Cancer Patient Experience Using Integrative Health Techniques

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Cancer Patient Experience Using Integrative Health Techniques

by

Spencer R. Bockover

A thesis submitted in partial fulfillment of the requirements for the degree of Master of Arts
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ABSTRACT

Objective:
From a patient-centered perspective, this study sought to explore cancer patient experiences using integrative health techniques, while undergoing or after having completed conventional cancer therapy.

Methods:
Recruitment and data collection both occurred within the Supportive Care Medicine Department of a comprehensive cancer center in the southeastern United States. The primary collection method was semi-structured interviews, of which 13 were conducted.

Results:
Patients using integrative therapies experienced a variety of physical and mental/emotional benefits from their chosen therapy, such as management of lymphedema and nerve damage, increased mobility, and improved self-confidence.

Conclusion:
Integrative therapies can provide many benefits to patients in mitigating treatment side effects and other cancer related symptoms. CAM practitioners themselves played an important role in post-treatment cancer support; both by acting as a health educator and by administrating the therapy itself.
CHAPTER ONE: INTRODUCTION AND RESEARCH PROJECT

Introduction

According to the Centers for Disease Control and Prevention (CDC), in 2014, 236,968 women were diagnosed with breast cancer, and of these women 41,211 died from the illness (CDC, 2017). The National Institutes of Health (NIH) estimate that there are 3,327,552 women living with breast cancer, corresponding to an 89.7% 5-year survival rate between 2007 and 2013 (NIH, n.d.). Although a high survival rate is seemingly positive, conventional cancer treatment such as chemotherapy and radiation can be physically, mentally, and emotionally demanding resulting from not only the multitude of possible cancer-related symptoms, but also treatment side-effects. To combat these effects, many cancer patients have turned to complementary and alternative (CAM) therapies, usually in conjunction with their conventional treatment.

The growing dominance of biomedicine in Western nations has resulted in many parallel forms of therapy being pushed to the periphery of the standard of care, labeled as complementary or alternative medicines (CAM). CAM therapies have begun to resurface and have steadily grown in popularity among the U.S. population over the past several decades, resulting from the new age holistic health movements of the 1960s and 1970s (Baer 2004). Even more recent is the incorporation of complementary and alternative therapies within a biomedical setting, now known as the practice of integrative medicine. Early on in the rising popularity of integrative medicine, anthropologists recognized the unique perspective anthropology could contribute to evaluating limitations of the current health system and the potential benefits of incorporation of beliefs and therapies from other systems (Adler 2002). This study explores CAM use in an
oncological setting, address why patients engage with these therapies, the roles they play in conventional cancer treatment, and if these therapies change the way patients perceive and discuss their illness.

Within recent years, more research has been conducted on the use of integrative medicine in oncology settings, better known as integrative oncology (Axtner et al. 2016; Ben-Ayre et al. 2015). Studies have shown that between 50-83 percent of cancer patients in the United States have reported using complementary therapies after their diagnosis of cancer (Davis, OH, Butow, Mullan, & Clarke, 2012; Judson, Abdallah, Xiong, Ebbert, & Lancaster, 2017). Therefore, the focus of these studies have been on the ability of integrative medicine and complementary therapies to address symptom management and quality of life in cancer patients receiving or having received conventional standards of cancer care. Quality of life in studies of integrative oncology incorporates all factors necessary for carrying out daily functioning including, physical, emotional, and social functioning, as well as addressing disease symptoms and treatment side-effects (Leppert, Gottwald, & Forycka, 2015). However, more research is needed to assess the role these therapies play in the mitigation of treatment side effects and cancer-related symptoms when used in conjunction with, or following conventional care. Addressing the efficacy of these therapies is undoubtedly important, but what is often lacking from these reports is patient motivations for utilizing complementary therapies and the patient experiences and perceptions of their illness that may change through CAM use during cancer treatment. Understanding the motivations of why patients choose to use CAM therapies from the very beginning helps to avoid miscommunications, and allows the patient, practitioner, and oncologist to be in sync during the treatment process. By understanding patient motivations and preventing
miscommunications in care, this can in turn improve or mitigate bad experiences for patients during treatment.

**Research Project**

Building on prior research in the area of integrative oncology, this study attempts to explore patient experience of using CAM therapies while undergoing, or having completed, conventional cancer treatment. The literature on women with gynecological and breast cancers show a high utilization of CAM and integrative medicine therapies (i.e. yoga, meditation, etc.) by this population (Judson et al. 2017; Moonsammy et al. 2013; Hwa Do, Hyo Choi, Su Ahn & Yong Jeon 2017; Zhang et al. 2016; Lin, Frawley, Denehy, Feil, & Granger 2016; Tao et al. 2016; Tiezzi et al. 2017). This study reflects a similar trend with a sample population made up of women with breast and gynecological cancers. This study addressed broad areas of quality of life, motivations for using CAM therapies, and patient-physician interactions were addressed through three fundamental research questions; 1) For what reasons do patients seek CAM therapies as part of their cancer treatment and what gaps do these therapies fill in the biomedical cancer treatment system?; 2) What effects have CAM therapies had in the process and experience of patients undergoing cancer treatment, and how do patients perceive the efficacy of these treatments? and 3) How do patients undergoing CAM therapies perceive and describe their illness?

Unlike many of the other studies cited throughout this study, the aforementioned questions were addressed through a qualitative approach, using semi-structured interviews. A popular approach in the social sciences, qualitative research gives the researcher the advantage of spending longer amounts of time with study participants. When asking questions regarding perceptions and experiences, semi-structured interviews that allow study participants to freely
discuss their thoughts and concerns is an advantage over a purely survey, control trial, or other quantitative approach.
CHAPTER TWO: RELEVANT LITERATURE

Introduction

This chapter explores oncological and anthropological literature as it relates to complementary and alternative medicine. The first three sections focus on aspects of quality of life, as well as the physical and mental/emotional effects that CAM therapies can have. The last several sections discuss anthropological literature on discourse and phenomenology in relation to biomedicine, cancer, and CAM. This chapter seeks to present current social science and medical literature, discussing them in tandem to emphasize the benefits anthropological research can add to studies of integrative oncology.

Quality-of-life and Complementary Therapies

This study examines integrative oncology and supportive care medicine used among the patients at a large comprehensive cancer center in the southwest. Integrative oncology, a subset of integrative health, combining alternative and conventional treatments, takes a patient-centered approach and seeks to spark the body’s innate ability to heal itself physically, mentally, and emotionally shifting the focus of care from illness to the overall wellness of the patient (Axtner, et al., 2016; Cramer et al., 2012; Mulkins & Verhoef, 2004). The use of this approach helps to change the paradigm of cancer treatment within a biomedical setting, from treatment of symptoms to promoting quality of life, well-being, and sustainable lifestyle change (Ben-Arye, et al., 2015; Cramer et al., 2012). Incorporated within this type of care, practitioners address patients’ concerns, goals and coping strategies to maintain a sense of well-being, and quality of life during and after treatment (Ben-Arye et al., 2015; Zhang, Li, Zhang, Yu, & Cong 2016).
Patient concerns are well founded as conventional cancer treatment comes with serious potential side effects on top of other cancer-related symptoms. Cancer-related symptoms and treatment side-effects that patients may face include, but are not limited to; gastrointestinal stress, poor sleep quality, cancer-related fatigue, depression and emotional distress, bodily pain, and even sexual dysfunction (Gross, Cromwell, Fonteyn, Matulonis, & Hayman 2013; Tao et al. 2016; Tian, Lu, Lin, & Hu 2016; Tiezzi et al. 2017). Along with several of the aforementioned symptoms, many of the participants in this study also experienced neuropathy and lymphedema; two side-effects in particular often treated using complementary therapies.

**Physical Treatment Side-Effects & Cancer-Related Symptoms**

Three of the main complementary therapies that are used to address physical manifestations of treatment side-effects and cancer-related symptoms are aerobic exercise, yoga, and acupuncture. As a rehabilitation tool, exercise routines geared toward stretching, strengthening, and increasing aerobic capacity have been shown to not only be cost effective ways to address treatment side-effects and cancer-related symptoms, but also to improve physical functioning and cardiovascular response, while decreasing bodily pain and lower-limb edema (Hwa Do, Hyo Choi, Su Ahn, & Yong Jeon, 2017; Moonsammy et al, 2013; Zhang, Li, Zhang, Yu, & Cong, 2016). Exercise, when used among patients in conjunction with adjuvant therapy, is especially effective in decreasing the effects of cancer-related fatigue (Hwa Do et al., 2017; Tian, Lu, Lin, & Hu, 2016). Research suggests a specific exercise technique, yoga, provides positive benefits for cancer patients. The type of yoga used by cancer patients emphasizes posture, breathing techniques, meditation, mantras and lifestyle changes; which has been associated with effective pain management and better physical and social functioning (Harder, Parlour, & Jenkins, 2012). On top of these benefits, a study by Archer, Phillips,
Montague, Bali, and Sowter (2015) showed that the reduced stress and anxiety, as well as improved sleep quality that came with yoga as exercise, increased women’s everyday physical capabilities giving them more confidence, therefore encouraging more active engagement in the yoga program. These studies point to the potential benefits for breast and gynecological cancer patients when incorporating exercise into their cancer treatment or recovery. Studies have shown acupuncture helps mitigate several cancer related symptoms and treatment side-effects. According to research by David O’Regan and Jacqueine Filshie, acupuncture interacts with the nervous system enabling it to aid with pain, nausea and vomiting, gastrointestinal side-effects, hot flashes, xerostomia, fatigue, and dyspnoea (O’Regan & Filshie, 2010).

Mental/Emotional Health During Conventional Cancer Treatment

In women with breast and gynecological cancers, the potential negative side-effects of conventional treatment or cancer-related symptoms should be taken into account when considering the impacts to emotional, social, and spiritual functioning during treatment (Leppert, Gottwald, & Forycka, 2015). Most notably, high levels of cancer-related fatigue, linked with high risk for sleep disturbance and symptoms of depression, have been documented in women with ovarian cancer (Zhang, Li, Zhang, Yu, & Cong, 2016). Exercise training is one avenue that organizations such as the American Cancer Institute and the American College of Sports Medicine have suggested to address cancer-related fatigue (Lin, Frawley, Denehy, Feil, & Granger, 2016). Moreover, some studies have shown that pairing home-based exercise regimens with cognitive behavioral therapy as a way to address the psychological and emotional aspects of cancer-related fatigue has had a positive impact on not only fatigue, but also depression and sleep quality, while being a sustainable way to make improvements during treatment (Moonsammy et al, 2013; Zhang et al., 2016). Parallel activities that go along with exercise
routines, for example the deep and focused breathing exercises in yoga and the use of humor among support groups, have also been shown to help produce feelings of calm, reinforce social bonds and collective strength, de-privilege stress, allow for better control of negative thoughts, and ease the pervasiveness of troublesome thoughts (Archer et al., 2015; Bouskill 2012). These studies show that exercise programs developed for women with gynecological cancers can help, not only physical distress of conventional cancer treatment, but also conceivable emotional and psychological impacts as well.

While conventional cancer treatment can come with a certain amount of mental and emotional strain, so can the diagnosis of cancer itself, as prognostic judgements of patients can have a tangible effect on patient healing (Thompson, Ritenbaugh, and Nichter 2009). Reportedly, 35-38% of patients diagnosed with cancer face substantial emotional distress, while newly diagnosed individuals and patients facing recurrence reported feelings of hopelessness (Faller et al., 2013; Tian et al., 2016). For some women, the diagnosis of cancer, followed by treatment can lead to a loss of self-confidence, self-image, and a transition in identity, on top of significant disease-specific worry (Bouskill 2012; Lin et al., 2016; Olesen et al., 2015). Two techniques have been used to address these challenges: mindfulness-based cognitive therapy and mindfulness-based stress reduction. Mindfulness in this instance is based off of a specific Buddhist meditative tradition that engages in a state of consciousness that facilitates openness and acceptance toward one’s own experience (Cramer et al., 2012). These two strategies have been found to be effective in addressing emotional challenges such as distress, anxiety, depression, and helping patients to start the process of reconstructing their identity and building their self-confidence (Cramer et al., 2012; Marchand, 2012). Studies by Malicka, Kozlowska, Wozniewski, Rymaszewska, and Szczepanska-Gieracha (2016) and Olesen et al. (2015) have
also found that an important piece of improving emotional distress was addressing fears of recurrence and having the support of other women who share similar experiences. These studies have shown ways in which emotional distress can be addressed to improve mental health throughout the process and cancer treatment and recovery.

**Discourse & Cancer**

Cancer, breast cancer in particular, did not always receive the public support and pink ribbon campaigns of today. In fact, Susan Sontag, in her book *Illness as Metaphor*, discusses the public perception of cancer as a disease of the insufficiently passionate or sexually repressed (1978). However, throughout the 20th century discourses of cancer, specifically breast and gynecological cancer, began to change. Early public discourse of cancer treatment in the 20th century centered around early detection and self-examination. According to the treatment model of the time, discourse among doctors and public health professionals insisted that early detection could lead to more effective treatment, but many women viewed the dominant message of early detection as one that placed blame of the cause of cancer on women, while also evoking a fear in women of their bodies (Aronowitz, 2007; Gardner 2006). Up to the late 1900s (1970s-1980s) public dialogue around cancer stayed stagnant, until the rise of women’s cancer advocacy organizations and feminist health movements. Cancer advocacy groups began to have a significant impact on the public awareness and discussions surrounding cancer in regards to funding, survivorship, and research (Bell, 2014). Feminist health movements began to shift the way that women could discuss cancer and set a foundation for advocacy groups to become the educators of other women through women’s clubs and public health campaigns (Bell, 2014; Gardner, 2006). The lobbying of breast cancer advocacy groups, not only introduced women’s voices into political debates on cancer care, but also contributed to the spike in breast cancer
funding in the 1990’s that led to breast cancer being the rallying point for the national cancer movement, resulting in the cultural dominance of breast cancer in the United States today (Bell, 2014; Gardner, 2006; Kaiser, 2008).

There is no doubt about the severity of cancer, given that it is the second leading cause of death in the United States (U.S. Cancer Statistics Working Group, 2018). Moreover, there is no shortage of discussions of cancer given the rhetoric of new treatment developments, fundraising, social media, etc.; making the language of cancer just as ubiquitous, if not more so, than the disease itself (Agnew, 2018). In regards to cancer, metaphor has come to play a significant part in not only discussions of cancer and the scientific and medical knowledge surrounding it, but also the illness experience of cancer patients (Agnew, 2018; Sontag 1979). The most prevalent of the metaphors is the so-called ‘war on cancer,’ which came from both, the discovery of bacteria as a disease causing agent that “invaded” or “infiltrated” the body, and the early connection that cancer research and treatment had with the advancements of military weapons technology (Agnew, 2018; Sontag, 1979). As Susan Sontag states in her book Illness as Metaphor, “There is the ‘fight’ or ‘crusade’ against cancer, cancer is the ‘killer’ disease; people who have cancer are the ‘cancer victims’…treating cancer as no mere disease but a demonic enemy…” (1979, 57).

Of interest in this respect is how CAM therapies integrate into prior social science work on national and international discourse of the “war” on cancer, as well as the shift in language from a ‘victim’ of cancer to a ‘survivor’ where patients, through sheer will and with a “fighting spirit,” beat or conquer their illness (Good, 1991; Kaiser 2008). An initial cancer diagnosis can be an isolating experience, and the process of recovery can also be a process of reconstructing identity (Olesen et al. 2015), especially when patients are pressured, through national discourse and the U.S. biomedical culture, to adopt the role of, and identify as, a survivor (Kaiser 2008).
The term “cancer survivor”, a term that combines more than 100 fairly distinct diseases under a single umbrella, can be defined as shared experiences of diagnosis and the physical and psychosocial hardships that come along (Bell, 2014; Mulligan, 1985). However, this implies that women embrace this terminology and disregards patients that shape their own meanings, or actively reject the traditional role of the survivor (Kaiser, 2008). For these individuals, what sort of “alternative meaning” do they adopt during recovery or the remainder of their treatment (82)?

This study will seek to address how patients interpret these possible alternative meanings and how CAM therapy users describe themselves and their illness.

**Phenomenology & Complementary Therapies**

Previous research attention has been given to evaluating the evidence-base and efficacy of various CAM therapies through randomized control trials (RCTs) as a primary form of treatment for various diseases and conditions. While this is still the case for many published studies, the nature of CAM therapies using randomized control trials (RCTs) as the sole study design to generate evidence and evaluate efficacy disregards and overlooks the therapeutic effects and the shift to a perspective of wellness that are brought about by CAM therapies (Thompson & Nichter 2015). RCTs are generally designed to examine the absence of disease, however to effectively study CAM therapies, study designs must also look to wellness and the addition of therapeutic effects that patients experience when utilizing these types of therapies.

There are many elements to therapy management and the therapeutic process. Such elements range from material resources and emotion management to adjusting to a post-surgery body, and construction/co-construction of illness narratives; as well as any social, ideological, or economic constraints that may present themselves (Csordas & Kleinman 1996; Hatala & Waldram 2016; Hauge 2016; Nichter 2002). The therapeutic process is a subjective experience.
which surrounds a patient's mode of being-in-the-world and their emotional flexibility, defined as “... the general ability to adapt by changing one’s cognitive state, stance, or behavior” (Hinton & Kirmayer 2017; Lende & Lachiondo 2009). A shared ‘mythic’ and cultural world, or simply the shared belief system between the patient and healer, is symbolic of and sets the foundation for the therapeutic relationship between the patient and healer. The role of healer in the case of Western biomedicine and complementary therapies can be played by either a physician, a CAM practitioner, or both. The therapeutic relationship between the healer and the patient is a crucial part of the therapeutic process as it can have major impacts on healing outcomes (Hatala & Waldram 2016; Moerman & Jonas 2002). Patients’ that see their healer as experienced and competent are more likely to have positive health outcomes (Thompson, Ritenbaugh, & Nichter 2009).

The Therapeutic Process: Symbols & Symbolic Healing

Symbols and symbolic healing play a large part in a patient’s conscious interpretation of healing and the meaning that is assigned to what healing is or should be. A seminal piece written by James Dow (1986) argued that the cultural mythic, a system in which both the healer and patient believe, was connected to symbolic healing, as curing occurred through the restructuring of a patient's disordered mythic world. While Dow believed that healing took place in the mind of the patient, his contemporaries Andrew Hatala and James Waldram believed that the shared meaning in the cultural mythic was not necessary for embodied healing to occur (Hatala & Waldram 2016). Regardless of the cultural mythic, many anthropologists and other social scientists believe that symbols, sometimes referred to as shifters, can affect a patient's psychological process, promoting flexibility in the way the mind responds to experience;

Andrew Hatala and James Waldram define healing as a “...transformational process designed to alter that patient’s existential engagement with the world” (Hatala & Waldram 2016). Bodily sensations and sensorial experience play a large role in the healing process. Thompson, Ritenbaugh, and Nichter (2009) discuss the need to focus on the positive effects of embodiment in the healing process through bodily sensations and aesthetic experiences in what they refer to as optimal healing environments. Healing is facilitated in these environments through the symbols that are attached to objects within the therapeutic environment. In the case of complementary therapies such as yoga, meditation, massage therapy, and acupuncture these symbols consist of music, oils, incense, or simply the act of entering into the therapy room. These are products or places that encourage the physiological link between smell, emotion, mood, bodily sensation, and the embodied transformational process (Hatala & Waldram 2016; Hinton & Kirmayer 2017).

Transformative Process

Mulkins and Verhoef (2004) describe the inner reflection incorporated into yoga as part of the transformative process that some cancer patients go through after diagnosis. Confronted with one’s mortality, a diagnosis of cancer can seem like a death sentence to some patients as it highlights the unpredictability of life (Hauge 2016). However, patients’ awareness of their mortality, American oncology discourse of hope, and biomedical pursuits for a cure, clash creating a struggle for life (Good, 1991; McMullin 2016). Bettina Hauge (2016), in her study of cancer patients that decide to return to work during their treatments, positions time at the center of the struggle. During conventional cancer treatment, a patient’s life can be consumed by doctor
appointments and treatment sessions, pushing all other normalities of life to the periphery. This period, post-diagnosis treatment or waiting for treatment results, is what Hauge (2016) refers to as “time beyond control.” This is a period of time of heightened vulnerability. However, many participants in Huage’s study returned to work, changed their diet, or continued/started exercise as a way to reclaim identity or start to construct a new narrative for themselves. Hauge refers to this period as “taking control of time.” In the case of the patients seen at the research site’s supportive care medicine department (SCMD), many utilized several of the same strategies. However, differing from Hauge’s sample, many of the patients at the cancer center focused on complementary therapies to help reconstruct identity, narrative, and re-order their lives.

Mulkins and Verhoef argue that some patients go through a transformative process when incorporating complementary therapies into their treatment plan. The holistic nature of complementary therapies and aspects of self-reflection sparked by therapies such as yoga, can perhaps help patients to navigate the ubiquitous cancer messaging and discourse, as well as the oncological biotechnical embrace, empowering patients to place cancer within the broader context of their life, instead of at its center (Good 2001; McMullin 2016; Mulkins & Verheof 2004).

The ways in which individuals perceive and experience the social and material environment around them have been studied by philosophers, anthropologists, and others through the theory of phenomenology, a theory of experience and perception (Ram & Houston 2015). Utilizing a theory of phenomenology to guide ethnographic field methods can enrich how we understand people’s lives, concerns, and engagement with their daily realities, whether cultural, biological, psychological, economic, political, sensorial, or environmental (Desjarlais & Throop 2011). Through this perspective, anthropologists have been able to apply the theory of
phenomenology to such topics as embodiment, sensory perception, intersubjectivity, sense of place, as well as illness and healing (Katz & Csordas 2003; Ram & Houston 2015). Medical anthropologists are a group that have taken particular interest in phenomenology (Ram & Houston 2015), and have continued to utilize a phenomenological perspective following the lead of prominent anthropologists Arthur Kleinman (1980;1997) and Byron Good (1994). The work of Kleinman and Good applied phenomenology to healing rationalities and experience, and began to apply this type of analysis to Western biomedicine. Medical anthropologists today counter the reductionist approaches in Western biomedicine by incorporating a phenomenological perspective to study holistic forms of healing that approach illness as an experiential and subjective event (Kaufman 1988), such as the transformative process described by Muklins and Verhoef.

The transformative process described by Mulkins and Verhoef is a phenomenological shift in cancer patients that unfolds through four steps: 1) looking at other options; 2) doing the inner work; 3) witnessing a shift in well-being; and 4) seeing the world through new eyes (center (Muklins & Verheof 2004). Not all patients may experience this transformative process, but for those who do it can result in a new perspective on, and command of, their illness. This phenomenological aspect of complementary therapies is missing from most studies evaluating their efficacy. Although this process may be difficult to capture through a RCT study design, ignoring its presence overlooks the therapeutic effects on wellbeing and quality of life. An anthropological approach, and taking a qualitative research perspective when working with cancer patients using CAM therapies can help to complement clinical trials already being conducted on the efficacy of CAM therapies. Moreover, qualitative research on the experiences of cancer patients in the SCMD at the cancer center could help anthropologists and other
professionals in medicine and public health learn how CAM therapies influence or effect the transformative experience described by Mulkins and Verheof or how these types of therapies aid in identity reconstruction and adapting discourses of hope when biomedical treatments fail to meet patient needs. By using a phenomenological approach to examine CAM use among cancer patients in SCMD, this study can aid the shortcomings of RCTs by collecting qualitative data that reinforces the emphasis on the therapeutic effects on wellness and wellbeing provided by these therapies.

**Patient-Physician Encounter and Complementary Therapies**

Complementary and alternative therapies can be a contentious issue among bio-medically trained healthcare providers. Because of this, patients may be utilizing CAM therapies, but not disclose this to their healthcare provider (Davis, Oh, Butow, Mullan, & Clarke, 2012). Moreover, poor communication between patient and physician, or even physician and CAM practitioner when coordinating care, can leave patients with the responsibility of navigating their illness and treatment (Stub, Quandt, Arcury, Sandberg, & Kristoffersen, 2017).

Productive communication is an essential part of the patient-physician encounter. This includes not only discussion of medicine, but also the intonation used as well as any subconscious beliefs or underlying meanings that may not come to the fore (Kuipers, 1989); this type of communication is especially important when patients are utilizing CAM therapies. Integrative oncology seeks to place the patient at the center of his or her own care right from the start. This type of care introduces a new dynamic to the patient-physician encounter. First it is important to determine why patients are choosing to use these therapies and what their expectations are in regards to what role CAM therapies will play in their treatment. Patients may choose to use complementary treatments for a multitude of reasons such as, 1.) dissatisfaction
with conventional care that “destroys” inside the body instead of boosting its natural defenses; 2.) mitigating treatment side-effects and cancer-related symptoms; 3.) preference for emotional and humanistic care; 4.) increased quality of life; 5.) a view that complementary treatments are a last resort; or 6.) to gain more control over their treatment (Aronowitz 2007; Axtner et al., 2016; Davis et al. 2012). Effective communication about complementary therapies and disclosure of this treatment, however, may be very dependent on the relationship a patient has with their physician (Stub, T., Quandt, S. A., Arcury T. A., Sandberg, J. C., & Kristoffersen, A. E. 2017). However, physicians with limited to no knowledge of CAM therapies thought that patients were using CAM as a cure for cancer (Stub et al., 2017). These assumptions can put a strain on the patient-physician relationship and facilitate misunderstandings. Mette Terp Hoybye and Tine Tjornhoj-Thompson (2014) discuss the concept of mutual recognition in their study of encounters between patients and physicians during cancer care. Here mutual recognition refers to the desire to be acknowledged and affirmed by another through caring communication (i.e. listening, understanding, accepting, tolerating, and confirming the individual). Treating patients as more than simply a medical record, and forming a therapeutic relationship where patients are brought in as an active participant of their care, is an important aspect for frameworks of care that shape positive outcomes and maintain a patient’s sense of self after cancer treatment (Huage 2016; Hoybye & Tjornhoi-Thompson 2014; Kaiser, 2008; Mulkins & verheof 2004; Stub et al. 2017).

Complementary therapies add another layer of complexity to the patient-physician encounter due to possible negative perceptions of physicians regarding these types of therapies. Physicians may not inquire about complementary therapies, and if patients sense possible disapproval by their physician, they may not inquire about or disclose their use of
complementary therapies (Davis et al. 2012). However, physicians may attempt to branch out from the paradigm of conventional biomedicine to enter into integrative patient-centered care, and by doing so have an opportunity to support and encourage a transformative process in their patients (Mulkins & Verhoef 2004; Thompson & Nichter 2015). Therefore, physicians trained in or familiar with CAM therapies can illuminate patient expectations of these therapies and be able to communicate with and refer patients to these types of therapies more effectively, thereby engaging patients in dialogue, making them an active participant in their cancer treatment (Ben-Arye et al., 2015; Marchand, 2012; Stub et al., 2017). Anthropologists can play an important role in promoting open communication and collaboration in the patient-physician encounter through trying to understand the phenomenological aspects of complementary therapies and patient transformative processes through the use of these therapies. Anthropologists can also promote CAM practitioner-physician communication, acting as a cultural broker to encourage the use of integrative cancer care (Thompson & Nichter 2015).

Conclusion

This study seeks to better understand CAM use in an oncological setting. To do so, three fundamental questions will be addressed; 1.) For what reasons do patients seek CAM therapies as part of their cancer treatment and what gaps do these therapies fill in the biomedical cancer treatment system? 2.) What effects have CAM therapies had in the process and experience of patients undergoing cancer treatment, and how do patients perceive the efficacy of these treatments? 3.) How do patients undergoing CAM therapies perceive and describe their illness? By using an anthropological perspective this study will contribute to the literature through the addition of patient motivations for the use of CAM therapies, analyzing discourse around the “fight” against cancer, as well as a phenomenological examination of the therapeutic and
transformative process that patients utilizing CAM therapies may experience through their cancer treatment.

This study cites a vast literature incorporating integrative medicine, oncology, as well as linguistic and medical anthropology. Using literature from various fields helped to form the questions for this study, and address the gaps and some of the ways in which these fields may work in tandem. While much of the integrative medicine and oncology studies relied on a largely quantitative and control trial approach, the linguistic and medical anthropological studies contextualized the biomedical approach of these studies through history and a qualitative approach. This study sought to utilize conversations on the discourse of cancer and foundational medical anthropological works to broaden how and what questions were asked about CAM therapies and how/why patients used them.
CHAPTER THREE: LOCATION AND STUDY DESIGN

Research Setting

This study was conducted throughout the spring and summer of 2018 in the Supportive Care Medicine Department (SCMD) of the cancer center, which provides various resources for outpatients, inpatients, and their family members. Oncologists can refer patients to the SCMD at any stage of their cancer, from diagnosis to advanced stages. Supportive care medicine aims to minimize the negative impacts of serious illness, and seeks a holistic form of care addressing the physical, emotional, social, and spiritual challenges that arise for patients and their families during cancer treatment (n.d.). Support from the department extends to patients both going through curative cancer treatment and hospice end-of-life care. The philosophy of supportive care medicine is to consider the well-being of the individual, moving focus away from the disease itself, and exploring all reasonable options for treatment (n.d.).

The resources provided are generally divided into three major categories, including: palliative medicine, behavioral medicine, and integrative medicine. The focal point of palliative medicine is pain and symptom management. However, the management expands to both the physical and emotional needs of the patient, offering both pain management and spiritual support. Behavioral medicine addresses issues of depression, sleep quality, anxiety or other psychological symptoms through psychiatric medication management and/or psychological therapies. Integrative medicine offers such services as: mindfulness meditation, guided imagery, yoga, massage therapy, and acupuncture.
This site was chosen based on the reputation of the cancer center being a high-class facility seeing a total of 60,426 patients in fiscal year 2017. The principal investigator (PI) for this study was Lora M.A. Thompson, Ph.D, a clinical psychologist in the SCMD at the cancer center who provided guidance on protocol development, protocol submission for scientific (i.e. cancer center review board) and ethical review (i.e., USF Institutional Review Board (IRB)), and recruitment of participants.

**Participants**

The sample population for this study included 13 adult patients, who had completed or were receiving conventional cancer treatment at the time, were experiencing symptoms and/or potential side effects of said treatment, and were using complementary therapies as part of their cancer care. As previously stated, the literature on integrative oncology indicates high utilization of CAM therapies by women with breast and gynecological cancers. While all participants were female, this study did not incorporate sex or gender in the eligibility criteria. However, to be included in this study, patients had to have been utilizing integrative medicine therapies (i.e., yoga, meditation, massage or acupuncture) in conjunction with, or after, their conventional cancer treatment (e.g., surgery, chemotherapy, radiation therapy, stem cell transplantation, hormone therapies). All participants were 18 years or older, were able to speak and understand English, and had no documented or observable hearing loss or speech problem that would have made it difficult to complete an interview. Participants that did not meet the age, speech/hearing, or language requirements were excluded from the study.

**Recruitment**

Clinical information systems (i.e., Capstone, Powerchart) were used to identify potential, eligible participants scheduled for a visit in the Supportive Care Medicine (SCM) and Integrative
Medicine (IM) Clinics (both clinics are part of the Supportive Care Medicine Department and SCM providers often refer their patients for IM services). The researcher then alerted the patient’s care provider of potential eligibility for study participation. If the researcher was not available to meet the potential participant, then the care provider gave the patient a flyer in order to contact the researcher if s/he were interested in participating. If the researcher was available to meet the potential participant, then the care provider would make introductions. Afterward the researcher and potential participant would meet in a private area within the SCM or IM clinics to confirm eligibility and provide study information according to a standard script. Patients who verbally agreed to participate were able to review and sign the consent form immediately.

If there was not enough time to fully review the study and the eligibility criteria (for example, researcher was asked to give up the private room, or the patient had to leave for another appointment), the potential participant was asked if s/he could be contacted by telephone or seen in person at the cancer center at another time. These possible second recruitment contacts would also follow a standard script. If they agreed to another contact, then a phone call or in person meeting was scheduled. If there had been enough time to review the study and eligibility, but more time was needed for the decision, patients were able to take the consent document home for further review, and the researcher arranged a follow-up with the potential participant by phone or in person during another appointment visit. Patients who agreed to participate were asked to return the signed written consent form by mail using a postage paid envelope or in person at their next clinic visit.

Data Collection

Data collection methods for this study was made up of 13 semi-structured interviews with patients from the SCM Department. Interviews continued until thematic saturation had been
reached. After in-person written consent had been collected, the participant was asked if they would like to immediately complete the in-person interview, or would like to schedule it for a future date. For in-person interview, a private room in the cancer center was utilized as a quiet space to conduct interviews. If an in-person interview was inconvenient for a participant, the participant was offered a phone interview. All interviews lasted approximately 30-45 minutes and were audio recorded for the full time. For participants returning consent by mail, they chose to schedule an in-person or telephone interview. If more convenient for participants, after verbal agreement to participate by phone, patients were allowed to choose a future day/time for an interview and were advised that this scheduled interview day/time was tentative and only confirmed once the consent document was received, as no interviews were conducted prior to receipt of the signed informed consent document. In the event that a participant was unable to complete the full interview (e.g., time constraints, becomes ill), they were given the option to complete the remaining part of the interview in person or by phone at another time.

**Measures**

Interview questions sought to address the patient’s motivations for use and thoughts on the role integrative medicine therapies in regards to managing their symptoms or their overall quality of life. Interview questions also sought to understand patient’s reasoning for seeking out CAM therapies, how patient’s found out about CAM therapies (i.e. referred by their physician or discovery through another avenue), patient’s experiences using complementary therapies, patient perceptions of the efficacy of the therapies, and if using these therapies have changed the way in which patients perceive or describe their illness. During these interviews (see Appendix A for interview guide), patients were asked to elaborate on their conventional cancer treatment, what aspects of CAM modalities they viewed as beneficial during their illness experience (i.e. time
spent with practitioner), finances and insurance involved in their care, and how they felt these therapies had impacted their overall quality of life, in regards to physical, mental, and emotional health.

Data Management & Analysis

Analysis for this project was made up of the data collected from semi-structured interviews with participants. Interviews were transcribed verbatim and analyzed through an interpretive approach using discourse and narrative/content analysis (Bernard, 2011; Markovic, Manderson, & Quinn 2004) to develop codes that were then group into themes. These themes were, in turn, used to examine the language used by SCMD patient to describe their illness and experiences using CAM therapies. Another goal of this analysis was to identify patient reported outcomes of supportive care therapies as a way to manage symptoms of cancer and side-effects of cancer treatment, or examine the transformative process in their cancer care. Lastly, analysis sought to identify perceptions of complementary therapies and to generate patient reports of the efficacy of supportive care therapies. A codebook was developed to record and define each theme. All themes were color coded and had a corresponding numeric code for ease during analysis of transcribed interviews. Development of codebook and coding of transcripts was done by the researcher.

Ethical Considerations

The development of the methods and study designs for this research were done in accordance to the ethical standards of the American Anthropological Society (AAA), and was reviewed by both the Institutional Review Board (IRB) of the University of South Florida and the Scientific Review Board of the cancer center. The potential risks for participants of this study

1 IRB #33608
were deemed minimal. The participants of this study were at no risk of physical harm. However, the risks of emotional discomfort when discussing sensitive topics relating to cancer and its treatment were considered. These concerns were weighed against the benefits of the successful completion of this study, and deemed acceptable. Participation in this research study was optional, and participants could choose not to answer questions in interviews that made them uncomfortable, and could decline participation in the project at anytime. This includes after the consent process was complete. In an effort to ensure confidentiality, pseudonyms were used for all participants. Moreover, no demographics or clinical information were collected as part of the study.

The insights gleaned from this study on patient motivations for using CAM therapies, the role CAM plays in cancer treatment, and how these therapies may change the ways in which patients perceive, experience, and describe their illness will be essential elements of future cancer care. Getting data on potential positive impacts on the quality of life in cancer patients, is not only important for the promotion of these types of therapies in future use, but also to make them more accessible through coverage from insurance providers. Lastly, qualitative evidence supporting CAM therapy use by SCMD patients provides data for other institutions to adopt this as a standard of practice. Increased adoption of integrative oncology techniques by prominent institutions will, hopefully, ultimately lead to long-term changes in health policy and conventional cancer treatment.
CHAPTER FOUR: THE DIAGNOSIS

Introduction

The next three chapters of this thesis will discuss the results of the study at the SCMD of the cancer center. Each chapter will focus on a specific theme that emerged from the coding process of the interviews. The themes were developed to follow the sequence of stages through the cancer journey experienced among the participants in this study. The stages are as follows: the diagnosis, the therapeutic process, and lastly, returning to a new normal. Each chapter will correspond to a stage in the cancer journey, with various recurring themes throughout all the stages.

The analysis of interview data seeks to bring together the areas of inquiry of this study: quality of life, motivations for using CAM therapies, and patient-physician interactions to address the guiding research questions of the study. To reiterate, there were three fundamental questions asked at the beginning of the research process: 1.) For what reasons do patients seek CAM therapies as part of their cancer treatment and what gaps do these therapies fill in the biomedical cancer treatment system?; 2.) What effects have CAM therapies had in the process and experience of patients undergoing cancer treatment, and how do patients perceive the efficacy of these treatments?; and 3.) How do patients undergoing CAM therapies perceive and describe their illness? This chapter will address patients’ experience of diagnosis, and interactions with their physicians and CAM providers. The upcoming section will discuss the role that CAM therapies played in conventional cancer treatment as well as some of the gaps they fill. The next chapter will emphasize the physical and mental benefits that many participants
experienced from using CAM therapies. The last chapter of analysis will detail participants’
steps to return to normalcy in their daily routine and their struggle with identity and what it
means to be a cancer survivor.

The Surprise of Diagnosis

Susan, a pseudonym I have given her (pseudonyms were given to all study participants),
a woman in her mid-thirties, was the first person I interviewed. We sat in a small private office
and made small talk as I set up my interview recorder. I started by asking Susan to discuss her
experience when she was first diagnosed, and what her diagnosis was.

I was diagnosed in July of 2017 with stage four metastatic breast cancer. I thought I was a
pretty healthy person, I’d exercised regularly, had a good diet and everything, so it was a
real shock. I mean I didn’t know anything about cancer to begin with and then to find out
(stutters) it was the incurable kind was, uhm, was really hard to deal with.

A theme that shines through not only discussions with Susan, but other participants as well, was
shock and surprise at the diagnosis of cancer. Morgan, another woman in the study, echoed these
feelings of surprise stating: “It was quite a surprise. An unpleasant surprise. I felt terrible, I don’t
know how to describe it. I felt really terrible.” In Susan’s case, she believed that she was a
healthy individual following all the appropriate diet and exercise recommendations for a healthy
lifestyle. Susan also described her experience with her doctor and breast self-examinations:

I went to the doctor regularly, but never felt any lumps, never did any scans. I
had…uhm… I had asked my doctor at my appointments just a couple of months before
‘when do I need to start getting a mammogram,’ and she was like ‘don’t worry about that
until you’re 40” so I was a little angry that no one had never thought to test for
anything… not they…uh… not that they really had a reason to.

For many women, the age to start considering mammograms starts around 40 years old, if there
is no prior history in the family, as Susan’s doctor told her. However, what does this mean for
women that get diagnosed significantly younger than this baseline? For Susan, this meant
constant reflection on something she could have done differently, some sign she could have been looking out for, or something that could have tipped off her doctors.

Almost immediately after their diagnosis, many of the women began their treatment, often receiving information at an overwhelming pace. Meghan describes her feelings of receiving information for her treatment, saying: “...honestly when they give you all that information it kind of goes in one ear and out the other because you are so overwhelmed.”

However, women such as Alice hit the ground running meeting their treatment with intensity and resolve. In our discussions Alice described to me her diagnosis experience stating:

...of course I cried the first time, but as soon as I went back home I talked to my husband and he cried too... so uhm I start getting all the information and where I will get my treatment, and he told me to slow down. I said no, because if I slow down I die.

For many women in the study, slowing down wasn’t an option. Conventional cancer treatment is often a barrage of appointments and seeing specialists for chemotherapy, surgery, radiation, etc. that can last for months, or for some, years. Because of this, the interactions and relationships that a cancer patient develops with their physicians and allied health providers is extremely important for the therapeutic and healing process.

**Physician/Patient Interaction**

Jessica had a particularly interesting interaction with her physicians during her diagnosis. She explained to me that her reaction to the news that she had cancer was nothing short of a panic attack. Apparently such a panic attack that doctors at the hospital she was in admitted her to the stroke ward to spend the night. She elaborates by telling me:

...the pathetic thing was that they were like ‘oh, she’s just anxious,’ so they gave me nothing. So I spent overnight in the stroke ward having to kind of deal with it...and then I said well I better chill out or they will never let me out of here.
Jessica, after learning that she had breast cancer, was left to deal with the realization alone in the stroke ward. It is this type of incident that can quite possibly have negative effects on health outcomes for cancer patients. Not only that, but it can severely damage the relationship that patients have with their physicians. However, Jessica adds that she did have physicians throughout the duration of her treatment that were helpful in many different ways.

Michelle, another participant in the study, was from the very beginning of her treatment told that the life expectancy of her particular type of brain cancer was 3 months. Issuing this life expectancy to Michelle sparked her complicated relationship with her doctors. Michelle and I discussed her reaction when she was told she only had a few months to live, she said the following: “I was like you’re only going to live 3 months; I don’t know about you, but I’m going to live longer than that….they talk to you in a way that I don’t think is right because they put that in your head.” Although Michelle had many positive things to say about her physicians, as the interview progressed it seemed that her complex relationship with physicians also was in some part due to the fact that Michelle was raised to depend on natural therapies and not Western biomedicine.

Michelle told me stories of her many years of treatment, particularly a clinical trial she was a part of. As the trial progressed she began to have serious reactions to the medication. Her and her family advocated for a switch back to the drug that had produced remarkable shrinkage in the size of her brain tumor and that produced little to no side-effects. However, she expressed her frustrations to me about her conversations with her doctors during that period. “I said, ‘I am super sensitive, I’ve never taken medications a day in my life until I was diagnosed with cancer. Can’t you do a cycle by your body weight, can’t you do less for me? [They were like] no, no this is FDA approved so we have to follow, blah, blah, blah…” Michelle continued to be frustrated
with the rigidity and by-the-book attitude of many of her physicians. She described this to me as I asked her if the doctors had addressed her use of CAM therapies and surpassing her life-expectancy by years.

It’s been difficult to navigate because the FDA says you have cancer so you cut, radiate, and go on medication, that’s what you do…. So if you bring up things like I juice, you’ll get ‘well that’s not proven, you shouldn’t just live on juice alone.’ Well I don’t live on just juice alone, I incorporate that into my healthy eating habits. So they are not necessarily on board with it, but I don’t care because it is my own life…

Although Michelle has always relied on CAM therapies for her health, she firmly believes that her use of CAM, healthy eating habits, and daily exercise have been major contributors to not only exceeding her life expectancy, but also overcoming many of the side-effects from her treatment. She also discussed with me that her use of the therapies at the SCMD department at the cancer center have been to help work through some of the negative experiences she has had with her physicians.

**CAM Practitioners in Cancer Treatment**

For some of the women in the study, engaging in yoga, massage, acupuncture, meditation, and other forms of complementary therapies were an obvious addition to their care because they were engaging in these types of activities before their cancer diagnosis; in fact, seven of the study participants had tried or continuously engaged in at least of the therapies prior to their diagnosis. The most popular was yoga. However, these therapies were often seen as separate to their conventional cancer treatment and more of an avenue of healing and addressing the side-effects of treatment. While in the next chapter I will discuss how these therapies impacted their physical health, mental health, and recovery. In the following section I will discuss how patient interaction with various practitioners of yoga, massage, and acupuncture at
SCMD impacted overall health outcomes for patients and the initial difficulties patients had in connecting with these services.

As Jessica discussed with me her experiences in the stroke ward and other interactions with her doctor, two aspects that differentiated a good experience from a bad one were trust and time spent with the patient. Jessica had seen her chiropractor throughout previous years for various injuries, and also chose to use chiropractic adjustment during her cancer care for issues she was having with her shoulder. I asked her why she chose to use chiropractic adjustment, to which she responded, “I had known him for years because I had had some problems with like arthritis and neuropathy...I trusted him to do that to where he wasn’t going to screw up anything.” In conjunction with chiropractic adjustment, Jessica was using massage; a service offered at SCMD. Although we discussed many of the benefits of massage, Jessica mentioned that there was another layer of her time spent in massage therapy that was just as important in the healing process, “...doctors are very limited in the amount of time they can spend to talk to you these days, and while she’s [referring to massage therapist] doing the massage other things come to your mind that you can just throw out there and see if she has any suggestions.”

Because massage therapy offers a relaxing environment and is often in thirty minute to one hour sessions, Jessica had time to talk to her massage therapist about other complications or interruptions in her daily activities that she may have been experiencing. In Jessica’s case it was sometimes self-massage techniques she could do on her own if she could not schedule massage appointments for certain weeks, but other times it was suggestions to take her baths in the evening time instead of the morning, for relaxation and better sleep. Susan had a similar experience with her acupuncturist. During our discussion, Susan talked a lot about nutrition. It had always been a priority for her, and that did not change during her diagnosis. Because of this,
Susan mentioned to me the positive influence that the advice of her acupuncturist, who is by training a Doctor of Oriental Medicine, at SCMD has had on her dietary concerns.

Both Susan and Jessica discussed the extensive benefits that they received from the CAM therapies offered at SCMD. Several study participants, Susan and Jessica included, expressed frustrations in trying to find these services. For many, finding these services was done on their own accord from their own research or with the help of a family member. Julie, another participant in my study diagnosed with breast cancer, stated,

I went on the website, they don’t tell you this uhm your oncologist, the surgeon, the radiation person, they don’t tell you about these other options that [the cancer center] offers, which is a real shame… I said to both the oncologist, surgeon, and the radiation person, ‘you guys should be telling people about these things’.

Social workers played a critical role in the connection to services. Not only connection to SCMD services, but also to support groups and other behavioral health services. CAM providers also connected patients to other therapies within the SCMD network. That being said, it seems that the services provided in SCMD need to be better advertised to physicians that can then inform their patients, or they should be incorporated into the after treatment plan given to patients. Jessica discussed her surprise that these therapies were absent from the plan she was given.

I got something from [the cancer center] later like maybe… it was a long time later. It was like a plan after treatment therapy plan, like a plan for what was going to happen. And I was kind of shocked because there really wasn’t anything on there that involved this office or involved you know… I don’t know I just thought it would be on there.

Promoting these services for patients to use in conjunction with or after their conventional cancer treatment is particularly important as the practitioners at SCMD are specifically trained in how to deal with oncology patients and the treatment side-effects that many of them experience. This is one aspect of the SCMD services that many participants of the study mentioned. For example,
Susan discussed with me a somewhat traumatic experience she had while trying to continue pursuing yoga after her diagnosis.

I had done yoga before for years. Uh and actually had a meltdown in a yoga class right after I had been diagnosed. I thought ‘oh I’ll try yoga and it’ll feel good,’ and then we did a pose that…it just hurt and I couldn’t… I wasn’t able to get off the floor… it was not a great experience.

Susan continued to explain how things had changed since she had started using the yoga services at SCMD.

...being able to do it with someone that is trained in oncology and kind of [knows] what is going on with the cancer patient’s body so that she has that extra knowledge of how to modify things in an appropriate way I think it [is] really valuable.

Laura, echoed these same sentiments in our discussions in reference to the massage therapist she was seeing at SCMD.

...she has had quite a bit of training. I think there is a big difference between people that do it, because I have tried somebody in [name] and [name] and it’s not the same, I mean that same benefit.

The extra knowledge that these practitioners have is not only valuable in the sense that it provides patients with physical and mental benefits, but it is also necessary for their safety.

However, for some individuals such as Brittany and Shelby, who participated in group yoga classes, the times offered for yoga at SCMD were not convenient for their schedules. During our conversations I asked them if she ever felt uncomfortable in yoga classes not necessarily geared toward cancer patients. Brittany responded with the following.

...I’ve been doing yoga long enough that you just don’t do anything you’re not comfortable with. I don’t do the hot yoga classes or anything like that. Because of my back metastases I don’t do all the like head stand stuff if they do that in a class. So I have never felt uncomfortable…

Shelby echoed this by stating: “...there are all different types of yoga though, and I know which type of yoga is for me. So you know I usually go to classes suited for what I can do
successfully.” So while individuals like Brittany and Shelby successfully combined the services offered at SCMD and others outside, other individuals, perhaps those less experienced or acquainted with the type of therapies offered at SCMD, relied on the oncological expertise of the CAM practitioners to carry out therapies safely and appropriately.

Conclusion

The discussion of physician/patient interactions is not meant to be polemical, disparage physicians, or compare them with CAM practitioners. Many of the women in this study had positive things to say about their physicians and the care that they were provided. As one participant, Morgan, stated,

I trust the cleanliness, I trust the people… I know it is against all common sense, but it makes me feel good. I think because I trust the people here, because I have had a good experience here. Uh… you don’t feel like a big nothing in a big machine.

This discussion highlights and emphasizes the importance of the relationships between physicians/practitioners and patients, and the impacts they can have to health outcomes for patients. Nevertheless, doctors hold the primary role of treating the cancer in the body. The interactions between CAM practitioners and patients, and the therapies themselves, were a very important aspect of the physical and mental healing process of patient. The next chapter will elaborate on CAM therapies’ role in the healing process.
CHAPTER FIVE: THE THERAPEUTIC PROCESS

Introduction

This chapter will address both the first and second of the three research questions of this study: 1.) For what reasons do patients seek CAM therapies as part of their cancer treatment and what gaps do these therapies fill in the biomedical cancer treatment system? And 2.) what effects have CAM therapies had in the process and experience of patients undergoing cancer treatment, and how do patients perceive the efficacy of these treatments? The sections of this chapter are divided into the several aspects and benefits of the therapeutic process. The first section will detail the various treatment side-effects and other symptoms that patients experienced throughout their treatment. The second section will discuss various CAM therapies that patients in the SCMD department engaged in and the physical benefits of said therapies. Next, the benefits to mental and emotional health will be laid out. Lastly, this chapter will tie together these different aspects of the therapeutic process with a discussion on how the CAM therapies used by study participants changed their outlook on life and decision-making.

Cancer Treatment & Its Side-Effects

Individuals with friends or loved ones that have gone through conventional cancer treatment, or those that have been through it themselves, can attest that cancer treatment is hard on the body and takes a toll. Among the participants of this study the frequency and the severity of treatment side-effects varied, but there were certainly side-effects that were common among the group. For example, many participants of the study struggled with fatigue, nausea, loss of hair, pain in the bones and joints, neuropathy in the feet and/or hands, and lymphedema. These
main side-effects were also often paired with each other and/or other types of cancer or treatment-related symptoms. While some individuals had very few side-effects, others like Michelle, experienced so many that she wrote them all down before our interview. During our discussion Michelle read me a list of side-effects she had experienced that sounded like the end of a pharmaceutical commercial, “...diarrhea, extreme tiredness, weight loss, I was irritable, had to urinate frequently, loss of appetite, fever, weakness, sleeplessness, eyesight change, muscle weakness, vomiting, nausea…” However, these were relatively minor compared to the more severe reactions she had to some of the early medications she was prescribed, such as an immunotherapy drug that caused such an imbalance in her liver enzymes that is was like she had hepatitis, or the steroids that shut down her lungs multiple times.

Two of the less common side-effects experienced by study participants were chemotherapy induced menopause and difficulty with language and memory. Jessica and Kelly both experienced a “chemopause” and expressed having difficulty managing the hot flashes and hormone imbalances caused by their chemotherapy treatments. Moreover, Laura and Kelly both experienced minor changes to cognitive abilities. Laura mentioned to me that she had trouble pronouncing words occasionally post-treatment, which was demonstrated during our discussion. “Right, uhm, after the mastectomy I had reconstructive (had trouble pronouncing the word) surgery, sorry that is another chemo problem, some of the time things don’t come out right, I’m sorry.”

Kelly is a speaker of English as a second language, but at a native level. I asked her if she thought the memory impairment she was experiencing impacted her ability to speak English. She mentioned to me some of the difficulty she had recalling certain words.
Yes it has, of course I understand everything and can express everything, but every now and then there are words that I just can’t think of in the moment… so I would say maybe my speech is not as eloquent as it was.

However, the memory impairment has not only impacted her ability to recall English words it has also impacted other aspects of her career as a professor in regards to memorizing students’ names as well as her ability to write research articles. She further explained to me difficulties she had with working.

Well for one I have a hard time sitting. So working on my computer is very difficult. I have to lie down and readjust and get up all the time. Uhm interrupt my workflow quite a bit… I can’t work for long periods of time on my computer anymore.

For Kelly and other study participants, the side-effects from treatment and other symptoms were a hindrance or interrupter to their daily activities and relationships with family members. Alice was forced to stop driving and Meghan had to plan her day so that important things were done before she hit a “wall of fatigue” as she described it. In our discussions she stated,

I know in the beginning it was definitely a choice of what I wanted to do, I had to make choices uhm like if I did one thing I couldn’t do something else. I basically had to have everything planned and done uhm if I was going to do anything or run any errands, everything had to be done by 5. Uhm because if it wasn’t done then I wasn’t going to get it done...

Fatigue in Meghan’s case made carrying out daily activities difficult because not only was she tired, but also there was a limited amount of time to get certain tasks done, limiting the amount she could do in one day. Fatigue was particularly hard on Brittany and Breanne, both of whom had young children. Brittany discussed pretty extensively her fatigue and other treatment side-effects in regards to her relationship with her kids.

...so I have 3 young children, and so particularly sometimes I’ll have to take a nap in the afternoon I am so tired. I’m able to function, but tiredness from chemo is different from regular tiredness so even after you rest…like it doesn’t go away.
Apart from the fatigue, Brittany also discussed with me some of the anger and resentment she had about cancer impeding on her relationship with her kids. Brittany was a special case as when she was diagnosed with cancer she was also 38 weeks pregnant. Because of this she could not breastfeed or hold her newborn for several weeks until after the initial phase of her treatment was complete. As a result, she had to find other ways to bond with her newest child. Breanne also experienced a change in her relationship with her children due to fatigue and other treatment side-effects.

I have two tiny children and at that point they were 5 or 6 and 2. Uhm and so they were active little people, and there were just so many things that I couldn’t do anymore. I used to be the one that gave the baths, and made dinner, and did a lot of the household responsibilities caring for them. As well as getting down on the floor and playing with them, or going outside and playing with them. The fatigue and the stress on my body from the chemotherapy, I couldn’t do most of that stuff. Mostly the second half of that 6 months, you know it is cumulative obviously. So initially it wasn’t as bad, but then as that cumulative impact grew, the second half of the chemo treatment impacted my ability to care for them and engage with them in the same way tremendously.

Study participants sought therapies to address the interruption of their relationships and daily activities in a variety of ways. In the beginning, as an attempt to mitigate some of the treatment side-effects and pain they were having, study participants Jessica and Laura at first took pain medications prescribed by their physicians. However, both Jessica and Laura became very apprehensive of these medications. Jessica explained to me that she stopped taking this type of medication because her body reacted so poorly she could not function normally throughout the day stating, “…they make me puke I don’t understand how anyone can really take… you know (laughs) stuff like that. You know because I’m under the table and really can’t function.” Similarly Laura was apprehensive of strong pain medications out of the awareness that they can be addictive. However, as the pain grew more intense her physician prescribed her a medication to help. Laura described to me her experience.
When I started on that I was fine at first and then when they started increasing the dosage it was like a blue cloud coming over me. I was like yes its hurting, but it was kind of I went through all of this to be feeling like this? It just wasn’t me, and I started reading through the side-effects and one of them was depression and suicidal thoughts. Well that scared the crap out of me (laughs).

In lieu of taking pain pills both Jessica and Laura relied on CAM therapies to help with restoring mobility and increasing their capabilities throughout the day. When I asked Jessica why she chose to engage in CAM therapies, she described her decision-making process as follows.

...when I’m looking at alternative care I’m like ‘will this help me where I have to take one fewer pill?’ Like what are the things that I can’t do, what are the daily acts of living that I need to do. I need to be able to stand up and make dinner, sleep, you know stuff like that...You know like those would be wins right you know. So, and then fewer pain medicines and you know Ibupofens or whatever.

Throughout the time that I spent with patients in the SCMD department, this was a common theme in the decision to pursue CAM therapies. Moreover, those who did engage with these therapies touted many of the benefits that they reaped, physically, mentally, and emotionally.

The following section will elaborate on these benefits.

**Physical Benefits of CAM Therapies**

The common side-effects experienced by participants of this study have been listed. To reiterate, that list is as follows; fatigue, nausea, loss of hair, pain in the bones and joints, neuropathy in the feet and/or hands, and lymphedema. Patients utilized massage therapy, yoga, meditation, physical therapy (separate from SCMD), and acupuncture to address many of the side-effects listed as well as some not listed. This section will focus on the physical benefits that patients experienced while using CAM therapies.

Table 1 below shows the use of particular CAM therapies by the 13 study participants. Many participants were interested in trying other services in SCMD, time permitting. Use of these therapies by patients varied from once a week to one to four times a month. Of the patients
that used massage, the primary concern was to address swelling from the lymphedema, as well as neuropathy and fatigue.

**Table 1.** CAM therapy use by study participants.

<table>
<thead>
<tr>
<th>Participants use of CAM therapies</th>
<th>Yoga/Meditation</th>
<th>Acupuncture</th>
<th>Massage Therapy</th>
<th>Two or more services used</th>
</tr>
</thead>
<tbody>
<tr>
<td>Laura</td>
<td>7</td>
<td>6</td>
<td>7</td>
<td>5</td>
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</table>

Laura explained to me some of the benefits that she had noticed from using massage.

> I have found that the neuropathy in a couple of days it’s not as bad and I sleep better, especially after having the lymphatic massage, uhm one visit and I was so… I could feel a difference… you know I could tell I went down size wise from the swelling and uhm some of the time could lose two or three pounds after a day of being here and sleep through the night.

Michelle also used massage to manage her lymphedema. However, she paired it with acupuncture, using a technique called venting, to reduce the intense swelling she was experiencing at a certain period in her treatment. She explained the process to me.

> I went to see the acupuncturist and he did a cool technique called venting where it vented the skin and you could see water droplets on my legs because it was venting it out. And went back again that week to get rid of that and help the side-effects move along. And of course another physician does manual lymph drainage...

Along with venting, several participants used acupuncture to address nerve damage causing neuropathy as well as GI issues. Laura and Michelle were not the only ones that experienced benefits from lymphatic massage, Brittany discussed with me the help that massage had provided for managing her fatigue, noting that the benefits last for several days. Brittany also utilized yoga and other daily forms of exercise such as swimming to manage her lymphedema.

> So yoga I think really helps because of lymphedema, I think it is just good to get exercise. I think you just need daily exercise... but I think with my back pain and stuff they [yoga and swimming] really help. If I don’t do it I can notice a difference.
Alice also engaged in yoga/meditation, not for fatigue but to help manage pain.

I think it has helped me... well I just started it, but I think it has helped me a lot because before I would have like a lot of pain. Basically I am 24 hours in pain...you know I mean I think it gives you more strength. It helped me because I don’t feel the pain as much on my left side.

As well as helping manage fatigue throughout the day, yoga/meditation also helped to increase mobility. Meghan explained to me that while the meditation portion worked on her mind, the physical aspects of yoga helped to restore her ability to carry out her daily activities, albeit in a modified way.

Because the yoga is more about trying to get the movement back into my daily activities. Uhm because I do find that there are things that I used to do before... well maybe I can still do them, but I need to modify them a little bit. I know that the yoga has been helping me with that because I have seen how you know you can still do the same thing or get the same effect but you have to modify it a bit... I mean you might be doing a movement or a pose in yoga, but it’s going to help you do vacuuming or it’s going to help you do laundry because you are using the same muscles.

Jessica also relied on therapies such as massage to help her increase her ability to perform daily activities.

So, there are like little things like enhancements, they’re not a pill, they get you through the day you know and they’re like fine tunings instead of like oh well I have to sit with my legs up all day and not do anything today.

Similar to Brittany and Alice, Julie and Kelly paired massage with various forms of daily exercise, such as walking and biking, to increase energy and aid with strength and mobility.

However, massage was their primary form of supportive care as they both described to me that massage was their only relief from intense pain. Kelly discussed with me the difficulties she was having.

...my leg is uh very stiff and swollen. In order to get some relief my husband tried to do some massage and it seemed to make a difference. And so I asked my oncologist what he thought about massage therapy, and he recommended [it]...
Well it has really helped me in my day-to-day life in that it has uh made my pain less. It has given me more mobility. And it has given me hope that with time you know if I continue doing the massage therapy that the scar tissue will improve and maybe give me more mobility in the future...massage therapy has given me hope that there is relief in sight.

Julie also turned to massage therapy for muscle rigidity and pain she was starting to experience after radiation. Massage for her was a huge relief, as she explains.

...it was like a pain all the way through up the back of my neck through my head on the right-hand side. I could just not get rid of it no matter what exercises I did. Even the ones they gave me [in physical therapy]. So I said ‘you know what, massage has worked on other muscles, why wouldn’t it work on this.’ So I went for my first session, and I gotta tell you, the first session I cried because the pain went away.

Among the participants that were interviewed, it was common to combine some form of daily exercise with massage therapy, yoga/meditation, or another service offered at SCMD. This was either stimulated by the fact that an individual engaged in daily activity before their diagnosis and it was a normal part of their routine, or because they were recommended by their provider to start engaging in more activity as part of recovery. The latter was the case for Morgan, who began to increase her activity level at the recommendation of her physicians. Along with walking she began to use the yoga/meditation provided in SCMD, with a certain amount of skepticism believing it wasn’t for her. However, after a few sessions her perspective had changed.

I think the first time I did go to yoga, I told [providers name]… I told her uh that I don’t believe it is going to do anything for me because I am not the meditation type. And when she… at the end of the session you are supposed to think of something good or wish for something good and I thought that was nonsense. It changed me a little bit. I saw... I started feeling wow uh the hour that I get rid of everything in my mind and I just concentrate on me and myself and my well-being. Uh just like one hour of watching a beautiful sunset. It makes a difference. It makes a very big difference...it makes me feel good. It makes me feel alive.

While the therapies themselves provided benefits, the time spent with the practitioners was also beneficial for patients. During many of the interviews for this study, participants
recounted their CAM practitioner giving other helpful advice to elongate the benefits of the therapies, or other things that they could do to continue improving their quality of life. Susan described to me her meeting with her acupuncturist that would also involve discussions of nutrition. Jessica described to me her massage therapist teaching her how to tape her shoulder herself when it became uncomfortable, and giving her advice on re-arranging her day for better relaxation at night. Brittany also began to perform daily yoga stretches on her own, as she could not attend a class every day. So while practitioners performed their individual specialty, they also often acted as educators in maintenance and self-care techniques. Although many participants chose to engage in the services offered at SCMD for their physical benefits, many of the therapies also provided a benefit to the mental and emotional health of participants. Analysis will now turn to those benefits, as well as the role that CAM therapies played in participants’ overall cancer treatment.

**Mental/Emotional Benefits of CAM Therapies**

From the previous section discussing the side-effects of cancer treatment, it is obvious from the experiences of study participants that conventional cancer treatment brings physical challenges. However, the mental and emotional struggles that patients face during treatment should not be overlooked. Meghan said it best during our discussion.

“I don’t believe that you can just fix the body and ignore everything else. I think that it is all connected. Uhm, I think that your body, mind, spirit all of it. I don’t think you can go through something like that [cancer treatment] and not, you know, work on the mental or emotional part of it, it just doesn’t work.

The two main CAM therapies that patients used to address the mental/emotional aspects of cancer care were massage and yoga/meditation. However Brittany and Meghan accessed other resources such as Behavioral Medicine (psychiatry/psychology) services and support groups to process some of what they were going through. Although support groups are not directly within
SCMD, they will be included in the larger discussion of mental/emotional supportive care of cancer treatment.

Massage therapy was typically a CAM therapy chosen to address physical side-effects of treatment. However, the ambiance of the room with soft lighting and tranquil music playing in the background, makes it a naturally relaxing environment. As a result, massage was strategically scheduled around other appointments and more stressful parts of treatment. Jessica in particular used this strategy; in our discussions together she described to me that she would schedule massage sometimes before her other appointments because it put her in a good frame of mind to ask the right questions of her physicians. However, other times she would schedule her massages after all of her appointments as a reward. Moreover, for Jessica massage was more than an avenue for relaxation, massage was also used as a way to get back in touch with her body, perhaps reluctantly at first, after having a mastectomy and choosing not to undergo reconstructive surgery, “I think it is changing the way that I look at my body overall, you know this is the body that you have...it gives me a chance to get in touch with parts of my body you know maybe parts I didn’t want to touch…” because of the physicality and intimacy of massage, it forced Jessica to start to accept the transformation that her body had been through. She discussed this with me at length.

...I haven’t been that queasy about not having a breast, cause I’m not reconstructed, but I can imagine for some people that might be a really big deal to look down and see a big scar or something like that. But with massage you’re touching those scars, you’re touching that part of your body you’re almost like bringing it in as a part of your body you know and it’s to the point to where I don’t feel the need to fix…it’s kind of like ‘okay’... like that’s what you look like now. That’s what the balance of your body feels like.

Through using massage, Jessica began to embody her scars and gradually accept the aesthetic changes of her body. At the same time that Jessica is discussing the intimate reconnection that
massage is providing between herself and her body, she is also explaining to me that her expectations for massage aren’t so high that it needs to fix all of her problems, but simply help to increase her mobility and take some of her physical pain away.

Yoga/meditation was another avenue in which patients could address mental/emotional aspects of their cancer care, as well as the general stresses of treatment. Susan chose yoga/mediation as yoga was her primary athletic outlet pre-diagnosis. Although the yoga she engages in currently is different than what she was previously used to, Susan discussed with me that continuing to do yoga has given her the confidence that she can still do things she enjoyed before she was diagnosed with cancer.

I had done yoga before but it had always been an athletic pursuit for me, but this is a much more mindful practice… learning how to do some of the same things that I did before but in a way that is safer... It’s giving me ways to do things that I did before just slightly modified and uh within the limitations that I have now. So that’s been really good, just knowing that I... that I can still do it, you know it’s a little different but it’s something that I can still do.

Susan is correct in her assessment of the mindfulness of the yoga performed at SCMD, as it is paired with meditation. Incorporated within the mindfulness practices in the yoga sessions are positive affirmations, likely the influence of Susan’s increased positivity and confidence. While Susan discussed with me the value she saw in continuing yoga, she also described how engaging in meditation had reframed her outlook on life.

It’s brought a level of focus, I think the meditation especially helps to just calm my mind, and we do a lot of positive affirmations and just talking about, you know, there may be a lot of things we can’t control, but there are a lot of things that we can control, and taking ownership of what those things are...when everything is so chaotic, it’s nice to come to a safe space and… everything is very serene and you have the music playing, and it’s just a very calming effect.
Both yoga and meditation helped Susan to begin to take back control of her life, yoga increasing her physical capabilities while meditation increased her confidence and belief in herself.

Lastly, psychiatry, support groups, and group acupuncture were services that Brittany, Breanne, and Meghan utilized for mental/emotional support during their treatment. Meghan in particular utilized behavioral medicine services to come to terms with the changes that her particular type of cancer meant for her ability to have a family. Through utilizing psychiatric services Meghan was increasingly able to cope with her diagnosis, “I know in the beginning I couldn’t even get through an appointment without crying because of what this particular cancer and diagnosis meant for me. Uhm, so and now I can.” Attending support groups provided a similar type of coping for Brittany. Although her cancer did not affect her ability to have a family, she was diagnosed with stage four cancer. Brittany bounced around to several support groups, as her treatment took her to various facilities. Finding a support group specifically dedicated to stage four patients proved to be slightly more difficult, however Brittany described to me the importance of the information that was presented at these groups and the value of spending time with others that were in a similar situation as her, especially individuals with children. Breanne also discussed with me the mental/emotional benefits of participating in group acupuncture sessions. Similar to Brittany, Breanne was able to build a sense of community and encouragement by spending time with individuals in a similar situation as herself.

My acupuncturist was amazing and she intentionally, though not really outwardly obvious, but intentionally put me into community treatment with two other women who were about 6 months ahead of me in their own breast cancer treatment...it kept me hopeful. It kept my eye on the goal of there being an end to the process...I heard about the success they had in ‘oh my energy is coming back’ or the improvements they were having in their return to normalcy that they had, and that kept my eye on the end goal.

Breanne discussed with me extensively the encouragement and positivity that she experienced and took away from group acupuncture sessions. She also described her use of CAM therapies
during her treatment and the fact that they have allowed her to engage with life at a level she believed wouldn’t have been possible without them. Many other participants in the study echoed these sentiments and described the role of CAM therapies as an essential support piece to continuing to live the way that they want to throughout their treatment or while building a new type of normal in their life. Morgan described how CAM therapies have helped her continue on with activities she enjoys after her treatment.

...it gives me the energy, it gives me the uh ability to continue my life almost as if I’m not ill. I really believe without all the activities here, and not only here, I wouldn’t have the energy to do what I am doing. And objectively I am doing quite a lot (laughs).

On a similar note Meghan expressed to me what she believed the role CAM has played in her overall treatment experience stating, “You know honestly without doing all of these I would not be where I am today if I didn’t do...if I didn’t add all these therapies to it [her cancer treatment].” Lastly Shelby expressed how she believed the yoga/meditation and acupuncture have decreased her treatment side-effects, increased her mobility, and given her more control over her life. However, she emphasized that the biggest role that CAM therapies have played in her cancer treatment has been in increasing her overall ability to cope with her treatment, she stated: “...it makes me believe in myself that I can cope with this current treatment plan that I am on, and when it no longer works I have confidence that I will be able to meet any challenge of the next treatment.” So while the role of CAM therapies varied for all the participants in this study, many expressed the value that they added to either increasing their mobility or physical capabilities, providing emotional support through either conversations with the practitioners themselves or the community of patients, or providing a positivity and change in mindset to aid in persevering through the rest of their treatment.
Conclusion

This chapter sought to highlight the treatment side-effects and other cancer-related symptoms, such as fatigue, lymphedema, or neuropathy that study participants experienced throughout the duration of their treatment. Moreover, to address these side-effects study participants relied on various forms of CAM therapies to address both physical and mental/emotional difficulties of their treatment. The analysis of the study data in this chapter emphasized the role that CAM therapies played in the broad treatment and support regimen for patients and the benefits that they provided. In the next chapter the discussion will turn to participants trying to return to a “normal” life. This includes continuing to examine how participants’ perspectives on life and decision-making has changed since their diagnosis, struggles with identity and being a cancer “survivor”, as well as external factors such as insurance that can hinder participants’ abilities to continue utilizing the services within SCMD.
CHAPTER SIX: PIECING TOGETHER A NEW NORMAL

Introduction

After the rush and chaos that is conventional cancer treatment, some may feel at a loss with what to do afterward, how to continue progressing with their care, or how to start putting their life back together. During interviews with several study participants, these were only some of the many concerns that were expressed. In this last chapter of analysis, the third and final research question guiding this study will be addressed; how do patients undergoing CAM therapies perceive and describe their illness? The sections of this chapter will focus on how participants’ perspectives on life and decision-making changed post-diagnosis, what their life has been like after conventional cancer treatment, struggles with identity and the “fight” against cancer, as well as the stressors and gaps that were left in post-treatment care and support.

Post-Diagnosis Perspectives and Decision-Making

For many of the study participants cancer had inserted itself into the middle of their lives putting careers on hold for some and pushing most other activities and responsibilities to the periphery. Going through cancer treatment also had a profound effect on participants’ perspectives on life and their decision-making. In many cases a change in perspective on life came with the realization of the fragility of life, or in some cases the realization that patients had a limited amount of time left to live. Kelly was very upfront with me about her time to live, “My cancer is pretty deadly. I mean it’s cancer. So uhm I’m reminded every day, or I remind myself every day that I don’t have much longer to live.” Both Meghan and Breanne echoed similar
feelings about their situations and discussed with me their transformed views of life and time.

Meghan stated,

My perspective on everything is pretty much different. I could say that I’ve always thought certain things or have said certain things before, but didn’t live it... Whereas now, I guess you don’t live it because as you think ‘oh I have plenty of time to do that’ kind of thing, I would say everything changes when you get a cancer diagnosis, because you realize that there is a finite amount of time.

Adding to this, Breanne discussed how she views her new found realization of finite time.

I engage in life now with a level of gratitude that I didn’t have before. Uhm, like a level of mindfulness and gratitude in simple daily things uhm in my relationship…you know every once in a while I look around and I am just so appreciative to be here…

Along with a change in perceptions of time came a change in the decisions that study participants were making and how they thought about decision-making going forward in their life. For Shelby, prioritization of her decision-making was focused around her relationship to friends and family, as well as pushing to make goals and aspirations a reality. Susan discussed with me how her change in perspective since her diagnosis has focused on prioritizing her decision-making on things that make her happy and that she feels will add to her life. She contrasts these decisions with those she made in her pre-diagnosis period that may have revolved around doing things to please others. In this regard, she referred to her new decision-making as, “...empowering in a strange way.”

Meghan discussed changes in her decision-making in regards to her career trajectory.

I’m looking for another job, and you know, there are lots of things that are going to have to change because of what has happened in the last year. And I also, as far as work and things, uhm I look at them in a more uhm like I want it to mean something, I want to give back. I don’t just want to be a robot that works kind of thing.

For Meghan, the limited time that she spent working took on a new meaning. However, Meghan was not the only study participant that re-evaluated her career and what the future had in store.
As a professor, Kelly discussed with me struggles she was having continuing to conduct research and what it meant to her as her career shifted with her diagnosis.

So on one hand no my research is not as important anymore because my careers plans are no longer very rigid and with a specific kind of focus because I don’t know how much time I have. Uh, on the other hand I do enjoy my work, but in other words I don’t push myself on the research end anymore like I used to...so it is more of a positive experience.

Breanne, like Kelly, changed her job prioritizing her health and happiness.

I uhm totally changed not my profession, but what job I was in because I just felt like I was not... there were a lot of things about my previous job that were draining and exhausting and were not healthy and were really weighing me down. So I decided to get out of that job and to move on to something that was healthier and a more fulfilling job for me.

Meghan, Breanne, and Kelly changed their perspective on work to prioritize the fulfillment that they received from it instead of work for works sake. This was a common theme among many study participants, such as Brittany, choosing early retirement to spend more time with her children. Moreover, Breanne also made changes in her decision-making that focused on family. For her, although her outlook was good and she is still in remission, she planned for a time when she may not be there for her children.

...sometimes I’ll make decisions in preparation… small things like if I wasn’t here at some point...So like the other day for example I bought a book on helping… it was a little book for my daughter on helping to uhm figure out relationships and friends and navigating the world of popularity that often comes up when girls… well when kids in general move up from middle school to high school. So like I still would have bought that book anyway, but I bought it now because I feel like I prepare a little earlier now, because I really want her to have this so I’m going to get it now.

The changes in decision-making as well as coping with the trials and difficulties that come with cancer treatment can be overwhelming when trying to move forward with your life. To aid in this process the cancer center offers a class called Transitions specifically targeted for patients having difficulty trying to return to a “normal” life. As Meghan told me, “You’re almost kind of in a different world once you have a cancer diagnosis uhm and it’s a little odd sometimes to get back
into regular everyday life…” Given that cancer patients find themselves in a “different world” some study participants struggled with how their diagnosis changed their lives and being labeled a survivor in the “fight” against cancer.

Identity

In regards to identity, it is important to discuss how study participants viewed their illness, or whether they identified themselves as ill at all. Michelle and Alice did not see themselves as being sick or having an illness. Michelle explained to me that this viewpoint for her is to facilitate positivity and prevent unnecessary negativity, “…constantly putting that negativity in your body saying oh I have this, I was only given this much to live. Whereas I say, I don’t have cancer. I don’t have any more brain tumors in my head, you know and just go on and enjoy my life…” Alice echoed these sentiments stating that she continues to move through her life as if she weren’t sick and focus on the positive. However, with the treatment side-effects that Alice experiences, she explained that it can be difficult on occasion to move on from her diagnosis, “It reminds me that I have a condition, that I have cancer when something hurts, when my side hurts real bad, or when I want to do certain things.” Alice addressed her side-effects and the long length of her treatment admitting that she feels she is slowing down from her normal rapid pass of life.

... I understand why, it’s been long since I’ve been getting the treatment. So I talk to myself, “yeah [says her name] it’s understandable, it’s been 3 years nonstop, I’m only human.” I try to enjoy it the most that I can, I don’t get depressed because of that, because I am grateful, but I know I am getting more tired and I’m slowing down. I wish I could do more things, but I am doing the things that I enjoy.

Alice recognizes the limitations and difficulties of her condition and has resolved to continue living her life the way she sees fit. As she told me during our discussions, “You cannot change your personality based on having a condition.”
Another study participant, Breanne, struggled with her identity as a cancer survivor specifically in regards to the discourse around the “fight” against cancer. She discussed with me at length her views on survivorship, the healing process, and how she believed those concepts conflicted with contemporary discourse on cancer.

...there is a lot of talk and theory around, especially breast cancer, about fighting it. Like you’re going to fight it, and you’re going to beat it. I didn’t ever identify with that because to me that felt like fighting against my own body. The cancer obviously was uhm you know something that was bad, and it was in my body, but it was also my own self like it was also part of my body. So I really felt like from the beginning it wasn’t about fighting it was about healing, healing my body. How do I heal my body? Things have obviously gone array, genetics, environment, whatever those things are that have created an environment that has led to this, and so how do I heal my body from that?

After study participants completed their initial treatment, CAM therapies were used in the post-care healing process. CAM therapies allowed participants to regain their strength and mobility to continue their daily activities. These therapies also aided in the coping process and other mental/emotional struggles participants may have been experiencing. The CAM therapies offered through SCMD took a holistic approach to treat, but also to heal. This fact, CAM therapies role in the post-care healing process, speaks to the importance of including these therapies in broader cancer treatment and care. However, these therapies do not come without cost. While some of the therapies are offered as free services through SCMD, others, especially private practice services, can be quite expensive. Moreover, many CAM therapies are not covered by insurance, as seen through interviews with study participants. Alternatively, some therapies may be covered while others are not. Many study participants had difficulty keeping up with the costs of these therapies and found them to be at times a financial burden. As a result, some individuals stopped using certain therapies, or made sacrifices in other areas in their life to accommodate. The next section of this chapter will highlight some of the difficulties study participants experienced with insurance and the effect that it had on their care.
Insurance and the Financial Burden of Care

From the interviews of this study, it became apparent that there was mixed insurance coverage for CAM therapies among study participants. While some individuals were fully covered for the services they utilized, others had limited to no insurance coverage. In Susan’s case, yoga was a free service offered by SCMD and her acupuncture was partially covered. However, Laura, Kelly, Meghan, Breanne, and Julie did not have coverage for massage or other services and were all paying out of pocket. Of the supportive therapies that study participants used, it seemed that physical therapy was the only therapy that was consistently covered through insurance. Perhaps this is a result of physical therapy not being classified as a CAM therapy and being housed in a separate department. It is also worth noting that, for many participants, massage was often paired with physical therapy to increase mobility and address the lymphedema many patients experienced. Not having coverage for CAM therapies such as massage and acupuncture that have been shown through the interviews in this study to have a positive influence on the physical and mental health outcomes for cancer patients is a major barrier in access to care. This gap in post-treatment supportive care can be detrimental to positive health outcomes and increased quality of life for cancer patients.

Because of a lack of coverage, many study participants discussed with me that they had to limit their amount of use of these therapies or discontinue use altogether. Kelly and Meghan both described to me the difficulty they were having in attending massage therapy regularly. Kelly stated that, “my insurance doesn’t cover it otherwise I would go every day if I could, or every other day, but my insurance doesn’t cover it so it’s kind of a question of… it’s a financial burden.” While Kelly had to cut back on her use of massage, Meghan had to completely discontinue her use, “As far as the massage, I have not gone I think [since] last month, and I
don’t have any more scheduled because I have to pay for that out of pocket.” Many other participants described similar difficulties of having to deal with the financial burden of no insurance coverage for their CAM therapy use. Out of the participants that had no coverage, some chose to sacrifice monetary spending in other aspects of their lives to be able to allocate funds to continue using the services offered at SCMD. Julie was one individual who chose this path saying, “I did pay out of pocket. You know, just like anything you make choices, and the choice is if you are going to do this, a lot of times you have to give up something else and I was certainly willing to do that.” Kelly also rearranged other financial aspects of her life to be able to afford continuing massage. However, for her the time she had to live was also a motivating factor; “Considering the fact that my life may not be much longer yeah I am willing to cut out things that I used to think were important that I don’t any longer…buying clothes or jewelry (laughs) or uhm art… my priorities have changed because of my diagnosis.” Because Kelly potentially only has a short time left to live, she prioritized her health to make the most of the time she has left.

Breanne faced many difficulties with insurance through her treatment. Not only did her insurance not cover the massage or acupuncture services, but Breanne also reached catastrophic maximum on her insurance two years in a row because of her treatment. This resulted in her having to pay thousands of dollars in medical bills even with insurance covering a majority of her treatment. Breanne was just one study participant that was forced to continue working during her treatment to cover the costs. Breanne spoke with me about the financial difficulties she experienced throughout her treatment.

...we don’t have a savings account, or we didn’t have a savings account for a long time anymore (laughs). We blew through our cushion of savings. Uhm, which you know makes you a little more anxious day-to-day…but also that was kind of another thing on
the list of like I don’t want to sacrifice these things [CAM therapies] so our income needs to stay the same in order for me to be able to do them.

There was that much benefit to those other treatments. They improved my symptoms, my quality of life, and my emotional well-being, but it was so very worth it in the grand scheme of finding the money to do it.

For Breanna and others prioritizing these therapies as part of their treatment and healing process was critical to continuing to improve their well-being and quality of life.

Conclusion

This chapter discussed the transformation process that study participants went through as they progressed through their treatment. Many study participants experienced a change in their perspective on life, which in turn resulted in a change or modification in their decision-making processes. Some study participants also experienced a change in their identity. After a diagnosis of cancer, patients may have differing ways that they identify themselves or describe their cancer. Some study participants did not describe themselves as sick or having an illness. They focused on the positives and improvements they were making. Breanne pushed against the contemporary discourse of cancer treatment and the “fight” against cancer. For her this went against the act of healing her body instead of fighting against it. Lastly, this chapter emphasized the struggles that study participants experienced with insurance coverage for CAM therapies. While some were covered, other were not. This resulted in some participants having to space out their use of CAM therapies, while others discontinued use all together.
CHAPTER SEVEN: DISCUSSION AND CONCLUSION

Discussion

The interviews for this study were conducted with the goal of increased understanding of CAM therapies and their role in conventional cancer treatment. To further this understanding, it is not only important to study the efficacy of these therapies, but to understand the motivations behind why patients choose to use them. This study attempted to examine why patients incorporated CAM therapies into their cancer treatment regime, how patients utilizing CAM therapies perceived and described their illness, and lastly, how they perceived the efficacy of the treatments. This section will discuss the results of this study in connection to literature in anthropology and integrative oncology.

From the interviews conducted, it became apparent that the primary motivation to utilize CAM therapies either during or after conventional cancer treatment was to mitigate or address treatment side-effects. Individuals utilizing massage and acupuncture were doing so in the hopes of relieving the effects of lymphedema, neuropathy, GI issues, or just to relieve stress. Yoga/meditation were used for some as a way to work on the mental and emotional struggles they were facing. For others, yoga was a form of daily exercise. Participants of this study often used a combination of these therapies. Motivation for continuing CAM therapies, as discussed by study participants, was their belief in the efficacy of the therapies as participants began to experience increased mobility, a decrease in severity of treatment side-effects, and were able to restore their ability to carry out daily tasks albeit sometimes in a modified manner. Moreover, motivation to use CAM therapies also stemmed from apprehension of the pain medications and various other medications prescribed during cancer treatment. Many study participants discussed
during interviews their hope of decreasing, or preventing all together, the need for medication by using therapies such as massage and acupuncture. Decreasing dependency on medications was a major motivating factor for two study participants in particular.

Motivations for the continued use of CAM therapies, in some instances, clashed with insurance coverage of the patient. While some study participants had insurance coverage for the therapies they chose to use, others had sporadic coverage, or none at all. The individuals interviewed as part of this study were regularly paying out-of-pocket for the services they received, which ranged from $30 to $150 per session depending on the therapy. Some study participants found ways to cope with these added financial costs by making sacrifices in other areas of their life. Moreover, some individuals were forced to reduce their amount of therapy sessions or discontinue them all together. The effects of the struggles with insurance coverage on patients using CAM therapies is an area requiring further research.

This study supports the findings of previous research on the physical and mental/emotional outcomes of therapies such as yoga/meditation as a rehabilitation tool (Bouskill 2012; Harder, Parlour, & Jenkins, 2012; Hwa Do, Hyo Choi, Su Ahn, & Yong Jeon, 2017; Lin et al.; Moonsammy et al, 2013; Olesen et al., 2015; Zhang, Li, Zhang, Yu, & Cong, 2016). The aforementioned research in integrative oncology has attempted to numerically study the efficacy of CAM therapies. However, this study adds to this literature by incorporating qualitative research on how patients perceive and experience the effects of CAM therapies. Through the experiences of study participants, the results also support studies by Bettina Hauge (2016) and Mulkins and Verhoef (2004) in regards to the transformative process that some patients experience during their treatment journey. Through this transformative process, patients
are able to push cancer to the periphery of their lives instead of it consuming the center (Good 2001; McMullin 2016; Mulkins & Verhoef).

Questions of identity and survivorship arose in some discussions with study participants. Identity was discussed in several ways; coming to terms and reconnecting with the aesthetic of the body post-surgery, returning to “normal” after cancer treatment, as well as developing a meaning of survivorship and how it may match with contemporary definitions of and discourse around survivorship and the “fight” against cancer. Massage was an avenue used by one study participant, Jessica, to reconnect with the parts of her body she was still uncomfortable with. Through using massage she was able to embody her newfound scars and the aesthetic of her body. For Breanne, her struggle for identity was stimulated by contemporary discourse on cancer treatment and survivorship. Breanne did not feel comfortable classifying her cancer treatment as a battle. She felt that the cancer was a part of her body, the result of perhaps several factors. Her focus was not to stimulate an internal conflict, but rather to find out what had gone array and work on healing her body.

Breanne is not alone in her resistance toward the contemporary dominant discourse of cancer treatment. Her case is reflective of Kaiser’s study (2008) of women who do not embrace the meanings, terminology, or role of the traditional survivor. Survivorship is a complex topic in studies of cancer. A topic that was not, because of the scope of the research, sufficiently covered in this project. There is much more that could have been covered in terms of survivorship. Moreover, resistance to common doctrine and discourse of cancer is not the only aspect that complicates survivorship. Where are patients who experience recurrence or those individuals who no longer have cancer but rely on treatment indefinitely placed within the term survivorship? How are these individuals classified and how do they match up with the
contemporary discourse of cancer survivorship? When are you considered a cancer survivor? These questions remain difficult to answer in the existing literature and require additional study.

This study also supports study findings regarding the therapeutic relationship between healer and patient, and its effects on healing outcomes (Hatala & Waldram 2016; Moerman & Jones 2002). It became apparent during conversations with study participants that it was not entirely the treatment themselves that contributed to positive health outcomes but the relationship that formed between CAM practitioners and patients. CAM practitioners also played the role of advisers and health educators, in addition to professional practitioners. For many study participants, conversations with their CAM practitioner during treatment sessions played an important role in their mental and physical improvements. This supports the study by Thompson, Ritenbaugh, and Nichter (2009) that positive outcomes can be linked to patients perceiving their healers as experienced and competent.

Lastly, the research collected for this study drew from various fields to develop research questions and contextualize the data collection and analysis. Literature on integrative health techniques and therapies was used as a foundation to inform the study. Literature from linguistic and medical anthropology was used to contextualize the quantitative and control trial approach of much of the integrative medicine and oncology literature. This study between the integrative medicine and anthropological literature to draw them into conversation. Moreover, linguistic and medical anthropological literature was used to locate this study historically within the broader discourse of cancer in the United States, as well as the development of treatment and advocacy. The qualitative approach of this study is intended to complement the vast quantitative literature in integrative medicine and oncology.
Limitations & Directions for Future Research

This study in particular was focused on CAM therapies and their role in conventional cancer treatment, in regards to health outcomes. As a masters project, there were limitations to the time and scope of the research. Because of this, the study did not sufficiently cover questions of inadequacies in insurance coverage or alternative meanings of survivorship. Moreover, studies on access to and insurance coverage for CAM, as well as the experiences and intricacies of survivorship are important areas for further study. Further research could also study the link between alternative meanings in survivorship and the current discourse surrounding the “fight” against cancer. Also, the sample population of this study was all female, reflecting trends in prior research on CAM therapies (Judson et al. 2017; Moonsammy et al. 2013; Hwa Do, Hyo Choi, Su Ahn & Yong Jeon 2017; Zhang et al. 2016; Lin, Frawley, Denehy, Feil, & Granger 2016; Tao et al. 2016; Tiezzi et al. 2017). This makes the results of the study non-generalizable to other study populations. Future research could focus on a male study population to examine similarities and differences in the utilization of CAM therapies among males and females. Motivations may be different and outcomes may also be vary depending on category of cancer.

Recommendations to Practitioners

One of the major concerns among study participants was the difficulty in finding out about the therapies that are offered within the supportive care medicine department (SCMD) at the cancer center. During multiple interviews participants stressed their frustrations of the amount of independent research that went into finding the supportive care therapies. When participants did hear about what was offered in SCMD, it was through a social worker or another patient that had used one of the therapies offered. Most patients, with the exception of one or two, were not told of these therapies by any of their physicians. Many were surprised by this fact.
and took it upon themselves to inform their physicians of the benefits they have reaped from the therapies in SCMD. Several participants were adamant that they inform their physicians so that they might inform future patients. This is a major area of improvement. However, since physicians were not interviewed for this study, it is unclear why they do not inform their patients of SCMD. It could be the result of an aversion to the therapies themselves, or perhaps they are unaware of the fact that SCMD is there to offer these services.

Furthermore, the volume of work and limited amount of time that physicians face could be impacting the amount of time that oncologists can spend on care outside of conventional cancer treatment. This may explain why many study participants discovered SCMD through a social worker, if not through another patient or their own research. Whatever the case may be, there is a need to better understanding what is contributing to the lack of referrals and endorsements by physicians providing conventional care. To begin to increase physician referrals at the cancer center, targeted advertising may be a solution. The integrative medicine services at the cancer center are already heavily advertised through paper flyers, digital signage, blog posts and articles on the cancer center website, as well as through patient orientations. Select medical residents and fellows that choose to do so are also able to rotate through SCMD. The advertising that currently goes on inside the cancer center begs the question of what targeted advertising, to both patients and physicians, could be done to increase referrals and use of the integrative medicine services provided.

Lastly, a larger issue stemming from the findings of this study are the gaps in insurance coverage for therapies put into the category of integrative or complementary and alternative medicine. While some of these therapies are slowly being included in some insurance policies,
not all study participants had the luxury of coverage. Gaps of coverage for integrative medicine therapies can potentially have a major effect on quality of life for cancer patients.

**Contribution to Research and Applied Anthropology**

This study sought to increase understanding of the role that CAM therapies play within conventional cancer treatment. Contribution to previous research in integrative oncology was made by including qualitative data on patient motivations for using these therapies, as well as quality of life benefits patients experienced. Patients saw increased quality of life through physical, mental and emotional benefits; including changes to their outlook on life. In addition to bringing awareness to the benefits that the therapies studied can provide, this research also sought to highlight the importance of integrative medicine itself. Study participants chose to use integrative therapies primarily as a way to fill the gaps in conventional modes of care. The findings from this study will, hopefully, play a part in increasing awareness of integrative medicine as a whole, the training of professionals in the field, as well as increased utilization of these modalities in other cancer centers across the United States and abroad.

This study also connects medical anthropological discussions on phenomenology, identity, and discourse regarding cancer in the United States. The results of this study added to theoretical discussions on alternative medicine within medical anthropology, by adding the lived experiences of study participants and their decision to use CAM therapies, their struggles with identity reconstruction, and resistance to conventional discourse surrounding cancer treatment.

In addition to the theoretical contributions made to anthropology and integrative oncology, this study aimed to take an applied anthropological approach. First, this project highlighted the patient perspectives of CAM therapy use. More importantly, through this research came the realization of the lack of referral and endorsement of the therapies offered
within SCMD by individuals outside the department. Through dissemination of research results, there is a hope that increased awareness of the benefits of the CAM therapies offered will result in more physicians recommending said therapies to their patients.

**Dissemination of Results**

The results of this study will be disseminated to participants in adherence with the regulations and protocols of the cancer center, several potential avenues dissemination may occur, including academic publication, distribution of summary results to the P.I. of the study, SCMD and/or the cancer center newsletter with contact information of the researcher available for individuals interested to learn more. The results of this study may also be used by the P.I. of the study in presentations on integrative medicine both internally and externally.

**Conclusion**

This study asked three fundamental questions regarding CAM therapy use in conventional cancer treatment; 1.) Why do patients seek out CAM therapies and what gaps do they fill within biomedical cancer treatment? 2.) What effect have these therapies had on the cancer treatment experience, and how do patients perceive the efficacy of the treatments? And 3.) How do patients utilizing these therapies perceive and describe their illness. Semi-structured interviews revealed that patients had several motivations for pursuing CAM therapies, most notably as an attempt to decrease medications, to mitigate treatment side-effects and increase mobility, as well as increasing self-confidence and work through mental/emotional struggles of cancer treatment. Interview data from this study overwhelmingly support patients’ belief in the efficacy and positive outcomes that can come from utilizing CAM therapies in conjunction with or following conventional cancer treatment. Because of this, more effort needs to be put toward further incorporation of departments such as SCMD into hospitals and cancer facilities across the
United States. Along with this, policy changes need to occur for the incorporation of more CAM therapies covered through insurance plans. Paying out of pocket for the services offered through SCMD was a major concern for many study participants. Lastly, better overall marketing, for general audiences, should be put into place for CAM therapies to clarify what they are in order to work through the many misconceptions that surround complementary and alternative medicine as a whole. While this study does not promote or endorse all therapies that claim the label complementary or alternative medicine, there are therapies that are safe and that have had a tremendous positive effect on the cancer patients that have used them. The CAM therapies utilized by the participants for this study relieved and mitigated both physical and mental/emotional challenges that come along with conventional cancer treatment; helping them return to their day-to-day lives. In the end, this is all they hoped for.
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Appendix A:
University of South Florida Institutional Review Board - Study Approval Letter

February 19, 2018

Lora Thompson, Ph.D.
H Lee Moffitt Cancer Center
12902 Magnolia Dr.
MRC-SCM
Tampa, FL 33612

RE: Expedited Approval for Initial Review
IRB#: Pro00033608
Title: Cancer Patient Experiences using Integrative Health Techniques

Study Approval Period: 2/18/2018 to 2/18/2019

Dear Dr. Thompson:

On 2/18/2018, the Institutional Review Board (IRB) reviewed and APPROVED the above application and all documents contained within, including those outlined below.

Approved Item(s):
Protocol Document(s):
Thompson MCC 19450 Moffitt Protocol (Version 3) revisions 2-1-2018 clean.docx

Consent/Assent Document(s)*:
MCC #19450 Informed Consent (Version #1-2/07/2018).pdf

*Please use only the official IRB stamped informed consent/assent document(s) found under the "Attachments" tab. Please note, these consent/assent documents are valid until the consent document is amended and approved.

It was the determination of the IRB that your study qualified for expedited review which includes activities that (1) present no more than minimal risk to human subjects, and (2) involve only procedures listed in one or more of the categories outlined below. The IRB may review research through the expedited review procedure authorized by 45CFR46.110. The research
proposed in this study is categorized under the following expedited review category:

(6) Collection of data from voice, video, digital, or image recordings made for research purposes.

(7) Research on individual or group characteristics or behavior (including, but not limited to, research on perception, cognition, motivation, identity, language, communication, cultural beliefs or practices, and social behavior) or research employing survey, interview, oral history, focus group, program evaluation, human factors evaluation, or quality assurance methodologies.

As the principal investigator of this study, it is your responsibility to conduct this study in accordance with IRB policies and procedures and as approved by the IRB. Any changes to the approved research must be submitted to the IRB for review and approval via an amendment. Additionally, all unanticipated problems must be reported to the USF IRB within five (5) calendar days.

We appreciate your dedication to the ethical conduct of human subject research at the University of South Florida and your continued commitment to human research protections. If you have any questions regarding this matter, please call 813-974-5638.

Sincerely,

Kristen Salomon, Ph.D., Vice Chairperson
USF Institutional Review Board
Informed Consent to Participate in Research

Information to Consider Before Taking Part in this Research Study

Researchers at Moffitt Cancer Center (MCC) study many topics. To do this, we need the help of people who agree to take part in a research study. Research studies include only people who choose to take part. This document is called an informed consent form. Please read this information carefully and take your time making your decision. Ask the researcher or study staff to discuss this consent form with you, please ask him/her to explain any words or information you do not clearly understand. We encourage you to talk with your family and friends before you decide to take part in this research study. The nature of the study, risks, inconveniences, discomforts, and other important information about the study are listed below.

Please tell the study doctor or study staff if you are taking part in another research study.

We are asking you to take part in a research study called:

Cancer Patient Experiences using Integrative Health Techniques

The person who is in charge of this research study is Lora MA Thompson, Ph.D.. This person is called the Principal Investigator. However, other research staff may be involved and can act on behalf of the person in charge.

The research will be conducted at
H. Lee Moffitt Cancer Center & Research Institute, Inc.
(Moffitt Cancer Center)
12902 Magnolia Drive
Tampa, FL. 33612

Why is this research being done?

The purpose of this study is to:

- The purpose of this study is to understand the role of integrative health techniques, such as massage, yoga, acupuncture or meditation, in cancer treatment. For our study we are interested in why patients choose use these therapies, what gaps they may fill in conventional cancer treatment, and if these therapies help to ease treatment side-effects and cancer-related symptoms and to improve overall quality of life.
- A student will be conducting this study in partial fulfillment of a Master of Arts (MA) degree.
What will happen during this study?

If you take part in this study, you will be asked to:

- Complete one 60-minute interview by telephone or in person while at the Moffitt Cancer Center. The interview can be split into two interviews if you are not able to complete a 60 minute interview.

- The interviewer will ask you questions about your treatment side effects and cancer-related symptoms and their impact on your quality of life, your use of integrative health techniques, such as massage, yoga, acupuncture or meditation, and if integrative health techniques are beneficial to you.

- All interviews will be digitally audio-recorded, and the interviewer will also take notes during the interview. You will not be asked to report any personally identifiable information during the interview and no personally identifiable information will be recorded in the notes. Your interview will be transcribed into a written document and all written documents and notes will be kept in a password protected computer on the Moffitt secure server only accessible by the members of the research team. All research records will be kept for a period of 6 years after the study is closed and then will be destroyed.

How many people will take part in this study?

About 15-20 individuals will take part in this study at the Moffitt Cancer Center.

What other choices do you have if you do not participate?

You do not have to participate in this research study. Your participation in this study is voluntary. You can decide not to be in the study and you can change your mind about being in the study at any time. There will be no penalty to you, and you won’t lose any benefits.

Benefits

We are unsure if you will receive any benefits by taking part in this research study.

Risks or Discomfort

This research is considered to be minimal risk. That means that the risks associated with this study are the same as what you face every day. There are no known additional risks to those who take part in this study. However, it is possible that a question could cause you some emotional distress. You do not have to answer any questions that you do not want to answer. Should you experience any discomfort or distress, please inform the person in charge of the study, Dr. Lora Thompson at (813) 745-1418. Should you reveal any information that suggests potential harm to yourself or others then a member of your Moffitt Cancer Center clinical care team may be contacted to assist you.
Will you be paid for taking part in this study?
We will not pay you for the time you volunteer while being in this study.

Will it cost anything to be in this study?
There will be no costs to you as part of participation in this study.

The use and disclosure of your personal health information.
We understand that information about you and your health is personal, and we are committed to protecting the privacy of that information. Because of this commitment, we must obtain your written authorization before we use or disclose your information for this study. Research at the Moffitt Cancer Center may be undertaken jointly with the University of South Florida or other persons or entities under an organized health care arrangement. By signing this form, you are permitting researchers at Moffitt Cancer Center to use personal health information for research purposes within its organized health care arrangements. You are also allowing the Moffitt Cancer Center to disclose your personal health information to outside organizations or individuals that participate in this study. We may publish what we find out from this study. If we do, we will not let anyone know your name. We will not publish anything that would let people know who you are. If you do not agree to the use and disclosure described above, you cannot be in the study.

Who will disclose, receive, and/or use your information?
Federal law says we must keep your study records private. We will keep the records of this study private by keeping them in a locked area or on a secure computer. To do this research, the following people and/or organization(s) will be allowed to disclose, use, and receive your information, but they may only use and disclose the information to the other parties on this list, to you or your personal representative, or as permitted by law:

Every research site for this study, including the Moffitt Cancer Center, and each site’s study team, research staff and medical staff; Any person who provides services or oversight responsibilities in connection with this study; Every member of the Moffitt Cancer Center workforce who provides services in connection with this study; The person who is responsible for the study nationwide or worldwide (study chairperson); Any laboratories and other individuals and organizations that use your health information in connection with this study; Any sponsor of the study, including the following sponsors:

Any federal, state, or local governmental agency that regulates the study (such as the U.S. Department of Health & Human Services (DHHS) and Office for Human Research Protections (OHRP));

Other government agencies in this or other countries;
The designated Protocol Review and Monitoring Committees, Institutional Review Boards, Privacy Boards, Data and Safety Monitoring Board and their related staff that have oversight responsibilities for this study;
The National Cancer Institute in evaluating the ongoing research of the Moffitt Cancer Center as a Comprehensive Cancer Center;
The organizations and people listed above may employ or pay various consultants and companies to help them understand, analyze and conduct this study. All of these people may not be known now, but if you would like to have more specific information about this at any time during the study, you may ask the study doctor and your questions will be answered.

Moffitt Cancer Center cannot guarantee the privacy of your information, or block further use or distribution, after the information has left the Moffitt Cancer Center. Others listed above may further disclose your information, and may no longer be covered by federal privacy regulations.

If all information that does or can identify you is removed from your records, the remaining information will no longer be subject to this authorization and may be used or shared for other purposes.

You might have the right to see and copy your health records related to this research. You might not be able to see or copy some of your records until after all participants finish the study. If it is necessary for your care, your records will be provided to you or your regular doctor.

What information will be used or disclosed?

By signing below, you authorize the use and disclosure of your entire study record and any medical or other records held by Moffitt Cancer Center, including, but not limited to, HIV/AIDS, mental health, substance abuse or genetic information. The purpose for the uses and disclosures you are authorizing is to conduct the study explained to you during the informed consent and research authorization process and to ensure that the information relating to that study is available to all parties who may need it for research purposes.

Your authorization to use your health information will never expire unless and until you expressly revoke it in writing to the investigator on the first page of this form. If you revoke your authorization, you will not be able to continue in the study.

By signing this form, you authorize the use and/or disclosure of your protected health information described above. Your information may also be used as necessary for your research-related treatment, to collect payment for your research-related treatment (when applicable), and to run the business operations of the Moffitt Cancer Center.

Any data collected prior to your letter will continue to be used as necessary to preserve the integrity of the study, however no additional information will be collected after you withdraw your authorization.

You will receive a signed copy of this form.

What happens if you decide not to take part in this study?

You should only take part in this study if you want to volunteer. You should not feel that there is any pressure to take part in the study, to please the investigator or the research staff. You are free to participate in this research or withdraw at any time. There will be no penalty or loss of benefits you are entitled to receive if you stop taking part in this study.

New information about the study

During the course of this study, we may find more information that could be important to you. This includes information that, once learned, might cause you to change your mind about being in the study. We will notify you as soon as possible if such information becomes available.
Moffitt Cancer Center Injury Statement

If you believe you have been injured as a result of your participation in this study or if you have questions about your rights as a person who is taking part in a research study, you may call the Moffitt Cancer Center Risk Manager at 813-745-4219. Moffitt Cancer Center and its investigators have made no provision for monetary compensation in the event of physical illness or injury resulting from this study. Likewise, Moffitt Cancer Center and its investigators have made no provision for payment of lost wages, disability, or discomfort in the event of physical illness or injury resulting from this study. Florida law (Statute 768.28) limits the liability of Moffitt Cancer Center. This statute provides that damages are available only to the extent that negligent conduct of a Moffitt Cancer Center employee caused your injuries, and are limited by law. A copy of this statute is available upon request at 813-745-1869.

Where can you get the answers to your questions, concerns, or complaints?

If you have any questions, concerns or complaints about this study, or experience an adverse event or unanticipated problem, call Lora MA Thompson at 813-745-1418.

If you have questions about your rights as a research patient at Moffitt Cancer Center, call the Corporate Compliance Department at The Moffitt Cancer Center at (813) 745-1869.

If you have questions about your rights, general questions, complaints or concerns about this research, or questions about your rights as a person taking part in this study, call the Division of Research Integrity and Compliance of the University of South Florida at (813) 974-5638.

Consent to Take Part in this Research Study and Authorization to Collect, Use and Share Your Health Information

It is up to you to decide whether you want to take part in this study. If you want to take part, please sign the form, if the following statements are true. A representative of the Moffitt Cancer Center must answer your questions completely before providing this form to you. You or your personal representative should read this form and understand it before signing below.

I freely give my consent to take part in this study and authorize that my health information as agreed above, be collected/disclosed in this study. I understand that by signing this form I am agreeing to take part in research. I have received a signed copy of this form to take with me.

_____________________________________________  ________________
Signature of Person Taking Part in Study  Date

_____________________________________________
Printed Name of Person Taking Part in Study

Statement of Person Obtaining Informed Consent / Research Authorization

I attest that the participant named above had enough time to consider this information, had an opportunity to ask questions, and voluntarily agreed to be in this study.

_____________________________________________  ________________
Signature of Person Obtaining Informed Consent / Research Authorization  Date
Printed Name of Person Obtaining Informed Consent / Research Authorization