with the committee chair. Changes to the recruitment strategy were detailed above, but the changes were not sizeable changes. Incorporating a research assistant for the completion of the social media postings might have aided in recruitment.

Support group contacts referred five participants. Some of the support group attendees, who did not meet the inclusion criteria, forwarded information to support group members who might be eligible. This word-of-mouth was detailed in Chapter 3 and was key for the snowball or chain sampling strategy. Four participants became aware of the study through flyers located in oncologist offices. One participant became aware of the study through personal interactions.

Enrollment started in late November 2016. The first participant was enrolled in January 2017, with the final participant enrolled in June 2017. As I mentioned in a previous section, I found recruitment difficult. After multiple discussions with the committee chair and adequate data collection consensus was reached, and the decision was made to close recruitment with 10 participants. I transcribed and analyzed the participant interviews. Saturation was achieved through the multiple steps of data analysis detailed above. When no new codes, categories, or themes emerged, the committee decided that I reached data saturation.

I could not locate a comprehensive list of all cancer treatment service locations in California. Options to create a list of California cancer centers with data, purchased from the California Department of Health, were cost prohibitive for this study. Thus, I changed the original plan to collect cancer center materials in the form of pamphlets and public or community-based newspapers or magazines. I decided to conduct a web search using Google. The term *Cancer Treatment in California* was used for the search. I reviewed the first 10 results and ads produced by this search and created 159 links. From the 159 links, I identified 53 California cancer service locations. I did not include cancer services

outside of California in this review for advertising language; however, I personally viewed the TV advertisements while in California. Minimal research existed on the language used during the advertisement of cancer services, but research did exist, which would be useful to understanding that language. However, this aspect was not the focus of this research study. I completed a search of advertising language for each California cancer treatment location. In addition, I kept notes of personally viewed television advertisements about cancer that I viewed while in a California location. The web-based cancer advertising findings are presented in the data analysis section.

Data Analysis

I conducted the analysis of participant responses using hand coding, categories, and theming activities. I first coded participant responses to interview questions in three phases. Interview Questions 1, 3, 4, 7, 9, 10, 11, 12, 14, 15, and 16 made up Phase I. I coded and themed Interview Questions 2, 5, 6, and 8 in Phase II. Phase III included Interview Question 13, and I evaluated and coded the web-based cancer center's advertising as a final phase.

I began interviews by asking participants to recount the day they received their diagnosis. Most participants began responses with a recollection of precise dates and locations where they were when they received their diagnoses. Many of the participants stated they recalled exact locations, times, or even the weekday. Examples of precision in recall included P1 stating, "I remember exactly, the phone was on my desk and it was exactly 3:35." P5 added, "It was late afternoon." Six participants received their results over the phone. Of the six participants who received phone confirmations, four

participants were called by their physicians. None of the participants expressed

displeasure with the ways in which they received their results. Multiple participants

expressed that they did not like waiting as long as they did for results.

All codes, developed from the hand coding exercises, were evaluated, and the

overarching themed categories were established. The primary categories included (a)

family/social dynamics, (b) psychological/emotional distress, and (c) decision-making.

Cancer advertising follows the data analysis section and provides the secondary data

review detailed in the study plan. The following sections and paragraphs will provide the

research findings and supporting data. The final step of analysis includes evaluating the

themed categories and understanding the influence of the categories on the original

research questions.

Family/Social Dynamics

Every participant described a variation of family/social dynamics. Field

observations occurred during interviews, and participant terminology were used to

understand the influence of support or additional stress from experiences within the

family/social dynamics. Participants spoke of positive situations that were the foundation

that helped them get through their journeys. Participants also described situations that

caused additional stress, pressure, or unease that included the loss of privacy, family

tensions, and unsolicited input. Some patients detailed mixed situations with the

existence of both positive and negative family/social dynamics.

Supportive. Supportive examples included unwavering family and social support.

P4 stated, "My daughter and my grandson are like my guardian angels. There have been

no secrets… I have such a wonderful support system. I have my faith, my church family, a wonderful job." P9 added, "She's been there every step of the way with me. Every doctor's appointment… I would have been totally lost if it hadn't been for my wife."

Participants also described support as coming from their places of employment and friends. P8 stated, "[They] have all stuck it out and they seem to do whatever they can to help us out." P2 added, "She came in, got the brush, put my hair in a bun, and ran out with the car double parked." In addition, P1 stated, "One of our friends barbequed and only invited a couple of our friends so that I could get out of the house… she also had the sanitizer at her door."

Positive family/social dynamics also came in the form of support groups. P3 stated, "Having guys that I could talk to… We became pretty good friends. It was nice to have somebody to talk to." P10 added, "[They were] very supportive and so understanding and they really took me under their wing."

Additional stress, pressure, or unease. The second category of family/social dynamics included codes consistent with additional stress. The theme of additional stress included categories of loss of privacy, family tensions, and unsolicited input. This category evolved, as participants detailed the behaviors of others.

Descriptions of disregard for personal boundaries included the loss of privacy or modesty. P5 said, "Everyone gets to see you" P1 added,

> I told them I did not want them to cry. I did not want them to break down. They
> needed to go in there and listen… Also, I needed them to be the ears for me. In
> case I couldn't pay attention… she said I was being ridiculous.

P2 stated, "This is how I needed to deal with this. I did not want [family member] involved." Participants insisted that support was very helpful, but privacy, modesty, and a sense of individual control should be preserved.

Participants described situations of family tension prior to the diagnosis. P1 said, "[They] came around more out of guilt." P6 stated, "There has been a little bit of tension between the family. Although my doctor did request that I reach out to those family members… I chose not to." P2 stated, "[Name] usually made it about them." P3 also stated, "There is a hatred between her and I that goes real deep… I just did not want the kids to have to live through that drama."

Unsolicited input from the family/social circle were described by participants. P2 stated, "He called me and told me I do not have cancer…you are not going to have chemo, chemo will kill you… I was so pissed off. Don't tell me what I am going to do." P10 described the dramatic response from a sibling: "Oh my gosh, you might die." Participants also described alternative treatment methods as examples of unsolicited pressure. P3 stated, "[Name] was really trying to push [the] product… and saying well you gotta take more." In some instances, participants described telling individuals to stop. P1 said, "I don't need you to question everything… I have to believe that the decisions I'm making are right."

Psychological/Emotional Distress

Some of the examples included in the previous section of added stress could transition in this category of psychological/emotional distress. If or when that transition occurs would be different for everyone. This category of psychological/emotional distress

developed during the coding process when statements from participants described experiences with greater emphasis than the earlier category of family/social dynamics. This section includes the categories of (a) shock, confusion, or fear; (b) emotional distress/fatigue; and (c) other feelings of guilt and participant identified psychological needs.

Shock, confusion, or fear. Participants described shock, confusion, or fear (current or long-term). P1 said, "I just remember breaking down." P8 added, "I am pretty much still in denial for the whole thing." In addition, P10 included, "It is just so much to take in. It is really best absorbed in pieces." Moreover, P3 stated, "It struck me pretty hard." Some participants detailed a sense of confusion or, as stated by P2, an "inability to focus or complete even the simplest task without instruction." P5 said, "It isn't chemo brain, it is cancer brain." P10 included, "It's very hard to be the cancer patient and be the advocate because you are so sick and your overwhelmed." In addition, P6 said, "It has been an ongoing mourning process."

Fear was described in examples of short or long term. Fear statements included immediate reaction, survival, and long-term impact of this journey. P10 said, "Cancer is no longer a death sentence. But, it was very scary." P7 included, "In my mind, it's like we gotta do something starting tomorrow." P1 included, "[I had to] live for the babies." P2 also included, "That was my fear, that my kids were going to have to be without me." P7 stated, "Just to know that you need to be here for your family is what makes you want to fight." In addition, P10 stated, "It was a really big deal to go through it. Because to have little kids [made it hard]."

Participants described examples of long-term fear. P5 said the following:

I was really afraid of the chaos and the stress it was going to cause, cuz it does…
Even after you are done with treatment it's there. It's like it will be there forever. I
am not afraid of it killing me, I am afraid of the stress.

P1 stated, "The doctor is not going to see me every day … who is going to watch
me, to make sure that it doesn't come back? … I wanted to be monitored still more
closely. Also, they don't do that." In addition, P3 included, "I was more fearful for my
kids, their thoughts. What I could do to keep things on a normal basis around the house."

Emotional distress/fatigue. The category of emotional distress/fatigue included
descriptions more profound compared to the previous section of shock, confusion, or
fear. This section developed from participant responses about the emotional toll of telling
others, especially children, about their diagnoses. In addition, the psychological and
emotional toll of treatment side effects, such as intractable pain, were present. Finally,
other feelings of guilt and participant-identified psychological needs were described.

Telling others about the diagnosis of cancer was described as causing additional
pressure or emotional fatigue in some participants. P4 stated, "When I told [name][they]
immediately broke down…. [they] got very emotional. I was consoling [them]." P3 said,
"When I broke the news to them my daughter took it pretty hard my son was okay,
what's the next step?" P5 included, "My [relative] was the hardest one to tell. Because
my dad died from colon cancer. I was upset to tell him … I was bawling then and I said I
need to tell [relative]." In addition, P2 said, "That is hard because when you have to tell
people repeatedly when you see them it gets draining."

Participants described even greater emotional distress when they had to tell children. P2 said, "In my head, I had this fabulous plan; it was this after school special." P4 included,

> There is going to come a point when we need to talk to the children, when we need to share with the children. But, I said we need to pray about this before we do it because. I don't want to scare them.

> P5 stated, "I waited a few days to tell them. But, I told them, and I was really strong and only had a little tear. But they didn't have a lot of questions." Participants also acknowledged not being completely truthful with children about the extent of disease. P2 said, "I was worried… the older one was really freaked out. [Child] still doesn't know that it was the same cancer."

Some participants described side effects as considerably more intense compared to expectations. The experiences of extreme pain and expressions of psychological distress were important to define. P10 said, "For 3 straight days, I was… practically wanting to die." P1 stated, "What if the next one kills me? … my body hurts so bad. Also, it's gonna get worse next time. So, I don't want to do it. I'll take my chances." P7 included,

> They tell you about losing your hair and stuff like that but they really don't tell you about the psychological part of going through. At one point, I wanted to quit. They don't tell you the psychological part of what chemotherapy does to you.

Other feelings of guilt and participant identified psychological need. Feelings of guilt or other strong emotions were described by some participants. P2 said, "I feel

horrible about being alive sometimes because it is not fair. Why is she dead and I am alive?" Some emotions were associated with participation in support groups. P4 stated, "I feel kind of bad… I have not had that journey to go through. I have not had those extreme side effects and the sickness and the lack of support." P5 also stated, "It is overwhelming because every day someone new is diagnosed and comes on board."

Participants described identifying the building-up of stress and need for psychological support. P3 said, "I feel, you need some kind of psychiatric evaluation… All the sudden, the reality of everything falls on top of me and I start crying." P2 stated, "Because of the stress, I cannot work. I would burst in to tears at work. I couldn't focus. I could not do my day-to-day job." P7 included, "I don't think I was ever scared. It was just time for me to get off this roller coaster because it is just the emotions that get you more so than the treatment." One participant described benefiting from the experience with cancer in others to help them understand the psychological impacts of cancer. P4 detailed the following:

> I learned a lot because of a wonderful social worker at the cancer center. While [family] was in chemo, I was in therapy with the social worker. I learned a lot about cancer. The things I learned from the social worker and the things I learned about myself. One of the things that have always stuck with me is when the therapist told me is [the patient] had the tumor, but the entire family has the cancer. In addition, it is so true. It affects every member, everyone that is close to me this is affected. I learned a lot about that process. So, I was kind of ready for it. Like, I just got to take an easy path.

Decision-Making

This section details the final theme developed from the interview data analysis: decision-making. Participants described factors that influenced decision-making that did not fit into the categories of family/social dynamics or psychological/emotional distress, but these were significant for their journeys. Categories within this theme included (a) influenced by experience of cancer in others, (b) avoidance, and (c) selection of treatment location.

The decision-making roles, described by participants, varied and included examples of both SDM and patient directed care. Eight participants described being presented with treatment options and being allowed to select their treatment course. P2 described,

> We discussed a lot that day. I think my appointment was 2 and a half hours long. Then another hour with the [navigator]. [The doctor] did go over the options. [The doctor] said basically you have three options that you need to think about.

In some instances, participants expressed feelings that included a lack of agreement from the oncology team, but these remained consistent with SDM. P2 stated,

> I made the decision that night. Also, I haven't changed it… I could tell that [the medical team] didn't agree. They [asked], "Are you sure you want [surgery]?" I said, "Yep, sorry." But, they never made me feel like I was making a wrong decision.

P4 said, "[The provider] didn't seem happy about doing that. He thought it was kind of severe. But, I said, 'No, that is what I want.'"

One participant described switching providers based on the lack of agreement with the treatment plan. P10 said,

I felt like [provider] was overdoing it. I had done my own research and saw how awful radiation is, it just does terrible things to you… and I didn't want it, and I didn't feel like it was required. The only decision I felt I made, and I still consider it probably one of the most important, was rejecting the radiation. That was a cognizant decision I made… I found a doctor that I felt I could work with better… it was oh so much a more agreeable plan to me. It didn't feel as over the top.

One participant described leaving their community to seek medical advice and treatment. P6 said,

I learned that it's important that you don't just take your doctors word for it that you research, and you go in there prepared and asking your doctors questions. If your doctors see that you are ill informed then they can easily just point you in the wrong direction. But, if they see that you are on top of it and that you are as knowledgeable as possible in the area given the resources that you have, I feel like they do a better job.

Influenced by experience from cancer in others. In some instances, participants described ways in which the cancer journey in others influenced their personal treatment decisions. The amount of influence varied between participants. P2 said, "I am going to fester with cancer and it is going to spread to the rest of my body. I know that has something to do with [relative]." P5 added, "My father went through the colon cancer… I was really afraid of the chaos and the stress it was going to cause." P2 also added, "One

participant detailed seeking more aggressive surgery due to witnessing poor outcomes in family… [they] withered away. It was a horrible thing to witness. I wanted to do the exact opposite."

Other participants wanted to forgo a modality of treatment due to the side effects they witnessed. P10 stated, "One man had been receiving radiation to his head. The radiation is what finished him off." P3 added,

My wife went through some heavy chemotherapy… it was supposed to give her a better quality of life… which neither one of us could see. If it came back [for me], the options for surgery were off the table. Also, then I would have had to do some heavy chemotherapy.

In two participants, the experience with cancer occurred after the participants' diagnosis and during their treatment. P1 said, "Well, a couple of months in to [my treatment], [name] cancer came back. Everywhere… I freaked. I cried like for days straight." P6 stated,

I did later learn, now going through my experience, [family] had a very similar diagnosis… but [they] didn't do any follow-up treatment. [They] took [their] doctor's word for it. Also, as a result, about a year after, [they] had cancer and was supposedly in remission it came back… that, for me, played a huge role on my decision on what I should do and shouldn't do.

Avoidance. Examples of avoidance were described: "I didn't want to know anything about anyone else that died" (P2). P4 stated the following:

To be honest… I really felt led to just close it. I don't need to go there… I don't

need that to be what fills my mind on a daily basis. I had faith in my doctors, and

I have faith in my god. That is what I choose to fill my life with, is that faith. So,

it is not about being ignorant. It is just that I don't want all that negativity. I don't

want all of that in my mind.

P9 stated the following:

One of the biggest coping mechanisms was the layoffs at my work. I think that

situation helped me through this. I am glad that I kind of remained as oblivious to

it as possible that I just don't think I would get it done if I (unfinished)… I

couldn't do it again; let's put it that way.

Decision-making roles, described by participants, varied from research to full

decision-making. Some participants decided to transfer decision-making roles to others.

Participants described being exhausted or confused and wanting to avoid negative

information. P4 stated, "She writes everything down, she does research, she asks

questions. I kind of listen to it … a couple of times my daughter says, no mom, that is not

what the doctor said." P10 stated, "It's very hard to be the cancer patient and be the

advocate because you are so sick and your overwhelmed." In addition, P2 stated, "I

wanted [name] to extract the information that was helpful and give it to me." P8

commented, "[Name] did a lot of research… doesn't like to share stuff that is negative or

bad, so unless it is really important, we haven't talked about it." P9 included, "You know,

I never had to because my wife, oh gosh, my wife does a ton of research… so, she

basically broke it down for me… balancing optimism with reality."

Full transfer of decision-making was described in three participants. P8 commented,

>   [I] pretty much left it in his hands" (P8). "I am just the patient. I just have to do what people tell me to do. It's a pretty easy job. I just do what my wife tells me and the doctors tell me. I go along.

P4 stated the following:

>   I put my care in the hands of my wife in the sense that she knew; she has been quite the blessing to me; she was there to understand what I was going to go through. It is not about being ignorant. It is just that I don't want all that negativity; I don't want all of that in my mind.

Selection of treatment locations. The selection of treatment locations included influence from external sources, as well as personal or family knowledge of treatment locations. The main driver of external influence in the selection of treatment location was insurance. Nine participants confirmed being referred to their treatment locations by their insurance companies.

Feedback was provided by the nine participants referred to treatment locations by insurance companies. Participants described examples of being satisfied, as well as being frustrated with providers or insurance companies. Comments, regarding being satisfied, included the following: (a) "People may talk bad about [insurance], but [they have] been great to me" (P1); (b) "[We] heard nothing but good words about [physician]" (P8); (c) "The [facility] up here is as good as you are going to get… the doctors here are highly

regarded" (P3); (d) "[Provider] was a very nice… Very soft spoken. Very calming. Gifted in what she does" (P4); and (e) "I had a really good experience there" (P5).

Statements of frustration were focused on wait times, delays in treatment, or facility size and volumes. P2 stated, "I do have to say they [provider] kept delaying my surgery. Also, a lot of back and forth." P5 commented the following:

I had to go the whole weekend waiting… plus three days for the lab work. I recommend not ever doing it on a Friday because it seem to extend. It was horrible. Also, they didn't call me… and I told her I was all upset not knowing.

P8 included, "In my opinion [facility name] has become such a cattle call." In addition, P9 commented, "My wife was very much afraid that I would be just caught up in the system and be another number." P1 stated, "I walked in there, and I said, 'Oh my God, this place is huge. So many people everywhere. So many rooms, so many whatever.'"

Dual Process (FTT)

Overall, more gist responses were provided from participants than verbatim responses. Cancer stage is the nomenclature used to define the extent of disease. The cancer stage is coding schema built on specific information about the primary tumor site, nodal status, and metastatic disease.

Some participants provided their cancer stage at various points in the interview and with varying levels of recall:

The only other question I knew to ask was the stage because I knew stage is something people ask about. I felt very blessed that I was told I was stage II. They

found three lymph nodes and they removed them, they were clear. My

understanding is that is next to nothing. (P4)

P1 stated the following:

They explained to me after surgery I would either remain [same stage], if nothing

had changed. Or if they found it in the lymph nodes it [the stage] could go up…

LN were clean I still remained [the same] stage.

P8 commented, "Because it is… Stage IV. Ninety-five percent of everything is

not very positive on the internet." In addition, P10 stated, "It came back thankfully only

Stage I." P6 provided the cancer stage early with multiple verbatim details about the

testing and results that lead to the revelation of a higher stage from Stage I to Stage III.

P6 also left their community to seek a higher level of care.

Five participants did not mention cancer stage in their interview response until

they were specifically asked toward the end of the interview. They provided verbatim

details of cancer stage, specific tests, facility names, or other responses significant to

cancer staging: "It didn't spread that much. It spread to two Lymph Nodes… one lymph

node completely was healed up, there was no more cancer in it" (P9). To retain

confidentiality of the remaining four participants, quoting their responses was

inappropriate (i.e., P3, P5, and P7). One participant included only a statement of the stage

and referred to the binder that holds the information about their diagnosis: "[They] gave

me this stupid cancer binder. I did not want the binder, it says I have cancer" (P2). This

participant also included, "In addition now I don't even know, remember what I have"

(P2).

Verbatim examples existed related to descriptions of treatment: "The surgery I had was what they call a [procedure name]. They go in and take out your lymph nodes along with the [organ]" (P3). P10 stated, "[I] went to the internet and looked up the effects of radiation on the [body site], and I saw all sorts of awful possibilities that were pretty good possibilities not just 5%." P1 commented the following:

> [Doctor] said basically you have 3 options. One is to not do nothing at all because every person has the right to decline treatment. Everybody has a right to not want to go through the chemo and the radiation and everything else… even though [doctor] doesn't recommend it. [Doctor] went over the next options… But, [doctor] has said no matter which… I chose out of those options. The percentage of my survival was exactly the same.

Participants included statements that indicated a lack of complete understanding prior to starting treatment: "But, there were some things that were just left out in that conversation. Or it was skimmed over" (P3). P10 commented, "I wish someone had given me more thorough information." Participants also described a lack of understanding specific to the area of pain control and the options available to them:

> No one told me that you need to take the pain meds before your treatment so that they are already on board… This one particular drug just made me so miserable with pain, and then I found out I could have taken something else. (P10)

P1 stated, "I never knew, they give you medicines, but the medicines have all kinds of different effects. They treat all kinds of different things with one little chemical in there or whatever."

The last interview question asked participants if they believed emotion or information provided more influence during treatment decision-making. Four participants easily said emotions. P1 stated, "Emotion. So, that I could still live." P3 commented, "I think it was more emotional. What I have been through with my wife and kids." In addition, P7 included, "But, it is the emotional, knowing that you have to keep going, the knowing that this too shall pass this is almost over." P8 stated, "Probably emotion. Also, having my wife talking so highly of [doctor] for so long."

Three participants stated both emotion and information influenced treatment decision-making: "I think it was emotionally driven but I did have some real statistics" (P2). P5 commented, "Emotions for the doctor I chose… But otherwise, the medical facts." Moreover, P10 observed, "I went with medical data and studies and proof… when I made my decision [not to have] radiation, it was somewhat emotionally driven. You don't have to decide everything the first day."

One participant exchanged the term faith for emotion and stated both faith and information played a role:

> My faith I would have to say comes first. But, I cannot leave out the medical information that I have gained also because, to me, God has given me both. He has given me my faith, and He has given me the blessing of having doctors, and nurses and medicine that is used to be able to fight it. So, I wouldn't be able to choose one over the other. It's a mesh.

The remaining two participants stated information drove their decision-making: "Knowledge. I feel that sometimes if we let our emotions take over we don't always make the best decision" (P6), while P9 stated, "The factual parts by a long shot."

Cancer Advertising and DTCA

The first portion of cancer advertising includes participant interview responses followed by the secondary data review. I asked participants what they could remember about cancer advertising prior to their diagnoses. Recall of cancer advertising was not significant for the period prior to their diagnosis: "Before I had cancer, I didn't pay attention" (P1). P5 stated, "Not before," while P1 continued, "After the diagnosis of cancer, participant responses included high levels of exposure to advertising." P5 observed, "Now, it is like every other commercial on TV has something to do with cancer awareness." P5 commented, "Now, I see it all the time. It's like was this around before, and I never noticed it or what's happening?"

Not all responses to cancer center advertising generated positive memories. For example, P1 remembered, "A cancer lawyer suing because the hair didn't come back because of the chemo." P2 stated, "It's always the bald people." P3 commented, "There is a lot of that stuff going around… it kind of irks me." P4 mentioned, "Class action lawsuits, it's cancer, cancer, cancer!" In addition, P7 stated the following:

> You know the thing that gets me about the TV… some of the things to prevent or help with a cancer… when you listen to the side affects you are like I don't want that. I understand they have to give information but sometimes all that information can wait until the person asks about it.

P9 commented, "They always seem very positive, you know, that almost every cancer can be cured. But, unfortunately, I just don't think that may be the case." P10 remembered the following:

What I recall the most are… the pills, the detox, the organic juicing. It's all over the internet. It's on the TV. Also, I had a number of questions because of course they give their convincing arguments, so I remember that more than I remember what you might call legitimate pharmaceuticals.

DTCA. The secondary data review focused on messaging in cancer advertising. Previous researchers have included advertising methods and exposure of patients to marketing in their literature (Abel et al., 2009; Tan, 2015; Vater et al., 2014). I concentrated on web-based advertising messaging to complete this secondary data review. I reviewed the verbiage of 53 California cancer treatment locations. The facilities included in the secondary review are provided in Appendix D. I located and reviewed mission statements for 25 facilities, and advertising tag lines for 18 facilities. No advertising was identified for 10 of the 53 facilities.

Mission statements focused on phrases that promoted partnerships, communication, treatment options, care statements, and the physical environment of the facility. The messaging categories that developed during the secondary data analysis included (a) treatment/technology and quality, (b) fighting terms and hopeful messaging, and the (c) team approach. I provide detailed secondary data findings in the subsequent paragraphs.

The first category, established during the secondary data review, included treatment, technology, and quality. I observed descriptive marketing terms to promote the treatment options, skill, or quality of care offered at the advertising facility. The terms included advanced, evidenced-based, high-quality, innovative, latest, leading-edge, new and better, personalized, powerful, progressive, premier, sophisticated, state-of-the-art, unparalleled, and world class/renowned. There were several combinations of terms facilities used to establish their expertise that were identified in this category, such as "Our community of cancer experts provide highly-skilled care and compassionate support."

The next category I observed included fighting terms and hopeful messaging, which included statements to arouse images of successful outcomes. I identified multiple emotionally charged messages and phrases of hope. For example, one facility included the phrase: "Cancer doesn't have to stop you." Additional fighting terms identified included battle, beat, cure, fight, hope, or mobilize, with phrases, such as "We all can beat cancer," or "Once you choose hope anything is possible."

The third category observed was team approach. Phrases associated with team work included messaging that reflected communicating, collaborating, and helping in the fight, such as "You are not alone," or "We're here to help." Additional examples of messaging included being here, working together, or helping "you and your family through the entire cancer journey." Other messaging observed in this category included statements of help, not being alone, support, or being together. Phrases included staff that

was "dedicated to the principle of complete care for people with cancer and their loved ones."

The final category, I observed during the secondary data review, was the physical environment of care. Facilities used messaging to advertise the physical environment, such as an "environment that promotes healing," which included phrases that suggested the facility could promote calm and decrease stress. Additional examples included the promotion of healing or healing environments. Facilities were also described as being designed to simplify or ease the process, such as "We have carefully designed our cancer centers to simplify and ease the process."

Evidence of Trustworthiness

Credibility

I used participant in-person interviews, follow-up calls, and literature review as triangulation methods. I held in-person interviews in neutral locations at the preference of participants. In-person interviews facilitated episodic-memory, along with prolonged contact and the follow-up call. Prolonged contact with the data through multiple reviews led to meeting data saturation.

As recommended by the expert panel, I completed member checking using interview strategy. I re-asked questions requiring more clarity during the interview or during the follow-up call. I transcribed the interviews prior to the follow-up call, and any questions identified during transcription were asked at the time of the follow-up call.

In addition, reflexivity is vital for research credibility. Researchers should understand and recognize personal biases, as well as the potential influence this could

have on scientific rigor (Probst, 2015). Credibility for the study findings included repeated committee work and personal sessions with the committee chair. The "continuous process of self-reflection" fostered during committee work and personal researcher preparation also increased credibility (Darawsheh, 2014).

Transferability

The focus of transferability or generalization involved predicting patterns, as suggested by a researcher (Saldaña, 2016). Prolonged contact with interview audio recordings, transcripts, and secondary data was completed. The extensive time spent with participants and reviewing data facilitated transferability. After multiple sessions of hand coding, categorizations, and thematic analysis, I achieved generalizability.

Dependability

I closely followed the research plan for this study to increase the dependability of study results. I developed audit trails using tables and other documents created during the collection, review, analysis of interviews, follow-up calls, and secondary data review. Researchers could then easily audit the study purpose, participant selection process, data collection, length of study, detailed analysis, and decision-making processes.

Confirmability

I captured all interview transcripts and follow-up call in one document for each participant. All notes, developed during the hand coding and thematic analysis, including coding approach, tables, and other notes, were retained. The literature review indicated variables that I used for reference only during the initial review of study findings. I developed the codes, categories, and overall themes organically from the data. I

highlighted codes clearly associated with literature review identified variables for re-review.

I completed the process of analyzing participant interviews using several phases of hand coding. I reviewed audio interviews and transcripts multiple times. With each review of audio or transcript material, the codes were reviewed, new codes added, or previous codes modified. I then moved codes into categories and used these for theming activities. The phases of the coding process were detailed in the data analysis section, which included three phases. All portions on the coding, categories, and themes were captured on sheets that could be used for study auditing to increase the confirmability of study findings.

Summary

The conflict between emotion and cognition during decision-making for people diagnosed with cancer varied for every individual. Using the theoretical framework of FTT, this study was designed to fill a gap in the current literature. Scholarly research allowed greater understanding of the decision-making needs and promoted scientific rigor and generalizable findings.

In this chapter, I consolidated and analyzed the transcribed interviews. Using hand coding, I developed categories and completed the thematic process. Three overarching categories emerged that included family/social dynamics, psychological needs, and decision-making. In addition, I analyzed interviews for existence of FTT (verbatim and gist recall). I completed a secondary data review that focused on evaluating the language used in web domains of cancer centers in California.

The next chapter will include the discussion, conclusions, and recommendations from this study. Related peer reviewed literature findings will be introduced, along with the study findings in Chapter 5. The identified unique patient variables will be presented and the influence on decision-making detailed.

Chapter 5: Discussion, Conclusions, and Recommendations

The continuum of care, from diagnosis to treatment decision-making, is dynamic and evolving. The increasing complexity of cancer treatment decision-making is fueled by continued breakthroughs in research, changes in reimbursement, sicker patients, and an aging population. The focus for this study was to further scholarly research into the understanding of participant identified factors that influenced the treatment decision-making process.

The study was designed using FTT, a dual process for decision-making. FTT focuses on the conflict between cognition and emotion. With FTT, the focus results in verbatim and gist memory recall. There is a need for a greater understanding of how individuals organize, synthesize, and recall information for cancer treatment decision-making, as identified in the literature by Reyna et al. (2015). This case study included interview findings from 10 participants with a first diagnosis of cancer. Using open-ended questions, participants told stories of their cancer decision-making journey.

When asked about their journeys, participants did not automatically include detailed specifics of their diagnosis. Rather, most participant responses included details of the components of their lives that cancer disrupted. Most of the participants' feedback focused on the areas of family/social dynamics, psychological needs, and diagnoses and treatment decision-making factors. During this profound time of cognizant disruption, were expected to make sound and well understood decisions, with possible lifelong implications. Participants wanted to, themselves or through loved ones, understand the extent of their diagnoses and treatment options.

Interpretation of Findings

Family/Social Dynamics

Every participant reported family/social dynamics using a variety of illustrations. The range of experiences varied from supportive to causing added stress, pressure, or unease. Interpretations of participant responses included loss of privacy, family tension, and unsolicited input, as provided in this section. This theme was supported through literature review findings by multiple researchers (Bodie et al., 2011; Epstein & Gramling, 2013; Feng & Magen, 2015; Imber-Black, 2014).

Supportive. Within the theme of family/social dynamics, I observed participant responses that indicated gratitude for various offerings of emotional, spiritual, and other types of support. P4 shared, "They have stood by me at every appointment and everything that is connected with this disease." P2 added, "I have a great group of girls to carry me." In addition, I located literature review that supported the interview findings of individuals diagnosed with cancer benefiting from the support of their individual circles and other communities, including places of work (Kroenke et al., 2013; Trudeau-Hern & Daneshpour, 2012). Moreover, findings in the literature showed individuals needing and even relying on the support of others (Lillie et al., 2014; Shin et al., 2013; Tallman, 2013). Other researchers suggested the quality of the support messaging, as well as the size of the support system is important (Lutgendorf & Anderson, 2015).

Additional stress, pressure, or unease. Participant responses were interpreted for the category of additional stress, pressure, or unease. Illustrations by participants

included descriptions of the loss of privacy, preexisting family tensions, and unsolicited input. This category was primarily the description of the behavior of others.

Participants described the loss of privacy or levels of control of personal boundaries. P5 stated, "Your dignity goes out the window." Joseph-Williams et al.'s (2014) research showed support for complaints of lack of privacy in the health care setting. For some participants, too much attention or other boundary infractions were not what they wanted or were comfortable with. P3 expressed, "All of the sudden everybody wants to take care of you. Also, I am just the opposite." Participants were sensitive to the feeling of others and did not turn people away. However, the lack of boundaries caused the participants additional stress. I also identified some literature about the overstepping of caregiver boundaries, not the boundaries of patients (see Trudeau-Hern & Daneshpour, 2012).

Tenuous or strained family relationships prior to the diagnosis of cancer fostered additional stress for some participants. P1 stated, "My [family] showed up. Also, I was like, "What the heck are they doing here?" I am not close to my family. Never been really close to my [family]… The day I was diagnosed, they showed up." This preexisting stress made navigating family conversations more difficult for participants. Imber-Black (2014) highlighted the challenges families faced when they were not equipped to have discussions related to chronic life-threatening illnesses. Families not equipped to have these discussions could do more harm to participants and to relationships (Feng & Magen, 2015; Imber-Black, 2014; Lutgendorf & Andersen, 2015). Imber-Black (2014) included illustrations of the presence and influence of unaddressed issues within family

or social relationships. Imber-Black's research also showed examples of questions to aide in family discussions.

Descriptions of increased stress when unsolicited input was encountered were provided by participants. P1 shared, "This relative kept comparing my treatment to [theirs]. …[they] would say why are they doing that? My doctor didn't do that. Or why didn't they do this because my doctor did? You need to get a new doctor." Expressions of self-doubt were detailed when participants faced continued unsolicited input. P1 reflected, "I am second guessing my decisions on my life… [they] put doubts in my head." Feng and Magen (2015) conducted research on the presence of unsolicited advice and relational closeness. Feng and Magen (2015) suggested that unsolicited advice, when not given in a "skillful" way can be harmful (p. 13).

Psychological/Emotional Distress

According to the NCI (2012), psychological stress can "reduce the quality of life of cancer patients" (para. 2). In this section, I provide detailed interpretations of the themes that developed based on the psychological or emotional distress reported by the participants. I located terms related to emotional or psychological distress in many cancer related literature reviews (Clarke et al., 2015; Leonarczyk & Mawn, 2015; NCI, 2012; Tevaarwerk et al., 2016; Siegel et al., 2012; Tallman, 2013). The categories included (a) shock, confusion, or fear; (b) emotional distress/fatigue; and (c) other feelings of guilt and participant identified psychological needs.

Shock, confusion, or fear. Participants detailed shock, confusion, and fear at and immediately following their diagnoses. P8 expressed, "It couldn't be real." Participants

also detailed being confused or the inability to concentrate. P5 stated, "I made at least four wrong turns on the way home. I just sat in the parking lot for a while." P2 said, "I felt like it was a black tar going in to my brain." Trudeau-Hern and Daneshpour (2012) spoke of the emotional journey that included "feeling overwhelmed, isolated, exhausted, and disconnected" (p. 543). Multiple articles, found in the literature, showed support for responses to the traumatic experience of a diagnosis of cancer. Literature findings indicated the complexity and overwhelming nature of this diagnosis (Epstein & Gramling, 2013; Gibbins et al., 2014; Livaudais et al., 2013; Moore, 2014). Jacobsen and Andrykowski (2015) also reinforced the idea of the presence of heightened levels of anxiety during the period surrounding diagnoses and early decision-making processes.

Fear was also described as long-term. Participants expressed their concern for what would happen after treatment. P5 shared, "Even after you are done with treatment it's there. It's like it will be there forever." Other researchers have detailed the importance of considering and addressing psychological needs for patients after treatment. For example, Imber-Black (2104) noted potential emotional reactions to anniversaries of illness and potential changes in family rituals due to illness. Stanton et al. (2015) suggested that there had not been attention given to the potential effects and long-term costs associated with the psychological or physiological conditions that patients endured after treatment. Cognitive dysfunction can be caused by treatment, as in the case of chemotherapy or chemo-brain (Green McDonald, O'Connell, & Suls, 2015; Moore, 2014). However, the cognitive dysfunction can occur or be exacerbated by tension, lack of sleep, or other factors (Moore, 2014).

Emotional distress/fatigue. I observed increasingly pronounced descriptions from participants of emotional distress that was more prominent compared to in the previous category. My interpretation of the interview findings for this section included analyzing the emotional toll experienced by participants when they told others, especially children, about their diagnoses. I provided an analysis of the psychological influence from treatment side effects and participant identified feelings of guilt and unmet psychological needs.

Emotional distress was described when participants had to tell others of their diagnosis of cancer. Increasing levels of worry were detailed when children were involved; for example, P4 stated, "I don't want to scare them," P2 added, "I was freaking out about telling my kids," and P5 shared, "I found out it was [Stage] II, and I never told them. It's just, I did not want their world to be chaotic more than it had to be." I observed statements of emotional fatigue during the interview process and found four of the 10 participants included some reference to emotional fatigue. The frequency of reported emotional distress or emotional fatigue was also well supported in the literature (ASCO, 2015; Green McDonald et al., 2015; Jacobsen & Andrykowski, 2015; Siegel et al., 2012; Tevaarwerk et al., 2016). I also identified literature that included findings that individuals diagnosed with cancer became increasingly anxious as the end of treatment approached and less interaction with their oncologist was expected (Jacobsen & Andrykowski, 2015). Leading organizations in oncology have published extensively on the need for increased attention in support for emotional distress in patients diagnosed with cancer (ASCO, 2015; Green McDonald et al., 2015).

Examples of agonizing pain due to side effects of treatment were followed by statements of participants wanting to quit treatment or more severe. P10 stated, "I am practically suicidal I am in such pain." Previous research findings showed the prevalence of individuals diagnosed with cancer, and experiencing significant pain was as high as 33% (Dy et al., 2014; Jacobsen & Andrykowski, 2015). The psychological influence of intractable pain was also supported in the literature (Cella & Stone, 2015; IOM, 2013). Glass et al. (2012) also recognized pain in research that developed questions for providers to use in deciding pain control options with patients. Extreme stress is also known to have physiological implications, even including disease progression (Lutgendorf & Anderson, 2012; NCI, 2012).

Other feelings of guilt and participant identified psychological need. I observed statements of guilt from participants. For instance, variations of survivor guilt were described. P2 asked, "I am happy to be alive but how come I got the pass?" Participants noted that support groups could initiate guilt or other feelings of distress from the constant reminder of cancer. P5 shared, "There [are] like 2,000 members. Also, I am starting to feel a little down." I located literature that supported participant suggestions of additional stress from support groups, as well as guilt associated with more favorable outcomes compared to what others have endured (Burg et al., 2015; Green, Wodajo, Yang, Sleven, & Pieters, 2017).

One participant out of 10 interviewed received a formal referral to a psychologist. The referral to the psychologist came after the participant made the request. Asking participants if they would have benefited from psychological support was not part of the

study design. However, Croyle (2015) completed a literature analysis of research specific to the contributions of psychology in comprehensive cancer treatment. Studies showed support for reporting unmet psychological needs and an increase in psychological distress after treatment was completed (Burg et al., 2015; Cella & Stone, 2015; Stanton et al., 2015). In addition, screening for psychological needs was reported in the literature as an important component of comprehensive cancer care (ASCO, 2015; Green McDonald et al., 2015; Trudeau-Hern & Daneshpour, 2012).

Decision-Making

The final theme to be interpreted and presented is decision-making. Decision-making is influenced by the many themes presented in this research. In this section, I explain the following categories identified for decision-making: (a) being influenced by experience of cancer in others, (b) avoidance, and (c) selection of treatment locations. This theme rounded out the findings specific to decision-making from interview responses for this study.

SDM and patient directed care examples were provided in Chapter 4. Participants described the use of SDM with their providers and complemented the communication of the cancer team. For example, P1 stated, "My appointment was 2 and a half hours long. Then another hour with the [navigator]… [the doctor said] you have three options that you need to think about." P2 said, "I made the decision that night… they never made me feel like I was making a wrong decision." A significant volume of literature regarding SDM was reviewed during the preparation of the study proposal. The SDM literature suggested that many providers were not consistently communicating with patients and

were not using SDM skills (Back et al., 2014; daCosta DiBonaventura et al., 2014; Epstein & Gramling, 2013; Glass et al., 2012; Joseph-Williams et al., 2014; Livaudais et al., 2013; Pass et al, 2012; Thorne, Oliffe, Stajduhar, Oglov et al., 2013). There were no statements provided by participants to support framing or other types of provider messaging that influenced the participants (Back et al., 2014; Broniatowski & Reyna, 2013; Epstein & Gramling, 2013)

Participants also described leaving current providers to find someone they felt more comfortable with. For instance, P10 shared, "I found a doctor that I felt I could work with better… it was oh so much a more agreeable plan to me." P6 also stated, "I went out of network, paid out of pocket to see another doctor to try and get someone else's feedback on it. Because I felt like I was getting the run around." I identified literature that showed support for the issues associated with disagreements between patients and providers, as well as the potential negative influence this could have on overall care (Kane, Halpern, Squiers, Treiman, & McCormack, 2014).

Influenced by experience from cancer in others. Experience with cancer in others was detailed as influencing decision-making for some participants. Participants detailed the influences that occurred when they witnessed unfavorable outcomes. This aspect led to decision-making requests for more treatment or less treatment compared to what providers recommended. For example, P2 asserted, "I am going to be aggressive. I don't care." Requests for less treatment were also described, as P10 claimed, "It [the radiation] eventually killed him." P3 also shared, "It was supposed to give her a better quality of life… which neither one of us could see." Literature findings showed the

influence of past experiences with cancer on patient decision-making and the willingness of patients to endure the side effects of aggressive treatment (Gibbins et al., 2014; Imber-Black, 2014).

Avoidance. Participants described delegating roles to others during the decision-making process. P2 said, "I didn't want to really know." P4 added, "It isn't that I am sticking my head in the sand, it is just that in my heart and in my soul, I really don't feel the need to have to dig in to all of that." I located literature that showed support for the participant responses of wanting to delegate responsibility of treatment decisions (Back et al., 2014; Livaudais et al., 2013; Pass et al., 2012). Researchers have also noted that not all patients were comfortable with the responsibility of decision-making, feeling overwhelmed or burdened with the responsibility (Back et al., 2014; Livaudais et al., 2013; Pass et al., 2012). The literature review findings showed more study results that reflected a reliance on others to help navigate the information overload. This reliance on others differed from statements of avoidance reflected in the current study findings. Literature review findings that showed support for SDM and the benefits of receiving treatment information when patient support members were more prominent (Lillie et al., 2014; Shay & Lafata, 2015).

Selection of treatment locations. All participants stated they were directed to the treatment locations by the insurance company. Participants also reflected on their satisfaction or dissatisfaction with referral process. One participant left his or her community to seek treatment. He or she reported leaving due to mistrust of the medical

providers. Livaudais et al. (2013) included a reflection of mistrust of the medical profession, which one participant demonstrated:

> I went out of network, paid out of pocket to see another doctor to try and get someone else's feedback on it. Because I felt like I was getting the run around. After hitting all these brick walls, I said, I am going to pay the out of pocket costs and go to a doctor that is not governed by the insurances and that they still hold value in their Hippocratic oath, and I am glad that I did. (P7)

Researchers have suggested underlying cultural differences influencing the selection of treatment location, not asked in this study (Joseph-Williams et al., 2014; Livaudais et al., 2013; Singh et al., 2010).

Dual Process (FTT)

FTT consists of the combination of verbatim recall, gist recall, and the conflict between the two (Reyna et al., 2015). This section provides the interpretation of participant verbatim and gist recall associated with FTT. The participant responses to the interview question about the influence of emotion or information on their decision-making process is provided within this section.

All participants offered recall of their cancer stage. The responses could be considered verbatim: "[The lymph nodes] were clear. My understanding is that is next to nothing" (P4). Participant statements also showed areas of incomplete understanding after treatments were decided and begun: "Some things [were]… skimmed over" (P3).

Understanding of pain control is another area of misunderstanding: "No one told me that you need to take the pain meds before" (P10). P1 commented, "I never knew…

the medicines have all kinds of different effects." It was unclear if any of the responses represented rote memorization.

Verbatim recall refers to detailed information, made up of complex concepts including survival statistics, risk ratios, or percentages for treatment success (Reyna et al., 2015; Smith et al., 2013). Gist recall is also referred to as the fuzzy portion of decision-making. Gist recall develops from unconscious awareness or individual perception, and represents vague or qualitative concepts (Reyna et al., 2015; Smith et al., 2013). My observations and interpretations of participant responses included a lack of focus on the specifics of the diagnosis. Participants responded with greater emphasis on how cancer impacted their lives. Recent FTT research was published in 2016 that indicated the existence of false memories associated with complex decision-making (Reyna, Corbin, Weldon, & Brainerd, 2016). When verbatim recall was not offered, questions were re-asked, but participants were not pressed to remember specifics to avoid unintended distress.

I overserved participant interview responses that placed greater emphasis on the weight of emotions versus information during decision-making. P1 stated, "So, I could be here for my kids." In addition, P3 stated, "What I have been through with my wife and kids" as being more influential to decision-making. I also observed participants detailing a combination of emotion and information as influential to treatment decision-making. For example, P2 stated, "Emotionally driven… [with] some real statistics." P4 stated, "It's a mesh." In two participants, information was more influential in their decision-

making. P6 stated, "If we let our emotions take over, we don't always make the best decision."

Cancer Advertising and DTCA

The interpretation of the participant interview responses, regarding cancer advertising and the secondary data review, are provided in this section. Recall by participants about cancer advertising suggested participants were not aware or did not draw from previous DTCA exposure. Participants suggested sensitivity to cancer advertising increased only after their diagnosis: "Before I had cancer, I didn't pay attention" (P4). P1 commented, "[We] would sit laughing because it seemed like as soon as I was diagnosed every other commercial is cancer treatment." The literature review for DTCA and marketing of cancer services showed examples of mass media or fame could influence medical decision-making (Lebo et al., 2015). In addition, I found research that was specific to exposure to DTCA and the potential influence of DTCA exposure (Abel et al., 2009; Tan, 2015). Abel et al. (2009) suggested that increases in TV were correlated with increased exposure in DTCA. Abel et al. also suggested that there were no significant changes in therapy options for participants, as being caused by DTCA.

Some participants responded unfavorably to cancer advertising: "Every other commercial on TV which I am so sick of looking at TV I don't even turn it on anymore" (P4). P8 stated the following:

> We started seeing a lot of these commercials "if you want to live longer," and we thought that was in very poor taste. That type of advertising… we thought it was in really poor taste. It is more of a scare in our opinion.

Vater et al. (2014) suggested the increased use of "emotional appeals that evoke hope and fear" (p. 818) in DTCA by cancer centers.

DTCA. The categories that developed during the secondary data analysis of cancer advertising are presented in Chapter 4. The categories include treatment, technology, and quality; fighting terms and hopeful messaging; team approach; and physical environment. The overall interpretation of the secondary data review follows the categories at the end.

Advertising statements, regarding treatment, technology, and quality, focused on promoting the services offered by the advertising facility. These included the following: (a) "Our unique blend of cancer research and patient care results in new and better treatment options" and (b) "our state-of-the-art diagnostic capabilities and leading-edge treatment options." Vater et al. (2014) included findings that supported the promotion of services. Vater et al. furthered that the promotional advertising only noted the benefits of their services. Vater et al. also noted potential risks with treatment, alternative options, or insurance coverage were not included in the advertisements.

Fighting terms and hopeful messaging are abundant in the advertising data analysis. The prominent terms identified in this category included fight or fighting, beat, and cure. In addition, I identified words of hope, compassion, and well-being. Vater et al. (2014) focused on a proliferation of "emotional appeals." Hope was also a prominent finding in Vater et al.'s research. Other researchers have shown an interest in studying the impact of hopeful messages for individuals diagnosed with cancer (Schapmire et al., 2012).

The next category contained terms associated with team work. Examples included the following: (a) "Working together we'll find the answer;" (b) "we encourage and promote communication;" and (c) "decide together on the best course for each patient." The terms prominent in this section were also prominent in the literature identified for SDM and other patient directed decision-making literature (Elwyn et al., 2014). Vater et al. (2014) identified this type of advertising strategy in their research. In the Vater et al. research, terms related to team work were included in the advertisement of services.

The final category includes the physical environment. This is a small segment of the secondary data analysis. Examples include the following: (a) "We have carefully designed our cancer centers to simplify and ease the process," and (b) "in an environment that promotes healing." Vater et al. (2014) identified this type of advertising strategy in their research. In the Vater et al. research, terms related to environment were included in the advertisement of services.

I could not make correlations between participant recollection and cancer advertising, which was not the focus of this study. Literature findings showed that cancer advertising lacked regulatory oversight, such as the regulations imposed on pharmaceutical advertising (Schenker et al., 2014; Tan, 2015; Vater et al., 2014). Tan (2015) and Vater et al. (2014) suggested DTCA was controversial and focused on using messages to stir up emotions to influence treatment decision-making. Literature suggests a continued use of ambiguous wording and lack factual support in advertising statements (Schenker et al., 2014; Vater et al., 2014).

Limitations of the Study

The study protocol for data trustworthiness were closely adhered to as designed. I followed structures for credibility, transferability, dependability, and confirmability. I used member checking, prolonged contact with the data, audit trails, and hand coding, respectively. This section will provide the study limitations.

The recruitment strategy was a limitation. Collaborating with one or more community based cancer centers would have been a better approach. The daunting and lengthy task of IRB approval should have been attempted for this study. Recruitment using the originally designed methods was extremely time consuming to produce the needed participant counts.

The review of DTCA required modification from the original study plan. I removed pamphlets and newspaper advertisements as secondary data materials. Asking participants to track the frequency of their exposure to DTCA could have been beneficial.

Recommendations

Interview findings showed that the decision-making life-cycle after a diagnosis of cancer was a far more dynamic and chaotic experience. Participant interviews proved the cancer journey focused more on how the disease influenced the lives of individuals and their support circles. Research findings also indicated the assumptions that the patient support circles and previous experiences with cancer in others provided a substantial influence on patient decision-making.

Continued scholarly research, focused on defining factors that influence decision-making after a life-threatening diagnosis, are warranted. Examples of additional research

can include recurring clinic based research interviews. Real-time interviews may allow individuals to identify the complex and evolving needs across the continuum of care.

Most participants detailed unmet psychological support. The area of psycho-oncology was not the specific focus for this study. The significance for assessing and meeting the psychological needs of participants go beyond the emotional influence and have physiological implications, as represented in oncology literature (DellaRipa et al., 2015; Lutgendorf & Andersen, 2015). Further research in understanding the roadblocks or challenges individuals face in receiving needed psychological support is significant.

Researching the existence or absence of psychological distance is also recommended. Two sets of researchers alluded to the potential influence of psychological distance on decision-making (Aning et al., 2012; Fukukura et al., 2013). Due to the amount of psychosocial distress experienced after a diagnosis of cancer, it would be beneficial to evaluate the benefits of psychological distance in cancer treatment decision-making.

Implications

Few statements have the power to strike fear in to the hearts of individuals, as the three words: "You have cancer." This research can create positive social change through the advancement of scientifically validated research focused on supporting patients during the decision-making process. Oncology health care professionals and health care leaders can use the findings and recommendations during programmatic development to ensure patient centric approaches to decision-making.

The unique individual needs and resources for each patient creates an exceptional challenge for health care professionals. As the current research shows, the decision-making process is influenced by more than what occurs within the walls and conversations of healthcare providers. Psychological stress, family or social pressures, and other needs influence patient decisions and behavior. One may use the findings and recommendations from this study to show areas where additional studies can bring about added positive social change.

Conclusion

In the process of delivering cancer care, health care teams must embrace all diverse and complex patient needs. The delivery of healthcare is in crisis, and cancer care teams face deciding way in which to meet these needs, in some instances, with limited resources. The evolution of comprehensive cancer teams is a strategic opportunity to find successful solutions to meet these diverse needs. Teams should include providers trained in the psychological component of the diagnosis of cancer as a compliment to the support of physicians, nurses, and other allied health. Research continues to evolve the understanding of ways in which individuals organize, synthesize, and recall information. This inclusion of behavioral specialist or oncologic psychologists, as an expected part of the cancer team, is in the best interest of patients and families during such a trying time.

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Appendix A: Advertisement Flyer Language #1

A research study opportunity is available that is focused on developing a deeper understanding of the treatment decision making experiences for patients newly diagnosed with cancer. You are invited to take part or share this information with someone you know.

Criteria for Participation

- Adults, ages 25-80 without cognitive impairment

- Living in California at the time of diagnosis

- Without a previous diagnosis of cancer

Benefits of participating in research
- You can help researchers provide detailed findings that can help future

  patients diagnosed with cancer navigate the decision making

- Findings can also provide the healthcare industry with opportunities to

  develop patient centered best practices for decision making.

For more information about participating in this research please contact the research at XXX@waldenu.edu or call XXX

Or find research specific on the following social media sites:

 https://www.facebook.com

 https://www.linkedin.com

 @

Appendix B: Interview Protocol

Thank you for your agreeing to participate and for taking the time to allow me to interview you today.

As we reviewed in the consent, I will be audio recording the interview.

I might take notes on my clip board while you are speaking to help me keep track of follow-up questions.

The confidentiality of any notes will be protected at the same level as all of the data.

We have planned this interview to last no longer than one hour.

If it looks like we will run short on time, I will ask you if you would like to extend the interview time before proceeding.

Just a reminder, the interview can be stopped at any time.

Do you have any questions before we get started?

Interview Questions, Section I

1. **Interview Part 1-**

    1. Starting with the day you found out you had cancer, tell me everything you can remember about your experience.

        i. *Sub-questions to facilitate the discussion:*

            1. *Tell me anything you remember about the information your provider(s) shared with you about your diagnosis.*

            2. *Tell me anything you remember about the treatment information your provider(s) shared with you.*

    2. If you took others with you when you received your cancer diagnosis tell me about the experience.

    3. Tell me about your experience discussing your personal health beliefs or individual values with your provider.

        i. *Sub-questions to facilitate the discussion:*

            1. *Tell me what you remember about discussing treatment options.*

> 2. *Tell me what you remember about any questions your provider(s) asked about your personal beliefs.*

4. In the days immediately following your diagnosis, tell me anything you can remember about steps you took to help you understand your diagnosis:

   i. *Sub-questions to facilitate the discussion:*

      1. *For instance, what steps did you take to research your diagnosis?*

5. Tell me about the reactions or responses from your family or other members of your support circle when they found out about your diagnosis.

6. Tell me about any members of your family or support circle that you did not want to tell about your diagnosis, and why?

7. Tell me anything you can remember about discussions you had about your personal wishes for treatment. Maybe spiritual or cultural beliefs?

8. Tell me about anyone outside of your family and friends that you spoke to about your diagnosis.

9. Tell me about any experiences you had with calling a help line, or attending support programs.

10. Share with me your experience with selecting the location to receive your treatment?

    i. *Sub-questions to facilitate the discussion:*

       1. How did you decide on which providers to see or facilities to go to?

       2. *How many facilities did you consider before deciding where to go for treatment?*

11. Tell me about any second opinions or other providers you spoke with before deciding on a treatment plan.

2. **Interview Part II-**

1. Prior to <u>*your*</u> diagnosis of cancer, tell me about any experiences you had with cancer;

    i. Sub-questions to facilitate the discussion:

      1. Tell me about family members or friend that had with cancer.

      2. Tell me about any experience you have had as a care giver for a someone diagnosed with cancer?

      3. Tell me how you think your past experiences with cancer influenced your cancer decision making.

  2. Tell me about any anything you can remember about cancer related advertising.

    i. Sub-questions to facilitate the discussion:

      1. Tell me about any advertising for cancer facilities or treatments you can recall.

  3. Tell me what you remember about your cancer stage.

3. Interview Part III- other

  1. In the previous section we discussed your experience when you learned about your diagnosis of cancer. We also discussed your experiences with cancer prior to your diagnosis.

  2. Is there anything you feel we have not discussed and you would like to share with me about your journey?

  3. My last question. During the period of treatment decision making we have been discussing, which do you believe provided greater influence, information or emotion?

4. Journal Notes, Section IV-

  1. I am providing you with a journal that was detailed in the consent.

  2. Please journal any experiences related to your cancer journey in any way.

  3. There are no directions or rules for journaling.

  4. Include anything you wish to share.

  5. Select option for collection of journal (one option please):

    ☐ Researcher will personally pick up the journal from you.

    ☐ Journal notes will be scanned and sent electronically via an email.

    ☐ The journal will be returned via mail in a double envelope and postage paid.

5. Follow-up Call, Section V-

    1. Can we schedule the follow-up call now?

        i. If you need to look at your schedule, how would you like me to reach you to schedule?

            1. Date: _____

            2. Time: _____

If you need to reschedule the follow-up call, please email me at

XXX@waldenu.edu

Appendix C: Advertisement Flyer Language #2

Request for Participation. Tell you story, Share your journey. Contribute to research for the future. Recruiting volunteers to join a research study focused on the journey of participants newly diagnosed with cancer.

Background, purpose, and benefits of participation:

- The objective of the study is to contribute to the growing body of scientifically validated research surrounding the decision-making process, and to strive to understand and meet the evolving needs of patients diagnosed with cancer.

- Your participation can help future patients diagnosed with cancer navigate the decision-making journey.

- Research results can also provide the healthcare industry with opportunities to develop patient centered best practices for decision making.

Criteria for Participation:

- Adults, ages 25-80, without cognitive impairment

- Living in California at the time of diagnosis

- Without a previous diagnosis of cancer.

Participation Activities:

- One interview (scheduled)

- Personal journaling

- One Follow-up call (30-45 days after interview)

Study information can be obtained by contacting the researcher and on the following sites:

- American Cancer Society- Cancer Survivors Network http://csn.cancer.org

- Facebook https://www.facebook.com

- LinkedIn https://www.linkedin.com

- Twitter

Contact the researcher Bonnie Quinonez at XXX@waldenu.edu or, by calling XXX

Appendix D: Cancer Advertising - List of Facilities

Facility/Organization Name	
AIS Cancer Center	Mercy General
Beverly Hills Cancer Center	Methodist Hospital
California Cancer Center	Orange Coast Memorial Medical Center
California Oncology Central Valley	PIH Health Hospital - Whittier
Cancer Center of Southern California	Providence Holy Cross Medical Center
Cancer Treatment Center Anaheim	Queen of the Valley Medical Center
Cedars Sinai	Redding Cancer Treatment Center
City of Hope (Antelope Valley, Santa Clarita, Simi Valley, Duarte, Pasadena)	Saint Johns health center
Community Hospital of the Monterrey Peninsula	Saint Josephs
Cypress Women's Cancer Treatment Center	Saint Jude medical center
Eisenhower Medical Center	Santa Barbara cottage hospital
El Camino Medical Center	Scripps
Glendale Adventist	Sharp Mary Birch Hospital
Hoag Family Cancer Institute	Sharps Chula vista
Huntington Hospital	Sierra View
John Muir Concord	Stanford
John Muir Walnut Creek	Sutter Roseville
John Wayne Cancer Institute	Torrance Memorial Medical Center
Kaiser - Roseville	UC Davis
Kaiser - Santa Clara	UC Irvine Health Chao Family Comprehensive Cancer Center
Loma Linda Cancer Center	UC San Diego Moores Cancer Center
Long Beach Memorial	UCLA Medical Center
Marian Regional Medical Center	UCSF Medical Center
Memorial Medical Center	USC Norris Cancer Hospital-Keck Medical Center of USC