CARING FOR CANCER: UNDERSTANDING THE ACCESS AND PERCEPTIONS OF PSYCHOSOCIAL CANCER SERVICES IN NORTH TEXAS

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It is estimated that nearly 14.5 million Americans are living with cancer today. A commonly overlooked component to quality cancer care, as defined by the Institute of Medicine, is the role of psychological and social support. Better known as psychosocial support, these needs reflect a broad spectrum of obstacles or assets in an individual’s personal life that may help or hinder their healing experience. Some psychosocial examples include coping skills, transportation to medical appointments, or appropriate knowledge to mitigate the physical impacts of the cancer process. Research has shown that by addressing these potential needs, a better health outcome may be achieved for cancer patients. Through participant observation at local psychosocial service establishments and through semi-structured interviews with service providers and adults diagnosed with cancer living in the Dallas-Fort Worth region, this thesis research seeks to explore how local cancer patients are learning of psychosocial services available to them, what barriers may exist in accessing these services, and what individuals may be doing to address their psychosocial needs, both formally or informally. Results yielded recommendations for local psychosocial providers to adjust their marketing of services and kinds of services offered as well as yielded recommendations for future academic research.
ACKNOWLEDGEMENTS

In February 2011, my father was diagnosed with cancer. From that terrifying experience, I gained a glimpse into the challenges that people diagnosed with cancer encounter on daily basis that aren’t commonly acknowledged, despite the high prevalence of diagnosis. When the opportunity arose to conduct research, my personal passion drove my professional inquiry leading me to partner with the Cancer Support Community of North Texas so that I might systematically examine how people learn of and engage in psychosocial services – services that failed to garner my own attention when it was needed most.

Through the research process, I met a great many remarkable individuals who humbled me with their willingness to share their deeply personal stories and hard earned insights. This research would not have been possible if not for the openness of those who shared their thoughts and experiences with me. Nor would it have been possible without the support and guidance of those who have dedicated their lives to improve the experience of people affected by cancer. To the participants and organizations that worked with me: you have my most sincere gratitude and respect.

And lastly, I want to acknowledge my family, my friends, and my mentors who supported and encouraged me in a hundred different ways as I immersed myself in my education and research. This research is representative of the efforts of many caring and inspiring individuals who will not be forgotten.
# TABLE OF CONTENTS

ACKNOWLEDGEMENTS ................................................................................................................... iii

LIST OF TABLES .............................................................................................................................. viii

LIST OF FIGURES .............................................................................................................................. ix

CHAPTER 1 INTRODUCTION ............................................................................................................ 1

1.1 The Public Health Problem .................................................................................................... 1

1.2 Psychosocial Health ............................................................................................................... 2

1.3 Applied Anthropology ........................................................................................................... 3

1.4 Client: The Cancer Support Community of North Texas (CSCNT) ......................................... 4

1.5 Study Purpose ....................................................................................................................... 6

1.6 Study Limitations ................................................................................................................... 8

1.7 Deliverables ........................................................................................................................... 8

CHAPTER 2 CONTEXT AND BACKGROUND ..................................................................................... 9

2.1 Literature Review .................................................................................................................. 9

2.1.1 Impacts ........................................................................................................................... 9

2.1.2 Health Knowledge and Information ............................................................................. 10

2.1.3 Healthy Lifestyles .......................................................................................................... 13

2.1.4 Support Systems ............................................................................................................. 14
<table>
<thead>
<tr>
<th>Section</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td>5.2 Recommendations</td>
<td>69</td>
</tr>
<tr>
<td>5.3 Reflection</td>
<td>71</td>
</tr>
<tr>
<td>BIBLIOGRAPHY</td>
<td>73</td>
</tr>
</tbody>
</table>
LIST OF TABLES

Table 1: Sample population profile ................................................................. 34
Table 2: Sample cancer profile ................................................................... 36
Table 3: Sample population age demographics ......................................... 37
LIST OF FIGURES

Figure 1: Social ecological model.................................................................................................. 24

Figure 2: Physician recommended services.................................................................................. 61
CHAPTER 1
INTRODUCTION

1.1 The Public Health Problem

One of the largest threats to American health is the menace of cancer. To date, cancer is the second leading cause of death in the United States (Centers for Disease Control and Prevention, 2014). As a result, in 2014 it is estimated that there will be 1,665,540 new cases of cancer diagnosed, while 585,720 people are anticipated to succumb to their cancer during this same year. This translates to an incidence rate of 460.4 per 100,000 men and women newly diagnosed each year, and a lifetime risk of being diagnosed with cancer in nearly 40% of the population. The advent of new medical technologies during the last few decades has allowed for improved 5-year survival rates for 15 of the most common cancers resulting in a 66.1% 5-year survival rate for all cancer sites. The impact of these improved technologies is that more and more are people living with cancer for longer. Case in point, it is estimated that nearly 14.5 million Americans are currently living with cancer (American Cancer Society 2014).

Despite the benefits of technological advancements, individuals diagnosed with cancer may face complex biological and psychological challenges during their cancer journey and for the remainder of their lives. Many of the life-extending technologies like chemotherapy, radiation, hormone therapy or surgery, may adversely and permanently impact the pulmonary, renal, cardiac and neurological systems. For individuals between the ages of 18 and 48 who have survived for five years beyond diagnosis, 62% report the development of at least one additional chronic health condition. Of those, 27% contend with a life-threatening condition such as kidney failure or congestive heart failure (Institute of Medicine, 2008). Another
common impact of the cancer treatment process is cognitive impairment, more colloquially known as “chemo brain” (IOM, 2008). These impairments can include decreases in memory, ability to process information, attention and concentration. Fatigue, due to the cancer process or treatment process, is the most commonly cited impact of cancer and treatment, oftentimes resulting in reduced capacity to function or maintain employment. And lastly, persistent pain has been estimated to impact nearly one half of all cancer patients.

1.2 Psychosocial Health

Further complicating the biological challenges of the cancer experience is the often overlooked, albeit pivotal influence of psychosocial health. Psychosocial health is comprised of the emotional, mental and spiritual well-being of an individual in conjunction to their physical health. While firmly rooted in the possible depression and stressors that commonly accompany a cancer diagnosis, psychosocial health also encompasses the wide array of influences that can impact life and, by default, the cancer experience and potential health outcome. Issues of transportation, finances, coping skills, physical limitations, strained relationships, access to knowledge and resources are just few of the challenges that fall within the scope of psychosocial health. Psychosocial health services, as defined by the Institute of Medicine, are “...the psychological and social services and interventions that enable psychological/behavioral and social aspects of illness and its consequences so as to promote better health” (IOM, 2008). Common psychosocial health services include counseling, support groups, nutritional guidance, tailored fitness classes, and educational lectures to name a few.

The impact of psychosocial health cannot be overstated. In 2008, the Institute of Medicine released a comprehensive report that provides a substantial meta-analysis of the medical
studies to date that explore the relationship between psychosocial health and desired health outcomes. Overwhelmingly, past medical studies have shown that good psychosocial health had the ability to positively impact overall health outcomes. In response, it was decreed that quality cancer care must address psychosocial health. As a result, the American College of Surgeons Committee established a mandate that by 2015 all Commission on Cancer accredited cancer centers routinely screen cancer patients for distress and actively refer those in need to psychosocial support services (Cancer Policy, n.d.).

1.3 Applied Anthropology

In conjunction with public health efforts to improve population health and promote healthy lifestyles, applied medical anthropology seeks to provide practical and applicable solutions to a health topic (Association of Schools and Programs of Public Health, 2014). In order to effectively and appropriately accomplish this, applied medical anthropology utilizes a multifaceted toolkit of different methodologies, theories and concepts to gain deeper understanding of an issue. At the crux of medical anthropology is the intention to identify and understand the complex web of relationships between culture, society and biology, and how these forces work against or with each other to influence health understanding, conceptions, and outcomes (Hahn and Inhorn, 2009). As the name denotes, applied medical anthropology is the application of the collection of tools and concepts to a given health issue for the purpose of seeking a practical and sustainable solution (Van Willigen, 2002).

With this approach in mind, applied medical anthropology is ideal for the exploration of the psychosocial service awareness and utilization among the local cancer population. Despite a growing body of evidence to support the validity and need for psychosocial support,
established psychosocial centers local to the Dallas-Fort Worth area note low levels of participation, possibly suggesting a lack of awareness either of the benefit or of the availability of psychosocial resources. Applied medical anthropological research is well-suited to the examination of potential cultural beliefs, structural barriers and health concepts and behaviors that may influence psychosocial engagement.

1.4 Client: The Cancer Support Community of North Texas (CSCNT)

The Cancer Support Community (CSC) is a global non-profit organization that was established to be a provider of free psychosocial services to those who have been affected by cancer. As their mission statement reflects, the purpose of the Cancer Support Community is “to ensure that all people impacted by cancer are empowered by knowledge, strengthened by action, and sustained by community” (Cancer Support Community, n.d.). A critical distinction between the Cancer Support Community and many other psychosocial service providers is its emphasis on providing support to not only to the individual with cancer, but to the family, friends, and caregivers of those diagnosed with cancer to help build healthier communities of caring. The services provided are as varied as the people they are intended to serve, including, but not limited to: individual counseling, support groups, yoga, meditation, nutrition and cooking classes. They frequently offer educational lectures in which they invite individuals from different professions to speak on a topic related to cancer. For example, such professionals may include a lawyer who may come in and discuss estate planning, or a local oncologist to come in and speak further on a topic of interest while allowing for a lengthy question and answer opportunity (not normally afforded during a typical doctor visit). In addition to the services and classes offered, the Cancer Support Community also regularly offers social events like movie or
game nights, potlucks, cook-outs, and holiday parties to create a comfortable space for people of like circumstances to enjoy themselves (Cancer Support Community, n.d.).

The Cancer Support Community is the product of the 2009 merging of two well-known and well-established psychosocial service providers: the Wellness Community and Gilda’s Club. As a result, the Cancer Support Community boasts over 50 local affiliates and 100 online and satellite locations, some of which have maintained the original organization name. Much of the structure and philosophy of the CSC reflects the original charter and vision of Gilda’s Club. Gilda’s Club was founded in 1995 in honor of the legendary comedienne, Gilda Radnor, who passed from ovarian cancer in 1989. During her own struggles with cancer, Gilda lamented the lack of resources for addressing her needs outside her medical treatment. She envisioned a “warm and welcoming” place in which those with cancer could go to find support in order to reduce the sense of isolation, confusion and fears by sharing their “hopes and fears, wisdom and information” and learn to “how to live with cancer, whatever the outcome” (Bull 2006, pg. 13). Gilda’s vision can be seen throughout the CSC in numerous ways. Each CSC center is referred to as a “clubhouse” and those who join are “members” and never cancer patients. Rooms of in the clubhouses bear the names of “Gilda,” her husband, “Gene Wilder,” or her most famous Saturday Night Live character, “Roseanne Roseannadanna.” Lemonade and ice tea are always at the ready for members and the décor lacks the sterile and clinical feel of traditional doctors’ offices, instead offering a more “homey” environment with couches, blankets, and books to read by the fireplace (Bull, 2006).

In the North Texas region the Cancer Support Community offers three clubhouses; one in Dallas County, one in Collin County, and one in Tarrant County. All locations currently reside
on a Texas Health Resources campus, though prior to 2014, the Dallas clubhouse was a stand-alone facility in the Oak Lawn neighborhood. The recent relocation of the Dallas clubhouse, which is also the flagship clubhouse for the North Texas region, resulted in a temporary decrease in membership activity; though it should be noted during the course of my research, membership was beginning to rebound. Activity at the Collin and Tarrant clubhouses remains low due to the newness of each clubhouse; Tarrant County opened in March 2014 and Collin County opened in July 2014. The Dallas Clubhouse is currently in a temporary location on the fringes of the Texas Health Resource campus while a newer facility is under construction in the hospital as part of the oncology center. The intention is to provide a clubhouse convenient to those in treatment while increasing the awareness of their services.

1.5 Study Purpose

Initial contact with the CSCNT was made in February 2014 at which point a discussion of potential projects began between the newly appointed program manager and me. From the beginning, the program manager discussed the anticipated growth in membership in the foreseeable future, thanks in part to the upcoming requirement of oncologists to recommend and integrate psychosocial services into the cancer care plan. While site supervision and project proposal discussions fluctuated, the foundation of all discussed potential projects was to better situate the CSCNT for this growth.

During the summer of 2013, the LIVESTRONG Foundation conducted a needs assessment in conjunction with the CSCNT to better understand the experiences and needs of those affected by cancer in the Dallas area. Assessment data were based on an online survey that asked the participants, who were exclusively CSCNT members (N = 137), “To what degree
do you think the needs of cancer survivors are being met in the Dallas region?” Participant responses, measured by a 5-point Likert scale, were then categorized according to 1) physical and emotional needs or 2) financial and insurance needs. The assessment provided a sense of what needs are being met (understanding cancer diagnosis), moderately met (peer-to-peer support) or unmet (clinical trial information) among those affected by cancer in the Dallas region (LIVESTRONG Foundation, 2013).

While the LIVESTRONG Assessment provided insight into the extent that members felt their needs were being met in the Dallas region, an opportunity further existed to more deeply explore the circumstances that surround the awareness and perceptions of psychosocial services (such as what CSCNT provides). Additionally, the use and impact of current services and the absence of a desired service was yet to be fully examined. Because the assessment only engaged CSCNT members, an opportunity further exists to learn what “nonmembers” may or may not be doing to meet their psychosocial needs and what barriers or perceptions they may face in their cancer experience.

Research Questions

- What psychosocial resources, both formal and informal, are study participants utilizing and how have they been beneficial?
- To what degree are study participants aware of psychosocial resources and how are they learning of them?
- What barriers have study participants encountered in accessing resources? In what ways, if at all, have they been able to navigate those barriers?
- What perceptions, if any, do study participants have of psychosocial resources?
1.6 Study Limitations

Due to the nature of the study topic, a few limitations exist. These limitations are:

- Poor attendance. Due to the newness of clubhouses and the summer season, many events at the CSC and other organizations (e.g. The Cvetko Center at Baylor Hospital) suffered from poor attendance. Quite often, previously planned events for participant observation opportunities were cancelled last minute as a result.

- The summer season. During the summer, there are unique challenges: increased vacation travel and/or the impact of heat. This prevented several would-be interviewees from participation. That being said, the interview portion extended from mid-May to the first week of August.

- Cognitive restraints. Many participants struggled to answer questions that required memory recall, citing the impact of “chemo brain” on their ability to remember details. However, memory recalls are a noted challenge for healthy individuals as well.

1.7 Deliverables

Per the request of the client, a matrix of local psychosocial service options and providers was created. To supplement the local psychosocial service matrix, a condensed summary of research results emphasizing the current utilization of psychosocial services and desired services of the sample was provided in the form of a written report.
CHAPTER 2

CONTEXT AND BACKGROUND

2.1 Literature Review

To better address the various aspects of cancer, it is crucial that the complexities of the disease process on an individual's body and life is well understood and considered. To that end, a cursory summation of the most common ailments reflected in the literature, but by no means all of them, is listed in this section. In addition to these impacts, a brief review of evidence-based solutions is provided along with a glimpse into the burgeoning anthropological exploration of the cultural constriction and consequence of some of these impacts and solutions.

2.1.1 Impacts

Cancer is a disease of individuality, impacting each person in a unique fashion. Some people are barely touched by their cancer diagnosis and treatment while others find their lives irrevocably changed. Like the cancer cell itself that seeks to spread throughout the body, cancer can invade all aspects of an individual’s life, impacting one’s physicality, emotional well-being, relationships, occupation and finances to name a few.

Though it varies from person to person, there are several commonly reported impacts of cancer and cancer treatment, some of which were reviewed earlier in this paper, such as pain, fatigue and nausea. However, additional impacts exist that impede the healing process and increase the complexity of daily life. Depression is another frequently reported impact with a prevalence rate between 20-66% among those diagnosed with cancer (Butow et al., 2002). In comparison, the national prevalence rate of depression is much lower at 9.1% (CDC, 2012).
Understandably, the fear, uncertainty, and vulnerability are increased among individuals with cancer (IOM, 2008). Mild to severe anxiety can occur, as can delirium and post-traumatic stress disorder (National Cancer Institute, n.d.) The stress of the cancer diagnosis and treatment process not only impacts the emotional well-being of the individual, but can decrease the body’s immune function, further challenging a desired positive outcome (IOM, 2008).

Similar to the emotional and mental impacts, the physical impacts are varied. The gastrointestinal system is easily impacted by some of the treatment options, resulting in severe diarrhea or constipation that must be carefully managed to avoid complications. In addition to hair loss, skin can become uncomfortably dry and itchy, the nails brittle and fragile, and painful sores may erupt in the mouth. Hot flashes, night sweats, and insomnia can challenge an already troubled sleep scenario, which in turn, impacts mental and emotional stability and coping ability. Risk of infection and exposure to communicable illness is not only high for individuals with cancer, but also dangerous. They must also contend with the threat of anemia or the possibility of sexual dysfunction or infertility (NCI, n.d.). The resulting physical impacts can hinder the most basic of daily activities. Bathing, feeding oneself, using a telephone, shopping or using transportation can become difficult, if not impossible for some. Suppressed immune systems can restrict an individual from leaving their house or interacting with loved ones creating a sense of isolation and loneliness (IOM, 2008).

2.1.2 Health Knowledge and Information

Arguably, one of the most critical components to achieving a positive health outcome, or at the very least easing the experience of the cancer journey, is the acquisition of adequate health knowledge. Few individuals who have been diagnosed with cancer have an
understanding of the cancer process beyond a cursory awareness that is informed largely by
the media or national awareness campaigns (Warren et al., 2012). Lack of additional
information acquisition, specifically in regards to prognosis, treatment options and supportive
behavior, restricts an individual’s ability to participate capably in the decision-making process.
As a result, the direction of treatment is commonly left to the indirect suggestion of the medical
team despite the attempts to avoid influencing a patient’s decision-making process. The
medical team, composed typically of oncologists, surgeons, radiologists and support staff, is the
preferred and most common source of health information cited by individuals diagnosed with
cancer (Mills & Sullivan 1999; Mayer et al., 2006; Lemire et al., 2008; Warren et al., 2012). This
inclination and dependence upon medical professionals to provide health information is
reflected throughout the literature and well supported through this study’s findings.

As stated earlier, the impact of adequate health knowledge can be reflected in several
ways. Similar to the results of this research, studies have shown that improved health
knowledge and informed consent are more likely to increase an individual’s satisfaction with
treatment and ability to cope with the cancer diagnosis and process, while simultaneously
decreasing levels of anxiety and communication strife (Mayer et al., 2006; Rutten et al., 2004).
However, information is not limited to a single source, with most individuals receiving
information from multiple sources. In addition to receiving health knowledge from medical
professionals, individuals learn from printed materials, other people (as in the case of friends or
support groups), organizational and scientific resources and lastly, media, listed in order of
frequency (Rutten et al., 2004). In terms of which sources outside of authoritative medical
knowledge are most frequently cited, this study shows a contrast in the most commonly used sources to previous studies, perhaps suggesting a change in time and preference.

An additional note on health information found in both the literature and this study is the willingness of the individual to seek to acquire health knowledge or not. Upon cancer diagnosis, many actively avoided exposure to health information, choosing instead to have the medical team direct their care with minimal explanation or to have loved ones review information and selectively inform them of the most pertinent details when necessary. One study by Mayer et al. focuses in detail on what differences exist between those who seek information and those who do not at a greater level than this study. What was found was that information seekers typically tend to be younger than 65 years, female, more proactive with their health care, with higher levels of education and income than non-information seekers. It was also noted that those with more common cancers, such as breast or prostate cancer, were less likely to seek information than those with less common and familiar diagnoses (Mayer et al., 2006).

For those who are desirous of more information, be it on their cancer prognosis or how to alleviate their symptoms or even their fears, studies have shown that few physicians sufficiently detect or address patient cues for more information help (Butow et al., 2002; Cormaroff & Maquire, 1981; Greenley, Young, & Schoenherr 1982). This is especially so for indirect cues such as body language, facial expressions and paraverbal communication. Despite the literature’s reinforcement of most patients’ high need of information, less than one in four patients are estimated to voluntarily reveal any psychiatric problems they may be experiencing or ask for additional information or support, particularly those in greatest need. Patients often
cite an unwillingness to further burden their already too busy medical team as well as their fear of being perceived as an uncompliant or an ungrateful patient as a reason for keeping their concerns quiet. Out of those who do seek information, 15% report leaving their doctors office without getting satisfactory answers from their medical team (IOM, 2008). Similarly, my own research supported the idea that patients do not wish to “bother” their physician.

2.1.3 Healthy Lifestyles

Studies show that lifestyle behavior, particularly in the form of physical activity and nutrition, may impact health outcomes. Proper nutrition, physical activity, and stress reduction has the capacity to not only aid an individual into remission or minimize symptoms, but may also decrease an individual’s risk for cancer recurrence (Coleman, Berg & Thompson 2014). The benefits of exercise include improved gastrointestinal function, increase in appetite and healthier cardiovascular systems. Improved nutrition, specifically in the increase of fruit and vegetable intake, may introduce much needed phytonutrients, antioxidants and fiber which have been shown to be beneficial to many people with a cancer diagnosis (Riboli & Norat 2003; Jones & Demark-Wahnefried 2006). However, as another recent study shows, higher consumption of fruits and vegetables is positively associated with higher levels of social support and with female gender as one recent study notes (Coleman, Berg & Thompson, 2014). More importantly, the implementation of good nutrition and physical exercise helps to maintain a healthy body weight, which is one of the most critical and well-documented needs of someone diagnosed with cancer. However, it is estimated that nearly 71% of cancer survivors are overweight or obese, complicating their health objectives and status (Jones & Demark-Wahnefried, 2006).
The popularity of yoga as a means to maintain a healthy lifestyle for cancer survivors or those in treatment is growing. It has been shown that yoga, meditation, and guided imagery are positively correlated with improved overall health by lowering levels of stress hormone and cholesterol (Surbone & Baider, 2010). The American Cancer Society defines yoga as an “exercise that involves a program of precise posture, breathing exercises, and meditation” (ACS, 2008). Some evidence shows that yoga can improve quality of life by connecting the mind, body and spirit, reducing stress, increasing tranquility and happiness, improving stamina and overall well-being. Newer research has begun to suggest that regular yoga practice may decrease inflammation in the body and improve levels of mental fatigue, depression and insomnia (Kiecolt-Glaser, et al. 2014). Yoga was demonstrated to have popular appeal and impact among participants in this study.

2.1.4 Support Systems

In times of crisis, many people turn to their faith and spirituality as a coping strategy which proved to be true for many of the participants in this study. Though not an extensively researched topic, many of the studies that have been done on the role of faith or spirituality and coping with cancer support a beneficial effect (Vachon, 2008). Initial evidence shows that for some, spiritual beliefs were a source of strength and comfort that helped to alleviate some of the anxiety, fears and depression that accompanied the cancer diagnosis (Surbone & Baider, 2010). Connection to a spiritual belief system or spiritual community, whether established prior to diagnosis or discovered as a result of diagnosis, helped some individuals to process their emotions or to find purpose and meaning in their experience to the extent that many noted, both in the literature and this study, that spiritual well-being was an important element in
decision making and quality-of-life considerations (Surbone & Baider, 2010). More recent research has begun to show the positive impact of spiritual practices on human biology resulting in reduced blood pressure and improved immune function (Vachon, 2008). As a result, more oncology practices are beginning to inquire about spiritual beliefs as part of the psychosocial screening process so that an individual’s belief system can be better incorporated and supported (Surbone & Baider, 2010).

Support groups are another means of providing psychosocial comfort and guidance for many, although they are not without their complications. One such example that highlights the cultural impediments of the support group construct can be seen through an ongoing public health educational intervention directed towards an African American community of women who have been diagnosed with breast cancer. Once a diagnosis of cancer has been established, public health efforts move to the tertiary stage of the prevention spectrum. In this third and final stage, the focus becomes less about the prevention and screening of disease and more on the treatment, management and mitigation of disease. This includes aspects like fighting the disease, finding ways to prevent co-morbidities, pain and symptom management, and quality-of-life issues (Remington, 2010). A common modality of tertiary resources to which public health initiatives attempt to direct individuals to is support groups. However, in the case of many African American communities, women are not participating in support groups despite best of the efforts from the public health awareness and education campaigns. In fact, those who predominately utilize support groups are young, white females of higher socioeconomic status. Anthropology has provided invaluable insight into why this may be (Matthews, 2009; Erwin, 2009). Though the effect of support groups is undeniably beneficial for some, it is a tool
that has been shaped by culture and is not easily applicable or appealing cross-culturally. Support groups provide a space to acknowledge and discuss disease, perceived weakness, and fears. However, not all cultures and peoples agree with or encourage the discussion of feelings, fears or illness with many actively rejecting the behavior entirely. The emphasis on the need to join a support group shows the poor understanding and appropriateness of using a wide spread educational interventions (Matthews, 2009; Erwin, 2009).

The construction of support groups in particular has been a source of anthropological study in recent years. In addition to the issue of applicability and appeal to the cancer population as a whole, those who would normally be inclined to join support groups have begun to criticize the practice. The rise of the support group, rooted in the belief that people have an impulse to communicate, and doing so in a structured environment can be beneficial, was in concert to the rise of the American self-help movement of the 1960s and on. As the movement grew, biomedicine began to influence the increased use of support groups to better suit their objectives. It was at this time that more oncologists began to favor the routine practice of informing patients of their cancer diagnosis, when in previous years many did not tell patients they had cancer. Despite the increase in informing patients they had cancer, many physicians would avoid full disclosure if the prognosis was dire. However, this began to change as oncologists realized support groups could potentially improve a patient’s emotional behavior despite ill news. To this end, oncologists began to embrace support groups, though not because they acknowledged the physical benefits of therapeutic modalities, but rather because oncologists hoped support groups would help patient’s better cope with their prognosis and interact more pleasantly with their medical team (Matthews, 2009).
Public health initiatives also endorse the benefits of support groups. Support groups represent an epidemiological level of prevention, known as the tertiary stage. At the point of disease development and progression, the tertiary stage of prevention represents health-promoting efforts that seek to minimize the impacts of disease while preventing the worsening of the condition (Gordis, 2009). Support groups, where peers can find common ground and share their experiences with each other, provide an opportunity to share information and increase knowledge on coping strategies. Support groups also have the potential to connect those in need with new, understanding and supportive relationships that may help to reduce depression and anxiety. As a result, individuals may increase their self-efficacy, believing they are “capable of carrying out a course of action to reach a desired goal” (Bandura, 1997; IOM, 2008).

The literature reflected that for many, the emphasis on the need to be positive in the face of cancer became *modus operandi* of support groups. Discourse, behavior and cultural framing of cancer became rooted in the need to promote positivity. As a result, many feel a filtered space is produced in support groups that only allows for the expression of optimism and nothing more. Many participants remarked that while it was nice to be upbeat at times, other times existed when they were too tired and sick to put the energy into the presentation (Matthews, 2009); that at times, they needed the space and freedom to be raw, gritty and real so that they could process their all of their feelings and not just the ones that were expected of them (Matthews, 2009). The pressure to remain hopeful and positive is compounded both inside and outside of the group, with some beginning to correlate their remission to their upbeat “fighting spirit.” Many felt that this creates an unrealistic expectation that the promise
of beating cancer is dependent on the adoption of an eternally positive outlook. This is further complicated as those outside of the support group, such as doctors, friends and families, reinforce the demand for maintaining unwavering optimism. Some cancer-stricken individuals felt they were constantly held exclusively responsible for their cancer outcome while at the same time denied the opportunity to process the negative emotions that naturally come with a cancer diagnosis. As a result, many find that support groups further alienate them and make them feel like a failure for their inability to remain entirely positive (Matthews, 2009).

The literature on support groups, coupled with participant observation on support groups, led to specific questioning of participants in this study about their utilization and perceptions of formal support groups. The use of formal support groups, that is to say groups that are moderated by a trained professional, was beneficial for most who were involved in them; however, only a small portion of the sample utilized formal support groups for various reasons which will be explored in depth later.

2.1.5 Emotional and Mental impacts

The cultural pressure to maintain a healthy, cancer-free image can be seen in other ways as well. One commonly critiqued promotion is the “Look Good, Feel Better” campaign to assist with cosmetic make-overs for chemotherapy patients. These efforts benefit some but pressure others to maintain a publicly healthy façade when they would rather focus their limited energy on other things. There is also the pressure to cover a head that lacks a full head of hair due to the chemotherapy process. Outside of the public unease of seeing a woman with spotty patches of hair or no hair, doctors have also classified patients who are unwilling to wear a wig as uncompliant or “aggressive” (Pool, 2011). Another issue of constructed presentation
that many have researched is that of scars and their representation of the cancer experience. An interesting contradiction exists in that scars from cancer treatments are encouraged to be viewed as a badge of honor of a warrior who bravely fought and won their battle with cancer. However, some believe that such scars are only suitable for the private spaces in life, and not for public consumption. Mainstream culture has created an expectation of how the cancer patient should present themselves to the public, which leads to a further cultural denial of the everyday nature and threat of cancer (Jain, 2007; Pool, 2011).

The women who were sampled in this study were almost exclusively appreciative and positive about the “Look Good, Feel Better” program, finding it helped them minimize their sickly appearance and maintain a sense and image of normalcy. It was a benefit to them to learn how to draw on eyebrows that they had since lost to chemotherapy and how to neutralize the greyish tone to their skin. Not all women objected to their altered appearance, however. Some wore their bald heads uncovered as a means to invite strangers into conversation and others were content with being creative and fashionable with their head scarves.

Anthropology has also explored other elements of the cancer experience. The role of gender, how it is constructed, and how it influences health perception and behavior is a complex and powerful point of study in anthropology. In numerous ways throughout the world, the influence of men on women’s health has been evident through practices such as the restriction to reproductive control or the increased exposure to sexually transmitted infections (Dudgeon, Matthew & Inhorn, 2004). However, men have also been shown to neglect their own health in part due to the cultural conception of masculinity. A common social construct of masculinity is rooted in the image of a man who is strong, independent and virile. He may
adopt “manly” behaviors such as high alcohol and red meat consumption, smoking, and working long hours in order to reinforce the image of masculinity, behaviors that have also been shown to have adverse health effects. To screen for cancer either as a part of routine prevention or because of the development of a symptom may challenge the masculine idea of strength as it courts the possibility of illness, and illness is akin to weakness (Courtenay, 2000). The role of gender may in part account for the fact that men have a 1 in 2 chance of developing cancer in their lifetime and a 1 in 4 chance of dying from it when women only have a 1 in 4, and 1 and 5 chance, respectively (ACS, 2013). Unsurprisingly, despite attempts to increase male recruitment, the sample size was predominately female, supporting previous research that men are less likely to engage in health behaviors or communication.

The impact of gender on health has been identified by anthropology in other ways as well. In particular, the complex and meaningful symbolism of female reproductive organs has been a prolific source of study and strife throughout all stages of the cancer process. A very common construct of womanhood around the world has been expressed in the physical artefacts of a woman’s breasts and reproductive organs. Ethnographies from different studies have revealed that the fear of losing one’s breasts, ovaries, uterus, et cetera, has been a preventative force for cancer screenings (Erwin, 2009; Erwin et al., 2010). Through qualitative methods that encouraged personal conversation, many women expressed that if they were screened and found to have cancer, they feared they would lose the body parts that shaped their femininity. In turn, they would lose their husband, their ability to have children, and their identity as a woman (Erwin, 2009; Erwin et al., 2010).
In a similar vein, those who are forced to undergo the cancer experience, from point of diagnosis, through treatment, and ideally onto remission, often struggle to find ways to suitably present themselves to the world. Anthropologist S. Lochlann Jain wrote frankly on the difficulties she faced when justifying, even to herself, the decision to remove only one breast, but leave the other non-affected one. The presence of one breast, which could never achieve suitable balance with her new prosthetic breast meant that she was unable to escape public acknowledgement that she was a cancer patient. A pair of breasts, either removed as a single unit or still visible as a single unit, provides an opportunity to promote the image of health and normality either as a public denial of cancer, or as a hopeful badge of survivorship as the case may be with double mastectomies. But retaining a single breast became an obvious beacon of cancer that discomfited all parties, including herself (Jain, 2007; 2013).

At times, participant conversations in this study wandered into similar and intriguing territory in a handful of ways. Similar to the mental and emotional exercise that Jain undertook with her reconstructed body, image and associated sexuality and gendered identity, several of the women remarked on parallel journeys. This did not prove to be a strong theme in my research, though a few women did organically express some degree of personal and conceptual struggle with the loss or reconstruction of their reproductive organs. While this might have been an avenue for further exploration, the research design did not allow for more than a superficial opportunity for participants to acknowledge a deeper symbolic value associated to their reproductive organs.

A final, albeit complex, emotional impact to be briefly noted above and beyond the commonly associated depression and anxiety, are the embedded socio-cultural messages some
individuals encounter. A common critique in the literature and in social media questions the “pink ribbon culture” – the reimaging of the breast cancer experience to promote hope, positivity, and empowerment. Despite well-meaning intentions, many state that their feelings, experiences, and gritty reality in fighting for their lives are devalued in favor of maintaining the above uplifting image; similar to the earlier support group discussion (Lehman, 2012). Social critic and political activist, Barbara Ehrenreich, famously stated that “positive thinking seems to be mandatory in the breast cancer world, to the point that unhappiness requires a kind of apology” (Lehman, 2012; Ehrenreich, 2009 pg. 26). Though this topic was not a specific question asked during the course of interviews, most participants would reveal either their appreciation for, or frustration with, breast cancer culture.

Another facet of the pink ribbon culture that emerged during some interviews came from participants who did not have breast cancer. Frequently, side comments were made that expressed a participant’s frustration that their cancer lacked the same awareness, support and resources that breast cancer does. As more than one interviewee said, “breast cancer isn’t the only cancer!” As telling and intriguing that these comments were, the study did not allow for a structured examination of this particular avenue.

2.1.6 Barriers

Beyond the primary and obvious obstacles of ill health, the cancer journey is often littered with numerous other barriers. As is the case with many chronic diseases, finances can be severely strained due to lost work and/or exorbitant medical bills. It is estimated that one in five Americans with a chronic disease has problems paying not only their medical bills or health insurance, but their rent or mortgage, food or the cost of transportation (Tu, 2004: May &
Cunningham, 2004; IOM, 2008). As some of the participants of the sample noted, strained finances kept them from traveling to a psychosocial function such as a support group or restricted them from seeking additional, uninsured guidance from a nutritionist or physical trainer.

Though information on disease and treatment has been shown to be very important to patients, it is repeatedly reported from sources like ASCO, ONS, and AOSW, that patients most frequently request information on support services; information specifically on support groups are the most requested psychosocial service. (Matthews et al., 2004; IOM, 2008). Failure to refer psychosocial information on to patients has been listed as a leading cause of patient dissatisfaction and a contributing factor to anxiety (Chapman & Rush, 2003; IOM, 2008). Along those same lines, inadequate social support has also been shown to further complicate healing outcomes and the cancer experience. The composition of social support varies from person to person, but typically is comprised of family, friends, community members and others within a social network and provides an individual in need with emotional, instrumental, appraisal and informational support (IOM, 2008). Specifically, lack of information whether from one’s medical team or social networks, has proven to also be a large barrier to the benefits of psychosocial services. As was the case of much of the sample, patients are desirous of information on support services and what is available to them (IOM, 2008).

2.2 Model and Theoretical Frameworks

What informs research inquiry and analysis is the implementation of theory or a model as a framework to guide the interpretation and understanding of data. A theory or conceptual model provides a systematic way to reveal and understand relationships between events and
variables that then further offer an opportunity for real world application and resolution. To that end, a collection of applicable theories and models drawn from anthropological, public health and other social science arenas were used for this study as a means to decipher and describe the processes in place and to offer potential insights and recommendations for future action (NCI, 2005).

2.2.1 Social-Ecological Model

A cornerstone theoretical model that is commonly used in public health to examine the influencing factors of health behavior and health outcomes is the social-ecological model (SEM). The core assumption of SEM is that health is affected by the “interaction between, and the interdependence of, factors within and across all levels of a health problem” (NCI, 2005). Meaning, individual health and health behavior is influenced by the dynamic interplay between multilevel social systems. These levels of influence grow in scope and are categorized in ascending order as: individual factors, interpersonal factors, institutional or organizational factors, community factors and lastly, public policy factors (NCI, 2005).

Figure 1: Social ecological model
(Agency for Healthcare Research and Quality, 2013)
As the figure shows, the individual, comprised of their personal characteristics, motivations, behaviors and habits is situated in the center of influence. The interpersonal factors that interact and influence the individual are people like their family, friends and medical team. Institutional or organizational factors include health care clinics, employers, church and groups like CSCNT. Research institutions, public health departments and the media reflect the larger influence of the community while the macro level of public policy influences individuals through federal agencies, national advocacy programs and legislators on local, state, and national levels (CDC, 2013).

When applied to the issue of cancer and coping strategies, SEM allows for a holistic examination of the different components that either supports or prohibits the use of psychosocial services on several levels. For example, an individual may acknowledge on a personal level the need for counseling services, but their medical insurance may not allow for access to a counselor, creating a barrier at the policy level. Or, as the CSCNT has often noted, physicians may lack awareness of organized support communities where they can refer patients, reflecting a disconnection between interpersonal and community levels, respectively. As a result, patients dependent upon their physician for information on such services because of their individual characteristics (factor), have a decreased opportunity to be exposed to potential psychosocial services.

2.2.2 Social Support Theory

A more nuanced and focused approach to understanding the impact of human relationships is known as the social support theory. Numerous studies have shown the relationship between the health of an individual and the perceived and actual support received
from those they know, be it professional or social relationships. Social support systems, as
defined by Caplan “help(s) the individual to mobilize his psychological resources and master his
psychological, emotional burdens; they share his tasks; and they supply him with extra supplies
of money, materials, tools, skills, and cognitive guidance to improve his handling of his
situation” (Caplan, 1974). Social support systems in turn impact an individual’s health
education, health behavior and decision making process. As such, the composition of social
support may have a beneficial impact on an individual’s health or, in the absence of support, a
possible deleterious effect. Social support is a multifaceted, complex concept that is
categorized into the following:

• Emotional support: the expressions of caring, love and empathy given to the individual
  in need

• Instrumental support: the tangible help, aid and service provided to the individual in
  need

• Informational support: the advice, suggestions, and information given to individuals to
  help their decision making process

• Appraisal support: the information, affirmation, and feedback and individual that aids
  with self-evaluation

In other words, the friends and family of a woman diagnosed with cancer, who sit and
listen with a compassionate ear, provide emotional support. Her husband provides
instrumental support as he collects her prescriptions for her or drives her to and from the
infusion center for her weekly chemotherapy treatment. The medical professionals, who
explain her diagnosis and treatment options, provide her informational support. The best
friend who assumes the role of her cheerleader, reminding her of her strength, fortitude and ability to overcome cancer is giving her appraisal support (Glanz, Rimer, & Viswanath, 2008).

A key facet of this study was to help identify the ways and means local people diagnosed with cancer cope with their diagnosis and where they learn of coping strategies. Since many of the coping strategies are rooted in support systems, identifying the different types of support will help to source common gaps or strengths in support categories that can be potentially addressed in the future.

2.2.3 Authoritative Knowledge

Though traditionally used in the anthropology of pregnancy and childbirth studies, authoritative knowledge offers a conceptual model to better understand the relationship between physicians, patients, access to information and the subsequent shared decision-making process. Simply defined, conventional authoritative knowledge is the knowledge dispensed by those in position of authority (Jordan, 1993; Warren et al., 2012). In our American biomedical paradigm, authoritative health knowledge is dispersed by the medical professionals of that system who act as brokers of the wisdom that is produced from leading research organizations such as the National Cancer Institute, American Cancer Society, Cancer Research Institute, et cetera. What makes it authoritative is the social systems that wittingly and unwittingly affirm the power and validity of the knowledge base and those who provide it – in the case of reputable cancer information, the medical professional and the compliant patient reinforce that power (Bali, 2005).

Authoritative knowledge is one of several knowledge systems. For example, embodied knowledge reflects the knowledge that is gained from the experiences of oneself and others
within one’s network of acquaintances, or traditional knowledge which is obtained through the cultural history and rituals inherited through generational transmission (Warren et al., 2012). People utilize parallel knowledge systems as suits them, though in most situations, authoritative knowledge is the most commonly used system. The increased popularity and acceptance of authoritative knowledge only further endorses and strengthens its authority. For cancer patients, authoritative knowledge represents evidence-based and scientifically authenticated biomedical knowledge that is imparted by credentialed medical professionals. Authoritative knowledge reaches for supremacy by its devaluation of other knowledge systems by deeming them as potentially ignorant or dangerous, thereby reinforcing a dependence on the system. Many individuals by default, rely heavily on authoritative knowledge for fear of incompliancy or risk of health outcome (Davis-Floyd & Sargent, 1996; Jordan, 1993, Warren et al., 2012). But as Brigitte Jordan noted, “the power of authoritative knowledge is not that it is correct, but that it counts” (Davis-Floyd & Sargent, 1996; Jordan, 1993).

Authoritative knowledge emerged very early during research process as the role of the medical teams in a participant’s life became readily and undeniably apparent in a variety of ways. Participants largely, if not exclusively, depended on the information provided to them by their medical teams. If information failed to be relayed, then participants often times went without that knowledge or awareness; oftentimes to their detriment. For example, many participants were unaware of the possibility or value of psychosocial services because no one on their medical team informed them. The dependence on the medical teams for information varied by participant, but was at times shaped by the insistence of the medical team or by the vulnerability of the participant. It is at this juncture that the combination of the selected
theories and conceptual models create complementary approaches to explore the different sources of information, support and selected coping strategies employed by the participants and what factors may influence their selections and outcomes.
CHAPTER 3
METHODOLOGY

3.1 Preliminary Investigation

As I began to refine the scope and focus of the research I would conduct on behalf of the Cancer Support Community North Texas (CSCNT), I employed participant observation as not only a means to establish a presence at the CSCNT and build rapport with members as mentioned earlier, but also as way to gain familiarity with the issues and concerns of members. H. Russell Bernard (2009) defines participant observation as a field methodology that involves the immersion of the investigator in the culture of study in order to intellectualize what is seen, heard, and experienced to gain a better understanding of the context. Participant observation was not limited to the early phase of research. Throughout the data collection I utilized participant observation at various venues including CSCNT, Virginia R. Cvetko Patient Education Center at Baylor Hospital, Yoga Bridge yoga classes, and various online support communities to increase my exposure and familiarity with the issues with which people affected with cancer contend.

I volunteered my time at the clubhouses (predominately the Dallas location), answering phones, welcoming members at the front desk, preparing for and supporting presentations and assisting in Noogieland day camp for children affected by cancer. I attended various educational lectures, retreats, and social functions listening attentively to the topics of interest and concerns of the members. The themes and terms that surfaced from this practice, later to be reinforced through discussion with CSCNT employees, helped to focus key word searches for related literature. Literature, selected according to the applicability of topic and date of
publication, was largely discovered through electronic sources such as Google Scholar, PubMed, Scopus and Academic Source Complete. Internet blogs, forums and public Facebook support groups were also reviewed to gain familiarity with vocabulary and popular topics, though were not relied on for factual content.

3.2 Recruitment

Upon the receipt of intuitional review board approval, the recruitment process began. The target sample population was 20 CSCNT members and 20 individuals not affiliated with CSCNT, referred to as “nonmembers.” Initial sample population parameters also included a cancer diagnosis within the last five years to ensure recent interaction with the medical oncology community, and an age requirement of at least 18 years or older. Recruitment of CSCNT members consisted of an email blast to members of all three clubhouses, as well as the posting of notices at clubhouses and on Facebook. Due to lack of response, I increased my presence at all of the clubhouses, though I never directly approached members to discuss potential participation. As more time passed with no participation, I began to briefly introduce myself and my project at the beginning of group functions, per the recommendation of the CSCNT. This resulted in a recruitment spike ($n = 11$), though less than the desired target number ($n = 20$).

To accommodate for the decrease in member participation, I increased the target number for nonmembers from ($n = 20$) to ($n = 30$). The recruitment process for nonmembers began with attempts to connect with oncology practices in the greater Dallas-Fort Worth area, to no avail. I contacted the leaders of 25 different local cancer support groups and though a few expressed interest, no participation resulted from cancer-specific support group recruitment.
This includes a Susan G. Komen newsletter notice that was sent on my behalf to registered women in the DFW area, with permission from the Susan G. Komen national office. One exception to this was the American Cancer Society (ACS) office, located in Denton, Texas. I interviewed two women from ACS Denton who were not only cancer survivors but providers for those who had been newly diagnosed, allowing me a unique and robust insight into the cancer experience. The women also connected me to another productive organization called Yoga Bridge. Yoga Bridge, a local non-profit organization devoted to providing free and low cost yoga to people affected by cancer, granted me access to a community of women who participated in my research in large numbers.

Over the course of recruitment, I contacted over 100 hundred religious organizations including churches of various denominations, synagogues, mosques, and non-traditional groups such as atheists and pagans. Roughly 10% of the religious organizations responded back favorably, though only two churches yielded participation. One church director in particular, a breast cancer survivor herself, organized two full days of interviews on my behalf with her church cancer care group, providing a wealth of in-depth and insightful interviews. It should be noted however, that large samples from this particular church as well as from Yoga Bridge, create the likelihood of sample bias.

The final productive recruitment strategy came from snowball sampling. Starting with my own network of friends and colleagues, I asked if anyone knew of potential participants who then in turn, reached out to their network of friends and colleagues seeking participants. The methodology was also employed upon the completion of each interview at which point I invited the participant to share my information with anybody they thought might be interested.
3.3 Data Collection

In conjunction with the literature review and ongoing participant observation, the foundation of the data collection was rooted in semi-structure and in depth interviews with people in the DFW area who had been diagnosed with cancer in the last ten years. Initially, the target population was to be 20 members and 20 nonmembers, preferably equally divided according to gender, and diagnosed within the last five years. However, due to the difficulties in obtaining interviews, the parameters were adjusted to fit the available population. New sample parameters were expanded from a diagnosis within the last five years to receiving oncology treatment within the last ten years. This proved to be beneficial as it was not previously considered that cancer treatment would extend past the five year mark. For example, several women in the sample who had been diagnosed breast cancer many years ago are undergoing treatment with many protocols extending beyond ten years. Interview inquiries were not restricted once gender and non-membership quotas were met, resulting in a surplus of female and nonmember interviews. No recruitment distinction was made according to participant age, cancer type, socio-economic status or race/ethnicity.

Semi-structured interviewing is a hallmark of anthropological research. The format is based on a routinely used and organized interview guide that allows opportunities for more in-depth probing as needed in a conversational setting (Bernard, 2011). The greatest benefit of conducting semi-structured interviews for this research topic was that it provided the chance for participants to express themselves as they wished and to be truly heard. The greater majority of participants expressed appreciation to me for the simple action of being listened to, finding a form of therapy in the action. The time allotted during the interviews also gave the
participants the chance to talk out their thoughts, exposing a wealth of information in the process. In total, 44 interviews were conducted with people who had been diagnosed with cancer; however, one interview was ultimately not included in the data due to the length of time they had been treatment (over 20 years). Two interviews of the 44 were with individuals who worked with cancer communities in addition to their own cancer diagnosis. Two additional interviews were then conducted with providers who did not have cancer, but were still able to provide valuable insight. As a result, a total of 45 interviews were conducted and counted.

<table>
<thead>
<tr>
<th>INTERVIEWEES</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Individuals with Cancer</td>
<td>41</td>
</tr>
<tr>
<td>(Cancer reoccurrence, metastasis, secondary cancers)</td>
<td>(9)</td>
</tr>
<tr>
<td>Providers with Cancer</td>
<td>2</td>
</tr>
<tr>
<td>Providers without Cancer</td>
<td>2</td>
</tr>
<tr>
<td>TOTAL INTERVIEWS</td>
<td>45</td>
</tr>
</tbody>
</table>

Table 1: Sample population profile

All of the interviews, with the exception of one, were conducted in person at a location of the participant’s choice. Locations included a private room at a CSCNT clubhouse, a private residence, coffee shop or eatery. The single interview that was not conducted in person was recorded via Skype as the participant was traveling at that time. Prior to starting an interview, time was devoted to carefully reviewing the informed consent form, ensuring that each participant understood their rights before questions began. Due to my earlier participant observations with the tight-knit yoga and church communities, I realized that some participants might be very familiar with each other’s story and speech, and thus despite all confidentiality measures, the possibility of recognition among friends might exist. Therefore, part of the informed consent process was verbally expanded to ensure certain participants were aware of this potential risk.
3.4 Data Analysis

During the interview process, several themes began to emerge from the comments of the participants which were later confirmed through the process of coding, and analyzed using grounded theory (Bernard, 2006). Upon completion of each interview, the interview was transcribed using Google Chrome. The transcript was be uploaded to QSR International NVivo 10, a qualitative software analysis program, for coding and review. Quantitative data, largely in the form of demographic information and some qualitative interview questions, were analyzed using the software program IBM SPSS Statistic 22 (SPSS).
CHAPTER 4

RESULTS

During the course of interviews, many personal stories, insights, struggles, and triumphs were shared that exposed the complex and compounded nature of the cancer experience. Though several common themes emerged through the conversations, the topic that surfaced repeatedly through all the interviews was entrenched in the importance of information. The different facets of information, including source of information, category of information and interest in information that emerged from the interviews will be reviewed in the following sections.

4.1 Sample Population Profile

Despite efforts to recruit men, only 1% of the sample was male. However, the percentage of males in the research does reflect the Cancer Support Community North Texas (CSCNT) gender profile closely. Unfortunately, neither the CSCNT member population nor this sample population adequately represents the percentage of men diagnosed with cancer in the state of Texas.

In terms of cancer demographics, the sample population profile resembles both the population profile of CSCNT and the state of Texas. High prevalence rates of breast cancer, colorectal cancer and lymphoma were the most common cancers. However, other common cancers

<table>
<thead>
<tr>
<th>INITIAL CANCER DIAGNOSIS</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Adenocarcinoma</td>
<td>1</td>
</tr>
<tr>
<td>Breast*</td>
<td>25</td>
</tr>
<tr>
<td>Carcinoid</td>
<td>1</td>
</tr>
<tr>
<td>Chondrosarcoma</td>
<td>1</td>
</tr>
<tr>
<td>Colon</td>
<td>2</td>
</tr>
<tr>
<td>Hodgkin’s Lymphoma</td>
<td>1</td>
</tr>
<tr>
<td>Large T Cell Lymphoma</td>
<td></td>
</tr>
<tr>
<td>Leukemia*</td>
<td>1</td>
</tr>
<tr>
<td>Lymphoma</td>
<td></td>
</tr>
<tr>
<td>Melanoma</td>
<td>2</td>
</tr>
<tr>
<td>Multiple Myeloma</td>
<td>4</td>
</tr>
<tr>
<td>Non-Hodgkin’s Lymphoma</td>
<td>1</td>
</tr>
<tr>
<td>Ovarian</td>
<td>1</td>
</tr>
<tr>
<td>Prostate</td>
<td>1</td>
</tr>
<tr>
<td>Thyroid</td>
<td>1</td>
</tr>
<tr>
<td>Uterine</td>
<td>1</td>
</tr>
<tr>
<td>Vaginal</td>
<td>1</td>
</tr>
</tbody>
</table>

Table 2: Sample cancer profile
*Indicates a secondary cancer diagnosis
such as lung and prostate were not well represented in this sample, which most likely is a result of the low male participation.

Nine participants experienced a cancer reoccurrence, metastasis, or development of secondary cancer.

Providing a sample participant was over the age of 18, no specific efforts were made to recruit according to age. This resulted in the average age of 51 years for sample participants. In comparison, of the average age of CSCNT members is 53 years

<table>
<thead>
<tr>
<th>AGE GROUPS</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>20-29</td>
<td>1</td>
</tr>
<tr>
<td>30-39</td>
<td>1</td>
</tr>
<tr>
<td>40-49</td>
<td>8</td>
</tr>
<tr>
<td>50-59</td>
<td>12</td>
</tr>
<tr>
<td>60-69</td>
<td>17</td>
</tr>
<tr>
<td>70-79</td>
<td>5</td>
</tr>
</tbody>
</table>

*Table 3: Sample population age demographics*

4.2 Impacts

To better understand the cancer experience and what may influence the healing process and subsequent outcome, the impact cancer may have the body and on the life of the diagnosed must be explored and acknowledged. As is the case with the biological nature of a cluster of cancer cells, cancer as a diagnosis can seep into every corner of life, affecting the simple activities of everyday life to larger life decisions and interactions. Though these impacts are varied in type and severity, the most common categories of complaints are explored below.

4.2.1 Physical Impacts

The well-known and feared image of a cancer patient is a gaunt, ashy-toned individual without hair. While the loss of hair was traumatic for many of the participants – indeed, several
remarked that loss of hair was more devastating than the loss of a breast – the physical manifestations of disease and the treatment process is expansive and potentially permanent.

Neuropathy, typically resultant from the effects of chemotherapy, radiation, or the cancer process itself, is one artifact of the cancer experience that was expressed in a large portion of interviews. The Mayo Clinic describes neuropathy as damage to the nerves, usually the sensory nerves, that results in symptoms such as, but not limited to the following: temperature sensitivity, pain, burning, or tingling in the extremities, or difficulties grasping objects. The symptoms can be temporary or permanent, and can cause great pain or challenge daily living (Ness, 2010). Unfortunately, there is no known cure for neuropathy.

The devastation of neuropathy was obvious as one participant tearfully explained,

I have neuropathy horribly, horribly bad, in both my legs. Days I stumble, I fall I walk with a walker on those days that I can't get it together (Participant 41, Multiple Myeloma)

Another participant described the lasting legacy of neuropathy on her life saying,

I've had neuropathy in the feet for 8 years or more. I've had it real bad in this hand since I started the treatment in the liver in November of 2010, so getting close to four years. I mean, drop stuff. It's too hard to grasp stuff. (Participant 20, Breast Cancer)

Not all participants were affected by neuropathy, though everyone feared its impacts.

However, all participants noted the profound fatigue that accompanied chemotherapy and radiation treatments. Unlike tiredness, which is associated with sleep quality and can be rectified with additional sleep, cancer-related fatigue encompasses a less precise, more all-encompassing physical and mental exhaustion that persists throughout the day without recourse or solution. Its impacts have been described as “paralyzing”, preventing people from executing the most basic of daily activities (Scott Hamilton CARES Initiative, 2014).
The impacts of treatment options and the cancer progression were not limited to neuropathy and fatigue. A host of complaints were noted from the effects of radiation treatment:

And then when they took the medical tape off, after 30 session of radiation, all the skin came off. It was literally raw. And it was more painful than the operation or anything else. It was horrible. (Participant 16, Breast Cancer)

Or the inconvenient nausea that accompanied chemotherapy:

I carry a vomit bag in my purse, a couple in the van, because there was a period of time where all of a sudden I would feel sick and once I threw up I would feel fine. So I’m sitting there in line waiting to pick up the kids and I am feeling sick so I popped a Zofran...And then I....I'm thinking...‘oh you're gonna get real sick’. So I'm getting my wash cloth that I carry and my bottle of water with me, and I’m thinking, ‘you’re going to get sick!’ Open my door and wetten my wash cloth and threw up in line. And then three times before I got to (Names Street). And I threw up three more times on the way home trying to drive with my left hand on the wheel, my right hand on my vomit bag.....And trying to keep my eyes open to make sure I am on the road and I said, ‘I'm not getting off on the access road because there is no shoulder.’ – (Participant 20, Breast Cancer)

To the collective physical effect of treatments and the experience:

My body hurt. My brain hurt. Everything hurt. I’d been cut up and mutilated. I felt like Frankenstein. I couldn’t go anywhere. (Participant 18, Thyroid Cancer)

4.2.3 Emotional and Mental Impacts

As the literature reflects, the diagnosis of cancer and the subsequent journey can be an overwhelming and emotionally taxing process. At times, interviews became emotionally charged as participants recalled the early moments of diagnosis shock and chaos, or noted frustration at obstacles they encountered along the way, or reflected on the people and points in time to whom they were immensely grateful.

Very frequently, participants would reflect on the early stages of their cancer journey noting the shock, numbness and fragility that took them by surprise. Many approached their
earliest doctor appointments stoically and with a sense of practicality, never believing their capable brains and spirits could become immobile. It came as a shock to several how vulnerable and in need of support they would become. As summated by one participant:

The first meeting that I went into, the people that did the biopsy, when they gave me the final results, I realized then...I thought, ‘you know, I can handle this. I can do it on my own.’ I couldn't even tell them what my zip code was that day. (Participant 6, Breast Cancer)

From December until June, I was so wrapped up and really overwhelmed by the treatment and the surgery and the recovery from the surgeries that that didn’t even ... It’s not that it didn’t register because I did my crying and that sort of stuff, but it wasn’t until I hit the bottom that I thought, ‘I can’t do this. I just ... I cannot do this by myself.’ (Participant 32, Breast Cancer)

Others noted the sense of isolation that came with their diagnosis:

When I was diagnosed, I was the only one on the planet that day. You know, and I know that 8 or 9....I used to know the statistics and I don’t know any longer, but 8 or 9 hundred ladies are diagnosed every minute. But on that particular day, I was it. (Participant 15, Breast Cancer)

This participant was not alone in her acknowledgement that while she knew she was one of many to be diagnosed with cancer that day, the impact and gravity of the diagnosis made her feel alone. As another participant similarly stated:

I knew, logically ... I mean, I’m an educated person. I knew I wasn’t because there are millions of women, every year that are diagnosed with cancer. But, on a personal level, it was just me. (Participant 32, Breast Cancer)

While the large majority of the participants struggled at one point or another with fear, anxiety or difficulties comprehending their newfound circumstances, several participants discussed the darker emotional and conceptual battles they fought. Accompanying the physical changes to the body are the emotional tolls those changes foster. For some, there is a realization that the
body is under invasion and the acknowledgement of reduced physical capacity leads to additional grief. One participant encapsulated this well when she said:

(it was) very emotionally depressing, because I realized my body is no longer the same. I mourned and I cried and I cried and I really wanted to die. I did not feel good at all. I have never wanted to take medicine ever, and all of a sudden, I’m dependent on a medicine for the rest of my life (Participant 18, Thyroid Cancer)

Another revealed the severity of her circumstances when she explained:

After my mastectomy, I totally lost it. And that was October 1 when I had my surgery. Of course I was in pain, but I think more of a...feel like....less of woman afterwards. Um, and I ....I think....I really....I think also, too....after surgery, come home kind of like you really don’t have anybody to talk to. It makes me...got more depressed. And a week after I tried to O.D. (Participant 11, Breast Cancer)

This participant, as a well as a few others, touched on an aspect of the cancer process that was noted in the anthropological literature though not directly asked during the interview process. Through her comments, she gave indication of the complexity that surrounds the surgical removal of gendered body part. That is, are there further implications of losing a body part beyond the necessity of saving one’s life? As she and others revealed: yes, there are. However, as follow up questions revealed, individuals are typically left to their own private devices when attempting to comes to terms with their altered sense of femininity/masculinity, their weakened self-perception, or in the words of one participant, “what (they’ve) lost.”

Lastly, several participants mentioned the impact of the breast cancer culture – namely, mainstream familiarity with breast cancer and the accessibility of breast cancer resources. For many of the women in the sample who have been diagnosed with breast cancer, the support and positivity of the breast cancer culture and community was welcomed. However, several did note dissatisfaction for two reasons: Women were made to feel less deserving of support, specifically from other women, because in comparison their journey was less severe. Or, more
commonly, women who were stage IV felt abandoned by the community and culture. Similar to what the literature noted, these women felt that their circumstances were minimized or even ignored in favor of the “fluffier” efforts. As one female participant said about the breast cancer events,

They just wanted to talk about hair loss and makeup. I don’t care about hair loss anymore. I just want to yell at them, ‘losing your hair is the least of your concerns. Help me now. Help me live.’ (Participant 15, Breast Cancer)

4.2.3 Cognitive Impacts

Second to the issue of fatigue, cognitive changes were the most commonly cited impact. However, more so than fatigue, struggles with cognitive abilities like “chemo brain” were surrounded by feelings of fear and grief. One participant relayed the limitations and terror that accompany her reduced cognitive state by explaining:

I don’t go but a five-mile radius around from my house because I’ve gotten lost and didn’t know how to get home and I had to call somebody to tell me how to get back. I’ve lived in this town for 30 years! (Participant 41, Multiple Myeloma)

Chemo brain, another frequently cited cognitive impact among participants, is a poorly understood mechanism of the treatment process that is not always made clear as a risk to participants. Those who were aware of the possibility of development oftentimes poorly understood the reality of the condition. Chemo brain forces some to relinquish their highly demanding cognitive jobs or a degree of pride in their mental agility.

...chemo brain, it is a true experience. And for me, that’s been a loss. It’s knowing you’re not as sharp as you used to be. It’s humbling. (Participant 40, Breast Cancer)
4.2.4 Surroundings

During the course of conversation, several participants mentioned the impact of the medical atmosphere of the various hospitals, physicians’ offices and treatment centers on their psyche. Aspects of the chemotherapy in particular were noted at times to either be comfortable or upsetting, depending on the layout of the room. The few positive comments related to infusion centers typically referred to private rooms that were homey in nature and separate from others. Mostly, people remarked that infusion centers that were crowded with sickly, bald patients increased their depression and anxiety. Some participants even went so far as to “shop around” for infusion centers where they could feel the most comfortable or scheduled appointments at times when fewer people would be there receiving treatment.

One participant described how the medical facilities influenced his state of mind by saying:

You’ve got to drive down cancer road to cancer building, to the cancer floor, to the cancer wing, to wait in the cancer waiting room with all the other cancer patients who are standing there with the IV poles and wheelchairs. It’s scary, I tell you… I would have been crapping my pants because you’re in there in the mix master with all these people who are so sick and it’s just …you’re soaking in cancer. It’s supposed to give you the feeling that, hey! You are in this big machine that’s going to shine its unbelievably bright clean light on your disease, you know, and illuminate it with such detail it’s going to be forever wiped out, you know. And all it does for me anyway, is just engender fear.

(Participant 4, Prostate Cancer)

4.3 Support Communities and Coping Strategies

One core tenet of this research was to better understand the ways and means CSCNT members and nonmembers alike were attempting to cope and to mitigate the impacts of cancer on their bodies and lives, be it through formal or informal channels. This information would help the CSCNT to refine or strengthen their selection of supportive services to those in
need as defined by the participants. For most people diagnosed with cancer, support comes from a composition of different sources according to their needs, the appeal of the source and the availability of that source.

4.3.1 Support: Family

For over 55% of the participants, family was cited as a primary level of support in some small fashion. Family members, most especially significant others or adult siblings, provided support in at least the most practical and instrumental ways, such as transportation to and from medical visits and providing meals. While some participants received additional support in the form of emotional support and understanding, many participants regretfully mentioned they felt their families could provide more support.

My husband…I just wish my daughters would be more attentive to my needs (Participant 41, Multiple Myeloma)

I’ve got a great husband and stuff but he was pretty much useless to me. I mean, until I got into treatment and he made sure I had good meals to eat and that kind of stuff...but any kind of discussion on this stuff at all....and my kids weren’t helpful with that either because they think I was always the strong female that could handle everything and I kind of fell apart for a while and I don’t think they understood. (Participant 38, Uterine Cancer)

I mean, that....my loving family....they do not....they still avoid...you just don’t want to talk to them about that kind of thing (Participant 11, Breast Cancer)

4.3.2 Support: Friends

For those who chose to share their cancer diagnoses with others (a few in the study opted to keep diagnosis private), friendships became a source of potential support. Though many related a story of one or two disappointing friendships, the overwhelming majority of
participants were humbled and shocked by the expressions of support from their friends. One participant expressed this division of friendships well when he said:

One thing I’ve discovered about this ...is that there’s two groups of people. There’s one group that wants to know everything, they want to do everything, they will make themselves available....and they’re right there. There’s a second group. Some have become extremely distant....They don’t talk a lot. They don’t seem to want to know anything. (Participant 8, Lymphoma)

For those who found comfort and support in their established community of friends:

My family is great, but you know, friends serve a particular purpose of you know...sometimes I just don’t feel like I can really burden my sister, you know? ...So it’s just good to have a friend. They have a dog in the fight but not the way your family does. (Participant 5, Chondrosarcoma)

Many noted that cancer revealed new friendships, in two key ways. One way was through the introduction of new cancer patients to other cancer patients through cancer specific support communities (to be explored in greater depth later). Another way was through casual acquaintances that oftentimes developed into strong bonds. This was a particularly common occurrence with those who had a breast cancer diagnosis. Once word spread throughout a network (e.g. parents of their children’s friends, church groups, work groups, hobby groups, neighbors, et cetera), another woman with breast cancer would reach out and offer support. Several forged fruitful friendships through unknown or little known survivors reaching out to them. Two participants spoke to this point when they said:

We were friends, but we were more like acquaintance friends from before this whole thing happened...She went to every single chemo with me except for like two. (Participant 7, Breast Cancer)

And then as the word spread outside of this community, among my friends, I had other old friends that I had met along the way there were acquaintances that I had, contacted me as well. So my network just broadened (Participant 40, Breast Cancer)
4.3.3 Support: Church and Faith

Many of the participants found comfort in their faith and/or church communities. When asked “When you have a particularly bad day when you are feeling poorly or upset, what do you do to get yourself through it?” the most commonly cited coping strategy was “pray.” While over 30% of the sample was active in their church communities, not all churches offered robust support for cancer needs. Some held group meetings once or twice a year while others met more frequently and organized care strategies to support church members in need. One participant spoke about the great impact “chemo fairies” had during her greatest time in need.

Every time I came home from a chemo treatment, I would have a basket waiting for me at my door. So I think it was seven or eight women and I kind of had a suspicion who it was, or at least one or two of them. But that was really, really cool. (Participant 6, Breast Cancer)

Her chemo fairy packages would always contain a selection of items that she would most likely need or want at that particular phase in treatment. For example, the package contained a pen and journal, another package would have specialty lotion to treat her skin as the chemo and radiation began to break it down, and the final package contained a celebratory bottle of champagne that coincided with her final treatment.

4.3.4 Support: Formal and Informal Groups

While most of the participants found strength and aid through their friends, family, and church community (in that order), roughly 25% of the participants found support through an organized support group, monitored by a trained facilitator through the CSC, their doctors office, or through a national cancer organization such as Susan G Komen. The value of these groups can be seen through comments like:

They make me feel normal. They keep my sanity. (Participant 12, Carcinoid Cancer)
It helps to be able to talk about it and not...you know, feel like somebody is going to go, ‘oh you’re just weighing me down with your...you know.’ (Participant 21, Breast Cancer)

It’s a place to go with people of our own group. I mean, our own society, you know? (Participant 43, Skin Cancer)

However, not all participants found solace through a formal support group. A few selected to try joining a support group but failed to connect with the people or the premise, while others held negative perceptions of them. For example, one participant noted her hesitancy in trying a support group:

I think I wouldn’t mind to share it (her experience). I wouldn’t be...I wouldn’t mind to have them share with me, but I think that...I think I just rather to....not to feel more depressed than I am. (Participant 11, Breast Cancer)

Adding to the perception that support groups are places that might increase depression, several were actively advised against support groups by their medical team. For example, with more unique and incurable cancers like Multiple Myeloma, medical teams warn that information and stories of hope would not be applicable, and therefore unnecessarily troublesome.

Less formal support groups were also mentioned by several participants. These groups took form in one of two ways. One way was through patient creation and management of a Facebook page. For participants with less common diagnoses, Facebook support groups provided the best and sometimes only means of connecting with others in similar situations. The other form developed organically through routine activities with other patients. Yoga Bridge provides numerous examples that elucidate this point. For example, the intention for many participants when signing up for yoga classes was to improve their physical well-being. However, an overwhelming amount of participants noted that in addition to the physical
benefits of yoga, they found supportive friendships and a sense a community within the yoga community.

...and the yoga, by far, is the best, you know, support. They don’t even know what we are doing for each other. It’s just the fact that you go there and you have people with similar situation, whatever it is, and you know. (Participant 15, Breast Cancer)

4.3.5 Support: One-on-One Counseling

Less than 10% of this study utilized individual counseling sessions. Of those who did, most had sought counseling services prior to their diagnosis and incorporated cancer issues as needed in their already established counseling routine. Few explicitly sought individual counseling because of the cancer. However, it should be noted that all CSCNT members receive individual screening sessions with a social worker prior to being permitted to engage in clubhouse activities. While these early individual sessions are utilized by the CSNCT to screen for mental health and connect new members to the appropriate resources, the members view them as individual counseling noted the benefit to their well-being though none in this sample sought continued individual counseling as a result.

4.3.6 Support: Medical Community

A final level of support that was mentioned in some interviews, though not all, was the support of the medical community. This support came from different factions of the medical community, including the different physicians, nurses and case managers with whom the participants interacted. An overwhelming majority of participants remarked on the demeanor of the physicians, noting the elements that made either a positive or negative impression on them. Favorable and comfortable impressions for many were personable actions such as a hug or inquiring after the participant’s life outside cancer. Many physicians displayed an overly
positive demeanor and made comments such as “Don’t worry, we’ve got this” which was met with strong mixed emotions. Some participants found the confidence reassuring while others found such comments demeaning. All participants appreciated the quality time with their doctors where they were not rushed and were able to ask any and all questions they might have had. The physician’s disposition and accessibility seemed to largely inform participant’s opinion as to whether they had a good doctor or not.

A key resource that was available to some participants was a nurse navigator or case manager, provided either through the hospital system they were receiving treatment or through their insurance company. For a few participants who were enrolled in a clinical trial, their clinical trial coordinator played a similar role. Regardless of the title, this individual was able to provide additional support and guidance for participants; provided, of course that the participants understood their purpose. A handful of interviewees mentioned access to a nurse navigator or case manager, but failed to understand their purpose. As far as they understood, their presence was merely another individual to juggle. However, for those who connected to the resource, the benefit to them was great. As one participant explained:

..She contacts me at least once a week and you know, to talk about my...whatever. Whatever is on my mind about my appointment and how things are going and she keeps up with it. I am amazed. She must take really good notes because she always keeps up very well. And sometimes, you know, I don’t’ think of it until I am in the idle of a conversation with her and then I’ll think of something and she’s giving me information...she has some really good insight and then I’ll tell her things that the doctor said to me and like, I have neuropathy and we talked about that. And you know...she said ‘here’s some things that you can ask the doctor’ and you know, that’s kind of helpful to have someone who knows. (Participant 21, Breast Cancer)
4.3.7 Physical Coping

As previously mentioned, the progression of the disease and the treatment process can adversely impact the body, from minor to more profound effects that can be temporary or permanent. In response, several participants sought physical activities that would either improve their outcomes or help alleviate physical, emotional or mental strains.

The most commonly cited physical coping methodology was yoga. While it should be noted that a large portion of the sample was sourced from Yoga Bridge, a non-profit yoga studio and instructor-training studio structured to meet the unique needs of oncology patients and survivors, the larger overall sample (over 40%) benefitted from yoga at different locations. Several additional participants expressed desire to try yoga but had yet to do so. Many of the participants were new to the practice of yoga, but sought it out as a means to improve physical stamina, increase their flexibility post-surgery, or gain a general sense of feeling better. However, for nearly all of them, yoga superseded the bonds of physicality and impacted their emotional and mental well-being.

One participant explains that in addition to the reduction of backaches and stiffness, yoga helps you with your mind. It calms you. Cause you are very excited and you have a lot of unspent energy and thoughts and just...makes you concentrate and be...calm. (Participant 15, Breast Cancer)

Another participant discussed how yoga benefitted her in unexpected ways. When speaking of the discomfort and difficulties of lying still for 45 minutes in a MRI machine, one participant explained how her yoga experience helped her...

...and I could feel my heart rate increasing and I just thought....’I’ve never thought myself claustrophobic but this is just miserable’. And I told myself, ‘you have to find a way to hold still’.... and I could just hear Susan’s voice saying, ‘you can’t control much but you can control your breath. So....breathe’. It (Yoga) gave me some techniques that I
could use to, you know...when everything else is out of control that is what you can control. And it helped. It helped a lot. (Participant 14, Breast Cancer)

Other strategies to increase physical wellbeing included walking, gentle water aerobics and gardening, for those who were still permitted to do so. Gardening is typically not advised for women who have undergone lymphadenectomies, commonly occurring with breast cancer surgeries, due to increased risk of infection. A small few were able to participate in more organized fitness programs such as Fit Steps for Life or LIVESTRONG at the YMCA. Both programs offer more individualized fitness guidance tailored to the needs of those diagnosed with cancer.

4.3.8 Emotional and Mental Coping

Several of the participants turned to themselves for finding ways to process their grief, frustration or sadness. The most popular methodology that roughly one third of the sample mentioned was journaling. Participants would write down their thoughts, feelings, and experiences typically finding some measure of relief from the activity. Studies on subject have begun to reinforce the benefit of journaling to show that, not only does the activity improve physiological distress, but it can improve immune function, fatigue and post-traumatic stress (Carroll 2014). Other mentioned activities were puzzles, a collection of motivational quotes, and arts and crafts such as ceramic painting. Guided imagery taught either through a psychosocial center or at church as a devotional was frequently mentioned to be a calming activity.

4.4 Barriers

Navigating the cancer experience is rife with obstacles and challenges. Despite the existence of resources such as what the CSCNT provides, access and awareness of psychosocial
services is oftentimes hampered. As discussed earlier, the physical impact on the body can leave an individual with extreme levels of fatigue, pain or low immunity preventing the ability to travel to a resource for access. However, additional barriers were revealed through the course of data collection. The most common of which will be briefly reviewed below.

4.4.1 Information

Despite living in an information age, it was revealed that the largest barrier to an improved cancer experience was lack of information. Nearly 85% of participants expressed some degree of frustration at that there was still so much about their diagnosis they did not completely understand. This was especially true for those further along the cancer journey. While few participants wanted detailed information on their cancer type, prognosis and treatment plans during the early phases of their journey, there were those who wished for additional information on what side effects may occur, how they can improve their health through lifestyle choices, and how to connect with support resources. This became especially true as the initial shock and despair of the diagnosis eroded to acceptance.

One common example of a poorly understood potential outcome that surfaced through the interviews was lymphedema. Lymphedema is the collection of fluid in the soft tissues that becomes visible through swelling due to the cancer process or cancer treatment, resulting in mild to severe discomfort and complications (NCI 2013). Breast cancer patients in particular are at higher risk for the development of lymphedema. This is because breast cancer surgeries commonly remove suspicious lymph nodes, thereby altering the lymph system and enhancing the risk of lymphedema (ACS 2014). However, few of the women with breast cancer in the
sample recalled learning of lymphedema from their medical team prior to the development of lymphedema, if at all.

Other issues of inadequate information emerged and will be explored in detail in a later section. Suffice it to say, lack of information created barriers to informed decision making, access to resources, support and potentially improved experiences to the majority of the sample. This gap in information was especially poignant for several interviewees. Lack of information or poorly understood information in several cases led to injury, development of co-morbidities, unnecessary isolation and strife, additional stress and in some cases, surprise reoccurrence of cancer; some of which could have been potentially avoided.

4.4.2 Location

While several psychosocial resources exist around the greater Dallas/Fort Worth Metroplex, they are unsurprisingly concentrated in the more concentrated population areas. While beneficial for those who live nearby, longer distances posed a challenge for those living further away. Participants were able to easily source oncological treatment centers outside of the city; however, many would have preferred to receive care from the larger institutions found in the city. The feasibility of contending with traffic, investing large amounts of time and energy when sick, arranging for a caregiver to assist in driving, or the cost of gas and tolls were prohibitive for much of the sample. The same was true for utilizing psychosocial services, which were fewer in access points than treatment centers. When speaking of participating in CSCNT events, one participant said:

...this place, is a little bit difficult to get to after a certain time because of traffic and everything. So I try to, you know. I am kind of limited on what I can do. (Participant 3, Lymphoma)
Another participant echoes the above sentiment as to why she doesn’t utilize psychosocial services saying:

That’s the problem with here. I live in Lake Dallas. I can’t get on a train. I come north to Denton or go over the Lewisville Bridge and the trains don’t necessarily go where the resources are located, you know. So it’s transportation. I don’t drive at night. And driving by yourself in the city is not necessarily a good thing if you don’t know where you’re going or the part of the city you are in. And with all the construction on 35...you can just forget it. (Participant 23, Breast Cancer)

An additional issue that surfaced during the course of interviews was the fear several participants had about venturing too far away from their medical team. As one participant mentioned, when speaking of her yearly visitation to her timeshare not more than two hours from Dallas:

“I was so afraid to get too far away from Dallas.” (Participant 40, Breast Cancer)

This reticence of being too far from the medical team was also a key decision for several participants, who were able to seek care from organizations out of town, such as MD Anderson or Cancer Treatment Centers of America, but were uncomfortable being too far from their medical team when home. A few participants were able to overcome this challenge by seeking a care plan from an outside organization then having a local oncology center refer to outside team, but doing so restricted their routine engagement in psychosocial resources.

4.4.3 Availability

A common barrier to accessing psychosocial services that was noted was availability of those services. For those in the sample who live in Denton County or further north, no formal support group services exist regardless of type of cancer. Individuals who wish to participate in support groups must either do so through their church, if possible, online, or drive a minimum of 30 minutes away.
Time of day also influences the ability of participants to engage in psychosocial activities. Many participants stated traffic as a deterrent as well as services that take place during the traditional work hours, particularly for those who maintained employment. Some participants stated that for those services that occur during evening weekend hours, lack of childcare was a barrier.

Because for like Baylor, they have their little calendar that you’ve looked at with all the little classes and stuff. I continued to work and I live in Carrollton, so most of the classes are during the day and they are not what I would want, you know. (Participant 38, Uterine Cancer)

Another participant further highlights the challenge of time, discussing what prevents her from partaking in the educational lectures that interest her:

So the programs that are at night and the times that they have them, you know, I have to decided and then ask my mom to babysit and give a whole night to go to the programs. It has to be really good, or else I am like…and then I have to give up a night with my kids to go to it. (Participant 5, Chondrosarcoma)

Time with her children is especially precious and important to her as she is terminal and contending with split custody from her recent divorce. As much as she’d like access to information and resources that would be highly beneficial to her cancer experience, she must prioritize the time she has with her children.

4.4.4 Finances

Finances are a barrier to participants in two critical ways. The first and most obvious financial obstacle is the cost of health. Insurance, co-pays, medication, treatment, transportation, and all the supplemental items that are needed such as bras specific to breast reconstruction or wigs for hair loss, are immensely costly. The second financial barrier is the management of medical and insurance bills. Many of the participants complained about the
amount of time, energy and frustration spent on attempting to understand and manage the
system. As one participant explains in exasperation,

Why are these bills pushed aside? Trying to fight that day to day....not fighting
Medicare, Aetna, and putting it together when you are dealing with numbers on the
phone. Push one to get this. Two, to get this. And some of the best paths that I've
gotten was to sit here for six hours to just make one phone call or two. (Participant 15,
Breast Cancer)

Another continues with as much frustration,

And that's the thing, you just don't understand...I mean, first of all, I am very slow since
my chemo and I don't know if it's because... you know? I feel like your brain is like this
too. If you haven't exercised it in a while you, you know? And I am sluggish and I am
stressed, and I am you know, just not the same as I was, but on top of that, there's
....when I worked, I got a statement of benefits from the insurance company and, ‘oh
you covered this, and you didn’t cover this’ and that is it and I had one insurance and I
pay that amount. Now it's, ‘oh well, now they won’t pay that’, but now I go submit it to
Medicare and I see what they pay and then I go back here and.....so it's not even...it's
just like, and maybe it will only take me an hour to deal with it, with every single thing in
your life is like that, like, ‘Oh, I got to do this form for this? Oh, I got to do this form for
that? Oh now I am?? Oh, I have a premium but only if I fill out this form’. And then I've
got to call them and then...so there goes three hours of your day on the phone with
some jackass. It's like, surviving cancer part that people don’t factor in, you know?
(Participant 5, Chondrosarcoma)

These comments are telling, exposing how the compounding impacts build, making the smallest
of tasks difficult and draining. To further challenge their situation, the effort to manage strained
finances becomes a job in itself.

4.5 Information Sources

A key research question was to determine where individuals were looking for
information and what kind of information they were seeking. This in part was fueled by the
CSCNT desire to better understand where nonmembers in particular where learning about
psychosocial services, if they were having their needs met elsewhere, or if they were falling
through the support cracks. The following subsections reflect the most commonly cited sources of information that emerged during the interviews.

4.5.1 Literature

Printed literature sources came in two main forms. The first was in the series of pamphlets, flyers and booklets that medical teams provide participants during the early days of diagnosis. Some patients receive overwhelming binders full of information that is too much to consume. Others pick up the brochures that can often be found in the waiting rooms and on the walls of the physician offices with a quick review of cancer facts and frequently asked questions on topics such as what to expect from your surgery, chemotherapy, radiation treatments, et cetera. The subject of side effects from drugs are commonly offered in larger, more difficult-to-digest information packets. Only a few participants noted this as an impactful source of help. Participants either felt the information was too limited or the more common complaint: the information as too much to contend with during that overwhelming period of adjustment, and therefore avoided. Two of many such comments on this point are:

I had a huge bag full of stuff, you know, that they gave me. Some of it, you know, I just couldn’t get through it. It was so much (Participant 6, Breast Cancer)

They didn’t really talk to me. They just kind of gave me the literature and then you go home and read it and kind of freak out, you know? And I guess if they thought I was really at high risk for something like that, maybe they would have talked to me more. (Participant 21, Breast Cancer)

The second source of printed literature noted was books. Though books were less popular as a common source of information, breast cancer participants noted books frequently. One book in particular was not only often and enthusiastically mentioned, but a handful of participants even brought their copies of the book to interviews. This book, commonly referred
to as the “breast cancer bible”, was Dr. Susan Love’s *The Breast Book*. While *The Breast Book* discusses the topics such as surgery, reconstruction options and treatment side effects, other books mentioned discuss topics such as how to cope with cancer, how to tell your children you have cancer, how to get your husband to understand your journey, and how to navigate the murky waters of body image, sexuality and cancer. As one participant enthusiastically explains *The Breast Book*,

> It provided me everything that I needed. Every symptom, every problem.....if I was going through the next treatment, I would look it up to see what to expect. (Participant 18, Thyroid Cancer)

4.5.2 Internet

Not surprisingly, the internet has become a more popular choice for resourcing information. Participants unanimously obtained information from well-established and respected websites like the National Cancer Institute, The Mayo Clinic, MD Anderson, American Cancer Society, Cancer.gov, and national organizations for specific cancers for information on their disease and treatment options. This proved to be beneficial for common cancers, but more challenging for the participants who had more rare cancers. A few others found information through more general Google searches or WebMD. Personal blogs, discussion boards and online support groups proved to have mixed results among the sample. Of those who used the internet to find information, many shied away from the less formal avenues, thinking the information would be less reliable, incorrect and potentially upsetting. However, several in the sample found great comfort in reading the experiences of others or learned new practical tips on how to cope.
Twenty percent of the sample population was actively advised by their medical team to avoid the internet completely, or was given a list of “approved” websites to peruse. This was in part due to accurate information and in part due to the potential emotional trauma participants may experience. As one interviewee said,

...they said, ‘Do not go on the internet’. They said, ‘Don’t. Just don’t it. Just don’t do it cause you know, just don’t. It’s not going to be useful,’ and it wasn’t. (Participant 4, Prostate Cancer)

Another participant who was not advised against the internet, but was critical and cautious of what she read on the internet regardless, said,

There are some discussion chats on breastcancer.org. That one, you have to be careful with because its individual women and yes, they’re going through the same sorts of....I specifically got on one chat for DIEP, but there was lots of doom and gloom. (Participant 32, Breast Cancer)

For those who sought information, most attempted to use the internet to some degree. Unless a participant had a more rare form of cancer, participants found internet information to be beneficial. Most searches were centered on the trusted and authoritative information websites like Susan .G Komen, National Cancer Institute, and Cancer.gov. However, a few individuals sought more personable and relatable information that could be found in chat rooms, forums and blogs. Here some participants found practical advice on where to shop for drain pockets, how to cope with skin changes and what to really expect from surgery.

4.5.3 Other Patients

The most helpful source of information noted by the majority of participants came through other patients whom they had met through cancer activities, online or through a mentor match. The ability to talk to someone else in a similar situation who was further along in the process provided a wealth of benefits to many of the participants. It allowed for the
participants to get a sense that they would be all right, and exposed them to tips and tricks on how to mitigate their symptoms and life with cancer. It also provided a sense of community and returned to many a sense of normalcy. One participant asked her physician to connect her with another patient in near identical circumstances: same type of cancer, same stage, same treatment plan. Though taken aback, the physician honored her request. The participant said of the experience,

And I said (to the physician), ‘Could you contact that person and see if they would be willing to meet with me?’ And so, I met with her three or four times throughout my journey...Because I just needed to see a healthy....an endpoint that got through...happily. (Participant 39, Breast Cancer)

Though a mentor match had not been an established protocol at that particular office, other facilities and stand-alone organizations provide this service. Another participant, who did not participate in a formal mentor match, further explains how powerful connecting with other individuals in similar circumstances can be:

I know like reading that other people have the same problems that I do, it’s like affirmation for myself...I’m like, oh! You have a bloody nose? I have a bloody nose, too. Good. OK. So we’re good. Even though the doctor is like, no, that bloody nose isn’t anything....OK. You can tell me that bloody nose is not related, but I’m going to tell you right now, I’ve got a bloody nose from the chemo. (Participant 7, Breast Cancer)

As her words show, many participants gain a sense of validation from their peers that they may not get from the medical community. The comfort this provides cannot be easily dismissed.

4.5.4 Organizations

Only a small segment of the population utilized (or was even aware of) educational and informational opportunities at organizations such as the CSCNT or local hospital systems. Not surprisingly, most of those who were aware were members of the CSCNT and took advantage of the classes and lectures at the clubhouses. A few members and nonmembers alike also
sought out educational opportunities through their doctor’s office or at the cancer resource centers of University of Texas – Southwestern (UTSW), Baylor Health Care System, or Medical City. These educational opportunities covered topics such as clinical trials, insurance, how to cook for cancer, and exercise. These were great sources of information and support that participants discussed at length. In particular, participants were most interested in information on how to combat the physical impacts of side effects such as chemo brain and neuropathy, and how to improve their nutrition.

Of the few participants who were familiar with CSCNT, most were only familiar with the former moniker of Gilda’s Club and not the new name. Despite a familiarity with either name, nonmember participants were unclear of the services available to them through the CSCNT, largely presuming the CSCNT was for end-of-life or hospice care. CSCNT faces a challenge in increasing new brand awareness.

4.5.5 Physician Recommended Services

![Figure 2: Physician recommended services](image)

Did anyone on your medical team recommend psychosocial services?

- 56% Yes
- 33% No
- 11% Unsure
One of the more complicated sources of information was the medical teams that treated participants. The degree to which medical personnel, be it the primary physician, oncologist, surgeon, radiologist or all the subsequent support staff, relayed information on diagnosis, treatment plan, and psychosocial services varied widely. For this sample, medical teams that were part of a larger institution, such as MD Anderson or Baylor that routinely provided psychosocial services and support on site, were more frequently cited to provide information above and beyond traditional treatment plans. This being said, as the figure shows, only 35% of the sample could recall someone on their medical team providing information on psychosocial services. The remainder of the sample either did not recall or did not experience a medical professional exposing them to support services, education classes, or lifestyle guidance. Numerous participants made comments along the lines of:

Nothing was recommended to me, although I wish it was. Because I think everybody should be, everybody who has a diagnosis of cancer should be, should receive these kinds, be available to and receive these kinds of services. I think it should go hand in hand with traditional medicine. Absolutely. (Participant 4, Prostate Cancer)

As the following comment shows, some participants were shocked that medical teams would even discuss items outside of strict biological treatment:

I’m surprised that there is even like…doctors who will offer that. Because none of mine, and I’ve seen like four or five oncologists, and none of them have ever said, you know, ‘There is support groups you can go to.’ None of them. (Participant 9, Breast Cancer)

One participant exposed the power that medical teams have in directing patient behavior when she said,

I thought, ‘Well, the doctor thinks this would be a good thing. Maybe I should go check this out.’ (Participant 36, Breast Cancer)
It is hard to say whether this participant would have sought psychosocial services without the recommendation of her provider; however, as her comment shows, the physician’s recommendation gave psychosocial services a degree of weight and validity, spurring the participant into action.

However, what became readily apparent throughout all the interviews was that the participants had expectations that their medical team would be the source for all pertinent information relating to their cancer experience. Whether it is feasible for physicians to routinely provide more all-encompassing and holistic sources of information remains to be examined, but what can be established is the expectation of patients that they do.
Cancer is well entrenched within the contemporary American life experience and is expected to remain so for years to come. Currently, it is estimated that 1 in 3 women and 1 in 2 men will be diagnosed with cancer in their lifetime with the number of new cases expected to double by the year 2050 (Chustecka, 2007). As stated earlier, this reflects the fact that nearly 14.5 million Americans are living with cancer today with 19 million expected to be living with cancer within the next ten years (ACS, 2014). As powerful as these numbers are, what they fail to suitably capture are the obstacles and difficulties, both large and small, that those 14.5 + million people contend with on a daily basis; many of which have the power to impact their quality of life or worse - their health outcomes.

In recent years, more attention has been given to the exploration of the connection between biological health and the forces that influence it with enough evidence to support the need to encompass and address these forces. Within the context of cancer research, these forces, psychosocial in nature, include the mental, emotional and physical well-being of an individual above and beyond the traditional scope of treatment therapies (E.G. chemotherapy, hormone therapy, radiation, surgery, et cetera). What composes psychosocial health is varied and unique to each individual person and their individual circumstances; however, common needs and themes repeatedly emerge that suggest a need for addressing them.

The most pressing theme that materialized from the literature and this study was situated in information and knowledge. What do individuals know? What do they want to know? And what are their sources of information as it relates to their psychosocial health?
Knowledge and information are critical to psychosocial and biological health objectives as they help to direct decision-making, engender patient satisfaction, increase awareness and access to support systems, and help to improve quality of life. However, knowledge and information are multilayered, complex and constantly evolving.

To the surprise of many participants, the desire and/or ability to seek information during the early stages of their disease process was minimal. Diagnosis and early treatment often creates a sense of great vulnerability and uncertainty, easily overwhelming the most stoic of individuals. In response, some participants actively avoided information, relying exclusively on their medical teams' discretion with perhaps the occasional validation of loved ones who researched on their behalf. This exposed an initial instinct and inherent faith in the authoritative knowledge that biomedical teams provide. Further strengthening the dependence on the authoritative voice of biomedical professionals is that fact that those who did seek information during the early days, did so as a supplement to the information given to them by their medical team and not as a contradiction. These individuals sought sources that better explained what their doctors told them or would help shape questions they could ask of their doctors. In a few cases, information seeking was expanded to find additional resources not mentioned by medical teams but were perhaps ones that were culturally familiar. For example, some participants sought out local or national support groups but few thought to seek information on oncological fitness due to lack of awareness. In other, more critical words, if medical teams did not actively expose patients to psychosocial resources, patients were not likely to seek them out on their own until a much later date, if at all.
Interestingly, information-seeking behaviors within this study appeared to increase as more time progressed from the point of diagnosis. It was not uncommon for participants who were in the late treatment stages or past treatment to begin encountering new needs or gaps in information. As side effects like neuropathy or chemo brain began to emerge, or as participants began to adjust to their new situations, participants would begin to look beyond their medical teams for additional facts relevant to their health. However, it is important to note that sources of information largely remained on the interpersonal level of the social-ecological model. Participants wanted to know information such as how to mitigate negative impacts, how to increase their overall health, or how to prevent the possible development of further health issues or cancer reoccurrence. Individuals also were spurred into information-seeking behaviors as they came into contact with other patients who increased their awareness of information needs. Information exchanges among individuals with cancer included varied and functional tidbits, like journaling when upset, not wearing a purse on the side where lymph nodes were removed or avoiding specific estrogen-producing foods for those who had hormone based cancers, were highly valued and appreciated among the participants. Looking back on their journey's, participants noted that they were desperate for information along these lines, rating it as one of the most helpful and impactful components to their healing experience. However, information such this was not always information participants knew to seek.

However, the learning of such prized and underestimated information from their peers and not from their medical team oftentimes led to increased dissatisfaction with authoritative knowledge as participants expected to learn of practical matters from their medical teams.
Further affirming the connection between patient satisfaction and medical team information are the stories from participants who sought treatment at more comprehensive facilities like MD Anderson and the Cancer Treatment Centers of America. Hospitals such as these routinely incorporate psychosocial services into their education and treatment plans so that patients receive nutritional and fitness guidance, counseling, social activities and coping strategies alongside their medicinal and surgical treatments. With the exception of one participant, those who received medical treatment from these facilities expressed high levels of satisfaction with their knowledge base and their medical teams as well as high levels of psychosocial engagement.

For the majority who learned from others, learning from one’s peers further illuminates the value and pathways of social support networks. As the gradual move away from the exclusivity of authoritative knowledge dispensed by biomedical professionals begins to be supplemented by the shared experiences and knowledge from peers, the need for informational support is shown. As participants repeatedly exhibited during interviews, a wealth of information relating to their general health and well-being is highly desired, but difficult to obtain at times either due to lack of exposure or lack of awareness. Further challenging awareness and access to quality information on psychosocial health, the internet as one of the most popular sources of information has been shown to be unreliable or upsetting for many of the participants.

Many participants manage to connect with informational support outside of their medical team by seeking emotional support first. Though most participants were not advised to seek counseling or join support groups, many reached a point in their journey where they felt
they needed to take action to improve their circumstances. This included finding services that would improve their coping skills or seeking others to speak with in a similar situation. In some cases, emotional support was introduced to them through others in similar circumstances who sought them out to offer their aid. Through the building of emotional relationships that were based on shared experiences, the opportunities naturally arose to provide support in other forms. The tightknit community of Yoga Bridge exemplifies this process well. Though the women tried yoga as a means to improve their coping repertoire, it became obvious to the observer and through interviews that many of the women found emotional, informational, appraisal and instructional support as they became teachers, cheerleaders and companions for one another.

The largest barrier to be revealed was in part due to the authoritative knowledge paradigm that prevented access to psychosocial information in many cases. However, this was not the only barrier to be exposed. Availability, applicability and accessibility of psychosocial services and information were also noted through interviews, much of which can be relied back to gaps in the organizational and community levels of the social-ecological model. Though some hospitals and public health departments (community level) attempt to provide educational and services opportunities, the majority of such services is primarily available in the more populated cities of Dallas or Fort Worth, and not its many suburban communities. Hours of availability often reflect normal business hours, alienating those who maintained employment or were dependent upon transportation from someone who works. Organizations such as the CSCNT (organizational level of SEM) attempt to support where those institutions are unable to; however, they contend with many of the same obstacles resulting in similar
restricted locations and hours of availability. In both scenarios, would-be participants must overcome potential barriers of ill health, transportation and availability to partake in their services. As noted earlier, the most productive level of support is situated, either by design or nature, in the interpersonal level of the model.

5.2 Recommendations

Recommendations fall into two categories: recommendations for current application and recommendations for further research. Per the repeated suggestion of the sample population, an increased awareness of the availability, value and variety of psychosocial services is essential. As the research has shown, there is not an adequate understanding or appreciation of psychosocial services. Or as in the case of Denton, TX and other less populated areas, an availability of such services. Special considerations of the unique physical, emotional and financial challenges that often accompany a cancer diagnosis must take place when offering such services. For example, the addition of child care during activities, the expansion of service hours or the development of a more robust online community might increase accessibility for some participants.

The initial issue of knowing where to look for psychosocial services remains a chief barrier. Many of the participants were not aware of the possibility of free educational lectures, free fitness or yoga classes, counseling, et cetera and therefore did not seek such information. The inherent dependence on the medical personnel to direct individuals to information remains a key challenge to bolstering awareness and engagement of psychosocial services. The upcoming mandate from the Institute of Medicine to encourage oncology practices to incorporate psychosocial services is one means to addressing this problem. However, the
cultural and structural feasibility of physicians adopting such behavior may prove to be a challenge. As such, an opportunity to explore how this may be best accomplished from the point of view of the medical community exists for future study.

A primary recommendation for the CSCNT is to bolster the level of interpersonal informational and support chains for its membership. A successful model that has been used elsewhere that could be replicated to achieve this is a mentor match program. Unlike a support group or social function, matching willing individuals with similar diagnoses, treatment plans and social characteristics provides the opportunity to address all levels of support from the social support theory from someone in similar circumstances. Participants who participated in mentor match programs often found a shoulder to cry on (emotional support) from someone who had gone through the similar circumstances they had gone through and succeeded (appraisal support). Mentors also dispensed advice and guidance (informational support) helping to direct individuals to the resources and sources of aid that they utilized (instrumental support). Those who connected with mentors found them to be the most beneficial sources of help and information throughout their entire healing process. Those who did not connect with a mentor, largely because they were unaware of such a possibility, expressed a desire to speak one-on-one with someone who had gone through their experience so they could ask specific questions, connect with someone who could understand them in a way no one else could, or as one participant said earlier, simply see someone on the other side of their diagnosis.

It has been shown that while beneficial, psychosocial services are poorly utilized or visible. How to improve the exposure of psychosocial services and thereby the quality of life for those living with cancer is no small challenge. Obstacles exist in numerous forms that inhibit
increased health knowledge and subsequent health behaviors. Creating and connecting cancer communities provides an opportunity to support existing inclinations of individuals to learn from each other. This study’s identification of the medical professionals as a dominant and preferred source of information, at least during the earliest phases of diagnosis and treatment, highlights the most natural pathway for people diagnosed with cancer to learn of and engage in psychosocial resources, both formal and informal. However, the infrequency of medical professionals connecting participants from this sample to such resources suggests an avenue for future research to unveil what barriers are in place to restricted routine psychosocial recommendations.

5.3 Reflection

This research provided me a wealth of learning opportunities that could never have been fully appreciated by simply reading a book. From start to finish, I had to learn how to persevere and adapt as I sought to develop a research proposal, build relationships with a client in a state of flux, adjust a proposal to meet a changing scope, and connect with a potential sample population that was at times understandably untrusting of my objectives. I was met with resistance from uncooperative medical offices forcing me to reconsider my recruitment strategies – the result of which led to fruitful and lasting relationships within the community. I struggled at times to maintain my objectivity in the face of injustice, heartache and pain, unsure of how best to respond to participants in genuine despair. Right or wrong, there were times that I overextended myself to offer personal aid and there were even more times when I was unable to let go of certain participants and their stories. As a result, the participants further fueled my drive to read more, learn more, volunteer more, and do whatever I can to gain a
better understanding of the issue these people face, and learn how to best help. I’ve been able to identify that my personal weakness as a researcher may be my difficulties in defining the line between person and professional. However, as is the case with many anthropologists, such a weakness may also be my opportunity to be an empathetic and passionate researcher and ally.

The greatest element and learning opportunity of this research were the participants themselves. Their graciousness in sharing their deeply personal stories with a stranger, their compassionate nature and desire to help others despite their own needs for help was deeply humbling and inspiring. More often than not, participants would cautiously enter the interview, noting they had nothing to say, surprising themselves at their wealth of insight. Though I always had faith in their knowledge, they would often surprise me in their gratitude. Despite some truly difficult and unfair circumstances, many would maintain their sense of hope, positivity and thankfulness for those in their life who supported them, be it their medical team, friends or family. More surprisingly, many expressed appreciation to me for the simple action of listening! The realization of the impact of the researcher is one that will forever remind me to be present and focused on the individual first and foremost, with research objectives second. The ongoing challenge will be on how best to satisfy both needs.


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