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*Exploring the Experience of Psychological Distress for Young Adults with Cancer:  
Implications for a New Diagnosis of Medical Traumatic Stress*

Audrey Ryan, LMHC, PhD candidate

Dissertation submitted to the faculty of the University Graduate School  
in fulfillment of the requirements  
for the degree  
Doctor of Philosophy  
in the Graduate School of Arts and Social Sciences,  
Lesley University  
March 2020

## ABSTRACT

The purpose of this qualitative study was to investigate how a serious medical diagnosis, such as cancer, can act as an acute or prolonged trauma. This was explored through the lived experiences of psychological distress of young cancer survivors. Participants were 12 men and women who had been diagnosed with cancer within the past seven years when they were between the ages of 18 and 39. From these interviews several themes emerged that describe the phenomenon of what I have termed *medical traumatic stress*.

Trauma from a medical event does not currently meet criteria for PTSD in the DSM-5 (2013) resulting in a diagnostic gap. Because PTSD was originally designed for a population of victims of violence and abuse, it does not align with the experience of non-violent traumatic events like disease. In addition, there are characteristics of traumatic stress caused by a medical event that are specific to the phenomenon itself rather than generalizable to other traumas. The discrepancies explored within this study were how medical trauma is caused by an internal stressor of the body attacking itself such that survivors may feel their body is no longer safe. Because serious illnesses are often chronic and lifelong they also cause future orientated concerns of prognosis and morbidity.

This study performed was a way to generate data towards building a conceptual model of *medical traumatic stress* that is outside of the conventional PTSD diagnosis. This was done by using results from interviews to create a follow up questionnaire where participants helped define their experiences of traumatic stress. The study concludes with a proposed diagnosis of *medical traumatic stress* including characteristics, themes, and symptoms.

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## CHAPTER 1- INTRODUCTION

This dissertation, *Exploring the Experience of Psychological Distress for Young Adults with Cancer: Implications for a New Diagnosis of Medical Traumatic Stress*, is an exploration into how a serious medical diagnosis can act as an acute or prolonged trauma. Psychological trauma is defined as a sudden, unexpected, or non-normative event that exceeds the individual's perceived ability to meet its demands and disrupts the individual's frame of reference and psychological needs (McCann & Pearlman, 1990). Because medical diagnoses are quite common, and many illnesses are curable, treatable, or short-term in nature, they may not be perceived as traumatic events. However, many illnesses are chronic, incurable, life-threatening, or life-shortening such as cancer, autoimmune diseases (e.g. multiple sclerosis), and neurological disorders (e.g. Parkinson's, ALS). In these specific instances, a medical diagnosis is much more likely to cause psychological distress (Hall & Hall, 2013).

The central premise of this dissertation is that a diagnosis of a serious medical illness, as explored through the experience of young cancer survivors, can be a traumatic stressor. However, medical trauma does not meet criteria for PTSD in the most current Diagnostic and Statistical Manual (DSM) (APA, 2013) resulting in a diagnostic gap. Because medical trauma is not in line with other traumatic events involving an external stressor it has been left out of the DSM-5 (APA, 2013) entirely.

More specifically, this author believes that traumatic stress caused by a medical event should have its own DSM diagnosis. The current construct of posttraumatic stress disorder (PTSD) may not align with the reality of what people experiencing medical trauma actually endure (Alonzo, 2000; Alter et al., 1996; Chalfant, Bryant, & Fulcher, 2004). Because PTSD was originally designed for a population of victims of violence and abuse, it does not align with the

experience of non-violent traumatic events like disease. In addition, there are characteristics of traumatic stress caused by a medical event that are specific to the phenomenon itself rather than generalizable to other traumas.

### **Purpose**

The purpose of this research inquiry was to explore the experiences of psychological distress of young adults diagnosed with cancer. From these interviews several themes emerged that describe the phenomenon of what I have termed *medical traumatic stress*. The study performed was a way to generate data that was then used to create this conceptual model of medical traumatic stress that is outside of the conventional PTSD diagnosis. There are currently no qualitative studies that address this specific phenomenon.

Using a trauma lens to look at medical diagnoses and chronic illness was instrumental in understanding their impact on mental health. This was achieved by capturing the lived experiences of those who have endured psychological distress from cancer. My leading theory was that characteristics of events surrounding a medical diagnosis affect how people may experience it traumatically and influence the severity of stress. These characteristics include how old the individual was upon diagnosis, how long it has been since the diagnosis, and whether the diagnosis was sudden and unexpected or more gradual after ongoing symptoms. Younger people who are diagnosed more suddenly may be most at risk for traumatic stress.

With the results of this study, I have created a model of medical traumatic stress that captures the intersection of medical illness and trauma. The questions I asked participants revolved around the lived experience of young adults dealing with a new medical diagnosis of cancer and specifically if and how they perceived their diagnosis and illness as a traumatic life

event. I explored the complex mechanism of traumatic stress and how it manifested within this population.

### **Personal Connection**

My own connection to this topic is personal and complicated. Nine months after my daughter, my first child, was born, I was diagnosed with a rare autoimmune disease. It happened very suddenly and unexpectedly, and I was completely blindsided. Now, looking back, I can reflect on how the timing was particularly bad and made my experience all the more difficult. As a first-time parent, I was adjusting to motherhood which I found very challenging both emotionally and physically. I was diagnosed with post-partum depression when my daughter was only a few months old and was prescribed an antidepressant for the first time in my life. I felt that both time and the medication slowly helped me rise above my constant feeling of being overwhelmed and anxious about caring for an infant.

Unfortunately, right as I was starting to feel better emotionally about parenting, I was given this devastating diagnosis. From the beginning of my experience with the medical community, I resisted the diagnosis and fought against it, but I inevitably lost. I experienced shock, denial, despair, and all the other stages of grief that come with a major life event. In the following three months I plunged into a deep depression which I can now identify as a major depressive episode. I no longer had an appetite and lost close to 20 pounds in two months. I had difficulty sleeping due to racing thoughts and needed various over-the-counter and prescription medications to sleep for any period of time. I lost motivation to do anything I had used to enjoy and struggled to care for my daughter, still an infant.

Looking back, I can now identify that I was traumatized by the entire experience. There were several aspects of my experience that were traumatic, starting with the biopsy and diagnosis

and then the shock of being given a label that I resisted to my core. It continued with encountering insensitive bedside manner from certain providers. I saw a neurologist who immediately pathologized my symptoms as somatizations saying I had an “affective anxiety disorder” rather than a medical condition. When I decided to get a second opinion from a naturopathic doctor, he reacted to my diagnosis by saying “how devastating and life changing” it must be for me, which confirmed my worst fears and only led to more grief and traumatic stress.

One of the most difficult things I experienced was having medical providers dismissing my emotional reaction to my illness. It was as if they felt it was an unnecessary reaction to something I had no control over, meanwhile assuming I should have complete control over my emotions. I felt invisible in many ways, that my identity had been somehow diminished by the disease, that I was no longer a whole person, that I was not as strong as I had thought I was. Looking back, I realize the diagnosis started an existential crisis.

What I wish had existed at the time was a better understanding of traumatic stress related to a medical diagnosis. I wish that my mental health symptoms had been seen as a normal reaction to an abnormal event rather than as an overreaction to something I could not control. I wish that medical providers had seen my emotional pain and acted empathetically rather than judgmentally and dismissively. I chose this subject because it is a phenomenon that I know exists but does not have sufficient research and conceptual understanding. I believe that it needs more awareness so that we can clinically support the people who are suffering.

Aside from my own experience, I have seen medical traumatic stress in my work and family life. I once worked with a young client who was diagnosed with stage 3 cancer and had all the signs of traumatic stress. Even though he had had no prior history of mental illness, he presented with acute anxiety, depression, and suicidal thoughts. His symptomology was a mix of



hyperarousal in the form of panic attacks and hypoarousal of not being able to get out of bed. He described ruminations and intrusive thoughts on his future and living life with a colostomy bag if they were unable to reverse the procedure. I advocated for this client to see a prescriber and obtain antidepressants and anxiety medication. Unfortunately, he attempted suicide and was placed in an inpatient psychiatric unit. Once this occurred, the hospital took over both his medical and psychiatric care, yet I wondered why those supports were not in place all along.

The maternal side of my family has a genetic form of cancer, Lynch Syndrome, that has affected various members who inherited the gene, including my mother who survived endometrial cancer and my aunt who is currently battling stage 4 ovarian cancer. I have witnessed their traumatic stress in relation to their illnesses and how the experience of cancer can be all-encompassing. I also experienced my illness as all-encompassing during the first year of diagnosis, struggling to think about anything else.

Because I have experienced illness as a profound life event, I believe many others do as well. Although not all cancer survivors experience their diagnosis and illness traumatically, I believe that many of them do. However, they may not have the language to describe their experiences and contextual support within the medical community. By focusing on the population of cancer survivors who identified as having had psychological distress, this research can act as a way to bring voice to this lived experience.

### **Research Question**

The overarching research questions explored in this dissertation are: What have been the experiences of psychological distress for young adults diagnosed with cancer? What elements of the experiences suggest potential for medical trauma? What helped or hindered one's coping with the diagnosis/treatment? From this exploration of psychological distress from cancer, I then

created a conceptual model of the phenomenon of medical traumatic stress. My goal is that this model can act as the beginning of academic literature to help further define the experience of medical traumatic stress.

### **Conceptual and Theoretical Framework**

In my literature review I explored the phenomenon of medical traumatic stress through the theoretical perspectives of trauma theory, relational theory, critical disability theory, and existential theory. In order to understand medical traumatic stress, I situated it within the context of current trauma theory. I chose to look at the experience of traumatic stress through relational theory because I am a relational therapist and my hope is that this research can influence clinical approaches to medical trauma. In grounding social justice within this subject, I have positioned medical trauma as it relates to critical disability theory. Lastly, I explored existential theory, as cancer is a life changing event that challenges survival.

The majority of current research that addresses disease and trauma are quantitative studies on cancer and PTSD (Alter et al., 1996; Arnaboldi, Riva, Crico & Pravettoni, 2017; Mehnert & Koch, 2007; Mystakidou et al., 2012; Swartzmann, Booth, Munro & Sani, 2017). There are very few qualitative studies that address the experience of disease as a traumatic event, which highlights why this inquiry is needed. Qualitative studies can also tell a story about the experience of trauma from disease that quantitative studies cannot articulate.

One area where there is qualitative research is on posttraumatic growth after cancer, which focuses more on existentialism and resilience than on the experience of traumatic stress (Denney, Aten & Leavell, 2011; Hefferon, Grealy & Mutrie, 2009; Laranjerira et al., 2013; Morris, Shakespeare-Finch & Scott, 2012; Morris, Wilson & Chambers, 2013). However, there are no qualitative studies that specifically address the phenomenon of traumatic stress as it

relates to illness. Because of this gap in the research, I designed this study to be a descriptive phenomenological exploration of the lived experience of psychological distress resulting from a cancer diagnosis.

### **Definition of Key Terms**

In this dissertation I refer to *Trauma* as a deeply distressing or disturbing experience, *Medical Trauma* as defined by the medical event(s) that causes trauma, and *Medical Traumatic Stress*, as defined by the traumatic stress reaction caused by the medical event. *Traumatic Stress* is a term that is commonly used to embody the reactive symptoms caused by a traumatic event considered life-threatening. Some symptoms of traumatic stress include anxiety, panic, depression, hypervigilance, numbing, and dissociation. Emotions that may surround the experience of traumatic stress are shock, disbelief, fear, sadness, helplessness, guilt, anger, and shame. The differentiation between traumatic stress and post-traumatic stress disorder (PTSD) is that the traumatic event does not meet criteria for PTSD in the DSM-5 (2013).

In my literature review I have uncovered three distinctions between trauma that warrants a PTSD diagnosis and medical trauma that have set the groundwork for the concept of *Medical Traumatic Stress*, which is not a term seen in the literature but that I have created in order to describe the phenomenon I have explored here. The definition that I have used for the purposes of this study is traumatic stress that originated from a medical diagnosis with these three features: 1) *Traumatic event originated by an internal stressor; the body attacking itself.* 2) *Future-oriented concerns of prognosis, functionality, and morbidity.* 3) *The body no longer feeling safe; survivors may feel betrayed by their body.* This definition of medical traumatic stress is used within the research protocol in a follow up questionnaire with participants so that it

can be further engaged, tested, edited, and discussed with those who have experienced this phenomenon.

### **Research Design**

In an effort to better describe the experience of medical traumatic stress, I have done a qualitative phenomenological study with participants who identified as having experienced psychological distress from their cancer. In my methodological section I explained the rationale of my research design and epistemological stance of constructivism. I also went into more detail about my positionality and reflexivity as a woman, a disease survivor, and as a counselor who has transitioned into a researcher.

In my design, I have identified the parameters of the participants I recruited along with how sampling, consent, and the setting of where data collection took place. The main source of data collection was semi-structured interviews as well as a follow-up questionnaire. Data analysis was a thematic analysis of the narrative using open coding (Marshall & Rossman, 2016). I also outlined validity measures, ethical issues, and implications.

### **Social Justice Perspective**

Lastly, social justice is addressed within my research protocol through critical disability theory by taking into account the ecological context of having a disability on a social-political-economic level (Devlin & Pothier, 2006; Zola, 1989). People suffering from chronic illnesses and diseases like cancer are often times living with invisible disabilities (Tobin, 2004; Banks, 2014). This study, along with prior studies, has uncovered the financial consequences of battling a major illness where people are often unable to work while concurrently having to face insurance companies and medical bills. In this sense, I view medical trauma as a social justice

issue, where disease survivors often suffer from limited functioning, diminished social and financial status, and possible discrimination as a result of health disabilities.

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## CHAPTER 2- LITERATURE REVIEW

The goal of this literature review is to unpack the current research surrounding the phenomenon of traumatic stress caused by a medical event. This review begins from the position of trying to understand the concept of medical traumatic stress in the context of current trauma theory. A core aspect of what differentiates medical traumatic stress from other traumas is that the psychological symptomology often times does not align with diagnostic criteria for PTSD. For instance, people with a major medical diagnosis do not have an outside perpetrator that originates their trauma, rather an internal stressor of disease. Those diagnosed with major illnesses also often have future oriented concerns of the trajectory of their disease, another factor that differs from our current understanding of trauma.

Theoretical underpinnings of this review are relational theory, critical disability, and existential theory. These theories were chosen because relational theory is the lens through which I approached this subject as a relational counselor. Critical disability theory is a lens in which to view medical trauma as a social justice issue where many people suffering from major medical illness face economic distress and carry an *invisible disability* (Tobin, 2004; Banks, 2014) around with them. Lastly, existential theory is the lens through which to look at how people make meaning of traumatic life experiences and find inner resilience to move on. These concepts are also addressed in my methodology as they influenced the questions I used to prompt participants in talking about their lived experiences.

Because medical trauma is not a well understood trauma, it needs to be investigated in the context of current trauma theory to see where it fits and where it does not. The Diagnostic Statistical Manual (DSM) diagnosis most commonly associated with trauma is posttraumatic

stress disorder (PTSD). Currently medical trauma is excluded from meeting PTSD criteria (APA, 2011). Psychological symptomology of medical trauma has some unique distinguishing features that are discussed here.

Relational theory (Saakvitne, 2017) is a lens to look at the role of counselors and how we understand and conceptualize grief, loss, and identity that are central to the phenomenon of interest in my research. Because in the trajectory of my career I am a counselor first and a researcher second, I felt the need to approach participants in my study through a relational lens of empathy, unconditional positive regard, and compassion. In asking participants to share their lived experiences with me, relational theory was a way to set the stage for creating a safe, holding space in which to understand their perspective.

Critical disability theory (Devlin & Pothier, 2006; Zola, 1989) is a vehicle to explore how social justice is intertwined in this inquiry, as people living with a major medical diagnosis are part of a vulnerable population. People with medical illnesses can carry the label of disability, sometimes visibly and sometimes invisibly. Looking at medical trauma as a social justice issues in itself can go beyond the conversation of disability to compounding factors of gender, race, and socioeconomic status.

Lastly, existential theory (Yalom, 1980) offers a lens through which one can look at how adversity can lead to growth for some trauma survivors. This final section was chosen in part because there is a wealth of literature of posttraumatic growth, meaning making, and resilience of disease survivors. This growing body of research gives hope to this population and is consistent with the heuristic nature of this study. Existentialism is also consistent with the methodology of phenomenology where participants were asked how they make meaning of their situation.

### **Inclusion and Exclusion Criteria**

For the purposes of this literature review, I focused on major medical diagnoses of life-threatening illnesses (e.g. cancer, Multiple Sclerosis) in adult populations. In my own qualitative study, I focused further on a young adult population with a cancer diagnosis, as their experiences may differ from those of older adult and elderly populations. I excluded studies that only focus on physical injuries caused by outside forces, such as car accidents, assaults, or natural disasters. I also excluded samples that included trauma of family members or child participants as well as any studies that implemented interventions. This is because the study did not include any child participants or the perspective of family members. I have decided to review both quantitative and qualitative studies on the topic of medical illness because there are not enough qualitative studies currently available on the topic for a full review, and the quantitative statistics are contextually important for understanding Posttraumatic Stress Disorder (PTSD) and other Diagnostic Statistics Manual (DSM) diagnoses surrounding medical trauma.

There is a dearth of literature addressing medical trauma as a phenomenon. Although there are several quantitative studies that address PTSD in cancer survivors (Alter et al., 1996; Arnaboldi et al., 2017; Mehnert & Koch, 2007; Mystakidou et al., 2012; Swartzmann et al., 2017), there are few qualitative studies that explore the lived experiences of this population. A larger surrounding issue in current research is that PTSD may not be the right diagnostic label for those suffering from medical trauma (Alonzo, 2000; Alter et al., 1996; Chalfant, Bryant, & Fulcher, 2004; Kangas, Henry & Bryant, 2002; Mehnert & Koch, 2007; Swartzmann, Booth, Munro & Sani, 2016). This literature review reveals that there is a gap of qualitative research on medical trauma with no current model for understanding and explaining medical trauma outside



of the PTSD construct. More qualitative data is needed to improve our understanding of this phenomenon.

The core argument of this literature review is that major medical diagnosis and chronic illness is a traumatic stressor and should have its own diagnosis that includes the specific characteristics that are more in line with disease survivors lived experience. This inquiry looks to define medical trauma in detail and develop a model to understand the phenomenon of medical traumatic stress outside of the PTSD construct. Here I have outlined the components of this literature review and how they are interrelated. In unpacking the literature around medical trauma, the goal is twofold; to describe it through trauma theory, symptomology, and diagnosis as well as theoretically understand it relationally, socially, and existentially. These themes also set the stage for the methodology chapter in developing an understanding of medical trauma through phenomenology.

### **What is Medical Trauma?**

Medical trauma is a concept that embodies the psychological aftermath of a significant medical event that results in symptoms of PTSD, depression, and anxiety (Hall & Hall, 2013). For many people given a sudden diagnosis of a serious illness such as cancer or multiple sclerosis, there are co-morbid psychiatric consequences in terms of coping and adaptation (Kulaksizoglu, 2007). Major medical diagnoses can precipitate crisis and chaos, grief and loss, and extreme life changes in the face of illness (Laranjeira, Leao & Leal, 2013). The diagnosis itself of a serious disease is a life-altering random event and can be quite traumatic, as it brings with it a permanently altered trajectory. In general, a threat to one's life is indicative of PTSD, and its symptoms include nightmares, social isolation, and a sense of foreshortened future (Alter et al., 1996).

Hall and Hall (2013) used the term *medical posttraumatic stress disorder* (MPTSD) to describe the ongoing trauma experienced as a result of medical procedures, illnesses, and hospital stays leading to clinically significant reactions such as PTSD, anxiety, depression, complicated grief, and somatic complaints. Specific memories of medical events can be experienced as traumatic to patients as an assault of their bodily integrity. However, the concept of MPTSD is not a widely accepted concept, with no current presence in academic literature and no representation in the DSM.

In many ways, medical trauma is disenfranchised trauma as it is under-recognized and poorly understood in our society (Hall & Hall, 2013). In general, we are socialized to cope with experiences in medical settings without much consideration of the psychological impact of illness. As a result, many medical environments are not properly equipped to address the mental health of their patients, who consequently, may feel that their experiences are abnormal if they have an emotional reaction. Perhaps this is the case because logically the origin of illnesses like cancer are seemingly out of our control, yet we do have some control over how we respond and receive treatment. Some may feel that there is no use in getting upset over things they have no control over. It also may be a reflection of medical training not properly addressing the psychological distress of illness. However, this outlook negates the experience of people who do suffer psychologically from being physically compromised.

In looking for existing concepts that relate to the psychological trauma caused by medical illness, there are some examples in the literature. The term *cumulative adversity* was developed by Turner and Lloyd (1995) to describe multiple traumatic events and their impact on psychological distress. Alonzo (2000) examined traumatic stress associated with chronic illness as part of the accumulated burden of adversity mapping out a model that “produces a continuum

of traumatic responses to chronic disease events ranging from benign anxiety to full-blown to PTSD” (p. 1480). Chronic and potentially life-threatening illnesses are the primary trauma resulting from ongoing symptoms, medications, and regimens. The secondary traumas are the experiences of events immediately following the trauma of EMS, ER, hospitalization, and rehabilitation. The tertiary trauma is the ongoing hassle of dealing with healthcare and insurance systems that are a reality in managed care. This model captures the many layers of trauma this population experiences and is a useful way to conceptualize the development of medical trauma.

A key difference in medical trauma from current trauma is that the locus of the stressor is triggered by an internally induced event rather than the external source of threat typically associated with PTSD (Green, Epstein, Krupnick & Rowland, 1997). Traditionally understood traumatic events, such as child abuse and combat, come from outside the individual, as these traumatic events are an external threat and come from an outside force that assaults the individual (Bloom, 1999). This is a fundamental difference between traditionally understood trauma and medical trauma because in the case of a serious illness or disease the traumatic event is coming from inside people against their will but there is no external force or person to blame for the illness itself.

With the onset of a disease, the origin of the trauma is coming from within the person where they are in a battle with their own bodies (Esposito, 2016). As a result, there is no perpetrator or abuser, a necessary trait for traditional models of complex PTSD (Herman, 1997) that involve an act of violence to be considered truly traumatic. Hence, medical trauma is outside the scope of being categorized in traditional trauma models.

Another difference from the current PTSD model is that rather than anxiety about a past event, people with medical illnesses have a future-oriented stressor, as they are worried about

their prognosis and lifespan (Kangas et al., 2002). Research has shown that cancer survivors are acutely aware of the physical effects of their disease and face an uncertain future with fears of recurrence and fear of dying (Laranjeira et al., 2013; Vachon, 2001). This uncertain prognosis that leads to future-oriented intrusions is a crucial dichotomy between traditionally understood trauma and medical trauma. Various studies have started to address the suitability of the PTSD framework for life-threatening illness (Alonzo, 2000; Alter et al., 1996; Chalfant et al., 2004). The discrepancies of an internal versus external source of the events as well as future-oriented stressors are key differences in medical trauma such that it deserves its own model and diagnostic criteria.

What is quickly apparent about medical trauma is that it is not the same as currently understand traumas and has some distinguishing characteristics. Namely, the origination of the traumatic stressor is internal rather than external such that it is commonly excluded from traditional trauma models. Another critical difference is that medical trauma brings with it future-oriented concerns of prognosis and lifespan which are not part of traditional trauma ruminations of past traumatic events. These concepts are further explored as they are fundamental to building a model for medical trauma.

### **Trauma Theory**

In trying to define trauma and how medical illness relates to trauma literature, it is necessary to refer to foundational aspects of trauma theory. Judith Herman (1997) in her seminal work, *Trauma and Recovery*, recounts her clinical work with victims of sexual and domestic violence, combat veterans, and victims of political terror. Because her definition of trauma centers around an act of violence, medical trauma falls outside the realm of what she would consider a trauma or meet conventional PTSD criteria. However, there are various elements of

her work that relate to the experience of medical trauma, specifically around the threat to life and bodily integrity.

Herman (1997) describes psychological trauma as an event that renders the victim powerless and helpless to an overwhelming force. The feeling of a sense of control, connection, and meaning in life are challenged and overwhelmed such that “helplessness constitutes the essential insult of trauma” (p. 41), as victims no longer feels control and agency over their own lives. These consequences relate to the concept of medical trauma because diagnosis often leads to a similar sense of loss of agency or psychological paralysis (Lefebvre & Levert, 2006).

Trauma challenges world assumptions of basic trust and a sense of safety in the world and robs the victim of a sense of power and control (Herman, 1997). People struggling with a new medical diagnosis lose their sense of assumed health and control over their bodies. Yet in Herman’s (1997) model of recovery of a single acute trauma, establishing safety begins with control of the body. The insult of medical trauma is the loss of a sense of bodily control, rendering the victim to feel helpless to the course of the disease. This distinction is another characteristic of medical trauma that does not fit into traditional trauma models.

However, there are aspects of Herman’s (1997) model of recovery that do apply as “helplessness and isolation are the core experiences of psychological trauma...empowerment and reconnection are the core experiences of recovery” (p. 197). Those struggling with medical trauma must overcome the adversity of their situation to find a pathway forward. This path involves restoring power and control to mitigate helplessness and finding social connection and support to mitigate isolation (Bloom, 1999; Herman, 1997; Saakvitne, 2017).

Another significant voice in trauma literature is Sandra Bloom’s (1997;1999); she developed *The Sanctuary Model*® for trauma treatment. Her work as a psychiatrist was

predominantly in inpatient clinical settings working with victims of childhood sexual abuse.

Despite the difference in the nature of the trauma, there are many similarities between her trauma theory and medical trauma experiences. As Bloom (1999) states:

a traumatic experience impacts the entire person- the way we think, the way we learn, the way we remember things, the way we feel about ourselves, the way we feel about other people, and the way we make sense of the world are all profoundly altered by traumatic experiences. (p.1)

People given a major medical diagnosis can experience it in ways similar to those of any psychic trauma in that it can be sudden, unexpected, and overwhelming. In an instant, people can be faced with the reality that they are no longer *healthy* but *sick*. The emotional impact can challenge their entire being and bring into question identity, memory, attachment, spiritual, and existential concerns.

Bloom (1999) states, “human beings will do anything to avoid feeling powerless” (p. 14). In particular, learned helplessness is a concept that resonates with medical trauma in that the victim is rendered helpless. Many people given an unexpected diagnosis have no recourse. There is no way they can fight back given this information; it is delivered as an irrefutable fact. Bloom (1999) states that “as a species we cannot tolerate helplessness- it goes against our instinct for survival” (p. 3), which is the double assault of medical diagnosis, creating helplessness while also questioning survival. The dilemma of patients quickly becomes that they cannot escape the reality of their diagnosis and are helpless to change it.

Kangas et al. (2002) differentiated life-threatening illness from other traumatic events because of the mistrust of the body’s physical integrity and lack of control over body function. Betrayal of the body is the extra burden of medical trauma, as there is no perpetrator. In

traditional trauma theory there is a person, people, or external event to blame for inflicting the pain. However, in medical trauma there is no place to point the finger. Some may point the finger at themselves, internally blaming their lifestyle choices which may have contributed to disease. This distinction of internal versus an external stressor is one of the main components of how medical trauma differs from traditionally understood trauma.

Bloom (1999) offered a model in *Creating Sanctuary* where the first step is creating safety, yet for many people given a medical diagnosis their bodies no longer feel safe, yet they cannot escape it. A common reaction to a traumatic event is feeling overwhelmed with emotions and losing the capacity to speak and put words to their experiences, which results in a shift to nonverbal reactions and physical sensations (Bloom, 1999). However, this experience in medical trauma is particularly burdensome as the body is now suspect; every sensation becomes a possible symptom of the disease, causing further confusion.

Kulaksizolglu (2007) found that symptoms of the autoimmune disease Myasthenia Gravis, such as fatigue, are also common in mental health disorders and can lead to misdiagnosis, suggesting that patients mental health symptoms can be intermingled with their medical diagnosis. A somaticized response to the traumatic news of a diagnosis, the feeling of chest tightening, loss of breath, chills, and nausea, could be confused as the illness rather than the body's response to hearing horrible news. From the moment a diagnosis occurs, for many the body can become a scary and confusing place to live.

Janoff-Bulman (1992) wrote about shattered assumptions and how trauma begins a psychological disequilibrium that shatters the fundamental assumption that the world is benevolent and meaningful, and the self is worthy. When people are diagnosed with a major illness the trajectory of their life is set on an alternative course where their health and survival

are no longer assumed. Although the physical aspects of medical illness and diagnosis are often well understood, the mental health components such as depression, anxiety, and PTSD are less recognized and commonly overlooked in this population (Alonzo, 2000; Hall & Hall, 2013). For many people enduring medical trauma every domain of their life is affected and their life moving forward is permanently compromised.

Exploring trauma theory through the work of Herman (1997) and Bloom (1999) demonstrates that medical trauma has various characteristics in line with traditionally understood traumas where victims are rendered helpless and lose their sense of power and control. However, a distinguishing difference is that the sense of safety that is lost for victims of violence is with the outside world and their perpetrator(s). Yet with disease survivors their sense of safety that is lost is within the physical body. The first step of recovery for trauma survivors in these traditional trauma models is to create safety in the body, yet this is the place of unrest for medical trauma survivors. This distinction is another core aspect of the evolving model of medical trauma.

### **Symptomology of Medical Trauma**

Currently, there is no specific diagnosis which embodies the psychological symptoms that arise in the aftermath of a medical diagnosis. Individual differences play an important part in determining the form that PTSD will take and no two people have identical reactions to the same events (Herman, 1997). Some people may be able to compartmentalize their illness and shut down what may seem like the unnecessary processing of the emotions surrounding it. Others may be able to go straight into problem-solving mode and focus on the things they do have control over, such as their treatment options. Yet denial does not make emotions go away, as



Bloom (1999) states, “emotions are built-in, part of our evolutionary, biological heritage and we cannot eliminate them, we can only transmute them” (p. 9).

For many people, a sudden and unexpected diagnosis brings with it a tremendous shock to the system. When blindsided by bad news, a flood of emotions is difficult to avoid. Harder yet is that a medical diagnosis brings with it an uncertain future. The brain has a lot of catching up to do in order to assimilate such ominous information and in that process a whole range of symptomatology could emerge. An extensive literature review of PTSD and the role of stress and traumatic stress in breast cancer patients by Arnaboldi et al. (2017) described:

When women affected by breast cancer are asked to recall the very moment of their diagnosis and cancer experience, a series of symptoms may appear including hyperarousal, emotional numbness, the sensation of the situation happening to a person other than self, and intrusive thinking together with nightmares and flashbacks that guide the clinician to understand how traumatic the cancer diagnosis was across the life span. (p. 473)

When people are given a sudden, unexpected medical diagnosis they are put in a position where they are forced to reckon with an inalterable situation. In a qualitative review of cancer-related PTSD literature, Cordova, Riba, and Spiegel (2017) conveyed how being diagnosed with and treated for cancer is highly stressful, and in many cases can be traumatic. Saakvitne (2017) describes how when people are faced with such a stressor they are provoked into intolerable emotional and physiological states and hence use extreme coping strategies to protect themselves. The symptoms themselves are part of these coping strategies. The most common reaction for those given unbearable news is to retreat into depression, dissociation, flight, and numbness (Herman, 1997; Kangas et al., 2002).

### **Fight, Flight, or Freeze**

The evolutionary stress response of fight, flight, or freeze is the biological reaction to trauma (Bloom, 1999). All symptomology of a traumatic event can be traced back to what is essentially instinctual for mammals. We either fight our attacker, run from it, or freeze from the shock of the situation. In the case of medical trauma, the attacker is more ominous; it is the cancer cells or the autoimmune reaction within the body.

Trauma symptoms develop as attempts to solve unsolvable problems created by the traumatic events and their aftermath, and symptoms are adaptations to intolerable experiences (Saakvitne, 2017). Hyperarousal to the traumatic news may also occur and include flashbacks, body memories, nightmares, and reenactments (Bloom, 1999). These symptoms are most commonly associated with combat veterans reliving their time at war. This symptomology is also possible for people who have experienced medical trauma as they may relive the moment of their diagnosis or have flashbacks of a surgery or procedure (Hall & Hall, 2013).

When neither fight or flight is possible, the parasympathetic nervous system and dorsal vagal system (Porges, 2011) are activated, causing a freeze or collapse response. Hypoarousal manifests as symptoms like amnesia, numbing, depersonalization, and derealization (Bloom, 1999). Notably, dissociation is the disrupted integrated functioning of consciousness, memory, identity, or perception of the environment (Saakvitne, 2017). Another common symptom is emotional numbing, a splitting between experience and feelings, which is a defense mechanism of avoidance where the pain is too much to bear so one shuts it down. For those suffering from medical trauma they may feel increasingly unsafe in their physical bodies as they are unable to escape their body where the trauma has originated.

### **Triggers**

Triggers for medical trauma may also vary. Hall and Hall (2013) developed a program to better describe the impact of medical trauma on mental health and explored how the knowledge of the illness itself can be the primary cause of the traumatic reaction, or the medical setting can act as the trigger. When the medical setting is the trigger, it is also the place that the patient must always return to for further testing, follow ups and procedures and yet they can feel an ecological discordance, powerlessness, and disorientation with that environment. One qualitative study looked at intrusive memories in patients admitted to the ICU and found that the majority of their cohort had experienced hallucinatory or delusional memories that merged with realistic events during their hospitalization (Wade et al., 2015). Researchers suggested that patients may have had post-psychosis PTSD rather than classic PTSD in this setting. Alonzo (2000) discussed how a potential consequence of medical trauma is that patients whose malignant memories of hospitalization are particularly intrusive may not return for follow-up visits and not comply with medical advice as a way to avoid additional medical encounters. The issue with maladaptive coping for people with chronic illness is that it can result in nonadherence to medical regimes, such as failure to keep appointments, nonadherence to medications, not following diets and exercise plans, and not taking care of self as advised.

As Bloom (1999) points out, when people are stressed they cannot think clearly and may demonstrate poor judgment and poor impulse control. People facing a new serious medical diagnosis may be so overwhelmed by it that they shut down. When the stress response is triggered they are simply unable to think and function clearly. In some cases, they may isolate to avoid further trauma in a medical setting which may result in non-compliance with the very treatment they need to survive. Non-adherence is a serious issue for this population and why medical facilities need more awareness around the psychological impacts of illness.

### **DSM and Diagnosis**

PTSD was first described in the Diagnostic Statistic Manual (DSM)-III-R (APA, 1987) with Criterion A including victims of or witness to combat, physical or sexual assault or abuse, violent crime or natural disasters, or other events considered out of the range of normal human experience. Chronic illness was ruled out as meeting the criteria for PTSD. Because of this exclusion there was a push to recognize that PTSD could be a consequence of a life-threatening disease in the DSM-IV (APA, 1994). Serious illness as a potential traumatic stressor was part of the DSM-IV criteria, yet it is not currently included in the DSM-5 definition of PTSD (APA, 1994; APA, 2013). In this sense, medical illness has been downgraded as a potential traumatic stressor in current diagnostic literature may be categorized instead as an adjustment disorder or acute stress disorder.

### **PTSD Controversy**

Wakefield (1997) argued that DSM-IV criteria for many disorders is overly inclusive by only addressing symptomatic criteria rather than contextualizing the diagnosis and taking into account the relationship between triggering causes and resulting symptoms. This earlier research has been cited in more current research on medical trauma and whether or not the construct of PTSD is appropriate (Chalfant et al., 2004). PTSD is particularly context-specific, as it requires a triggering event in order to meet diagnostic criteria (Wakefield, 1997).

Pai, Suris and North (2017) wrote about the controversy over changes to the PTSD diagnosis in the DSM-5 and how in many ways the new criterion more narrowly defines what is considered a traumatic experience, such that incidents like medical events are excluded. The DSM-IV-TR used the term “threat to physical integrity” (APA, 1994, p. 427), yet this language was removed from the definition of trauma in the DSM-5. This has resulted in medically-based

trauma being limited to a sudden catastrophe, such as waking during surgery or anaphylactic shock. Medical incidents that are considered non-immediate and non-catastrophic life-threatening illnesses, such as terminal cancer or a heart attack, no longer qualifies as trauma, regardless of how stressful or severe they are (Pai et al., 2017). Kilpatrick and colleagues (2013) did a comparison study of the DSM-IV/DSM-5 finding that 60% of PTSD cases that met DSM-IV did not meet DSM-5 PTSD criteria, as they were excluded because the traumatic events involved only non-violent injury or death. This revision of the definition of PTSD has resulted in a diagnostic gap. Hence traumatic events not meeting current diagnostic criteria, such as the traumatic nature of medical illness, are left unacknowledged.

Swartzmann et al. (2016) discussed how medical trauma may have been excluded in the DSM-5 criteria because “cancer survivors’ negative cognitions are related to future-oriented worries and concerns rather than memories of the past” (p. 335). Mehnert and Koch (2007) also address the need for subjective feelings of uncertainty, like the fear of a medical treatment, count among traumatic stressors that warrant a PTSD diagnosis. Several researchers seem unsure that PTSD is the right lens through which to look at medical trauma (Kangas et al., 2002; Mehnert & Koch, 2007; Swartzmann et al., 2016). As Green et al. (1997) stated, PTSD may manifest differently in patients with life threatening illness than in those with other traumatic events. Yet because medical illness no longer meets current DSM-5 criteria (APA, 2013), it is likely to be diagnosed along with other non-traumatic disorders or overlooked.

What is clear from this review of PTSD is that there is no current place in diagnostic literature for medical trauma. Because it is not in line with other traumatic events involving an external stressor it has been left out entirely. Since the DSM is the standard for clinical practice this lack of understanding of medical trauma leaves the population of disease survivors in a

lurch, invalidating the traumatic stress they endure. What is needed is either a more inclusive definition of PTSD or a separate diagnosis for those who have experienced traumatic stress due to medical illness.

### **Research on PTSD related to Medical Illness**

There are several quantitative studies that address PTSD in disease survivors, mainly cancer patients. It is important to address this research as it informs what has already been done to better understand trauma in disease survivors. Also, because this qualitative study involves cancer survivors, it is important to understand the literature around PTSD in this population as well as other disease survivors.

#### **PTSD in Cancer Patients**

Through an extensive literature review of PTSD in breast cancer patients, Arnaboldi et al. (2017) found that the prevalence of PTSD varies from 0-32% in studies depending on stage of the disease, time since diagnosis, and the instruments used to measure PTSD. Mystakidou et al. (2012) found that 16% of advanced cancer patients met criteria for PTSD and 2% other anxiety disorders with “the majority of advanced cancer patients reporting that their cancer diagnosis was the most significant traumatic event” (p. 131). In a meta-analysis, Swartzmann et al. (2017) found that people diagnosed with cancer had 1.66 times more likelihood than controls to develop PTSD and an overall absolute proportion of 10.8% met PTSD diagnosis. Mehnert and Koch (2007) found rates of PTSD of 18.5% in initial screenings and 16.3% six months later, suggesting that time mitigates traumatic stress. In another study, Alter et al. (1996) found that 4% of the survivor group who had been diagnosed at least three years previously met criteria for current PTSD and 22% met criteria for lifetime PTSD.

These statistics suggest that there are several variables that contribute to the level of PTSD found in cancer survivors. Specific factors include the type of cancer diagnosis, the age of the patient, the treatment type, and time since diagnosis (Swartzmann et al., 2017). Another notable difference were the instruments and assessments used to assess PTSD and trauma as they differed from study to study (Alter et al., 1996; Arnaboldi et al., 2017; Mehnert & Koch, 2007; Mystakidou et al., 2012; Swartzmann et al., 2017). A common limitation of some studies was that they assessed current PTSD rates and not lifetime PTSD, which overlooks how many cancer survivors have ever experienced PTSD or how many are likely to have PTSD right after diagnosis (Arnaboldi et al., 2017; Mystakidou et al., 2012; Swartzmann et al., 2017). In general, there are several factors that impact the likelihood of PTSD manifesting in cancer patients.

### **PTSD in Multiple Sclerosis Patients**

Multiple sclerosis (MS) is another serious disease in which there is some research exploring the traumatic response. Esposito (2016) wrote a dissertation exploring MS and trauma that found that a significant component of unpredictability with autoimmune disorders adds a component of distress. There is a large population of people with autoimmune disorders, yet there is limited research exploring the psychosocial effects. The psychological symptoms people with MS experience are similar to those of other illnesses like cancer and include intrusive recollection of events, avoidance, numbing, dissociative symptoms and depersonalization.

Carletto et al. (2018) found posttraumatic symptoms in 25.5% of their sample of MS survivors, yet only 5.7-8.5% had a confirmed diagnosis using the DSM-IV. In addition to research on life-threatening illnesses and trauma Carletto et al. (2018) also addressed the ongoing and future oriented fear of relapsing episodes of MS and the fear of progression of the disease. This relates to the many studies that demonstrate high levels of subthreshold PTSD in people with

cancer where they display significant impairment yet do not meet strict diagnostic criteria (Arnaboldi et al., 2017; Mystakidou et al., 2012; Swartzmann et al., 2017).

Chalfant et al. (2004) found that 16% of people diagnosed with MS met criteria for PTSD, whereas 75% reported intrusive thoughts related to future-oriented concerns about their prognosis. There were also high levels of symptom clusters for avoidance and hyperarousal suggesting that even when participants did not meet criteria for PTSD they continued to have various traumatogenic symptoms. These findings suggest that there needs to be a revised model of how to look at PTSD for medical trauma to better account for the future-oriented nature of their concerns.

### **Risk Factors for PTSD**

There are various risk factors and comorbidities associated with PTSD. Depression rates are typically much higher than PTSD with “rates of depressive disorders in oncology patients as high as four times than in the general population” (Banou, Hobfoll & Trochelman, 2009, p. 201) with half of cancer patients having depression. Esposito (2016) also found that upwards of 27-54% of people diagnosed with MS experience depression throughout their lifetime. However, depression and PTSD can also be comorbid, as symptoms of depression can mimic PTSD and vice versa. It is likely that many people who have medical trauma are just assumed to be going through a major depressive episode because trauma is not something expected or well understood in this population.

There are also various risk factors that make PTSD more likely. The most notable risk is a prior trauma history, which can be predictive of PTSD for cancer patients (Alter et al., 1996; Green et al., 1997; Green et al., 2000). Other surrounding variables to prior trauma that affect outcome are pre-cancer psychiatric diagnosis, recent life events, and their perceived social



support. When medical trauma is compounded on this earlier trauma it can become part of *trauma spectrum disorder* (Fullilove, Lown & Fullilove, 1992; Kreidler & Kurzawa, 2009), as there is a physiological impact of early childhood trauma on adult survivors. Early childhood trauma also disrupts attachment and can affect people's perception of the world and their place in it (Ainsworth & Bell, 1970; Bloom, 1999; Herman, 1997). Hence, people who have experienced childhood and prior trauma are particularly vulnerable to experiencing medical trauma.

Another significant risk factor is the younger the age of the survivor and the shorter time to diagnosis the higher rate of PTSD (Arnaboldi et al., 2017; Cordova et al., 2017; Hall & Hall, 2013; Mystakidou et al., 2012; Swartzmann et al., 2017). This finding makes sense because the younger a person is the more unexpected a cancer diagnosis will likely be. Similarly, the shorter the time since diagnosis, the more likely they will still be in shock and hence more psychologically vulnerable, not having had time to process and integrate the news. This analysis is particularly important to this research because it shows how younger age and early diagnosis are indicators of higher rates of PTSD, which is the demographic this study focuses on.

Hall and Hall (2013) developed a program to present at the American Counseling Association (ACA) in order to better describe the impact of medical trauma on mental health. In it they looked specifically at medical trauma, finding risk factors of age, socio-economic status, quality of social relationships, pre-existing mental health diagnoses, memories of the event, and length of stay. What is unique to their review of medical trauma is that it highlights how the specific memories of the medical diagnosis, procedures, and the length of stay in the hospital impact outcome. This is an area that needs more research to better understand this phenomenon. In this qualitative study, participant experiences of diagnosis, procedures, treatment, and prognosis and explored in how they may have contributed to traumatic stress.

### **Protective Factors**

There are various personal qualities and supports that can act as protective factors in medical trauma, such as having a strong social network and having active coping skills (Banou et al., 2009; Salick & Auerback, 2006). As Bloom (1999) states, “Social influence is a powerful force in human organization and can be used for both positive and negative purposes (p. 16). Social support is a key factor in both risk and recovery, as it mitigates the ability of a patient to be cared for outside the hospital, both physically and mentally. Mehnert, Lehmann, Graefen, Hulan and Koch (2010) surveyed 511 men with prostate cancer finding a lack of positive social support to be detrimental to outcome and a predictor of psychological co-morbidity. What is also notable about this study is that it is one of the few studies that looked at men with cancer and trauma, an under-represented population in the current literature.

Protective factors also include a positive quality of acceptance by family members and the family’s capacity to show flexibility in times of stress (Lefebvre & Levert, 2006). There are also better psychological outcomes when providers, such as mental health care providers and medical providers, communicate across systems (Ungar, Ghazinour & Richter, 2013). This is a key takeaway for future research, as there needs to be better coordinated care in order for people with medical issues to get the mental healthcare they need in tandem to cope.

### **Diagnosis as a Trauma**

One common theme in the literature is that the diagnosis itself, as a discrete event, is often perceived as traumatic (Mehnert et al., 2007; Mystakidou et al., 2012; Swartzmann et al., 2017). Alter et al. (1996) found that all cancer survivors in their study cited their cancer diagnosis as the worst event they had ever experienced. Many people have difficulty coping after a sudden and unexpected injury and may experience a “level of dissociation that often follows a

traumatic event in which individuals' psychological resources are temporarily overwhelmed" (Salick & Auerback, 2006, p. 1027).

The nature of a diagnosis being delivered by a healthcare provider as a hard fact with no recourse likely contributes to how it is perceived as traumatic by patients. Lefebvre and Levert (2006) discuss the grieving process of sudden and unexpected health situations and how it is a psychological process of reorganizing internally in order to adapt to the event and reorient their life. They acknowledge that when an event is sudden and unexpected the pain is all the more intense. Many patients are not prepared or equipped emotionally to deal with the aftermath of a diagnosis and its implications.

### **Non-PTSD Trauma**

Arnaboldi et al. (2017) found in their literature review that the prevalence of PTSD symptoms themselves without meeting all criteria for DSM diagnosis was upwards of 75% in breast cancer patients. This brings up a larger issue of how many people struggling with a new medical diagnosis are traumatized yet do not meet diagnostic criteria. There is some consensus among researchers that the cancer experience involves multiple traumatic events over the course of diagnosis and treatment, many of which are complex and repeated (Swartzmann et al., 2017). Subclinical PTSD symptomatology is very high, such that many people may not meet criteria for the DSM, but their experience is still traumatic nonetheless (Alonzo, 2000). Instead, their experiences may be attributed to more common co-morbid conditions of depression, anxiety, and adjustment disorder.

PTSD only seems to capture part of the experience as "the list of potentially psychogenic factors for PTSD may be growing, but at the core of the matter is that they are additive with other co-morbid experiences and pathologies" (Alonzo, 2000, p. 1478). This suggests that a

wider net is needed to capture this lived experience than the construct of PTSD. A better model might be to conceptualize trauma as being part of a spectrum rather than a set of specific criteria (Fullilove et al., 1992). This allows for the variability of lived experience and reactions to a traumatic experience without discounting these narratives as merely sub-acute.

An alternative concept that embodies similar symptoms but without a specific trauma that is required for a PTSD diagnosis is termed *prolonged duress stress disorder* (PDSO) (Scott & Stradling, 1992, 1994). If diagnosis of a disease is not considered a traumatic event in the DSM-5 (APA, 2013), then PDSO does appear to offer a recourse. The disorder is consistent with ongoing adversity and prolonged stress that people living with chronic disease experience. However, it is not in the DSM or ICD and is not well recognized or studied in the literature. In general, there does not seem to be an understanding of survivors of traumatic events like medical illness who do not meet strict clinical criteria for PTSD.

What seems more likely than meeting all the diagnostic criteria for PTSD, is having some of the hallmark symptoms. Arnaboldi et al. (2017) found that intrusion and avoidance symptomatology in the first 30 days since a diagnosis was 20% and usually decreased with time. In another study by Alter et al. (1996), participants rated how much they currently or in their lifetime had experienced PTSD symptoms such as re-experience (37% current; 48% lifetime), arousal (11% current; 30% lifetime), and avoidance (7% current; 30% lifetime). These findings suggest that many cancer survivors have some symptoms of PTSD post-cancer, although it is likely that many of these symptoms happen more often in the immediate aftermath of the diagnosis. This demonstrates how high distress is for this population at some point in their recovery, although it does not necessarily meet with all the criteria that is consistent with PTSD.

In general, there appears to be a gap in how to categorize and describe medical trauma in existing models of trauma. Alter et al. (1996) states, “although it is widely acknowledged that being diagnosed and receiving treatment for cancer are major and often traumatic events in one’s life, researchers have not agreed on exactly what psychological symptoms are to be expected for someone surviving cancer” (p. 140). A more accurate model of medical trauma would include the internal threat of disease, the nature of the future oriented concerns, and lack of safety in the physical body.

This exploration of existing research on disease survivors has uncovered more friction between the construct of PTSD and the experience of medical trauma. What is clear is that while some disease survivors may meet PTSD criteria, many more do not meet criteria yet endure traumatic stress. This research also highlights important risk factors that have contributed to the design my empirical study in identifying what specific population of disease survivors would best represent the experience of traumatic stress. This literature review also reveals gaps in the literature that highlight the need for a better understanding of how the experience of diagnosis, procedures, treatment, and prognosis contribute to traumatic stress. In the next section, I will explore how relational theory can be used to better understand the experience of this population outside of the medical and scientific literature, focusing on the person rather than the pathology.

### **RELATIONAL THEORY**

Once a person is diagnosed with a major disease they go from being a person to a patient in the eyes of the medical system. This is an identity shift that may cause a lot of resistance for people who are used to choosing when to seek medical care rather than being told the course of action they may need to survive. Having a major disease is extremely time consuming and

inevitably can cause psychological distress. The themes addressed here that come up often in counseling with disease survivors is how it impacts their sense of self, identity, grief, and loss.

Relational theory is a humanistic approach that emphasizes empathy, respect, understanding, and genuineness from the therapist (Saakvitne, 2017). At the core of traumatic experiences is powerlessness, which creates emotional and physiological experiences of fear and immobilization, resulting in helplessness and despair (Herman, 1997; Bloom, 1999; Saakvitne, 2017). The relational approach validates experience within the therapeutic relationship, which “from the outset is built on assumptions that the symptoms make sense, that clients are doing the best they can, and that the problem lies with what has happened to them and not who they are” (Saakvitne, 2017, p. 121).

In looking at trauma through a relational theory lens, the symptoms and behavior of a survivor of medical trauma can be de-pathologized (Saakvitne, 2017). This is an essential part of recovery for people who have already been pathologized with a medical diagnosis that they are powerless to change. Mental health providers that approach the survivor in a relational model work to counter over-learned negative beliefs about self and others and offset the pathology framework (Saakvitne, 2017).

This fundamental shift of seeing the psychological symptoms surrounding trauma as making sense in the context of what happened to them is affirming and humanizing for survivors. Therapists working with survivors need to bear witness to their trauma and the grief surrounding it by first acknowledging how the event is traumatic in their experience (Herman, 1997). In the case of medical trauma, victims may be viewed by outsiders as over-reacting and catastrophizing in respect to their diagnosis (Gauntlett-Gilbert, Rodham, Jordan & Brook, 2015). Because they may be blindsided by a new diagnosis and feeling overwhelmed, victims’ may engage in self-

blame, as there is no other culprit. Meanwhile, onlookers who learn the circumstances may pity them and treat them as wounded and vulnerable. This blame and pity from the self and others can be piled onto victims who are already suffering. Instead, we must acknowledge their psychic pain and create the therapeutic space to hold these difficult emotions.

The relational lens can also model secure attachment where the therapist acts as a secure base, offering psychophysiological regulation, consistency, predictability and the opportunity to make conscious the unconscious processes of attachment (Ainsworth & Bell, 1970; Saakvitne, 2017). The integration of relational theory, attachment theory, and feminist theory helps build a foundation for empowerment, mutuality, and sociocultural context in the construction of the client's narrative in therapy (Saakvitne, 2017). For people struggling with a new diagnosis, their support system is a key protective factor in their recovery, and the therapist can act as a hub for support in their care.

Exploring medical trauma through a relational lens helps humanize the people who will be potential subjects in this study. As a relational counselor who has worked with clients with major medical illness suffering from traumatic stress, the issues noted above are prominent themes that come up in counseling. In many instances, the diagnosis of a disease can result in client's going through the stages of grief (Kubler-Ross, 1969) in counseling. This emphasizes the need for relational supports to also be available in medical settings such as mental health providers and other healthcare providers who are relatable and caring with patients.

### **Grief and Loss**

Many people suffering from medical trauma and their families experience powerlessness and helplessness (Hall & Hall, 2013; Lefebvre & Levert, 2006; Saakvitne, 2017). Disease begins a process for an individual where there is a loss of control over the body and fear and uncertainty

about the future that are inherent to chronic illness. Alonzo (2000) reveals how people who suffer from major medical illnesses experience a sudden onset, lack of preparation, threat to life, and traumatic loss and collapse of the structure of the self. People who also lose mobility or bodily integrity due to their disease additionally experience a loss of autonomous functioning, loss of wholeness, and an inability to integrate the experience into the self-structure. Hottensen (2010) discusses how patients experience anticipatory grief, the feeling of grief occurring before an impending loss, after a cancer diagnosis and their resulting loss of identity, change of role definition, and fear of death. Grief is a common theme in the literature, as seen in Kangas et al. (2002):

It is important to recognize the grief reactions that people can experience after receiving a cancer diagnosis. Adjustment to a poor prognosis requires an adjustment period in which one needs to integrate much novel information, including reevaluating one's life goal. (p. 511)

Grief as a concept is typically associated with bereavement from loss of a loved one or other concrete losses. Hall and Hall (2013) acknowledge that “while there are a plethora of articles concerning grief and loss associated to losing a loved one from illness or accidents, there is scant research concerning the loss experienced by patients confronting medical trauma” (p. 4). The kind of grief that results from medical trauma may be more ambiguous as people may survive their disease initially, yet they must grieve the notion of being *healthy* and redefine what “healthy” means to them. With a major medical disease that is incurable and chronic comes the knowledge that the survivor is never not sick again while alive. There is a mourning process of one's sense of youth, vitality, and assumed health that are permanently compromised.



Lefebvre and Levert (2006) describe the grieving process of sudden and unexpected health situations as a psychological task of reorganizing internally in order to adapt to the event and reorient. They acknowledge that when an event is sudden and unexpected, the pain is all the more intense. As the authors state, “chronic health problems require that the person and his family give up the idea of being cured, to adapt themselves to the incapacities and learn to live with the health problem” (Lefebvre & Levert, 2006, p. 338). As a result, grief is inevitable as victims and their loved ones have to mourn their former way of life and find a way to move forward.

The model of the grieving process described by Lefebvre and Levert (2006) moves through the stages of grief, where initially people experience shock, denial, anger, guilt, and depression and then return to these feelings again, yet with adaptation such that they can evolve towards adjustment. The shock of hearing the news of diagnosis itself can lead to paralysis. This resonates with those who, upon diagnosis, experience denial and rejection of reality because it is too painful to process.

Doka (1989) coined the term *disenfranchised grief* to describe the experience of bereaved people whose rights, roles, or capacities with respect to grieving are not acknowledged by society. It is a term for people who have experienced a loss, yet those around them feel they have no right to grieve. This concept is relevant to medical trauma, as some people may not acknowledge chronic illness as a loss but rather see sickness as a fundamental part of the human condition. In this sense, many people with medical trauma suffer further because it is not socially acceptable for them to grieve.

Another concept that goes hand in hand with disenfranchised grief (Doka, 1989) is *ambiguous loss* (Boss, 1999), which embodies unresolved grief when there is no closure

regarding a loss. In the case of medical trauma, survivors may have a diagnosis but there remain several unanswered questions of what caused their illness and how the disease will impact their life moving forward. Ambiguous loss also captures how the person can fluctuate between hope and hopelessness without closure (Boss, 1999). This fluctuation describes the experience of many people who struggle with major illness, where at times they feel hopeful that one day there may be better treatment or perhaps a cure, and at other times they feel hopeless and powerless over their disease.

Authors Salick and Auerback (2006) developed a stage model of trauma and recovery in their qualitative study of participants with visible impairment from chronic illness or serious injury, expanding on previous work on how disability affects identity. The second stage in the model is *Diagnosis and Devastation*, where participants described the failure of their bodies and the loss of physical self, which results in devastation and withdrawal from the social world. Researchers found in their interviews that “following the diagnosis, nearly all participants suffered a period of depression and loss of hope” (p. 1028). This lack of hope is compounded by experiencing multiple losses concurrently, such as a sense of self, independence, decreased cognitive, and physical functioning and changes in family role, as well as secondary crises that can be existential, relational, occupational and spiritual (Hall & Hall, 2013). Hope is essential for recovery and yet many healthcare providers are discouraged to give their patients what they may consider to be false hope, such as a good prognosis or future cure. Because healthcare is not always integrated in this country, some medical facilities may not offer concurrent mental health services and must refer out for psychiatric services causing patients to fend for themselves once they are given devastating news from their medical providers.

Exploring how grief and loss impact disease survivors informs counseling practices for this population. It also highlights prominent themes that are addressed in the methodology section of this study by asking participants questions around their experiences of grief and loss in respect to illness. Another related theme is how disease impacts sense of self and identity.

### **Identity**

A central issue in chronic illness is the individual having to adjust from a narrative of being healthy to a narrative of being sick. Some research uses the term *identity renegotiation* (Laranjeira et al., 2013) while others have used the term *survivorship identity* (Little, Jordens, Paul, & Sayers, 2001) to describe the process of identity transformation in the face of illness. Many people may take their health for granted until they are faced with an unexpected disease. In cases where an illness has little to no behavioral influence, as in its attribution to genetics or bad luck rather than lifestyle choices, it is all the more shocking for the individual and could result in an identity crisis.

The intersection of identity and trauma is best understood in how a person's narrative is interrupted and often reshaped by a traumatic event. Addressing threats to physical integrity in her work on identity development, Kroger (2007) examines how a sudden disability or illness in adulthood can cause grief and impact identity and sense of self. The concept of the self being constant across past, present, and future is viewed as important for psychological health and involves coherence of a master narrative (Adler, 2012; Timm, 2015). For many people their master narrative may include characteristics like strength, resilience, and health, yet the onset of a major medical diagnosis could leave them feeling weak, vulnerable, and sick. This abrupt shift in narrative identity could result in a sense of loss of self (Alonzo, 2000).

Hall and Hall (2013) state that “when the self-identity is in question as a result of traumatic experience, there is often a redefining of oneself” (p. 6). A qualitative study by Auerback, Salick, and Fine (2006) used the case study of someone traumatized from medical illness who had “lost touch with who he was and where he was going” (p. 372). This addresses how a traumatic incident can leave victims stunned and unable to find their pathway forward. Much of the aftermath of a medical trauma can resemble an identity crisis of sorts where people can no longer orient themselves to their new circumstances, because they have no way of relating their new life to their old life (Auerback et al., 2006). The process of redefining oneself after a trauma is not a choice but rather something a survivor may have to do in order to move forward. There is limited research on how illness impacts identity. Banou (2009) called for future research to explore the role of self-esteem and its impact on the outcomes of disease survivors.

Esposito (2016) discusses how “individuals who experience profound, life-altering, or traumatic events integrate these events into their identities and begin to see the world through a different lens” (p. 2). For many, major illness sets the stage for chronic instability in people’s lives where they may experience ongoing vigilance about symptoms and the future. It is no wonder that disease can result in diminished self-esteem and challenge one’s self-identity, daily functioning, occupational status, support systems, relationships, coping skills, and overall satisfaction with life. Esposito’s (2016) premise of how chronic illness affects identity relates to this research study in how disease affects self-esteem and identity and results in grief and mourning for the former self.

Relational theory with its emphasis on humanizing experiences is an effective way to deconstruct experiences of grief, loss, and identity crisis for disease survivors. This exploration of the inner world of this population informed how to approach developing the questions that

were asked in the study to capture the lived experience of medical trauma. The next section explores how the outside world impacts experiences of medical trauma. Disease survivors carry a disability in an able-bodied world which is also compounded by factors of gender, race, and socioeconomic status.

### **Social Justice and Critical Disability Theory**

In looking at the intersection of medical trauma and social justice, many people struggling with a major medical diagnosis are visibly impaired and may face limited mobility, diminished social status, and possible discrimination as a result of their disability. People living with chronic illness who are not visibly impaired have instead an *invisible disability* (Banks, 2014; Tobin, 2004). While not readily apparent, invisible disabilities may still impact individuals in terms of life choices, overall resiliency, and ongoing needs to decide whether to reveal one's disability status. Thus, individuals with both visible and invisible disabilities are a vulnerable population in society.

The notion of disease survivors having an invisible disability (Banks, 2014; Tobin, 2004) is interwoven within critical disability theory, which examines the overall invisibility of the disabled population. Critical disability theory takes into account the ecological context of having a disability by examining problems of health and disease on a basic social-political-economic level (Devlin & Pothier, 2006; Zola, 1989). A critical lens can deconstruct the binary of disability and how throughout history disabled people have been invalidated, represented as inferior, and seen as second-class citizens (Swain, French, Barnes, & Thomas, 2004). Critical disability theory explores impairment and disability in a social context and how these concepts only exist in a normed society.

Dirth and Branscombe's (2018) model of social identity approach (SIA) examined disability in an ecological perspective, taking into account social, cultural, political, and historical factors. Impairments like chronic illness are viewed by the effect they have on people in multiple contexts of social, attitudinal, architectural, medical, economic, and political environments. It also evaluated how disability affects people of all ages, genders, and socioeconomic status when it comes to necessities like housing, transportation, and work. What SIA and critical disability theory taught us is that the world is not equipped for people with disabilities (PWD), whether it be how buildings are made, how we use public transportation, or expectations of people to work when they have physical limitations (Hahn, 1985; Zola, 1989).

PWD also face an enormous amount of stigma. In many ways, they are an oppressed minority in society that lives in the shadows. An example would be how many people avoid using wheelchairs due to its perceived stigma, while others choose not to self-disclose their disability at their workplace for fear of discrimination or stigma (Tobin, 2004). Through his own experience with disability caused by polio, Tobin (2004) talked about the ingenious ways PWD conceal their impairments and find ways to "pass as able-bodied" (p. 2). In masking his own disability, he revealed how "passing is possible not only because people have sufficient genius to disguise their identity but also because society has a general tendency to repress the embodiment of difference" (p. 3).

The conversation of disability also relates back to the relational concept of identity and the embedded identity crisis of medical trauma. Disclosure is a key factor for people with chronic illness and those struggling with invisible disabilities relating to identity and whether or not PWD identify as being disabled or rather deny that label. Yet regardless of whether people

think of themselves as disabled, they are likely to be affected by whether or not other people perceive them as disabled and how this can act as a form of oppression.

An example of this invisibility was in a study by Gauntlett-Gilbert et al. (2015) which discussed how patients with chronic pain presenting in the ER were told their pain was psychological and felt labeled as difficult patients due to the invisibility of their conditions. In her dissertation, Esposito (2016) looked at multiple sclerosis as part of the PWD population who are a hidden minority experiencing stigmatization and invisibility in our society. In her own literature review she makes several connections between physical and mental health and the high comorbidity of depression, anxiety, and PTSD of people with chronic illness. She called for an integrative approach to disability that treats both medical and psychological components of disabling conditions like MS.

In examining medical trauma as a social justice issue, disability only captures part of the social experience of this population. There are other compounding factors beyond living in a society built for the able-bodied which involve access to healthcare in a country that does not provide it for its people. In considering diversity, it is important to deconstruct how factors of race, class, and gender impact the experience of disease survivors.

### **Race, Class, and Gender**

Race, class, and gender impact health and access to healthcare yet the literature on medical trauma rarely addresses these factors. Smith, Chambers, and Bratini (2009) investigated oppression as a pathogen and how “oppression is a contextual factor but can also be a direct cause of emotional and physical trauma” (p. 160). Risk factors for medical trauma include low socioeconomic status, poor social support, and pre-existing mental health diagnoses, which are all more likely in vulnerable populations. Because minorities are oppressed groups already

experiencing internalized oppression, powerlessness, and social degradation these other traumatic experiences only compound this reality, making them more at risk (Smith et al., 2009). Saakvitne (2017) addresses how working with survivors of trauma often brings clinicians in direct contact with the impact of organized injustice and discrimination on the basis of gender, race, age, socioeconomic status, sexual orientation, and disability for our clients.

The injustices of society are also played out in social systems, such as the dispensation of healthcare in this country. Prior trauma is a risk for medical trauma (Alter et al., 1996; Green et al., 1997; 2000), and yet those most vulnerable to trauma are minorities, women, and the lower class. Those most vulnerable to traumatic injuries are then further vulnerable to discrimination and victim-blaming after those traumatic injuries occur (Saakvitne, 2017). Like many social issues, it becomes part of a vicious cycle where trauma begets further trauma.

The social and emotional consequences of complex trauma create cycles of deprivation and injustice where survivors are less able to advocate for themselves (Saakvitne, 2017). One benefit of counseling this population using a relational framework is that it can incorporate social justice by working to empower and collaborate with survivors to counter disempowerment, oppression, and exploitation. Counselors can act as advocates for clients by helping them identify and overcome systemic obstacles and coordinating care with other providers. Incorporating social justice into mental health care pushes the envelope as conventional practices can mask and support an unjust status quo which then perpetuates the marginalization of oppressed people (Smith et al., 2009).

### ***Race***

Some studies focus on the role race plays in illness and trauma. A qualitative study by Dzul-Church, Cimino, Adler, Wong, and Anderson (2010) addressed the experience of



underserved patients, the majority of whom were Hispanic and Black men, with serious illness towards end of life in an urban public hospital. Researchers found themes of estrangement, homelessness, substance abuse, and imprisonment shaped how participants felt about their illness. Because many of the participants lacked social support, their providers played a significant role in their care. Although several participants had a trauma history, it was not a focus of the study, nor was trauma addressed as it related to medical illness.

Another study by Myers et al. (2015) recruited African American and Latino participants to look at cumulative lifetime adversities and traumas by exploring the impact of discrimination, childhood adversities, chronic life stressors, and adult and child traumas. They found that the cumulative burden of adversities can be a predictor of mental health issues like depression, anxiety, and PTSD. This study builds on previous research of cumulative adversity by Turner and Lloyd (1995), who looked at the relationship between multiple lifetime traumas and psychological disorders.

Nobles et al. (2015) explored how race plays into PTSD and the disparity between Black and White people who experience chronic illness. In general, chronic illness is more common among Blacks than Whites, and this burden may be further exacerbated due to socioeconomic disadvantages, racism, and barriers to care (Nobles et al., 2015). They found associations between PTSD, chronic illness, and race to give further evidence of institutional racism impacting stress-related mental health conditions and chronic disease which may be greater among individuals affected by the social and economic disadvantages. Rates of trauma were higher for minorities, with Black participants having a lifetime prevalence of PTSD of 8.3% compared to Whites with 6.3% (Nobles et al., 2015). These results support the potential interaction between racial disparities and psychological distress for minorities.

Researchers have to start examining issues of race, class, and gender, as few studies address how trauma is impacted by sociocultural factors. Although there are no exemptions for those affected by medical trauma, the majority of research participants are White and middle class. Several studies listed in the limitations of their research that they had a homogenous sample of predominately White, middle class participants (Alter et al., 1996; Arnaboldi et al., 2017; Banou et al., 2009; Nobles et al., 2015; Salick & Auerback, 2006; Swartzmann et al., 2017). Yet risk factors such as prior trauma history and low social support suggest clinical implications of more treatment access for these vulnerable populations. Salick and Auerback's (2006) study did not account for financial stability and access to healthcare, which is not representative of the larger population of people suffering from disabilities that may not have access to similar resources. These limitations stress the importance of collecting data from a more heterogeneous pool of participants that represents the racial differences seen in our society, as they may experience different compounding factors.

### ***Class***

Class is also rarely addressed in research studies, yet trauma is more likely in low socioeconomic populations, as poverty is stressful and takes an emotional toll on poor people (Smith et al., 2009). People with fewer financial resources may not have access to the necessary medical and mental health care they need to recover from a trauma. In general, socioeconomic status is a risk factor for chronic illness and PTSD and hence also puts more vulnerable people at greater risk for medical trauma (Hall & Hall, 2013; Nobles et al., 2015).

### ***Gender***

Gender is also a factor that needs to be explored more in medical trauma. In general, women are more vulnerable than men to trauma, as “the traditional definition of femininity not

only allows for but encourages, powerlessness and therefore the open possibility of victimization” (Bloom, 1999, p. 14). Yet there are a disproportionately large number of female research subjects in studies addressing medical issues and psychological symptoms which may be a result of gender bias that women are more vulnerable to emotional distress and more likely to be study participants. Many PTSD studies also focus on breast cancer (Arnaboldi et al., 2017; Green et al., 2000; Swartzmann et al., 2017), which is typically specific to women. This emphasizes the research bias of addressing the psychological distress of medical patients with predominately female subjects.

Meanwhile, men may be less vulnerable than women in most domains of life, yet when it comes to trauma, “the traditional definition of masculinity does not allow for helplessness- you cannot be a victim and be masculine” (Bloom, 1999, p. 14). Because men are typically socialized not to show weakness, they may have less cultural understanding of traumatic injury. Future studies should focus more on how gender impacts medical trauma and internalized and externalized victimhood.

Meanwhile, the majority of studies focus on the female experience, such as Banou et al. (2009) examined 64 women’s pre-cancer history of traumatic experiences and interpersonal trauma and PTSD related to cancer. They found 59% of women had experienced one or more incidences of childhood abuse, over 60% reported loss of financial resources, and over 34% of women had clinically significant levels of depression. They also found a co-relation between interpersonal loss and PTSD and depression symptoms. This study suggests that women who have repeated exposure to traumatic experiences are at a heightened risk for psychological distress and PTSD from cancer.

### **Risk and Resilience**

Various studies looked at prior trauma as a risk factor and found that trauma predicts psychological distress due to lack of resources to deal with the trauma which then creates recurrent spirals of interpersonal loss (Alter et al., 2006, Banou et al., 2009; Green et al., 2000). This chain-of-pain (Kass, 2017) scenario is notable as it reveals how difficult it is for people to be resilient and adaptive in the face of illness when they are dealing with high levels of adversity in their lives.

Trost et al. (2015) studied the perceived injustice of those sustaining a traumatic medical injury and found significant associations between perceived injustice and demographic variables such as education, income, race, and age. They also found a correlation with the amount of perceived injustice and association with pain and quality of life outcomes. This implies that ecological factors that already contribute to the marginalization of minorities and people with lower socioeconomic status are further compounded by perceived victimhood from medical trauma.

Ungar et al. (2013) looked at social-ecological systems as a factor into resilience and how people overcome adversity. In their article they call for a definition of resilience that acknowledges the ecological system of human development (Bronfenbrenner, 1979) and how people are embedded in their environments and hence are products of that influence. Bronfenbrenner and Ceci (1994) argued that under certain circumstances a person's environment can be just as influential as their biology. In the case of trauma, nurture can contribute both to risk and recovery. The ecological system is where all events take place as "the more adversity a child is subjected to the more their resilience depends on the quality of the environment and resources that are available and accessible to nurture and sustain well-being" (Ungar et al., 2013,

p. 350). The ecological model is a helpful way to look at factors surrounding medical trauma that accounts for features like race, class, and gender and their impact on outcome.

In order for people to recover from trauma they need support from their environment. As Unger et al. (2013) stated, “resilience is more likely to occur when individuals and groups are successful at navigating to resources that support them psychologically and physically and negotiating for these to be provided in ways that are culturally relevant” (p. 361). What is clear from this research is that resilience is moderated by both context and culture. People that are marginalized have less power to influence the discourse that defines adaptive coping under stress and the way resources are provided to meet their needs. What Unger et al. (2013) called for is the need for marginalized groups to sustain a positive identity and sense of control as the minority. Counselors can assist in this process by using a relational model that incorporates social justice and can help advocate for minorities.

Using the lens of critical disability theory medical trauma can be seen as a social justice issue of a vulnerable population operating with an often times invisible disability (Tobin, 2004; Banks, 2014) in an able-bodied society. Further evaluating how medical trauma is impacted by external factors of gender, race, and socioeconomic status demonstrates how these factors of risk and resilience affect outcome. The ecological model (Bronfenbrenner, 1979; Ungar et al., 2013) then contextualizes the impact of the environment on the individual. This exploration of critical disability theory and social justice has focused mostly on risks associated with this population. The final section explores what factors contribute to resilience, meaning making, and growth for disease survivors.

### **Existentialism, Resilience, and Posttraumatic Growth**

This concluding section of the literature review focuses on how survivors of medical trauma are able to make meaning of their experiences. The diagnosis of a major medical disease often brings with it a fight for life. In the battle to survive disease, individuals are challenged with a threat to their existence that often leads to philosophical and existential questions. Medical trauma, like other traumas, derails the individual from their normal life course and leaves them trying to find a new path forward. In line with the phenomenological nature of this study, it is important to explore how the individual makes meaning of their trauma and what factors promote resilience and posttraumatic growth from surviving such adversity.

### **Existentialism**

The crisis evoked by a traumatic event begins a process of reevaluation where a person must confront big questions. Herman (1997) articulated this struggle of how victims of trauma ask “Why? Beyond this unfathomable question, the survivor confronts the incomprehensible question: Why me?” (p 178). The unexpected randomness of disease may leave victims blindsided and unable to comprehend why such misfortune would befall them. The philosophy of existentialism within psychotherapy (Yalom, 1980) is a way to view how medical trauma can be integrated into our understanding of the human condition. Stolorow (2015) stated that the significance of emotional trauma is that it “shatters our illusions of safety and plunges us into an authentic being-toward-death, wherein we must face up to our finitude and the finitude of all those we love” (p. 137). People in a major health crisis are ultimately battling with their own mortality. As Bloom (1999) states:

The experience of trauma shatters- often irrevocably- some very basic assumptions about our world, our relationship to others, and our basic sense of identity and place in the world. A sense of meaning and purpose for being alive are shaken. (p. 15)

Trauma causes a fundamental shift in how people perceive themselves within the world. Life is never the same after a medical trauma, as victims have to face their impermanence. Bloom (1999) addressed the existential crisis embedded within a traumatic event as “our sense of who we are, how we fit into the world, how we relate to other people, and what the point of it all is, can become significantly limited in scope” (p. 9). Many traumatic events challenge survival, and certainly in the case of medical trauma, such that all other aspects of life pale in comparison to the question of existence itself.

Some of the previous research surrounding how disease survivors make meaning of their circumstances used phenomenological inquiry which is the methodology of this study. Laranjerira et al. (2013) in a qualitative phenomenological study addressed how female cancer survivors attributed meaning to life after cancer finding themes of mediation between world, self, and others. Participants experienced shifts in self-identity, with more emphasis on finding meaning and purpose in their lives and a sense of authenticity. In this process of personal transformation through adversity, they found survivors had experienced a breaking point brought on by their cancer, arriving at an existential crisis which resulted in a reconfiguration of world assumptions.

A quantitative study by Mystakidou et al. (2012) found that PTSD was more likely in younger cancer patients and believed this was because anticipation of death prompted various existential concerns, feelings of loss of control, and psychological distress. A traumatic event changes people’s view of the world and how they live in that world. The diagnosis itself can also act as a divider in the timeline of one’s life, as everything that came before it was from a place of innocence and everything that comes after it may feel tainted by it. Lefebvre and Levert (2006) discussed how “in many sudden and unexpected health situations, the whole life prior to the

disclosure of the diagnosis is called into question” (p. 343). This is part of the existential crisis that is commonly embedded in traumatic experiences where people with chronic disease might ask themselves if they had taken their health for granted before their diagnosis and if they had been living their life to its full potential before being faced with their mortality.

### **Resilience**

Survivors must undergo a transformational process in order to evolve beyond their trauma, something Judith Herman (1997) termed the *survivor mission*. The reconstruction process occurs in three stages of creating safety, reprocessing, and integration within which strength, connection, and meaning must be found in order for reconnection to occur (Herman, 1997; van der Kolk, 2003). Auerbach et al. (2006) explored this model and how recovery from trauma involves a reconstruction of the assumptive world. Notable themes from participants of their study undergoing stem cell transplant treatment for multiple myeloma were the *physical deterioration and vulnerability, isolation and dehumanization, shock of looking at death in the face, and living while dying* (Auerbach et al., 2006). Yet these same participants were able to move on to a post-transplant existence where they were able to recuperate physically and interpersonally by making connections with other cancer patients and finding their own inner resilience. An important finding in this study was the idea of reframing the trauma to focus on strengths rather than deficits.

Another qualitative study looked at the healing journey of people suffering from trauma and illness (Scott, Warber, Dieppe, Jones & Stange, 2017). Researchers found that positive reframing was what facilitated the process of moving from suffering to healing, as one participant’s ability to “reframe his illness as something that could happen to anyone made him able to realize that he was not to blame for his illness” (p. 4). Participants described making



connections outside themselves and developing trusting relationships, once again demonstrating how social support acts as a protective factor. This study found that healing is an active process involving persistence, hope, self-acceptance, and the desire to help others. In order for people to progress towards healing they had to make meaning of their problems, accept responsibility for themselves, and reframe their experiences more positively.

Some research suggests that exploration of trauma-related existential conflicts has been found to be beneficial for people struggling with PTSD (Sigmund, 2003). This is likely because people may need to process their trauma in a larger context of how they attribute meaning to it. Bloom (1999) discusses how the process of recovery involves helping people focus on mastery and empowerment while avoiding further experiences of helplessness. Part of developing this mastery is by putting words to their experiences by creating a narrative of the events that happened to them and sharing it with themselves and other people. As Stolorow (2015) discussed in his work on emotional trauma, there is a context-embeddedness of painful and frightening memories that must find a context of emotional understanding where it can be held and integrated.

A valuable asset for maintaining well-being under conditions of poor health is a resilient personality (Unger, 2013). People who are resilient are able to make sense of their illness and find a pathway forward despite adversity. Iacoviello and Charney (2014) studied the personal attributes of particularly resilient individuals and found various common traits. They concluded that a number of psychosocial factors are associated with resilience such as optimism, cognitive flexibility, active coping skills, maintaining a supportive social network, attending to one's physical well-being, and embracing a personal moral compass. Those who have these personal traits are most likely to mitigate PTSD after a medical trauma and navigate a way forward.

Trauma survivors are commonly examined in risk and resilience models to determine what factors help or hurt them along the way. In investigating what helps them create meaning, existentialism is a way to look at the bigger picture of existence itself and how people view their own mortality. Philosophy and meaning making can then act as a bridge towards resilience for individuals overcoming adversity. More recently there has been literature focused on the personal growth that can occur after a traumatic event. The next section explores this body of work which has focused on how disease survivors create a new path forward.

### **Posttraumatic Growth**

Posttraumatic growth (PTG) is the process of how people overcome adversity through resilience and are able to grow interpersonally in spite of their challenges (Tedeschi & Calhoun, 1996). The premise of PTG is that trauma can act as a catalyst that promotes growth and enhances well-being such that survivors experience resilience, meaning-making, growth, and positive change. Several researchers have discussed resilience and PTG after a medical crisis. Arnaboldi et al. (2017) found that the use of active coping skills as well as optimism, spirituality, and positive attitude were related to lower levels of distress among women with breast cancer. In her dissertation, Esposito (2016) found that social support and personal mastery, or sense of control, were mediators for PTSD and posttraumatic growth for people with MS.

There are also several qualitative studies addressing PTG after cancer that explore themes of how survivors experience interpersonal growth through the adversity of disease (Denney et al., 2011; Hefferon et al., 2009; Laranjerira et al., 2013; Morris et al., 2012; Morris et al., 2013). One study by Denney et al. (2011) specifically looked at the role of spiritual growth following a trauma and found that many cancer survivors report transformation in this area. Morris et al. (2012; 2013) found that appreciating life more was the most salient theme of life change for

survivors, along with feeling compassion for others and instituting positive health-related life changes such as better diet and self-care. PTG allows for the possibility of transcending the negativity of enduring disease and how those who are resilient are able to grow from adversity and discover a new narrative and gain wisdom.

In a study by Lefebvre and Levert (2006) they created a model of the grieving process for those suffering from a sudden and unexpected health situation, which demonstrated how people move from suffering to resilience through the PTG process of adapting and rebuilding life after a medical trauma. They explored how losses can be an opportunity for people to discover new strengths of which they were formerly unaware. With a reframing of negative life experiences, such as adversity can lead to growth, a positive meaning can then be ascribed to the traumatic event. It can act as a turning point where survivors have a new awareness and gratitude for life.

Salick and Auerback's (2006) stage model of trauma and recovery for people with chronic illness and serious injury expands on previous work on how disability affects identity and specifically how adversity leads to growth. The later stages of the model of *Choosing to Go On* and *Building a Way to Live* is where people find an inner strength, deciding not to miss out on life and formulating a plan of how to move on and reclaim the physical body, utilize support groups, and find a personal meaning. The final stage of the model is *Integration of the Trauma and Expansion of the Self*, where participants described being able to move forward and rebuild their lives, give something back, gain new empathy from their experience, and have an increased sense of purpose and meaning. Participants articulated how suffering forced them to grow and were able to identify benefits in adversity by broadening a sense of self and emotional experience. A necessary part of transformation was the shift from hopelessness to hope.

Saakvitne (2017) states that “hope is an essential resource a therapist brings to work with survivors” (p. 126), as it reinforces the goal of rebuilding life after trauma. A qualitative study by Tutton, Seers, and Langstaff (2012) advocated that healthcare professionals offer realistic hopefulness to their patients as a way to facilitate emotional and physical recovery. This implies support for providers offering hope in hospital settings. Locating hope is essential for people who are traumatized and feel hopeless as a result of their diagnosis.

Hope can act as a protective factor. Interpreting the medical situation positively is regarded as the most effective adaption strategy for resolving psychological trauma (Lefebvre & Levert, 2006). Although this is a difficult challenge for many people, it suggests that it is actually necessary to find the silver lining of a medical trauma in order to evolve to a place of resiliency and some level of acceptance. Transformation can then take place through this process of adjustment, resignation, and reorganization when people can locate the inner strength and resources to cope. In unpacking how existentialism, resilience, and PTG contribute towards literature around medical trauma, there is more understanding around how people make meaning of their situation.

### **Conclusions**

This review of literature surrounding medical trauma has investigated four aspects of the phenomenon. Current trauma theory is a lens through which to understand symptomology and diagnosis and where medical trauma does and does not fit within trauma models and the PTSD diagnosis. Relational theory is a way of looking at the human being behind the medical diagnosis and how providers can best support disease survivors. Critical disability theory and the social justice issues of gender, race, and class are inherent in this topic, such as living with an invisible disability (Banks, 2014; Tobin, 2004). Lastly, existential theory and models of resilience and

posttraumatic growth are what bridges this literature review to the methodology of phenomenology in exploring how disease survivors make meaning of their experiences.

In the process of unpacking traditional trauma theory and how it relates to the concept of medical trauma, several notable discrepancies have been revealed. First of all, traditional trauma models involve an external stressor or aggressor who traumatizes the victim (Bloom, 1999; Herman, 1997). Most commonly this is seen in child abuse or combat situations, which are most commonly associated with trauma and PTSD. However, an external stressor is not in line with the construct of medical trauma where there is only an internal stressor of the disease itself that occurs suddenly and unexpectedly with no one to blame but the victim's own body.

The second discrepancy is that in traditional trauma models, survivors typically ruminate on past events of the trauma, whereas for many medical trauma survivors their ruminations are on the future and the unpredictable nature of their disease and its prognosis (Kangas et al., 2002; Laranjeira et al., 2013; Vachon, 2001). Conceptually, these are notable incongruences that demonstrate the need for medical trauma to have its own construct and theory to account for the differences in experiences from more traditionally understood traumas of abuse, violence, combat, and natural disasters.

The third discrepancy that is specific to medical trauma is that a diagnosis of a major disease results in the lack of control over the physical body. However, in traditional trauma models, the first stage of recovery consists of establishing safety by gaining control of the body (Bloom, 1999; Herman 1997). In the aftermath of a diagnosis some may feel betrayed by their bodies and unable to find safety internally. Almost in an opposite direction than traditional trauma theory, medical trauma occurs with an internal stressor, and safety may be found more externally from the physical self. Victims look outward towards others for self-protection and the

organization of a safe environment (Herman, 1997). This review of literature has uncovered these three distinctions between medical trauma and traditional trauma:

1. Originates from an internal stressor.
2. Future orientated concerns.
3. Lack of safety within the physical body.

The central premise of this dissertation is that serious medical illness is a traumatic stressor and should have its own diagnosis that includes the specific characteristics that are more in line with survivor's lived experience rather than trying to force a sub-group of traumatized people into a larger net (PTSD) that was originally designed for a population of victims of violence and abuse. The current construct of PTSD may not align with the reality of what people experiencing medical trauma actually endure (Alonzo, 2000; Alter et al., 1996; Chalfant, Bryant, & Fulcher, 2004). Ideally, there should be a more accurate diagnosis for psychological distress that can be understood by providers and given concurrently with medical treatment for their illness. This would allow for more systematic patient assessment and screening and result in more appropriate treatment in both medical and mental health settings.

The purpose of this research study is to explore the experience of psychological distress of young adults diagnosed with cancer. Using a trauma lens to investigate medical diagnoses and chronic illness is instrumental in understanding the impact on mental health. This is best achieved by capturing the lived experiences of those who have endured what they consider to be a medical trauma. Based on existing literature and theoretical perspectives reviewed here, it was hypothesized that the characteristics of events surrounding the medical diagnosis affects whether or not people experience it as traumatic and influence the severity of traumatic stress. These characteristics include how old the individual was upon diagnosis, how long it has been since

their diagnosis and whether the diagnosis was sudden and unexpected or more gradual after ongoing symptoms. My belief is that younger people who are diagnosed more suddenly are most at risk for traumatic stress.

This exploration of medical trauma and the experience of medical traumatic stress for disease survivors has reviewed the literature surrounding this phenomenon and suggests where gaps in the body of research remain. There are currently no qualitative phenomenological studies that specifically address the concept of medical trauma in the academic literature. The next chapter states the methodology used to capture the lived experience of medical trauma with the goal of creating a model for the phenomenon of medical traumatic stress.

### CHAPTER 3- METHODOLOGY AND RESEARCH DESIGN

This chapter discusses the research methods and rationale used to best support the research aims. The focal point of this research is to illuminate the lived experience of psychological distress resulting from a major medical diagnosis. Specifically, this study focuses on young adults given a cancer diagnosis because the literature suggests that young adults are more susceptible to psychological distress than older adults. The study was performed using the qualitative methodology of phenomenology. Through phenomenological interviews and analysis, the lived experience of participants can be better understood to uncover the structure and essence of their narrative and shared experiences (Marshall & Rossman, 2015).

Currently, there is very little research on the topic of medical traumatic stress and there are no qualitative studies that address the phenomenon. The rationale for using phenomenology is that it is the best methodology for understanding the essence of a specific phenomenon like the traumatic response to medical disease. This is achieved through exploration of the lived experience, consciousness, and lifeworld of the participant (Giorgi, 2009). In this way, research can act as a vehicle to give voice to cancer survivors who have experienced traumatic stress that is otherwise not described in the literature.

The descriptive method of phenomenology allows for an investigation into the lives of subjects that is open-ended and experience based (Giorgi, 2009). The hermeneutic tradition of Heidegger (1927/2011) acknowledges that there is no way to bracket our understanding as we are always in the world with others and there is no way to separate oneself from being within the world. The hermeneutic circle is an ongoing and iterative process of revision to challenge understanding and interpretation where the whole can be broken into parts and then synthesized (Giorgi, 2009). This framework allowed me to engage in the process of reflexivity while also



capturing the experience of participants, acknowledging that my interpretations and analysis inherently contained personal biases which were then made explicit.

The goal of this research inquiry was to bring to the surface the phenomenon of medical traumatic stress through the lived experience of adults given a diagnosis of cancer from medical professionals. The focus of qualitative questions surrounding this phenomenon were how participants experienced psychological distress in regard to their medical diagnosis, treatment, procedures, and/or future. Other surrounding questions explored how they experienced grief and loss and how their diagnosis has affected their sense of self and identity. The leading research questions are: What have been the experiences of psychological distress for young adults diagnosed with cancer? What elements of the experiences suggest potential for medical trauma? What helped or hindered one's coping with the diagnosis/treatment?

### **Epistemological Stance**

In this research study, my epistemological stance is through the constructivist paradigm with the relativist position that participants have multiple, apprehendable, and equally valid realities (Ponterotto, 2005). Constructivism is a paradigm that conceives learning as an active process where the learner is an information constructor. This process of actively creating subjective representations of objective reality aligns with my sense of myself in the world, how I experience meaning, and how I assume others do as well. Approaching my research from a constructivist stance, I believe reality is within the mind of the individual where there is no definitive universal truth (Ponterotto, 2005).

Using this paradigm, I approached this research with the belief that reality is constructed in the mind of the individual and that each person has a unique reality that is their own experience (Ponterotto, 2005). I believe my participants have their own narrative they have

accessed through reflection of life experiences which are influenced by their surroundings, values, mindsets, social interactions, and community (Gergen, Josselson, & Freeman, 2015). This also relates to the use of the ecological model (Bronfenbrenner, 1979) in my literature review as I see all phenomena through the lens of how society and people's surroundings affect their experiences of the world.

I also examined the data through the theoretical framework lenses of trauma theory (Bloom, 1999; Herman, 1997), relational theory (Saakvitne, 2017), critical disability theory (Devlin & Pothier, 2006; Zola, 1989), and existential theory (Stolorow, 2015; Yalom, 1980) that comprised the infrastructure of my literature review. I approached the research with the constructivist stance that knowledge is subjective yet with the assumption that society is essentially conflictual and oppressive (Marshall & Rossman, 2015). This stance allowed me to evaluate my findings in a sociocultural context, viewing medical trauma as a social justice issue.

### **Positionality and Reflexivity**

My interest in traumatic stress caused by illness has emerged from a combination of personal and professional clinical experiences. I once counseled a young adult battling cancer who experienced resulting depression, anxiety, suicidal ideation, and a suicide attempt despite having no prior psychiatric history. My mother had cancer and went through a major depressive episode, and my aunt currently has cancer and is struggling with her mental health. I also have four friends who have died from cancer. In many ways, I feel I have witnessed the phenomenon of medical traumatic stress both personally and professionally and want to find a way to describe it.

This topic also has a personal resonance with me because I was given a sudden and unwelcome diagnosis of an autoimmune disease postpartum that resulted in a major depressive

episode. I also experienced the diagnosis as a traumatic event and had various symptoms of PTSD including numbing, avoidance, and ruminations. What I experienced is what some may call an identity crisis where the idea of having a chronic illness was something that I rejected entirely. I felt powerless with the gravity of the diagnosis and experienced a psychological paralysis.

My assumption is that other relatively young adults given a sudden medical diagnosis experience similar traumatic stress. I expected to find themes of powerlessness, grief, and despair although I am aware that there are a variety of reactions to such catastrophic news. I also acknowledge that identity factors such as gender roles, race, socioeconomic status, as well as social support levels all vary from person to person and influence how they perceive their situation.

In examining reflexivity, the researcher must engage in a self-critical disclosure of interests, traditions, preconceptions, and personal relationships with the subject matter (Wertz et al., 2011). For instance, I have some insider status of being a disease survivor due to my personal experience with illness. It is necessary to be explicit about this personal bias and evaluate potential over identification with participants in my research. By acknowledging and explicating my own biases and expectations, the process of reflexivity has culminated within the course of my research.

In the hermeneutic tradition of Heidegger (1927/2011), I acknowledge that there is no way to fully bracket my understanding as I am always in the world with others and I cannot separate myself from being within the world. However, I wanted to minimize any influence of my own personal experiences on how participants felt about or responded to me as a researcher during the data collection process. To control for this, before and during the study I did not

disclose that I know and am related to several cancer survivors or that I have also struggled with chronic illness and resulting grief because I believed this might cloud how participants viewed my role. After the study was complete, I did share with interested participants some brief background information on how I became interested in the subject and my interest in describing the phenomenon of medical traumatic stress.

Another consideration I had to make was keeping within my role as researcher as opposed to therapist. Novice researchers must learn how to listen without the idea of fixing the problem and hearing their subjects without thinking about how to change things (Josselson, 2013). I had to be conscious of the role I played as a researcher versus a counselor. In order to minimize bias, I compartmentalized my inclination to respond to participants experiences and concentrated on the research objectives.

I tried to build a relationship of trust and warm regard with participants while also withholding my urges to counsel them or self-disclose, because I believed this could affect the trustworthiness of the study if there were any processing or commiseration on my part. In research, participants are the expert and the researcher must acknowledge that their role is to learn from participants rather than counsel them (Hunt, Chan & Mehta, 2011). By allowing participants to be the expert of their experience they were able to have their own voices heard, such as through representative quotes. I wanted to create a safe space for participants to share their journey with illness and not feel judged, pitied, or give off the message that they needed counseling.

There was also some concern about my own emotional responses to interviews. I am thankful to have a good deal of clinical experience in crisis work under my belt such that I am used to staying composed when hearing devastating stories. However, I have a lot more in

common with the participants in this study than I have with most of my clients. This is something I had to be aware of; that something they could say would trigger me in regard to my own emotional battle with illness. I decided that if I felt it was necessary, I would seek my own counselor during the data collection phase to help mitigate any of these concerns. I did in fact reach out and start working with a counselor during this time period as it did prove to be an emotionally challenging time for me and I welcomed the outside support.

In acknowledging reflexivity as an ongoing and essential part of research, I have built a deeper understanding of my own background and biases and have continually taken these factors into account as I moved forward through this study. Reflections on power and privilege and the ideological and political consequences of my research goals are embedded within the research process (Gergen, 2014). As Josselson (2013) stated, “The reflexive attitude becomes one of noticing what you are doing in the interaction, rather than trying to maintain the illusion that you are doing nothing at all” (p. 27). Using reflexivity as a central tool of qualitative methods allows for the human imperfection of the researcher to be part of the discovery process. I acknowledge how my own biases came up during this study yet with reflexivity my job was to name them (Luttrell, 2000) as they came up and make that process part of my research.

## **Participants**

### **Population Description**

The participants in this study were young adults diagnosed with cancer who felt they had experienced psychological distress in relation to their diagnosis, illness, and/or treatment. The National Cancer Institute (2018) defines adolescent and young adults as those diagnosed with cancer between the ages of 15-39. The American Cancer Society (2018) defines young adults as

those diagnosed between the ages of 20-39. This study further focused on the adult population within those criteria.

Inclusion criteria for the study were adults who are considered young for a cancer diagnosis as defined by being between the ages of 18-39 years old who have been given a diagnosis within the past seven years and identify as having experienced psychological distress from cancer. The stage, type, and prognosis of their cancer were not relevant to the study as the main subject of inquiry was their experience of psychological distress in regard to their illness.

Exclusion criteria were any potential participants who were in active treatment, such as currently receiving chemotherapy or radiation. However, if they were taking Tamoxifen or any other similar medication that is considered part of maintenance treatment they were eligible as this is considered non-invasive. During initial screening, any participants who identified as in emotional crisis were to be referred to a therapist for treatment instead of taking part in the research study. This did not occur but was part of the study protocol. I tracked the participation rate by keeping records of the number of people who inquired or asked to participate in the study over the duration of data collection. There were a small number of potential participants, approximately four, who inquired about the study but were ineligible because they did not meet the inclusion criteria due.

### **Recruitment and Sampling Process**

The recruitment method I used was a combination of convenience sampling and snowball sampling. Participants were mainly recruited through two online cancer support group forums, the Facebook Group: *Stupid Cancer Northeast* and a cancer support group on the website Reddit.com. I posted on those sites looking for participants with flyers (Appendix C) that gave basic information on the study. My goal was to recruit 8-12 participants for the study as I

believed this range would allow me to gather the data I needed to describe the phenomenon in question. I was able to recruit 12 participants for the study total; nine women and three men.

### **Consent**

Participants reviewed and signed an informed consent (Appendix A) before agreeing to participate in the initial interview. In both the informed consent and in my introduction, participants were notified that they could stop the interview at any time for any reason with no penalty. I also checked in with some participants as needed to ensure that they continued to give their consent to participate. This occurred when a participant became upset or tearful and I made it clear that they did not have to continue with the study or answer the question posed to them. None of the participants withdrew their consent and all of them completed the interview and most of them also participated in the follow-up questionnaire. I also provided resources for cancer support groups and counseling for all participants and had a clinician on call for them to speak to if they were in any distress.

### **Setting**

In-person interviews took place in my office in Kenmore Square. Because it was difficult to recruit locally, I performed the majority of interviews virtually using Google Hangouts and FaceTime software. Because all participants were recruited online the majority of them did not live in the Boston area yet fit the criteria and were open to participation in the study virtually.

## **Data Collection**

### **Interviews**

For data collection, I performed semi-structured interviews with participants lasting 60 to 90 minutes. After giving participants an information sheet (Appendix B) and obtaining consent, they engaged in audio-recorded interviews. Through the process of semi-structured interviews

(see Appendix C), participants were asked to explore their experience of cancer in outlined domains based on how I have conceptualized medical traumatic stress. In my interviews I asked six semi-structured questions that prompted participants to describe what experiences of their diagnosis and illness that have been particularly distressing for them. I also asked them how they made meaning of cancer, how it has affected their sense of self, and how they viewed the future. Through this process I was able to uncover common themes through different accounts that brought some insight into the experience of traumatic stress.

### **Follow-up Questionnaire**

In the informed consent, subjects were notified that they had the option of a follow-up questionnaire. After the interview, they were then asked if they were interested in participating. The questionnaire asked for written responses of how participants identified with the concept of medical traumatic stress (Appendix E). It was distributed through a secure email and was linked with the respondent's original transcript such that only the researcher knew who the respondent was, and the identity was kept confidentially. This data will be destroyed after five years.

As an incentive and compensation for their time, I offered a small gift certificate of \$25 for participants to engage in interviews. They were re-contacted after the initial data analysis of transcripts and asked if they would like to complete the follow-up questionnaire through email. Nine of the twelve participants completed the follow-up questionnaire. They then received \$20 for agreeing to do the questionnaire portion of the study which was optional.

### **Data Analysis**

My approach to data was through thematic analysis of the narrative (Wertz et al., 2011). Using manual coding, I read and reread the transcripts of my interviews to identify prominent themes. I then used different documents to keep track of different levels of coding which resulted



in both general and specific themes. Open coding allowed me to find patterns and identify key ideas in the data (Marshall & Rossman, 2016). Using the hermeneutic circle, I looked at the whole and then its parts in order to synthesize and analyze the data so as to understand, interpret, and uncover themes (Heidegger, 1927/2011).

I clustered the data around themes and was able to identify an essence of these lived experiences (Giorgio, 2009; Marshall & Rossman, 2016). Using thematic analysis, I looked for meaning units in order to uncover what participants had expressed about their psychological life (Wertz et al., 2011). To analyze the data, I created a table with general codes that was then grouped into larger themes. The four phases of coding involved reading the transcripts several times, discriminating amongst meaning units, finding a meaning structure from the meaning units, and then synthesizing this information into the essence of how participants described their experiences of medical traumatic stress (Giorgio, 2009). I was able to uncover thick descriptions from transcripts that revealed the lived experience of medical traumatic stress. Manual coding allowed for the best results as I was able to work intimately with the data. I also worked with a small cohort of four peers to engage in peer debriefing of generated themes. Any discrepancies on my findings were then resolved with faculty and my committee chair.

### **Validity Strategies**

Because this study focused on a fairly small, homogenous population, there is limited generalizability. In order to ensure the accuracy of my findings, I used validity techniques of triangulation of data sources, member checking, and peer debriefing (Marshall & Rossman, 2015). Triangulation of data was achieved by having two sources of information from participants with more opened-ended questions in interviews and more specific questions in the follow-up questionnaire. Member checking was achieved through allowing participants to

identify which themes resonated with them in the follow-up questionnaire from the initial thematic findings of the study from interviews.

Interview transcripts and follow up questionnaires were the sole measure in which textual data was acquired and analyzed. The validity claim is that my interview data was of a subjective domain, and hence I encouraged sincerity and authenticity from participants to ensure fidelity of this measure (Carspecken, 1996; Morrow, 2005). In order to minimize bias, I used a semi-structured instrument that minimized my contribution to the interviews. I conducted interviews in such a way as to allow participants center stage to lead the dialogue without judgement or interruption. After explaining the nature of the study, I then encouraged participants to respond to semi-structured questions in any way they felt inclined and share openly and freely in their own words.

After I completed my own data analysis, I engaged in peer debriefing. I worked with four peers from our doctoral student cohort who also engaged in a similar analysis of qualitative data and shared with them my initial findings and asked for feedback and further discussion. This process allowed me to open myself up to outside opinions of my analysis, as it is quite subjective, and I benefited from this external feedback. I took all feedback into consideration and incorporated suggestions into my subsequent drafts of this dissertation.

My hope is that even though this study was of a small scale, it has still produced a model of medical traumatic stress that can have some application to larger populations of cancer and disease survivors. I believe this study has the potential to have some level of impact validity (Massey & Barreras, 2013) in that it could act as a form of advocacy for people with invisible disabilities. By illuminating the experience of medical traumatic stress in adults with cancer, there can be more awareness around the impact of medical illness on mental health.

### **Ethical Issues and Implications**

Due to this research digging into the experience of people dealing with a cancer diagnosis there was a high likelihood of participants sharing negative emotions around illness that is potentially triggering for them. One notable ethical concern is that people diagnosed with cancer are part of a vulnerable population and asking them to recount experiences that were particularly traumatic for them in dealing with their cancer can cause further distress. In order to mitigate this concern, I was very explicit in my consent request about the nature of the interview and the possibility of the content being upsetting for participants. I believe saying this upfront helped prepare participants for this possibility. None of the participants withdrew their consent although several participants became visibly upset and some cried at some point during interviews.

It is important that researchers establish some restrictive boundaries for examining sensitive topics, as a participant's comfort level always takes priority over obtaining data (Hunt et al., 2013). When participant became visibly upset during the interview, I stopped the interview immediately and checked in and made it clear that we would stop at any time. I accounted for potential negative emotional responses by providing resources for support group and counseling for all participants and having a clinician on call with whom they could speak to if necessary. It was very important to me that participants have the support that they need, both during the interview session and outside the research setting. I checked in with them after the interview to ensure that any referrals for services that might help them in recovery were provided.

### **Multicultural, Diversity, Social Justice**

Although I would have liked to recruit a diverse subject pool that is representative of the larger population in regard to gender, race, sexuality, and socioeconomic status, it was beyond the scope of this research study. Due to the small sample size, the subject pool was fairly

homogeneous. Although I tried to ensure some level of heterogeneity, the majority of participants were White, middle-class women.

Factors of gender, race, sexuality, and socioeconomic status heavily influence how people experience adversity such as illness, considering the range of additional stressors such as financial status, cultural perceptions of illness, and access to healthcare. Critical disability theory was a leading lens I used in my literature review to approach this subject from a social justice perspective as participants suffer from an often times invisible disability (Banks, 2014; Tobin, 2004). In my data analysis I looked for oppression themes in relation to how disability, gender, race, and class were addressed for participants although this was limited in scope due to the subject pool.

### **Pilot**

For my pilot exercise, I interviewed two women diagnosed with breast cancer at ages 38 and 40 respectively and discussed their experiences with traumatic stress. In these interviews I piloted my current research protocol and also used it as an opportunity to also gain feedback about my questions. The women were open to participating when I asked them and agreed to be interviewed via Skype/FaceTime. I was unsure if either of them felt their cancer experiences were traumatic. Regardless, I felt they would be helpful in giving me feedback about my questions and revealing what comfort level they had as cancer survivors with addressing this subject that I could then apply to my larger research study.

My interview protocol elicited their experiences of traumatic stress in relation to cancer diagnosis, treatment, procedures, and the future. As it turned out, both women had experienced traumatic stress in at least three of the domains. Their interviews confirmed the phenomenon of

traumatic stress in respect to initial diagnosis, bedside manner, treatment and procedures, and the future.

Initial thematic findings for the cancer diagnosis included: *initial shock from something unexpected, difficulty processing information and organizing, hypervigilance*. Thematic findings for traumatic stress in response to treatment included: *bad bedside manner from un-empathetic providers who used shame or guilt in some way*. Thematic findings for traumatic stress in respect to surgery and procedures included: *body image changes after surgery, loss and grief in respect to physical attributes and sexuality affecting identity and relationships*. Lastly, thematic findings for traumatic stress in respect to prognosis and future included: *having to compartmentalize to cope, anxiety about reoccurrences, fear of dying alone*.

The pilot exercise was successful in exploring the phenomenon of traumatic stress in the various domains I had identified for my interview protocol. It was also very helpful in giving me the opportunity to use my research protocol and see how it came across. Both participants were able to help me refine and revise my questions so that they flowed better and were more user friendly for participants. I felt the pilot gave me a sense of how the actual study might go and made me more comfortable with rolling it out.

Expanding on the findings of my literature review, I proposed a methodology for a research study to further understand the psychological distress of cancer survivors. This qualitative phenomenological study focused on capturing the lived experience of psychological distress from cancer with the goal of conceptualizing this phenomenon and creating a model of medical traumatic stress. In the next chapter, I will share the findings of the study which was performed after receiving approval for the proposal from the dissertation committee as well as IRB approval.

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## CHAPTER 4- FINDINGS

### Introduction

The purpose of this chapter is to share the results of the data collection and analysis gleaned from the study methodology outlined in the previous chapter. The first part of this chapter will describe the population sample of the study and the role the researcher played in data collection and analysis. The next part of the chapter presents the results from the data collected and the thematic findings and representative quotes that emerged from the data.

The research questions I have proposed are: What have been the experiences of psychological distress for young adults diagnosed with cancer? What elements of the experiences suggest potential for medical trauma? What helped or hindered one's coping with the diagnosis/treatment? The research protocol addressed this question by asking for open-ended responses from participants around their experiences of diagnosis, bedside manner, treatment/procedures, grief and loss, future and meaning.

As a researcher collecting data from subjects, I kept as close to my script as possible. There were six questions I asked participants as well as some follow-up and clarifying questions as needed. Besides reviewing the information sheet and informed consent with participants before starting the study, I did not offer any other information about the study or myself. As a result of this adhering to this part of my methodology, I was able to minimize my influence on the data collection process. However, after all the questions had been asked and the interview was formally completed, I gave a brief description of the purpose of the study in efforts to develop a conceptual model of medical traumatic stress as well as discussing my motivations for researching the topic both personally and professionally.

The process of analyzing data involved taking the data from transcription software and editing them from the audio recordings. Once transcripts were revised and complete, they were read for initial coding; with various excerpts from the transcript were then highlighted. Follow up questionnaires were completed by participants in written form and were coded the same way as transcripts from interviews.

In the method used for coding data, each code represents and captures a primary content and essence of the datum (Giorgi, 2009; Saldana, 2016). The framework used to code was outlined in Saldana (2016) in coding for participant's voices, coding for emotion, and coding for values/beliefs/attitudes. Some in-vivo coding emerged where words stood out as codes that summarized, distilled, or condensed the data.

Once initial coding was complete, there followed a more extensive data analysis of creating categories, themes, and subthemes. Four categories emerged from the interviews that then acted as the framework for grouping subsequent themes and subthemes found within the data. The leading general themes started with the six interview questions participants were asked, and then several other themes emerged from the data. Overall, there are 13 general themes which then have various subthemes with the more prominent themes stated in bold italics and more specific themes, italics only.

For a theme to emerge from the data, it had to have been coded for two or more participants. Each theme is followed by N=, which signifies the number of participants who identified with that theme. When data from a particular subject was used in the analysis, the subject was identified by a number which only correlates with the chronology of participants interviewed for the study. If a representative quote was used, the subject was also identified by subject number only (for example S6 is subject number 6).

### Description of the Sample

Participants were recruited through two different online cancer support groups. The first was a Facebook group, Stupid Cancer Northeast, for young adults with cancer living in the Northeast, and the other was a cancer support group on the website Reddit. On both sites I posted a brief description of the study and asked for participants. The majority of respondents were women and it proved difficult to recruit men. This resulted in having to actively solicit male subjects towards the end of the data collection process. This was achieved by re-posting the recruitment information online and specifically asking male participants for their perspective. Hence the sample is not evenly balanced by gender, there being nine female subjects and three male subjects.

The sample of participants were men and women who had been diagnosed with cancer between the ages of 18 and 39, with diagnosis having occurred no more than seven years ago. The stage of cancer varied from stage 1-4 with some participants given different stages which is indicated by “V” as it was variable during their treatment with some being staged with a different prognosis than what they had originally been diagnosed. The types of cancer were also varied; three respondents had breast cancer, and three had Hodgkin’s lymphoma, and the rest had other forms of cancer. Participants lived in different parts on the East Coast and were largely interviewed virtually due to physical distance.

### Demographics

Current Age	Age at Diagnosis	Kind of cancer	Stage	Race / Religion	Gender / Sexuality	Marital status	Children
1. 20	20	Hodgkin’s lymphoma	4	White None	Female, Heterosexual	Partner	None
2. 40	39	Cervical cancer	1 V 2	White None	Female, heterosexual	Partner	None



3. 26	22	Multiple myeloma	1 V 2	White None	Female, Homosexual	Single	None
4. 37	35	Hodgkin's lymphoma	4	White None	Female, heterosexual	Married	son
5. 38	33	Breast cancer	2	White Catholic	Female, heterosexual	Married	son
6. 30	23	Breast cancer	1	White None	Female, heterosexual	Married	None
7. 32	27	Hodgkin's lymphoma	2 V 4	White None	Female, heterosexual	Married	daughter
8. 28	24	Leukemia	1	African American, Agnostic	Female, heterosexual	Partner	None
9. 28	25	Breast cancer	2	White Jewish	Female, Pansexual	Married	None
10. 24	22	Thyroid cancer	2 V 4	White None	Male, heterosexual	Single	None
11. 30	28	Colorectal cancer	3	White, None	Male, heterosexual	Single	None
12. 35	32	Non-Hodgkin's lymphoma	3	White, Christian	Male, heterosexual	married	son, daughter

## Results

There were three levels of thematic findings including categories, themes, and subthemes.

Results are condensed in *Table 1* and include the four categories, thirteen main themes, prominent subthemes, and supporting quotations from participants.

**Table 1**

Categories:	Themes and subthemes:	Supporting quotations:
<b>Cancer as a Trauma</b>	<ol style="list-style-type: none"> <li>Experiences of Diagnosis: <i>Shock, stress, the fog</i></li> <li>Experiences of Treatment and Procedures: <i>Exhaustion, pain, inactivity, hard, time-consuming, nervousness</i></li> <li>Experiences of Trauma: <i>Traumatic procedures, body trauma, past trauma,</i></li> </ol>	<ol style="list-style-type: none"> <li>"My whole world was rocked out of nowhere and it was really fast. I really didn't see it coming. I didn't have time to process it as it was happening."</li> <li>"There is so much pain and I was so uncomfortable for so long." "For two years I was in and out of treatment and didn't have much social life; I was too tired, too sick to hang out"</li> </ol>

	<i>physical reminders, vivid memories, ruminating thoughts, fear of hospital</i>	3. "My oncologist diagnosed me with PTSD; I had obsessive traumatic thoughts, like I convinced myself I had relapsed, and was always checking my lymph nodes".
<b>Who am I Now?</b>	<p>4. Experiences of Grief: <i>Anger, depression, denial, guilt, acceptance (or lack of), self-blame</i></p> <p>5. Experiences of Loss: <i>Physical loss, emotional loss, financial loss</i></p> <p>6. Fertility and Intimacy: <i>IVF, decisions around children, increased pain, decreased libido</i></p> <p>7. Identity: <i>Physical identity (body betrayal, body dysmorphia), self-identity (perceptions of self, all-encompassing), vocational identity, disability identity</i></p>	<p>4. "I was really angry for a long time, now I'm trying not to be angry. It brought out a side of me I've never seen before."</p> <p>5. "I definitely felt like I was very connected to my breasts, I had very large breasts that I was very proud of and there was definitely a feeling of loss."</p> <p>6. "Cancer robbed me of having another child and of my son having a sibling."</p> <p>7. "It's almost like grieving my old self in a way, like my innocence, I feel like I lost my innocence." "I would look in the mirror and I'm like, this isn't me, this isn't what I look like."</p>
<b>How Do I Cope?</b>	<p>8. Coping Skills: <i>Physical coping skills, emotional coping skills</i></p> <p>9. Support System: <i>Social self-care, importance of support system, advocacy</i></p> <p>10. Besides Manner of Providers: <i>Validating experiences, invalidating experiences, advocating for own care</i></p>	<p>8. "When I talk to other people with cancer, my first thing is to make a joke like, 'at least we're not dead' sort of thing."</p> <p>9. I have a great family, great friends. I think that's the only way to get through a situation like this, if you have a really good support system; it is hard."</p> <p>10. You can just tell when someone genuinely cares about you... I'm not just another case and another number, she [doctor] always prioritized my case."</p>
<b>What Does the Future Hold?</b>	<p>11. Future: <i>Changed perspective, new priorities, anxiety and fear of relapse</i></p> <p>12. Meaning: <i>Why me? rationalizing, new realizations</i></p> <p>13. Survivorship: <i>Survivorship as a way of life and pathway forward</i></p>	<p>11. I'm realistic, I know it could come back. I can't really plan my life in advance, which is very frustrating, because I don't know where things will be at."</p> <p>12. "I care for people more. I realized that things, life, definitely can be short. Everyone, they all have their own battles."</p> <p>13. "You've survived cancer, but what do I do now? It's a whole different way of living your life."</p>

### Categories

From reading and re-reading the transcripts of the twelve participants in this study four categories emerged from the data from which the subsequent thematic findings could be grouped

under. The first category was *Cancer as a Trauma* which then includes various themes such as experiences of diagnosis, experiences of treatment and procedures, and experiences of trauma. The second category was *Who am I Now?* which includes experiences of grief, experiences of loss, fertility and intimacy, and identity. The third category was *How Do I Cope?* which includes categories of coping skills, support system, and bedside manner of providers. The fourth and final category was *What Does the Future Hold?* which includes how participants talked about their sense of the future, meaning, and survivorship.

### **Thematic Findings**

The data was initially coded for themes that corresponded with the six study questions participants had been asked around *diagnosis, treatment and procedures, bedside manner of providers, grief, loss, and future*. There were seven themes that emerged from the transcripts and follow-up questionnaire data including: *fertility and intimacy, identity, trauma, coping skills, support system, meaning, and survivorship*. The phenomenon of *medical traumatic stress* was addressed within the follow-up questionnaire only where participants were asked to provide feedback on the developing model which included initial findings of the most prominent themes from interviews.

### **Cancer as a Trauma**

The themes and subthemes that emerged in this first category were the traumatic experiences surrounding cancer for participants. The cancer diagnosis and subsequent treatment and procedures were the main events that participants described as having been traumatic for them in some way. In sharing their experiences of psychological distress surrounding cancer, the traumatic nature of these experiences often surfaced for participants.

### **Experiences of Diagnosis**

Participants were asked about their experience of cancer diagnosis. There were three prominent subthemes that emerged in this category. The first theme was the ***shock from the unexpected nature of the diagnosis*** (N=9) which was expressed through language like feeling *stunned, shocked, surreal, overwhelmed, unprepared, numb*, with the news being *unexpected* and *mind blowing*. One participant described it as “my whole world was rocked out of nowhere and it was really fast. I really didn’t see it coming. I didn’t have time to process it as it was happening” (S1). Another participant stated, “It was so overwhelming when I was diagnosed, and you're literally, like, fighting to save your life, like it's very physical and very tangible” (S9).

The second subtheme related to diagnosis was around the ***stress of the unknown surrounding cancer*** (N=9), which was expressed through language like feeling *stressed, nervous, scared, worried, and fearful*. One subject talked about her struggle:

Just the fear of the unknown, for sure every day, yeah like I could handle the physical, but it's the mental that, you know, makes everything physically worse and just, you know, I ruminate on my thoughts all the time so that was definitely the hardest to cope with. (S1)

The third subtheme surrounding diagnosis was what was often termed ***the fog*** (N=8), where participants described feeling *confused, fuzzy*, and as if they were in a *fog*. One participant recalled the moment she heard her diagnosis: “It was like I was not in my body, it was a very strange experience. And you know, it was a fog. I don't remember what we talked about next exactly. I know, I started to cry” (S2). Several participants told similar stories of their diagnosis.

### **Experiences of Treatment and Procedures**

Participants were asked about their experience of treatment and procedures related to cancer. This theme has two categories of the ***emotional*** and ***physical*** aspects of this experience.

A prominent subtheme for the emotional experience that emerged was around the *time-consuming nature of treatment* (N=10), which was expressed by the majority of participants. One participant talked about *waiting* during her treatment: “It just feels like my life's on pause and I can't wait for it to be resumed” (S1). Other participants recalled waiting in the hospital for chemotherapy or surgeries for several hours. On a related note, some participants expressed that the *process of treatment was hard* (N=5) with surrounding feelings of *nervousness* (N=4).

A very prominent subtheme that emerged from the physical aspects of the treatment was feeling *tired and exhausted* (N=12) with one participant stating, “For two years I was in and out of treatment and didn't have much social life; I was too tired, too sick to hang out” (S3). Another common experience was *pain* (N=10), which was expressed by nearly all of the respondents with one stating, “There is so much pain and I was so uncomfortable for so long” (S4). Other physical symptoms of treatment that emerged were *feeling sick, uncomfortable, and experiencing side effects of treatment*.

The last prominent subtheme in this category, which was expressed both physically and emotionally, was *inactivity* (N=7) due to not being able to exercise, go to work, or do normal activities during treatment and procedures. Not being able to do normal activities of daily life due to treatment was a common experience for the majority of participants. For instance, one participant stated, “I like to work out, but I physically can't exercise, and I used to exercise for stress relief. It just feels horrible mentally, you know, when I feel physically ill I mentally tend to feel really crappy as well” (S1).

### **Experiences of Trauma**

Although the words “trauma” and “PTSD” were not used by the researcher during the interviews, there were various instances where participants brought up experiences around their

cancer that they felt were traumatic. The word *traumatic* (N=8) was used to describe aspects of their experiences that were particularly painful or salient. The term *PTSD* (N=8) was used by some participants who felt that they had experienced some form of post-traumatic stress in relation to their cancer. Some participants were actually diagnosed with PTSD. One stated, “my oncologist diagnosed me with PTSD; I had obsessive traumatic thoughts, like I convinced myself I had relapsed, and was always checking my lymph nodes” (S7).

One form of trauma was *body trauma* (N=5), where participants felt that what they had endured physically during their cancer treatment and procedures was traumatic to their bodies. Some participants talked in depth about *traumatic procedures* (N=6) they had experienced with their cancer. Two participants with breast cancer talked about their surgeries as traumatic experiences, while four other participants spoke about radiation being traumatic for them.

The subtheme of *past trauma* (N=2) came up with two participants who had been sexually assaulted before having cancer. Notably, one participant who had cervical cancer found radiation particularly traumatic because it involved an invasive procedure that brought back memories of her past trauma from sexual assault:

Knowing that there was some metal thing inside of you, in your vagina, just like you're a woman, and this is your most precious part of your womanhood. That procedure was a little traumatic. And not once did anybody ask me if I had ever had a sexual assault. And I wish they had because I'm a survivor of sexual assault and rape. So, going through that was I think scarier for me, just because the sensations reminded me of what happened to me as a preteen. It's like, for me, that was like the hardest part. I mean, being sick was bad enough, but then to have that happen. And you just feel violated. (S2)

The other sexual assault survivor also shared how her past trauma had affected her and how she had experienced similarities in emotions surrounding the traumas:

I had PTSD from a previous sexual trauma. And going through cancer, I noticed a lot of similarities in terms of like, like, the guilt of it, and like the shame of it. So yeah, definitely. Some comparisons there. But it's definitely different. (S9)

Other salient subthemes around trauma were *ruminating thoughts* (N=3) typically of relapse or death. Another subtheme was *vivid memories* (N=3) of salient or painful aspects of having cancer or treatment. Some participants spoke of the trauma of the *physical reminders of their cancer* (N=5), such as scars and hair loss, which in some cases also resulted in being seen as a cancer patient in public. One participant shared, "I have a scar on my chest, my port, and sometimes people stare; it happens a lot when I go out. Like, you're making me think of everything, you know?" (S8). Some participants spoke about *fear of the hospital* (N=4) and various aspects of the hospital acting as a trigger. One subject talked about how just the smell of the hospital is a trigger and makes her cry (S6). Other participants also expressed how being in a medical environment had been traumatic for them in some way:

Seeing a doctor now is one of my biggest fears, because you never know what they're going to tell you. Being in a waiting room, it's frightening now. And then, just like driving to the hospital, you're not just driving to the hospital anymore. Your life could be different. And that's a huge thing for me, because I'm gonna be going to the doctor for the rest of my life. And there's always that unknown now. Whereas before you just went to the doctor. That's not the case anymore. It will probably never be that case again. (S11)

It's just really traumatic, a doctor telling you a percentage, you know statistics of people who survived five years after. It's just, I'm used to going to the doctor for, you know, an ear infection. It was traumatizing to hear the treatment plan was six months, which seemed so long. But the most traumatic was just hearing the prognosis statistics. (S1)

I started to react the same way that I did after I had my last couple of biopsies, which was like, uncontrollable shaking. I got really, really cold. And I felt like I needed to, like, run away. But I had to tell myself like, no, this is something that you have to do. I'm crying, everything. (S8)

For many participants there were several aspects of the cancer experience they identified as being traumatic in some way. The next category addresses how battling cancer impacted their sense of self.

### **Who Am I now?**

For many participants cancer started a process of self-reflection and re-evaluation where they had to confront aspects of grief, loss, and identity. Cancer acted as a catalyst for participants with mourning their former selves, going through the stages of grief, and sometimes confronting an identity crisis of sorts. Issues of fertility and intimacy also emerged and how cancer caused participants to make decisions around whether or not to have children as well as how cancer impacted their sense of themselves as sexual beings.

### **Experiences of Grief**

Participants were asked if they had experienced any grief in relation to their cancer. Nearly all respondents expressed *feeling angry* (N=10) as a result of their illness. Anger was expressed in various ways by respondents, who said they were *mad* or *frustrated* by what they



had been through with having cancer. One participant stated, “I was really angry for a long time, now I’m trying not to be angry. It brought out a side of me I’ve never seen before” (S3).

Another almost unanimous experience of grief that participants reported was *feeling sad* or *depressed* (N=10), with one participant stating, “I was really depressed during that time period; part of my brain shut down- it took a few months for it to hit me” (S8). Although it is not one of the classic stages of grief, *guilt* (N=6) was a related emotion experienced by some respondents. One participant said, “There's a lot of guilt associated with, like, wanting to do more than you can or like, feeling like you're letting people down if you can't go somewhere” (S9). Another participant shared how he struggled with survivor’s guilt:

I think I struggled with survivor's guilt. I look at other people that I know that have cancer and haven't been as lucky as I am, and I struggle with that. I really do. Plus, where I had treatment you had to go through the Children's Cancer Center. And that that used to be really hard for me. Because, you know, I told my wife, I said “I would take it from each one of those kids if I could,” because I don't want them to struggle. I don't think they should go through it. (S12)

A smaller group of participants said they had experienced *denial* (N=4) at some point during their journey with cancer. One participant stated, “Denial was ignoring the symptoms. Why didn’t I go to the doctor sooner? There was a lack of awareness about my body, I guess” (S4). Another feeling some participants expressed was *self-blame* (N=2) in the sense that they felt that had not done what they should have done, such as get treatment sooner, or behaved in the way they did after their diagnosis towards friends and family after their diagnosis.

*Acceptance* (N=2) was only expressed by two participants, both of which were male. One who had thyroid cancer stated, “I decided to accept whatever was going to come. I’m very lucky.

I always kept a positive outlook on it because, in my mind, it was the ‘good cancer’” (S10).

However, two participants described a *lack of acceptance* (N=2) and feeling more complacency or resistance towards their cancer. One subject stated, “I feel like it’s going to take a really long time for me to accept what happened to me” (S1). Another participant reflected on her lack of acceptance:

I don't know if there's acceptance. I think there's complacency. Like, this is what it is, and I can't do shit about it. I don't fucking accept it. It bothers me still. I'm mad that I had to deal with it. I'm 30, but I feel like I'm 60. I'm mad that I have to look over my shoulder every day. (S6)

### **Experiences of Loss**

Participants were asked if they had experienced any form of loss in relation to their cancer. All of the respondents confirmed some form of loss; many of them had multiple losses that resulted from their cancer. The three subthemes of loss that emerged were *physical loss*, *emotional loss*, and *financial loss*.

*Physical loss* (N=11) was expressed in various ways such as from chemotherapy the *loss of hair, eyebrows, or eyelashes* (N=4). One participant stated, “I think that [losing your hair], it's definitely a stereotype. But that was so traumatic, and it wasn't losing the hair. It's that everybody knows now; you're not invisible” (S7). Another form of physical loss was *scars* (N=7) and *sensation* (N=4) from surgeries and other procedures. One participant talked about his concerns around his scar, “I worried about the scar affecting getting jobs. Like going into an interview and you know they see the neck. I didn't strangle myself, you know, I didn't cut my own neck” (S10). Another theme was *weight loss or weight fluctuation* (N=4) which was related to treatments and loss of appetite. Some participants had experienced a *loss of parts of the body* (N=3) that were

removed such as breasts and fallopian tubes that occurred from mastectomy and hysterectomy procedures. One participant stated:

I definitely felt like I was very connected to my breasts, I had very large breasts that I was very proud of and there was definitely a feeling of loss. I also strangely felt a loss when I had my fallopian tubes out. Because even though I don't know whether or not I want to have kids, there's something about not being able to have them naturally or like trying to get pregnant. (S9)

Related to the theme of fertility and intimacy, some respondents also talked about loss in relation to their *decreased libido* (N=4) as well as well as the *loss of fertility* (N=3). One participant had a devastating loss from a surgery to remove a tumor that affected his sexual functionality:

They had to take part of the nerve to my penis, so I wasn't able to get an erection after that. And then it got even more real that my life would be changed forever. And it didn't get better, you know, like, psychologically speaking. Now I knew I would never be the same. I couldn't get an erection. No man ever wants to hear that. (S11)

Several respondents reported a *loss of energy and general fatigue* (N=9) related to their cancer. Two participants described experiencing *chemo brain* (N=2), which is generally known to be a side effects of chemotherapy that affects memory, attention, and sensory functions. One participant talked about what chemo brain felt like for her: "I have memory loss from treatment, I need a planner to be organized, and it's been hard to try to realize that's something I'm gonna have to do forever" (S8).

Another prominent subtheme was the *loss of independence* (N=6) and having to depend on others for help during their cancer treatment. One participant shared this frustration: "I can't do this, I can't do that, I'm too weak, I can't do my own dishes, I can't do my own laundry, I

can't make any food. I hate feeling like this. I hate feeling helpless" (S2). Dependence on others was a common sentiment expressed by participants who needed the support from friends and family in order to get through their treatment.

*Emotional loss* (N=9) was a subtheme that emerged as participants often described some form of relational strain that occurred from cancer. The majority of participants talked about *isolation* (N=9) and feeling that people in their lives did not understand their experience of cancer. One participant stated, "I did feel very isolated. No one knew. I never talked about it with anyone and it's more something I just dealt with on my own" (S10). Various relationships were strained, specifically *friendships* (N=5), with one respondent reporting that she lost a childhood best friend: "The grief and loss was not only from like, my own identity, but like people in my life. You don't really know who's gonna be there for you" (S7).

Participants also expressed strain in their relationship with *significant others* (N=6) or spouses due to dealing with cancer. Three respondents reported their relationships ended because their partner was not supportive in the way they needed around their cancer. Several respondents also expressed that their *social life was compromised* (N=7) in some way due to cancer in that they were unable to spend time with friends or have the energy to go out.

Another subtheme that emerged was *loss of control* (N= 5), expressed by one participant thusly, "I've never felt that feeling where I'm not in control of my life" (S1). Another form of emotional loss that was commonly expressed was the *loss of assumed health* (N=6). Because the population of this study was younger, many participants had assumed they were healthy before their cancer diagnosis, such as this 20-year-old subject:

The hardest is realizing that you might die— like there's a chance that you'll die. It's definitely the most traumatic because I've never felt close to death before, if that makes

sense, even though I wasn't, but just, I never realized that it was a possibility, especially being so young; you kind of think you're invincible I feel like. (S1)

A lesser reported, yet notable, experience was *emotional invalidation* (N=2) where friends or family members were dismissive in respect to the participant talking about their cancer. One participant in particular had various forms of invalidation from someone she dated, her childhood friend, and her mother:

I remember starting to date someone, so he knew me just with the short hair, I still had the port in. And after like six months of dating, I think he told me like, "just get over it." I lost, like, my best friend since kindergarten, she said, "All you talk about is cancer, you just want to use it for attention." But it was my whole life at that point. You know? Even my mom said, "You gotta move on," but nobody really understood. (S7)

Some form of *financial loss* (N=10) was reported by the majority of participants. The most common source of financial loss was *not having a full income* (N=8) due to cancer treatment and having to either take time off from work or stop working for some amount of time. Several participants described being on Family Medical Leave Act (FMLA) or disability during their treatment. Another form of financial strain was around *medical bills* (N=3) and deductibles. One participant said that it took her a year and half to catch up financially, as she had only been making 60% of her salary with FMLA and had medical bills on top of her regular bills (S5).

Other participants talked about *insurance coverage* (N=3) being an issue. One was insured through the Affordable Care Act (ACA) and was going through her cancer treatment while some politicians were trying to repeal the ACA. She was worried that she would lose her healthcare at a critical time (S9). Another participant told several stories around her frustrating

battle with the insurance company trying to get her treatment and surgery covered: “It was out of my control, out of my hands, because the insurance company kind of dictates everything.” (S5)

### **Fertility and Intimacy**

Related to loss was how participants experienced physical changes to their reproductive and sexual selves as a result of cancer. A theme that emerged from interviews was around the role of *fertility* (N=9). There was not a direct question that addressed this topic, yet it surfaced in the majority of interviews. Two respondents went through in vitro fertilization (IVF) treatment as part of their cancer treatment due to the role that hormones play in gynecological cancer.

I don't think a lot of people talk about when they have to go through gynecologic cancer is that if you haven't had children yet, and you want to have them, and you have to go through this process of IVF, and if it doesn't work, you know... I was a mess after that. It was like I lost a baby and I didn't have a baby. It felt seriously like I had a miscarriage. I felt defective. You know? So, we did that first, but it didn't work out. (S2)

Another subtheme that emerged was *how cancer affected decisions around having children* (N=6). Two respondents expressed that they chose not to have children (or more children) because of cancer. Some respondents talked about feeling *ambivalent* about starting a family due to cancer, with one participant articulating her ambivalence about having children:

It's hard to think about having to take care of something else while having cancer. When I first got out of treatment, I was like, ‘I never want to do anything hard ever again.’ I'm not ready to put my body through any more trauma at the moment. (S9)

Another respondent had had a child since her diagnosis but expressed *guilt* about having a child knowing she had had cancer because it may come back (S7). Two other respondents already had

had a child before cancer and one of them stated that, “Cancer robbed me of having another child and of my son having a sibling” (S5).

Related to fertility was *intimacy* (N=4), being affected by cancer treatment and having *increased pain* and *decreased libido*. One participant talked about the effect on her relationship: “There’s a loss of a carefree feeling in my relationship, my libido, I don't feel like I'm a sexual being anymore, I don't feel sexy, or beautiful, or pretty” (S2). Another client talked about sex being painful but wanting to have sex because it was pleasurable during such a hard time:

Because of all my hormone changes, like sex, was very painful for me. That's something that really wasn't talked about when I was going through treatment, because there's definitely an emotional aspect to that as well. Like, wanting to feel close with your partner and like wanting to feel something good, but everything else feels so terrible. (S9)

In general, fertility and intimacy emerged as prominent themes for participants who felt their cancer affected their sex life and ability to have a family.

### **Identity**

Within the theme of identity there were four different ways that participants experienced identity shifts as a result of cancer including physically, sense of self, vocationally, and disability. Both *physical identity* and *self-identity* changes occurred for participants who observed a shift in their sense of self and their bodies. Another notable change for many participants was their *vocational identity* and what they were able to do in the workforce both during and after cancer. Lastly, some participants noted a change in identity in respect to the *visible and/or invisible disability* of having cancer.

The most common form of physical identity change was a sense of *body betrayal* (N=10), where participants felt their bodies had let them down in some way. One more specific subtheme

was *feeling older than actual age* (N=4), which was expressed through feeling that cancer had made their bodies feel older. One participant expressed, “I feel so much older than my actual age, and I don’t relate much to people my own age anymore” (S8). Related to this were participants expressing a *lack of body awareness, lack of trust in the body, or wishing for a different body* as a result of cancer. One participant stated, “I think I was really frustrated with my body. Like my body did this to me.” (S4).

A more poignant yet related subtheme was *body dysmorphia* (N=8) where participants expressed estrangement from their physical bodies. One version of this phenomenon was feeling as though the *body is foreign and not your own* (N=2). One participant stated, “I feel like my body was handed over to the doctors and now I don’t know what to do with it” (S2). Another client expressed a similar sentiment as to how she felt about her body post-cancer:

Now it kind of feels like I’m in the body of someone who I don’t really know, like there’s things about it that are vaguely familiar, but overall, just the way that I move and the way that I smell, it’s just not really me. (S8)

Several participants also spoke of *not recognizing themselves* (N=4). One subject stated, “I feel like the person I’m looking in the mirror at is a stranger” (S8), while another subject stated, “I would look in the mirror and I’m like, this isn’t me, this isn’t what I look like” (S5). Another recalled, “It took me a while to look in the mirror and see me, because I didn’t see myself for a very long time” (S7). This dissonance between the perceived self and physical self that comes with cancer was notable, as the majority of participants identified with some form of estrangement within their bodies.

The emotional sense of self was coded as *self-identity* where participants expressed how cancer had challenged their *perceptions of self* (N=7). In general, many participants described



some form of physical and/or emotional changes to their identity. One participant stated, “It’s almost like grieving my old self in a way, like my innocence, I feel like I lost my innocence” (S1). Another participant recalled how her identity had been brought into question through cancer: “Who am I? I’m not that, like, strong person I used to be. I wasn’t who I thought I was” (S4).

Several participants noted the *all-encompassing nature of cancer* (N=10). This was expressed in various ways, such as one participant’s stating that her, “life was on pause” (S1), while another wanted to, “get [her] life back” (S5), and that “it [cancer] consumed [her] whole life” (S7). The majority of respondents shared some sense of how cancer had had a drastic impact on their daily life in multiple domains. One participant stated, “I’m still trying to learn my new body and my new identity. I can’t do anything about it, you know, it’s gonna be part of me for the rest of my life” (S11).

*Vocational identity* (N=10) was also addressed by several participants, some of whom went out on *disability* (N=3), while the majority explained that they were *unable to work* (N=8) full-time or indeed at all due to their treatment. Cancer also was the catalyst for some respondents *changing jobs* (N=4), either because they were no longer able to do the work they previously had or their need to take time off from work caused issues. One participant stated, “I went back to work after treatment, but couldn’t do it, I was too tired, just mentally wasn’t really there. It was really sad because it was something I enjoyed doing but don’t have the energy for it anymore” (S8).

Participants who were students they talked about how cancer had *interrupted their school schedule* (N=3), with one participant being upset because she was told by a professor to just take a lesser grade for the course due to incomplete work. She had managed to pass despite her

absences, although she had been an “A” student before being diagnosed with cancer and felt this was a compromise (S2). Participants also talked about *needing flexibility for appointments* (N=4) at work and in school in order to continue being employed or enrolled, as they had several ongoing doctors’ appointments.

Another identity shift was confronting *visible and invisible disability* (N=6) which came up for several respondents. The majority of these participants talked about how their hair loss or scars from cancer had caused *people to notice* (N=5) their visible disability in public. Experiences of invisible disability also occurred when participants reported *not looking sick* (N=3), yet still feeling sick in public. One participant spoke about this experience of having an invisible disability in this context:

After going through everything, looking more towards, like, people with disabilities in general, and how a lot of disabilities aren't visible. Like when I was going through chemo, and I was on the subway, and I still had hair, or I had a wig on or something, and I just looked like a normal person, and really wanting to sit down, because I was like, really tired and not feeling well. But then not wanting to ask for a seat, because visibly I didn't look like I had disabilities. So, I just wanted to speak out more about that when it's really a second job and a lot of people don't realize that. (S9)

The specific *label of disability* (N=2) was only brought up in a few interviews where one participant stated that she had seen a therapist who viewed cancer as a disability but that this was not a treatment lens that worked for her (S6). Another participant stated that she did identify as someone with a disability:

I still consider myself as someone with a disability. Because even though I'm not really like going through cancer anymore, I still have, you know, seven different appointments

that I have to make every six months, and I still have to worry about, like the other breast for cancer and the ovaries for cancer. And at some point, I'm gonna have to get them out. So that's something that I actually think about in the future and kind of plan parts of my life around. (S9)

Lastly, identity also came out in how participants felt cancer played a role in life post treatment. Some spoke about how they *self-identify as cancer survivors* (N=3) and have sought out resources in the survivor community. One participant specifically stated that he did not identify as a cancer survivor and resisted the label due to stigma and feelings that his case of cancer was mild in comparison to other forms of the disease (S10).

### **How Do I Cope?**

Participants shared various stories around how they learned to cope with having cancer. Their relationship with providers often acted as a protective factor when it was a positive experience and a form of invalidation when it was negative. Many participants identified the various ways they had found to cope with having cancer as well as how they utilized their existing support systems and reached out to find new supports.

### **Coping Skills**

A theme that emerged from the data was how participants found different ways of coping with cancer and building coping skills both during and after treatment. Within this theme were ways participants coped both physically and emotionally. Specific subthemes around *physical coping skills* (N=5) included *exercise* (N=3), *mindfulness/meditation* (N=3), and various *alternative medicine* (N=2) activities like reiki, yoga, and massage. These subthemes were part of the self-care regime participants had acquired to cope with life during and after cancer.

All participants reported using some form of *emotional coping skills* (N=12) that included mental health care, self-care, and social self-care. There was a cohort of participants that reported they had had *mental health issues before being diagnosed with cancer* (N=4). They may have had previous experiences of being in therapy or seeing a psychiatrist for medication. A larger cohort stated that they had *sought therapy* (N=9) during and/or after treatment to deal with the emotional impact of cancer. Other participants saw a *psychiatrist for medication* (N=4) to cope with resulting depression and anxiety. One participant talked about why she sought therapy:

Nobody really understood; it was every single day, and then you're still so at risk of relapsing, it's like all you can think about. So, I decided, you know what, I can't expect people who have never gone through this to understand. So, I need to go find someone to talk to, so I can get it out. (S7)

Some participants used self-care methods that were more personal and individualistic to emotionally cope with cancer. These methods included using *journaling and blogging* (N=3) as a way to process and document their journeys with cancer. Another coping skill that emerged was *compartmentalization* (N=3), which was expressed as a tool to focus on other things in life besides the cancer. One participant stated, “so I just like, essentially, like I ignored it completely. It's what I did, which is like, that was the last thing I should have done. But to do that anyway, keeping busy to keep sane” (S3). Although this participant stated that compartmentalization may not have been the best decision, it was also what helped her through treatment as she continued working throughout chemotherapy and other procedures. This was also expressed by a participant who decided to work through her cancer treatment: “I avoided emotions and pushed them to the side, so I didn't have to deal with them, running away from emotions surrounding cancer was how I coped” (S6).

Another form of self-care that emerged as a subtheme was using perspective as a coping skill. Several participants identified that *staying positive* (N=5) was an important tool for them to cope with cancer. A related coping skill that emerged was *humor* (N=4) with one participant stating that dark humor for her was a way of “encapsulating that experience in a way that's meaningful; humor is a coping mechanism” (S6). Another participant talked about how humor was a way for her to deal with her cancer and relate to others about it:

I get people don't know how to deal with it because I don't know how to deal with it. When I talk to other people with cancer, like, my first thing is to make a joke like, “at least we're not dead” sort of thing. And like, other people are super sensitive about it. I'm like, but if you're really sensitive about it all the time, you know, like, people don't want to talk to you, and people don't want to be around you. And nobody wants to deal with that sort of thing. (S3)

### **Support System**

An important aspect of coping with cancer was connected to participants sense of their support system. A subtheme that emerged was *social self-care* (N=8), which addressed ways participants connected socially with other people who were struggling with cancer. There were various outlets people used to make these social connections including *survivorship programs* (N=5) and *support groups* (N=3). Several participants mentioned they had found support on *social media groups* (N=6). One participant stated, “I started looking on social media for someone else I could help; if someone had thyroid cancer, I might be able to post on there, you know, say it's all going to be okay, to talk them through it or talk to them about my process” (S10). Another participant was in a program that matched her with another young adult going

through treatment: “I was paired up with a friend with the same diagnosis; that support has really helped” (S1). One participant started her own social media support group for her type of cancer:

I realized after I was in remission that places like Facebook and Instagram are great resources to find other people with the same diagnosis. I was able to meet many other people and start a Facebook page for other people who have gone through or are still going through lymphoma treatment. (S7)

The majority of participants noted the *importance of a support system* (N=9) in dealing with cancer. This was usually expressed in talking about the role that family and friends played in helping them through the process of cancer both emotionally and physically. One participant stated that a silver lining of cancer was realizing who your supports and friends are (S2). This realization was made by other participants who highlighted the value of supports as well. One recounted, “We made it through and I have a great family, great friends. I think that's the only way to get through a situation like this, if you have a really good support system; it is hard” (S5). Another participant talked about how realizing what a good support system she had made her want to advocate for other people with cancer who do not have that kind of social support:

And that also kind of helps me just like thinking about all of the ways I have all of this help. And thinking about a lot of people who don't and are in a lot of really tough situations. So, wanting to advocate for them was really important to me. (S9)

The subtheme of *advocacy* (N=5) also came up for some participants. This was expressed by participants who spoke about *advocating for their own care* with providers as well as *advocating for other people* who are struggling with cancer. One participant identified as an activist and spoke about how her cancer led her to speak out politically about her experiences, specifically advocating for the ACA and Planned Parenthood which had provided her healthcare

during diagnosis and treatment (S9). Other participants spoke about how they had helped advocate for other people who were struggling with the same kind of cancer they had. In both instances, advocacy was a way for participants to take back some form of control.

### **Bedside Manner of Providers**

Related to social support is how participants experienced their relationship with healthcare providers such as doctors and nurses. Participants were asked about their experiences of bedside manner and generally shared both positive and negative interactions. Positive encounters were seen as *validating experiences* (N=9), where they described providers as *caring, empathetic, kind, gentle, and sweet* and mentioned feeling *listened to* and *prioritized by* healthcare professionals. One participant had built a close relationship with her oncologist:

You can just tell when someone genuinely cares about you and so I've always got the feeling that she genuinely cared about me and my case. I'm not just another case and another number, she always prioritized my case and so I was never waiting on scan results and she gave me her personal number so we text. She like checks up on me, which is incredible. (S1)

Another participant described his doctor as “nonchalant,” which made him feel reassured that he was in good hands and that his cancer diagnosis was not a life-or-death situation (S10). Yet another participant stated, “My oncologist said, ‘you didn’t cause this, so there is nothing you can do,’ and that was really important to me. It kind of like, put my mind at ease a little bit” (S9). In both these instances the provider made the participant feel *reassured* in some way.

Negative stories related to providers described by participants were seen as *invalidating experiences* (N=7) related to their care. The way participants talked about this experience was by identifying *insensitive providers*, who were described as *abrasive* and *unsympathetic* to their

situation, as well as feelings of *not being listened to* or *not believed* by their providers. One participant talked about writing an email after a doctor had not taken her initial symptoms seriously, which ended up being cancer: “This person didn't believe me, and this is what happened. Hopefully they learned from that to like, maybe take somebody else more seriously” (S7). A smaller cohort of participants talked about *advocating for their own care* (N=3) with providers as a way of feeling some sense of control over the process of treatment and procedures that were otherwise ominous at times.

### **What Does the Future Hold?**

Participants were asked about their thoughts of the future and they shared stories of how cancer had impacted their outlook on life. Several participants conveyed how cancer had caused a shift in their perspective and sense of meaning. Because cancer is often chronic, some participants also talked about survivorship and finding new ways to live life as cancer survivors.

#### **Future**

Participants were asked how cancer has affected the way they see their future. Strikingly, all of the participants spoke of *anxiety and fear of relapsing* (N=12). This theme was so prominent in interviews that it appears to be perhaps a universal trait of having cancer which is that despite being in remission, survivors worry about the possibility of the cancer coming back. Participants expressed this concern in various ways. One participant stated, “I'm scared, cancer can always come back, you know, I could get another cancer—it's unpredictable” (S1). Another stated, “I'm realistic, I know it could come back. I can't really plan my life in advance, which is very frustrating, because I don't know where things will be at” (S3), and another reflected, “I have more anxiety since my diagnosis, anxious about it coming back; that thought is always on my mind. Any little pain or ache I would freak out” (S5). In every interview participants



expressed this concern in some way. One talked about cancer being a voice in the back of her head:

When you have cancer, it's like you've got this thing in the back of your head, it's cancer talking to you and it's like saying, you know, "I'm not gone, I could come back," you know? Or "I'm already back. And you don't know it." There's a loss of security of your health, of feeling comfortable in your body. Trusting your body. (S2)

Another notable subtheme in this category was a *changed perspective* (N=10) with some participants describing being more *focused on present* (N=3). One participant stated, "It kind of changed my outlook because I just feel like every day is so important. I'm way more focused on the present than before" (S1). Another participant described how "it kind of forced me to just try to be more mindful of myself and my present surroundings. Be more introspective" (S6).

The other subtheme was having *new priorities* (N=10) as a result of surviving cancer. One participant stated, "I've matured really quickly; my priorities have shifted to things that matter like family, I used to spend time on social media; now I realize those things don't matter" (S1).

## Meaning

Participants were asked about existentialism and if cancer had brought about questions or concerns around their existence. What emerged was how participants had made their own meaning of the experience of having cancer. Some participants described having struggled with trying to understand their misfortune and asking the question *why me?* (N=4). A participant who was Jewish but non-practicing asked, "What did I do to make God punish me like this?" (S9).

Another participant shared:

Why did I have to go through this? I was healthy while my neighbor is smoking all the time. How did I end up with this? Why me? I don't understand why it was me and why then instead of in 10 years when I could balance it better. Why can't we get a break? (S4)

There was a smaller group of participants who expressed some form of *rationalizing* (N=3) that maybe their cancer made it possible for someone else not to have cancer. One participant stated, "If me having cancer meant that like, in some weird, like, universal way someone else didn't, then like, I am okay with that" (S9).

Several participants experienced a *new realization of meaning and understanding* (N=10) in their life as a result of cancer. This was said in various ways by participants who expressed that their struggle had led them to see life differently than before. One talked about how she wanted to be more creative and make more art since having cancer: "I found that the meaning of life for me was love and the purpose of my life was to create and connect. And I think that that was important for me to see" (S2). Other participants stated some new understanding about themselves and the world in different ways:

Everyone's going through something. It could be invisible; people who don't look sick who are sick. I try to tell myself like it's been a part of my story. I used to put up with a lot of crap. Now I just don't like to deal with things that aren't necessary. I'm definitely more in tune with my body now. (S7)

I care for people more. I realized that things, life, definitely can be short. Everyone, they all have their own battles, you know? You walk down the street; everyone's going through something. You know you can't really look at someone and know. There's just so much more behind people than what you really can see. It made me stronger mentally,

not physically so much, mentally, emotionally. It just made me stronger as a person, knowing I could go through something like that, and it all ends up okay at the end. It's just nice to know that I'm that strong mentally. (S10)

I try to soak up every sunrise now. I'm awake, you know, which I am a lot, so I try to watch every sunrise and look for the moon at night and look at sunsets at night. Just remember how incredible the world is. (S11)

I never went to church before but after I finished [treatment] my wife wanted to go to church and we go every Sunday now. I guess I had to find something to believe in to make it easier that if something does happen, I am going to go somewhere. I was raised [in the church] I just never practiced until now. I volunteer a lot through our church; it's given me more purpose. (S12)

Several participants expressed a new understanding about life in the wake of battling cancer.

### **Survivorship**

The last theme that emerged was around *survivorship* (N=6) and how participants felt about living the rest of their lives as cancer survivors. One participant described it as, “you’ve survived cancer, but what do I do now? It’s a whole different way of living your life” (S5). Some participants had been in remission for several years yet still struggled with coping and finding support in the long term. Most striking were the participants that felt like they received plenty of support during their treatment but *not enough support once they were in remission*:

I wish there were more survivorship options. Once you’re in remission they drop you. I need someone to talk to about my symptoms, how to reconstruct [my] life. What do I do

now? Online communities sometimes are where people with the most severe symptoms go and talk and the rest of us are quiet. (S4)

You've been diagnosed, you've been treated, and you are cancer free. So, it's like, all right. They throw you out to the wolves. Like, okay, try to survive, you know? You're back on your own, like nothing happened. And it's still in my brain. It's still in my mind. It's there. I have to kind of deal with it and just learn to live with that. (S5)

During treatment you're getting so much medical attention, and everybody like checks on you and, you know, friends and family. And then once you say like, "Oh, I'm done with treatment," everybody assumes like, "Okay, well, it's back to normal," and they just, they go back to their normal lives, but your life doesn't go back. And it was really hard to, you know, you feel really, really alone. (S7)

In the follow-up questionnaire participants were asked if there are there any resources or supports that they wish that were more available to them or other cancer survivors, and the majority of respondents referenced wanting more survivorship resources. One participant stated that she wished she had been able to connect with more people of same age with cancer, as she was young for having breast cancer (S5), while another wished she had been able to connect with more people with the same kind of rare cancer (S3). Other participants also talked both about being young with cancer and about there not being enough support for those in their age group with their type of cancer:

I wish there were more young adult cancer groups. As a young woman living in southern New England, the only support groups I could find were for breast cancer survivors. I

was not comfortable going to these support groups because I felt that the treatments were so different, it would be hard to really connect with anyone there. (S7)

There should be more therapy classes offered for cancer patients in different age groups. I'm 20, and unfortunately all of the groups I've been to have been with an older adult or elderly population. (S1)

The type of cancer that I had is sort of rare— as such, there was no one around me that I could talk to. There was little way to gauge if my experience was 'normal' compared to others. Even now, there is so little data on the long-term effects of most of my treatment. Also, if there was a way for young cancer survivors to reach out to one another. I did a bit of that on my own on social media, but it wasn't easy. (S8)

One participant specifically talked about how she wished there had been more resources available to her as a sexual assault survivor dealing with cancer:

I wish there could have been counseling specifically for people going through gynecological cancers who have a history of sexual trauma. That this group of people was approached in a different way by the doctors, somehow, to make the experience feel less horrific, less likely to bring back old memories of the body being violated. (S2)

This feedback from participants around survivorship and resource gaps in the field is informative for the implications of this research for clinical practice.

### **Debrief**

Participants were debriefed after the interview questions were complete and asked about their experience taking part in the study. The majority of participants stated that having the space

to talk about their cancer journey to an attentive, captive listener was a positive experience for them. Some participants noted that they do not speak much to others about a lot of what they shared in the interview. One participant made references to thinking about seeing a counselor multiple times during the interview and in the debrief said that talking about it made her realize that she should find someone to talk to regularly. Overall, participants described the interview experience as positive, despite the difficulty of the topic at hand.

### **Follow-up Questionnaire and Medical Traumatic Stress**

Participants were sent a follow-up questionnaire after their interview asking for them to respond to the concept of Medical Traumatic Stress (Appendix E). They were given the following working definition as:

- 1. Traumatic event originated by an internal stressor; the body attacking itself,***
- 2. Typically involves future oriented concerns of prognosis, functionality, morbidity.***
- 3. The body no longer feels safe; survivors may feel betrayed by their bodies.***

They were then asked to provide feedback in building a descriptive model that embodies the experience of traumatic stress caused by cancer.

Of the 12 participants interviewed, nine responded to the follow-up questionnaire. All of the respondents agreed with all or most of this definition with one participant stating, “I am relieved to finally read an accurate definition of what I am experiencing. Each point in the definition resonates with me deeply” (S1). Another participant stated, “I identify with all three parts of the definition. At some point during diagnosis, treatment, and survivorship I have experienced them all” (S5). These concepts seemed to resonate with participants who shared:

My cervical cancer can definitely be defined as medical traumatic stress. My body had attacked my cervix and then not knowing for months if the cancer was gone made me feel

my future was uncertain. I still feel that way. My future ability to parent a child is still hanging over me as I am now sterile and would only have the options to adopt or do a surrogate mother with a donor egg and my boyfriend's sperm. Also, I was constantly staring death in the face as my treatments ravaged my body causing my cells to die off and sickness to take over. I felt like I was dying. I definitely feel like my body is no longer safe, and that at any moment cancer or some other life-threatening disease could come back and take over. (S2)

I'm now constantly in a state of wondering about the future and have a hard time making future plans and focusing on the present, due to the fact that all my doctors are currently in my state and I still see [them] every three months. If I were to need treatment again I would need to be close by, which makes planning for the future almost impossible at this stage. Anytime there is a different feeling within my body I have to worry and say, "Is this the day that I find something else?" rather than look forward to staying in remission. (S3)

This definition very much captures the traumatic stress from my experience. The initial diagnosis was a shock; I went from healthy to my body 'turning on me.' I initially had many concerns that this was a death sentence and I would not be around to watch my son grow up. I always prided myself as someone who listened to my body, but after my diagnosis I could no longer trust it. (S4)

I identify whole-heartedly with this definition of medical traumatic stress from my experience. As a cancer survivor, it is hard to trust that I am healthy, and the fear of relapse/ secondary cancers from prior treatment never fades. (S7)

One participant did not identify with all aspects of the working definition in respect to the body attacking or betraying her. She conveyed this in her response:

I wouldn't necessarily say I felt betrayed by my body. I knew the BRCA1 gene ran in my family, so it was something I was expecting to happen at some point, just not that soon. I also didn't think of it as my body attacking itself. I felt that the cancer was separate from my body. (S9)

Participants were also asked what symptoms of psychological distress were most prominent for them. These responses varied and included *increased anxiety* (N=5), *feeling that body is no longer safe* (N=3), and *having nightmares about treatment, especially relapse* (N=2). Other themes that came up were depression and worries about long term functionality and relapse. One response to this question expressed various emotions and grief:

I felt guilt during treatment, wondering if there was something I did to deserve this. I also have a lot of irrational denial that I know isn't true (i.e. they just mixed up all of my lab tests). I've had to adjust to a new body again. I loved what my body was before and now it looks different from scarring and surgery. (S9)

Participants were also asked what was most traumatic about having cancer. Responses varied and included experiences from all the initial categories of diagnosis, treatment and procedures, bedside manner, and prognosis. One participant stated, "The beginning— when I was first told I had cancer. Learning and coming to the realization that my body could allow this to happen was overwhelming." Another participant simply stated, "The most traumatic part was



going from healthy and active to being sick” (S4). Participants varied in their response to this question with some reporting more than one traumatic experience with cancer:

The most traumatic part of the last four years of my experience I have would be the lack of support I find that I have. Most people would say that they’re a good support system because they ask how you’re doing and how treatment is on a weekly basis, but the most important thing would be people who can overlook this. Although cancer is a huge part of my life, I’m doing my best while in remission to make sure it isn’t my \*entire\* life. I still am a person outside of the doctor’s office. (S3)

I mostly feel that my body is no longer safe, and the chances of cancer reoccurrence can be greater. Losing my hair was traumatic; every time I looked in the mirror I did not look like myself. I looked so sickly. I felt like I lost my identity. (S5)

The cancer diagnosis itself was very traumatic. I was told via phone by a doctor who had reviewed my CT Scan and saw major evidence of disease. I was alone and was told I would need surgery to have a biopsy the very next morning as well as a port-a-cath inserted. I often re-play that day in my mind, as it was completely unexpected. Every doctor I saw told me it was very unlikely I had cancer, that swollen lymph nodes are normal, and I was “too young.” (S7)

Having so many tests done, getting a port put in under the skin in my chest, and having a strict diet during treatment made me feel as though my body was no longer my own. That feeling was exaggerated when one morning, I woke up, and I didn’t smell like myself

anymore. It felt as though I was in a stranger's body. Being in a hospital setting or even a doctor's office— with all of the smells of disinfectant— is still very triggering for me. Sometimes, I get a flashback to one of the first days after I shaved my head where I stood in the bathroom connected to my room, still attached to an IV drip and just stared at the fact that my brown face had a pallor to it that I did not recognize. (S8)

My first reconstruction surgery where they used my thighs to create my breast. This was a really, really difficult recovery. I was in the hospital for five days and recovery took multiple months. I was in pain for about a year. Fertility treatments were also challenging. (S9)

Lastly, participants were asked to identify which themes they felt were most notable aspects of dealing with the psychological distress caused from cancer. They were given a list of some of the prominent thematic findings from the initial interviews and asked to identify which themes they felt were the most notable aspects of dealing with the psychological distress caused from cancer and should be included in the definition of *Medical Traumatic Stress*. There were 15 themes presented, and participants highlighted the ones they felt were most notable for them:

1. The unexpected nature of the diagnosis. (N=5)
2. Feeling overwhelmed and unprepared in dealing with illness. (N=5)
3. Physical and emotional strain from time-consuming treatments and procedures causing stress, exhaustion, discomfort, and pain. (N=8)
4. Experiencing the stages of grief; most prominently anger and sadness. (N= 7)
5. Physical loss such as hair, weight, energy, and/or libido, and/or physical scars from procedures. (N=6)

6. Lack of physical activity due to illness. (N=5)
7. Decrease in independence and needing to depend on others for care (family, friends, and providers) (N=4)
8. Emotional loss of assumed health. (N=6)
9. Feelings of isolation, decrease in social life. (N=4)
10. Feelings of body betrayal such as a lack of trust in the body and/or body dysmorphia such as not recognizing self in mirror. (N=7)
11. Feeling lack of control, helplessness. (N=4)
12. Feeling the illness is all-encompassing. (N=5)
13. Inability to function normally in school or workplace settings due to illness. (N=4)
14. Uncertainty and anxiety over the future, fear of relapsing. (N=9)
15. Ruminating on death, morbidity. (N=4)

Several participants who completed the follow-up questionnaire wrote in their email that they had received some benefit from talking and writing about their experiences. One participant said she was going to bring in her follow-up questionnaire with her to therapy to talk about it with her counselor, as she felt it helped explain some of the feelings she has. Another participant talked about how the study was helpful for her in processing thoughts and feelings around her diagnosis. Several participants stated that they think the topic of the study is important and that they would like to read the final dissertation.

### **Conclusion**

This chapter has presented the results and findings from the interviews with 12 participants and follow-up questionnaires from nine respondents. The data collected was organized into categories, themes, and subthemes that help to further describe the phenomenon

of interest. The next chapter, the discussion, will go into more detail about what these findings mean in the context of existing research as well as the questions posed within this study.

## CHAPTER 5- DISCUSSION

### Introduction and Summary of Results

A recent study by Pranjic, Bajraktarevic, and Ramic (2016) found rates of distress in cancer patients as high as 76% and PTSD rates of 55%. This suggests that rates of psychological distress and PTSD could be higher than previously understood and largely goes undiagnosed and often times untreated. An article by Leano, Korman, Goldberg, and Ellis (2019) addressed how we may be missing PTSD in cancer patients and discussed the prevalence of what they called cancer-related PTSD (CR-PTSD). The risk factors they found from a literature review of CR-PTSD were advanced disease, young age, recently completed treatment, reduced social status, reduced education level, prior trauma, prior mental health issues, poor social support, and specific types of cancer.

This study focused on the risk factor of young age by recruiting young adults who identified as having experienced psychological distress as a result of their cancer diagnosis. The purpose of this study was to bring to light the lived experience of psychological distress of young adults who have survived cancer. This study was developed in an effort to fill the gap in qualitative research around the experience of psychological distress resulting from cancer. There are currently no other qualitative studies that focus on this phenomenon as the majority of research on cancer and psychological trauma and distress are quantitative. Because of the dearth of qualitative research on this topic, the methodology used for this study was phenomenological in nature and sought to uncover the descriptive experiences of young cancer survivors.

The leading research questions were: What have been the experiences of psychological distress for young adults diagnosed with cancer? What elements of the experiences suggest potential for medical trauma? What helped or hindered one's coping with the

diagnosis/treatment? These questions were investigated by interviews exploring diagnosis, bedside manner, treatment/procedures, and prognosis. Results from this study have demonstrated that psychological distress, often described as traumatic, was experienced by all of the participants in relation to their cancer. The four categories that emerged from interviews were *Cancer as a Trauma*, *Who am I now? How do I Cope?* and *What Does the Future Hold?* The follow-up questionnaire also gave participants an opportunity to describe their own version of medical traumatic stress and what aspects of their cancer they felt were most traumatic.

It is hoped that the findings of this research will help to contribute towards building a conceptual model of *medical traumatic stress*, which is the term used in this study to describe the experience of psychological distress resulting from cancer. The 12 participants in the study shared their experiences and uncovered various notable themes that resonated through the interviews and follow-up questionnaires. These results will add to the current body of work and notably the qualitative descriptive research of psychological distress surrounding cancer.

### **Discussion of Interview Results**

From the 12 interviews, four categories emerged of *Cancer as a Trauma*, *Who Am I Now?*, *How Do I Cope?*, and *What Does the Future Hold?* Subsequent themes and subthemes are discussed within these categories.

#### **Cancer as Trauma**

The majority of participants in this study reported various aspects of their cancer as traumatic experiences. The study protocol specifically did not include any language around trauma in order to see if it would emerge from the data. Unprompted, participants often used the words “traumatic,” “trauma,” and “PTSD” in reference to their experiences. There was not necessarily a specific aspect of cancer that was identified as traumatic. Rather, participants

reported multiple experiences as traumatic, such as diagnosis, losing hair, radiation, surgery, scars, and body estrangement.

An important overall finding of this study was that there were several aspects of the cancer experience that contributed to psychological distress. This echoes what previous research by Swartzmann et al. (2015) noted: “The cancer experience may involve multiple traumatic events over the course of diagnosis and treatment, some of which are complex and repeated” (p. 328). Because cancer treatment is often ongoing and repeated, like radiation and chemotherapy, there may not be a single event which survivors can point to as the trauma; rather, the whole experience may be perceived as traumatic.

The symptoms surrounding PTSD from cancer that were discussed in previous studies were largely confirmed in this study. In a prior study of breast cancer survivors by Arnoboldi et al. (2017), women who recalled their diagnosis and cancer experience exhibited symptoms of hyperarousal, emotional numbness, depersonalization, intrusive thoughts, and flashbacks. The symptoms participants in this study reported around traumatic experiences of cancer were intrusive thoughts, ruminations, vivid memories, nightmares, increased anxiety, and feeling that the body was no longer safe. Loss of control, helplessness, and fear of relapse were also reported by nearly all participants which is an important outcome of this study.

A recent study by Gesi, Carmassi, Sancassiani, Gadducci, and Dell’Osso (2017) looked at studies that addressed PTSD in ovarian cancer and found the most commonly endorsed symptom was a sense of foreshortened future which was experienced by the majority of their participants. Other reported symptoms included difficulties falling asleep, experiencing intrusive thoughts, memories, and images. Notably, this study affirmed that cancer is potentially more disruptive when experienced at a younger age with the perceived impairment of future plans. Specifically,

they identified that gynecological cancer threatens fertility and childbearing capacities, which may enhance the stressful and traumatic impact of the disease for young women. These findings are consistent with this study which found that cancer impacted *fertility* and *intimacy* for the majority of participants and also influenced their decisions on having children.

A study by Nipp et al. (2018) enrolled close to a thousand patients diagnosed with cancer who had been admitted for unplanned hospitalizations and screened them for PTSD. They found that a high proportion, 13.3%, of hospitalized patients with cancer experience PTSD symptoms, which were also associated with physical symptoms, depression, and anxiety levels. Other findings included that younger age, female gender, greater comorbidities, and gynecological cancer type were associated with higher PTSD scores. This research confirms the role of age in PTSD, but more interestingly, identified female gender as a risk factor which may explain why it was so difficult to recruit male subjects for this study. It was assumed that the lack of male participants was in part due to men not wanting to talk about their emotional journey of cancer, yet it may be more of an indication that trauma is less common for men than women.

There appears to be a range of reactions to the trauma of illness yet in this study there were not any notable differences from the traumatic reactions that resulted from acts of violence as described by Herman (1997) and Bloom (1999). However, there was a unanimous finding that all participants reported *anxiety and fear of relapse*. This is where medical trauma differs from traditionally understood trauma as participants expressed future-oriented concerns that are not typical of other traumas that occurred in the past were not ongoing the way illness often is. The unanimous symptom of anxiety and fear of relapse is one of the most significant findings of this study and has emerged as a fundamental aspect of the construct of medical traumatic stress.



Another notable finding of this study was how several participants described feelings towards their bodies as unsafe, estranged, and foreign. In traditional trauma theory Herman (1997) talks about the damaged self and how traumatic events violate the autonomy of the person at the level of basic bodily integrity where the body is invaded, injured, and defiled and control over bodily functions is often lost. Although this was in reference to victims of violence, there is a commonality with how participants in this study reported their experiences of *body trauma and dysmorphia*. Several participants in this study echoed these sentiments when talking about their sense of betrayal and estrangement from their bodies as a result of cancer. This suggests that body trauma may be a more universal aspect of trauma survivors, despite the difference in origin between traditional trauma from acts of violence and medical trauma.

The results of this study highlight the mind-body connection in how participants often experienced physical and emotional loss concurrently. Van der Kolk (2014) talked about how if people have a comfortable connection with their inner bodily sensations and trust them to give accurate information, they will then feel in charge of their body, feelings, and self. For people struggling with cancer, this comfortable connection within their bodies is often disrupted where participants described feeling betrayed and estranged from their physical bodies. Because the sample consisted of young adults, the impact of illness was particularly jarring as participants were often blindsided by their diagnosis. In feeling betrayed by their physical bodies participants often went through an emotional crisis in questioning their assumed health and sense of self and identity.

Another factor that Herman (1997) discussed was how trauma can cause developmental issues of childhood to resurface such as autonomy, competence, and identity. This challenge to autonomy was demonstrated in the subtheme participants described over frustration of *loss of*

*independence* in dealing with their cancer and how it affected their functionality in various domains in their life including vocationally, socially, and sexually. This was also reflected in how participants talked about feelings of helplessness and a loss of control over their lives in various domains.

Another developmental issue that could resurface is sexuality and intimacy. The emergent theme of *intimacy* reflects how cancer impacted participants interpersonal relationships and often resulted in increased pain and decreased libido affecting their sex lives. The findings also demonstrated that cancer had a large impact on identity for participants both emotionally and physically and affected them in multiple life domains. Identity issues will be discussed further below as part of the “who am I now” section.

### **Diagnosis as a Trauma**

Prior research has noted that diagnosis itself can be experienced as a discrete traumatic event (Alter et al., 1996; Mehnert et al., 2007; Mystakidou et al., 2012; Swartzmann et al., 2015). The three main subthemes that emerged within diagnosis in this study were *shock from the unexpected nature of the diagnosis*, *stress of the unknown surrounding cancer*, and *the fog* and confusion they experienced. The experience of *shock* was echoed in a study by Lefebvre and Levert (2006) where diagnosis was described as an unthinkable event that paralyzes psychological functioning from the shock of hearing the news. This paralysis is comparable to what many participants in this study described as *the fog* which is the cognitive disruption surrounding diagnosis where they were confused and completely overwhelmed. Research by Hall and Hall (2013) also discussed the disorientation of the hospital where patients are unaccustomed to being in a medical environment which is analogous to the confusion and fog that participants spoke of.

Other studies also addressed the psychological distress of diagnosis such as the stage model of adjusting from medical trauma developed by Salick and Auerback (2006), with *diagnosis and devastation* as the first stage. In this study participants expressed the initial diagnosis as being *surreal, unexpected, and mind blowing*, and reported feeling *stunned, shocked, numb, unprepared, and/or overwhelmed*. The diagnosis itself was also identified as traumatic for some participants with one talking about how she often replays that day in her head of learning her diagnosis unexpectedly over the phone.

### **Trauma of Treatment and Procedures**

Subthemes that came up around treatment and procedures in this study were the *time-consuming nature of treatment, feeling tired, exhausted, and experiencing pain and inactivity*. The aspects of treatment that were experienced as traumatic were more nuanced, with some participants reporting that having IVF treatment as part of preserving eggs before undergoing cancer treatment was traumatic, while others talked about radiation procedures and surgeries. Prior research by Alonzo (2000) talked about the traumatic potential of invasive medical therapies, while Hall and Hall (2013) discussed how trauma can be experienced as a result of medical procedures and long hospital stays, all of which is echoed within this study.

A notable finding of this study is that the medical environment itself often acted as a trigger for fear and anxiety. Specifically, *fear of hospital* was brought up by several participants. One participant spoke about how going to the doctor and sitting in a waiting room was frightening for him because he understood the impact of what could happen there (S11). Two participants spoke about the smell of the hospital being a trigger for them with one specifying the smell of disinfectant. Prior research has also shown that the medical environment can trigger

intense emotional responses (Hall & Hall, 2013). This study confirms those findings and may suggest another future direction of study addressing the impact of medical environment itself.

Yet another important finding of this study is the impact of previous trauma on cancer survivors. Previous research has found past trauma as a predictor of experiencing trauma from cancer (Alter et al., 1996; Banou et al., 2009; Green et al., 2014; Mystakidou et al., 2012). A prior history of traumatic experiences can make individuals more vulnerable to psychological distress from cancer. In this study, two participants reported past trauma of sexual assault. Both participants mentioned that this past trauma had affected the psychological impact of having cancer in some way.

One participant reported that her past sexual assault has been compounded by the radiation procedure for her cervical cancer which penetrated the same part of her body as her rape. The other participant spoke about how she had been diagnosed with PTSD due to her past sexual assault and how similar feelings of guilt and shame had resurfaced around her cancer trauma. Although this study is not large enough to make any conclusions about how past trauma impacts trauma from cancer, it does suggest that this is an area of research that could be further explored. Women who face gynecological cancer, in particular those who have a past history of sexual assault, may be more at risk for being triggered by invasive procedures.

### **Who Am I Now?**

#### **Grief, Loss, and Identity**

All of the participants in this study expressed forms of grief, loss, and changes to their identity that arose as a result of cancer. This relates to previous research by Lefebvre and Levert (2006), who identified how a sudden and unexpected health situation can lead to grief, loss, and changes to identity. Specifically, grief reactions as a result of a cancer diagnosis were addressed

in research by Kangas et al. (2002). In this study, the traditional stages of grief (Kubler-Ross, 1969) emerged along with other forms of grief, such as *guilt* and *self-blame*, that may be more specific to illness than the death of a loved one. The two most reported forms of grief were *anger* and *sadness*, while other participants described experiencing *denial* at some point, with *acceptance* being more elusive.

Participants in this study had all experienced some form of emotional and physical losses in the wake of cancer. Many subjects had to grieve their former lives before cancer before adjusting to their new reality as survivors. Perhaps what participants were experiencing was a form of anticipatory grief (Hottensen, 2010) where they had been faced with an altered sense of their future because of cancer and were forced to adapt accordingly.

An important finding of this study is that loss from cancer was experienced by participants in various domains of emotional, physical, and financial losses. The majority of participants had some form of physical loss of *hair*, *weight*, *energy*, and/or surgical *removal of body parts* often resulting in *scars*. Salick and Auerback (2006) discuss this in their stage model where the body fails and there is a loss of the physical self. What also emerged was participants describing a *loss of independence*, where they had to depend on others to get through cancer treatment.

This study focused on a younger population because previous quantitative research on PTSD and cancer found that younger cancer patients are at a higher risk (Arnaboldi et al., 2017; Green et al., 2014; Mystakidou et al., 2012; Swartzmann et al., 2015). A notable finding that may be more specific to young cancer survivors is a *loss of assumed health*. Older people facing cancer may have fewer assumptions that they should remain healthy later in life whereas younger people may have assumed that they would remain healthy until old age. Related to this

experience of emotional loss participants expressed feelings of *isolation* and *loss of control*. This is echoed in previous research by Alonzo (2000), which addressed the loss of self as a result of illness. Not only was the internal world of participants affected, but their external world was impacted relationally, as many described having a compromised social life and strain on existing relationships and friendships.

Experiences of grief and loss around the physical and emotional self then resulted in identity changes for participants. This relates to previous research on identity development by Kroger (2007), who examined how a sudden disability or illness in adulthood can cause grief and impact identity and sense of self. There were different ways that participants described being challenged by their identity in the realms of *physical*, *emotional*, *vocational*, and *visible and invisible disability*. Physical identity subthemes that emerged were *body betrayal* and *body dysmorphia* where participants described various feelings of estrangement from their physical bodies.

Self-identity was expressed in grieving the former self and coming to grips with the individuals perceived weaknesses under the pressure of having cancer. For some this was experienced as an identity crisis where they felt some aspect of their sense of self was compromised or brought into question by cancer. Perception of the self being challenged by the illness is likely what Auerback et al. (2006) noted as the identity crisis of medical trauma. This was also addressed by Hall and Hall (2013) regarding how self-identity can come into question as a result of a traumatic experience where there is often a redefining of oneself. Participants in this study talked about losing their innocence, grieving their former selves, and not feeling like the strong people they had though they were. This grappling of former identity is likely what

Laranjeira et al. (2013) termed *identity renegotiation* which is the transformation of self-concept brought on by a major life event like illness.

A major finding of this study was how grief, loss, and identity played an integral part in the overall psychological distress of cancer that participants spoke about. This was best summed up in how several participants talked about the all-encompassing nature of cancer. The challenge of cancer for participants was multi-dimensional, affecting all life domains, mind and body, with little or nothing left untouched from their prior lives before the cancer diagnosis.

### **Visible and Invisible Disability**

Several participants talked about their experience of cancer as a visible and/or invisible disability. In their study on psychosocial care in cancer patients, Grassi, Spiegel, and Riba (2017) talked about “visible cancers” such as breast cancer and head and neck cancer versus “less-visible cancers” such as leukemia and how this may contribute to the repercussions of body image for cancer survivors. Although this study was not large enough to show any discrepancy for the difference in psychosocial impact based on type of cancer, the majority of participants were impacted in physical ways such that they experienced a change in body image and many talked about their experiences of visible and invisible disability due to cancer.

Tobin (2004), a survivor of polio, talked about how the inability to disclose a disability is one of the markers of oppression; this was echoed by those participants in this study who felt the physical attributes of their cancer had outed their previous invisibility. Salick and Auerback (2006) also discussed the loss of participants’ health coinciding with their experiencing the visibility of their disability to others. This was demonstrated in this study by participants who talked about the difficulty of going out in public without hair and eyebrows from chemotherapy and having visible scars.

A notable way that disability was experienced by participants was *people noticing in public*. One participant talked about how she went out to eat with friends and someone working at the establishment noticed her shaved head and port and asked her if she had cancer. The participant shared this story as a traumatic experience, as she had been unable to hide her illness in that instance. There are aspects of identity that can be kept secret, yet the loss of hair for women or scars on visible parts of the body makes illness apparent in public, causing people to notice.

### **Social Justice Issues**

The social justice lens of this dissertation has been through viewing major illnesses like cancer as a disability, both visible and invisible. Swain et al. (2004) talked about impairment and disability and how historically disabled people have been represented as inferior, having their bodies invalidated. The majority of participants in this study echoed this sentiment on a more internal, personal level where they felt estranged and disconnected from their bodies with cancer as they were not the bodies they had come to understand previously. Stigma was also addressed by two participants who did not want to be labeled as having cancer due to fear of discrimination in employment or otherwise. These experiences echo how disabled people may view their bodies with cancer as shameful imperfections in an able-bodied society that has embraced the binary of being sick or well.

Although the central social justice issue highlighted within this dissertation was looking at cancer as a chronic illness and disability, both visible and invisible, there are other challenges this population faces. The stigma of cancer came up in one interview where a participant felt that revealing to others, specifically employers, that he had cancer could have negative repercussions. Tobin (2004) talked about how many people with disabilities choose not to self-disclose in the



workplace for fear of stigma. Three different participants who were dating while they had cancer spoke about how their health status caused those relationships to end. In general, the stigma of disability and of illness was reflected by some participants who experienced how their cancer diminished their social status in some way.

The majority of participants were also confronted with some kind of vocational obstacle that often led to financial loss. Although the population of this study was largely middle class and White, several participants talked about how being sick had set them back financially, causing them to worry about their ability to pay bills. Socioeconomic status can play heavily into the experience of illness and trauma with what resources are available to people when they are physically limited and often unable to work and provide for themselves.

Another social justice issue for this population is access to both medical and mental healthcare. Although all the participants reported having some form of health insurance, many of them still had deductibles, copays, and some procedures or medications that may not have been covered under their plans. One participant was insured through the ACA while some politicians were trying to appeal the law which would have eliminated her insurance in the middle of cancer treatment. Access to healthcare and obtaining coverage with pre-existing conditions is an issue many Americans face and is an ongoing social justice issue in this country.

### **How Do I Cope?**

#### **Social Support and Coping**

A notable finding of this study was that feelings of *isolation* were expressed by the majority of participants. This relates to previous research where loneliness was reported by cancer patients with PTSD (Swartzman et al., 2015). The way participants described their isolation was that they felt that the people in their lives did not understand what they were going

through, and as a result they found it harder to relate to peers and family members. This was also mentioned in previous literature by Hall and Hall (2013) in how established relationships may change as a result of illness. In this study subthemes also came up around strained relationships with significant others and social lives being compromised. In general, cancer is a major life stressor that affects how individuals relate to other people in their lives while going through such a personally challenging experience.

Prior research by Salick and Auerback (2006) identified the theme of *withdrawal* from the social world, in which some of their participants talked about feeling isolated and having friends that were not capable of dealing with their illness. This was expressed by some of the participants in this study and specifically one who had lost a childhood friend who was not supportive and dismissed her experience of cancer being traumatic for her. This experience of *emotional invalidation* was only expressed by two participants in the study yet was notable in the impact it had on them during such a hard time in their lives.

In contrast, the *importance of a support system* was echoed by the majority of participants who had to rely on friends and family to get through their cancer treatment. Prior research has found that having social support and active coping skills is a protective factor for cancer patients who are at risk for traumatic disorders (Banou et al., 2009; Dzul-Church et al., 2010; Mehnert et al., 2009; Salick & Auerback, 2006). Another notable aspect of this study is that participants were recruited through online cancer support groups, as many of the participants had utilized social media as a coping skill. Other forms of social self-care in this study were peer mentors, support groups, and survivorship programs. This relates to prior findings in the study by Salick and Auerback (2006) where participants who were further along in their recovery were

able to build support systems through support groups and locate peer mentors of others living with disabilities.

An interesting finding in this study was the coping skill of *humor* that several participants acknowledged. This relates to previous research by Salick and Auerback (2006) where humor was identified as a way for participants to manage the social discomfort around their limitations. Participants in the current study talked about how using humor had been a way for them to make light out of a bad situation and relate to others in a more positive way.

### **What Does the Future Hold?**

#### **Future, Meaning, and Post-Traumatic Growth**

Participants in this study were asked about how cancer had changed their thoughts about the future. The most prominent emergent theme that was shared by all the participants was ongoing *anxiety and fear of relapsing*. Because cancer is often perceived as life-threatening, previous research shows that many patients react to the diagnosis with fear, helplessness, and having a sense of a foreshortened future (Green et al., 2014). Prior research on multiple sclerosis also confirms ongoing future-oriented concerns about prognosis and relapsing episodes (Carletto et al., 2018; Chalfant et al., 2004). Research by Tacon (2011) with survivors of breast cancer found that participants struggled to come to grips with the long-term effects of the disease, such as side effects, a precarious future, and possible death. Because relapse is such an ongoing threat for cancer survivors, it appears to act in such a way as to not allow survivors to fully move on with their lives because they have no reassurance that the cancer will not resurface.

The majority of participants described how their *priorities* and *perspectives* had shifted as a result of having survived cancer, and this forced them to look at their lives differently by identifying what was important to them. Lefebvre and Levert (2006) talked about how with

resilience a positive meaning can be ascribed to the traumatic event through resilience, as was noted by several participants in this study. It also echoes what Scott et al. (2017) found in their research that positive reframing was what facilitated the process of moving from suffering to healing. The majority of participants were able to ascribe some positive value that came out of cancer that helped them gain a deeper understanding of themselves within the world. This echoes the work of Yalom (1980), who expressed how illness brings people closer to death in ways that make their mortality much more urgent. Participants in this study spoke about how they no longer spent time doing things that they did not consider worthwhile and tried to focus more on what mattered most to them in life, such as their loved ones.

The last question participants were asked in interviews was what ways cancer had brought about an existential crisis or search for meaning in their lives. What emerged around existentialism and meaning was how participants had grappled with the question *why me?* and *rationalizing* what had happened to them in battling cancer as young adults. This echoes the traditional theory of Herman (1997), in which victims of trauma ask, “Why me?” (p. 178) as they struggle to confront this unfathomable and incomprehensible question of their misfortune.

Likewise, this relates to previous research which revealed that younger cancer patients are more prone to existential concerns due to anticipation of death, a feeling of loss of control, and psychological distress (Chochinov et al., 2009, Mystakidou et al., 2012; Stolorow, 2015). In many ways emotional trauma shatters the illusion of safety, bringing people closer towards finitude and battling for mortality (Bloom, 1999; Stolorow, 2015). Young adults may be most vulnerable to this form of psychological distress because of their assumed health as they enter the prime of adulthood yet come face to face with a life-threatening disease.

Several participants shared parts of their philosophical journey of coming to grips with having cancer. The large majority of participants experienced a *realization of meaning and understanding* where the adversity of cancer caused many participants to view their life differently than before and find an inner resilience. These findings relate to existing literature on post-traumatic growth. Salick and Auerback's (2006) work on posttraumatic growth provides a stage model of trauma and recovery from medical trauma that was reflected in this study. Many participants moved through the stages of apprehension, diagnosis and devastation, choosing to go on, building a way to live, and integrating the trauma and expansion of the self.

Although most participants in this study were earlier on in their cancer recovery, some had vocalized a level of perspective change and resilience from their experiences. Cancer often caused participants to face their own mortality in such a way that catalyzed a new understanding of human existence, notably how other people struggle in ways that are not always apparent. Several participants demonstrated increased empathy towards others while also finding new ways to live their lives in ways that may be more authentic to their values. This study reflected previous research on how adversity can lead to growth once survivors are able to move away from their suffering towards living.

Research on resilience by Unger et al. (2012) demonstrates what factors allow for successful development under adversity. Resilience can depend on quality of the environment, which may speak to how the majority of the participants in this study identified they had a support system that had helped them significantly in their battle with cancer. In looking at participants through the ecological model (Bronfenbrenner, 1979), factors that contribute to resilience relate to general stability, such as having stable housing, supportive relationships, and employment. The majority of participants stated that they had a stable environment including

housing, healthcare, and some level of financial stability that allowed them to deal with cancer without the added burden of those life stressors.

Another notable finding of this study is that some participants expressed an increased level of compassion for others based on their own experience of adversity. This is echoed in research by Salick and Auerback (2006) who found that participants with chronic illnesses and disabilities developed a new empathy from their own experience and having a sense of compassion for others based on their own suffering. Several participants in this study expressed an increased understanding that other people are often dealing with something that cannot always be seen externally. This also relates to the stage model that Salick and Auerback (2006) developed, where suffering caused participants to experience personal growth and become more attuned with others. In general, a noteworthy finding of this study is how many of the participants experienced an increased sense of purpose and meaning in their lives as a result of cancer, this contributes to the existing literature on post-traumatic growth.

### **Survivorship**

Another finding in this study that is also affirmed in prior research was the need for more support around specific cancers as well as for young adults facing cancer. In general, there appears to be a disproportionate focus on breast cancer, both in the literature and within the cancer support community (Swartzman et al., 2015). Multiple participants stated that they wished there had been more supports available to people with cancers other than breast cancer as support for younger adults, since many people facing cancer are older adults. This relates back to the multiple reports of feelings of *isolation* that participants reported, which were in part due to not feeling well enough to socialize and in part due to feeling that no one else understood what they were going through as young adults battling cancer.

Another important finding mentioned by several participants was the feeling that there was *not enough support once they were in remission*. A longitudinal study by Chan et al. (2018) found that although PTSD rates of cancer patients decreased over time, 34% of their sample who were initially diagnosed with PTSD had persistent or worsening symptoms four years later. Researches called for early identification for PTSD in cancer patients and the design of risk-targeted interventions.

Several participants in this study felt they had received a lot of attention and support during their cancer treatment, yet as soon as they were in remission they felt almost abandoned. Participants told stories of how it had been easier for them emotionally when they were in treatment fighting cancer than when they were in remission because at least during treatment they had a place to focus their energy, and providers and family appeared more attentive to their needs. This is an aspect of the cancer experience that has clinical implications for how we treat cancer not just as an acute disease but as a chronic condition, as the survivors may never fully feel free of the illness regardless of their prognosis.

Lastly, survivorship was also related to what some participants felt was an identity of being a cancer survivor. This reflects previous research on *survivorship identity* (Little, Jordens, Paul, & Sayers, 2001), which describes the process of identity transformation in the face of illness. It also relates to the Herman's (1997) concept of the *survivor mission* to find a way to integrate the trauma into the self and find a pathway forward. A study by Auerback et al. (2006) that looked at cancer patients undergoing stem cell transplants found the theme of *living while dying* offered participants a way to make connections with other cancer survivors, focusing on strengths rather than weaknesses, and finding their inner resilience.

### **Discussion of Follow-up Questionnaire**

The follow-up questionnaire administered to participants was a way for them to give feedback on the developing model of medical traumatic stress that has been the focus of this dissertation. It also served as a form of member checking for participants to gauge their identification with emerging thematic findings from interviews. The questionnaire acted as a second level of data collection more focused on the evolving definition of medical traumatic stress which could be used as a tool to address the overall wellness of cancer patients.

The feedback from the follow-up questionnaire then acted as a way to shape revisions of the definition and themes originally proposed. Of the nine respondents, only one participant did not identify with the definition provided and specifically of the body betraying or attacking itself. Due to this feedback, I thought more about how to change the language of the diagnostic criteria while implying the same phenomenon. I then removed the word “attacked” and added the word “estranged” as an alternative to the word “betrayed.” I also paired down the 15 themes provided on the follow-up questionnaire to the 10 most salient themes that were identified by the majority of participants.

Based on the findings from interviews and subsequent follow-up questionnaires, I was able to narrow down the results into a tentative definition of the working model of medical traumatic stress. In concluding this research study, I have edited my final proposed definition of the phenomenon, which is comprised of three characteristics and the following 10 prominent themes:

#### *Medical Traumatic Stress*

##### **Characteristics:**

- A. Traumatic event originated by an internal stressor (disease) and the diagnosis of a disease.
- B. Typically involves future-oriented concerns of prognosis, functionality, and morbidity.



C. Perceived lack of safety within the physical body; the body may no longer feels safe, survivors may feel estranged or betrayed by their body.

**Themes, symptoms:**

1. The unexpected nature of the diagnosis.
2. Feeling overwhelmed and unprepared in dealing with illness.
3. Physical and emotional strain from time-consuming treatments and procedures causing stress, exhaustion, discomfort, and pain.
4. Experiencing the stages of grief; most prominently anger and sadness.
5. Physical loss such as hair, weight, energy, and/or libido, and/or physical scars from procedures.
6. Lack of physical activity; morbidity due to illness.
7. Emotional loss of assumed health.
8. Feelings of body betrayal or estrangement such as a lack of trust in the body and/or body dysmorphia such as not recognizing self in mirror.
9. Feeling the illness as all-encompassing.
10. Uncertainty and anxiety over the future, fear of relapsing.

To meet diagnostic criteria for this proposed diagnosis, a disease survivor would identify with all of the characteristics and at least half of the themes described here. This model of medical traumatic stress will continue to evolve, and my hope is that it will find a way further into academic literature. Outlining an initial diagnostic description of medical traumatic stress in this dissertation provides a starting place.

**Conclusion**

In this chapter I have discussed the findings of the study and their significance in respect to current literature. The four categories of *Cancer as a Trauma*, *Who am I Now? How do I Cope?* and *What Does the Future Hold?* were the leading outlines for addressing the findings of interviews in how participants described their experiences of psychological distress from cancer. From these categories thirteen themes and subsequent subthemes emerged. The follow up questionnaire was then developed as a way to further describe the phenomenon itself of medical traumatic stress such that participants weighed in on what aspects of their cancer experience were most traumatic and how they identified with preliminary themes.

Having a diagnostic tool for medical traumatic stress has implication for screening and treatment of psychological distress of oncology patients as well as other people facing major medical illnesses. Although this research has focused on young adults with cancer, the model of medical traumatic stress could be broadened beyond cancer to other serious illness which have lifelong consequences. This study further adds to existing research on the psychological distress of cancer by providing a model of the phenomenon. The final chapter will discuss notable findings, significance, limitations, recommendations for future research, and clinical implications.

## CHAPTER 6- CONCLUSION

### Summary of Dissertation

This dissertation explored the intersection of medical disease and mental health and demonstrated how a serious medical diagnosis can result in an acute or prolonged trauma. Medical traumatic stress is a non-violent trauma that currently has no DSM diagnosis and lacks conceptual understanding. This research study focused on the lived experiences of young adults diagnosed with cancer and their psychological distress in order to further identify and describe this phenomenon.

The literature review of current research that relates to disease and traumatic stress is limited and largely consists of quantitative studies of cancer and PTSD (Alter et al., 1996; Arnaboldi et al., 2017; Gesi et al., 2017; Mehnert & Koch, 2007; Mystakidou et al., 2012; Swartzmann et al., 2017). However, several studies alluded to the fact that PTSD may not be the most appropriate diagnosis for the phenomenon of trauma as it relates to a cancer diagnosis (Alonzo, 2000; Alter et al., 1996; Chalfant et al., 2004; Kangas et al., 2002; Mehnert & Koch, 2007; Swartzmann et al., 2016). There evolved three notable discrepancies between traditional trauma and medical traumatic stress from the literature review, including the nature of the traumatic stressor being internal versus external, the nature of concerns being future versus past, and the elusiveness of feeling safety within the body due to illness.

Expanding on these findings in the literature and taking into account the dearth of qualitative studies on this subject, I chose a methodology for this research to further describe the conceptual phenomenon itself. This qualitative phenomenological study focused on capturing the lived experience of psychological distress from cancer as a way to develop an understanding of medical traumatic stress. The goal was to conceptualize this phenomenon and create a model of

medical traumatic stress that can be further developed and explored both academically and clinically.

A model of medical traumatic stress emerged through this study by evaluating the experiences of the 12 participants. This involved refining the initial three defining characteristics of the phenomenon and then expanding upon them with the most salient themes found in the interviews and follow-up questionnaires. The 10 prominent themes that emerged from the data were identified by the majority of participants as intrinsic to their personal experiences of the phenomenon of medical traumatic stress.

### **Notable Findings**

A universal finding of this study was that every participant reported some level of *anxiety and fear of relapse* when asked about the future. This is where medical trauma differs from currently understood trauma, as participants expressed future-oriented concerns that are not typical of other traumas that have occurred in the past and were not ongoing. The results of this study confirm the premises that people facing cancer are future-focused, fearing relapse and dreading a foreshortened future.

Another important finding in this study were the different feelings surrounding traumatic distress from cancer that the majority of participants reported including helplessness, a sense of loss of control, and a loss of assumed health. Notably, there was not necessarily a specific aspect of cancer that was identified as traumatic. Rather, participants reported multiple experiences as traumatic, such as diagnosis, treatment, procedures, loss of hair, scars, and body estrangement. These findings contribute to prior research which suggests that the entire experience of cancer may be traumatic and ongoing (Swartzman et al., 2015).

A thought-provoking finding of this study is that the medical environment itself often acted as a trigger for hypervigilance and anxiety, which is echoed in previous research (Hall & Hall, 2013). Specifically, the theme *fear of hospital* was brought up by various participants who described how just going into a hospital setting was traumatic for them in some way. This highlights the importance of the perception of the medical environment and an understanding of how the traumatic experience of cancer is compounded by the fact that patients must continually return to the hospital, often numerous times, in order to receive the medical care they need to survive despite feeling triggered by the setting.

A noteworthy aspect of this study is that it included two participants who had had previous trauma from sexual assaults who felt that their past trauma compounded the traumatic experience of having cancer. Research suggests that a prior history of traumatic experiences may make individuals more vulnerable to psychological distress from cancer (Alter et al., 1996; Banou et al., 2009; Green et al., 2014; Mystakidou et al., 2012). This study supports the notion that prior trauma is a risk factor for cancer patients and perhaps particularly for female patients who have gynecological cancers.

This study focused on the population of young adults with cancer, and findings suggest that cancer may have impacted their identity development. The loss of assumed health that participants reported along with the body betrayal and body dysmorphia are notable aspects of identity renegotiation (Laranjeira et al., 2013) that young adults grappled with. Cancer is a major life event, and it triggered some form of self-concept transformation for the majority of participants who felt that the experience challenged their sense of self and identity.

An interesting finding in this study was the use of humor as coping skill, which several participants noted as a way to relate to others and make light of a dark situation. Other notable

coping skills included social self-care of both in-person and on-line support groups. Because participants were recruited from on-line support groups, this finding was not surprising, but it also emphasized the need for cancer patients to connect with other people struggling with the disease and receive social support. As found in other studies, the majority of participants who depended on friends and family during their treatment and recovery identified the importance of a support system (Esposito, 2016; Salick & Auerback, 2006; Scott et al., 2017).

Cancer survivors in this study expressed the need for more availability of same-age and cancer-specific support groups as well as survivorship options. This study affirmed findings in prior research that call for increased supports around specific types of cancers as well as for young adults facing cancer (Swartzman et al., 2015). Some participants also emphasized the need for long-term supports for cancer survivors who continue to struggle with psychological distress and ongoing life challenges once they are in remission.

### **Medical Traumatic Stress as a New Model**

Past attempts to describe the psychological distress of cancer patients have used the PTSD model. When patients do not meet criteria they are typically diagnosed with adjustment disorder, anxiety disorders, or depression. The proposed diagnosis of *medical traumatic stress* is a viable alternative to these various DSM diagnoses that describes the specific phenomenon of the psychological impact of diseases like cancer. PTSD is a model developed around victims of violence and abuse who were perpetrated by an outside stressor hence is not an appropriate model for the phenomenon of medical trauma. Other notable differences are the hallmark future-oriented concerns people living with chronic illness face as well as a lack of a sense of body safety and integrity.

Although adjustment disorder may seem like an appropriate diagnosis for people facing new life challenges, it only covers the first six months of transition after an event that causes distress and is not at all specific to what cancer survivors experience. In many ways adjustment disorder is more of a catch-all diagnosis for life transitions and is the same diagnosis given to people who report distress going through a break-up, moving, or starting a new job. What is lost in such a general diagnosis as adjustment disorder is the lifelong challenge of chronic illness and the unknown future it perpetuates.

Likewise, many cancer survivors may experience anxiety and depression, yet these are symptoms of a much larger picture of their ongoing reality in living with chronic illness. In general, there is no current diagnosis that embodies the experience of people facing life-threatening illnesses and the psychological impact. Having a diagnosis like medical traumatic stress would validate the experience of those struggling with psychological distress after a medical diagnosis and allow for new treatment models to emerge by drawing more attention to this phenomenon.

### **Significance**

There are currently no qualitative studies that focus on the phenomenon of traumatic stress from a medical diagnosis. Although this study highlights the experience of traumatic stress from cancer, the findings could be generalizable to traumatic stress caused by other major diseases. The hope is that this model of medical traumatic stress can begin a body of research to support the phenomenon and bring further light to this experience.

Because medical events are not currently recognized in the DSM-5 (2013) as a cause of PTSD, those who have had a recent diagnosis of a major illness may be given a more arbitrary diagnosis such as adjustment disorder. Further conceptual understanding of traumatic stress

caused by illness can give clarification that will have diagnostic and clinical implications. Namely, those struggling with traumatic stress from illness would benefit from a specific diagnosis that would help in prevention, screening, and treatment for people diagnosed with life threatening illnesses. Ultimately, I believe that medical traumatic stress should have its own DSM diagnosis so that it can be recognized in the mental health field as a common phenomenon that requires subsequent intervention and support.

### **Limitations**

There are several limitations to this exploratory study. Notably, there was a small sample size with limited generalizability. The experience of 12 cancer survivors cannot be broadened to represent the experience of the multitude of other survivors. Because this is a dissertation, it was also limited to only one person coding the data, which inevitably resulted in the bias of having the data analyzed by a single reader. In order to control for this, I worked with a peer review group of four students throughout the process of data collection, analysis, and the writing of the dissertation, allowing them to give and receive feedback. This group met in person every two to four weeks and spoke virtually regularly. The peers offered comments, opinions, and revisions to the drafts I presented to them throughout the process of data collection, data analysis, and discussion. This peer debriefing of findings acted as a form of triangulation.

Demographically, the study was also limited to nine women and only three men and may over-represent the female experience of cancer as a result. This imbalance in gender was due to the extreme difficulty in recruiting male subjects for the study. Although this difficulty in recruitment may not suggest that men have less psychological distress from cancer than women, it may suggest that they are less likely to want to share their personal experiences. As a result of



this gender imbalance, the female perspective of cancer is more heavily reflected in these findings.

The study was also limited in scope to predominantly White heterosexuals who live on the East Coast of the U.S.. There was one woman of color in the study, who cannot alone represent the experience of that demographic or bring to light any of the additional obstacles that race may contribute to one's experience of having cancer. There were two women who identified as lesbian and pansexual, who also cannot represent the experience of non-heterosexuals.

Another limitation was that all participants had some form of health insurance and claimed to have a support system of family and friends. The majority of participants were either married or partnered and received support during their diagnosis and treatment from a significant other. The minority of identified single participants also reported having the support of family and friends. Notably, the participants in this study found out about it through social media and were actively seeking support and thus may have formed a particularly action-oriented population as a result. This study has limited scope in illuminating the experience of people struggling with cancer who may be poor, uninsured, single, and without a support system of friends and family.

In reflecting on the methodology of this study, qualitative measures were generally successful in eliciting the experience of psychological distress surrounding cancer. However, there are some methodological improvements that could be made to specific parts of the study protocol that would strengthen the study if it were to be replicated. Most notably, there was a three-pronged question about the experiences of grief, loss, and identity from cancer that was too loaded. In retrospect, it would have been preferable to ask three separate questions around these concepts rather than lumping them together, as there may have been too many things for

participants to consider when responding to all at once. Another change would concern the last question about existentialism, as several participants had neither heard of this concept nor had a clear understanding of what it means, such that it had to be explained in the majority of interviews. A more appropriate question would have been to ask about meaning-making from the cancer experience, which is more straightforward.

Despite its limitations and proposed changes for a future interview protocol, the study seemed to be well-received by participants, and it gave them a space to talk about their emotional journey with cancer. Participants offered several unsolicited comments about how they felt some positive benefit from the study. These affirmations suggest that the study did provide some benefit in simply allowing a space for participants to process their cancer journeys. The hope is that this research will add to the larger body of work surrounding traumatic stress and illness and perhaps start a dialogue around the concept of medical traumatic stress as described here.

### **Recommendations for Future Studies**

The findings of this study have both theoretical and clinical implications. Theoretically, the concept of medical traumatic stress could be further researched towards building a more evidenced-based model that could lead to a potential diagnosis in the DSM, which would then have clinical implications. The central objective of this study is that focusing on the concept of medical traumatic stress can start a larger conversation around this phenomenon in future research.

This study focused on the experience of young adults with cancer, although there are many other serious and chronic illnesses that may also be perceived as traumatic. As part of the larger conversation about the phenomenon of medical traumatic stress, other illnesses could be explored in regard to their traumatic impact. For instance, research on multiple sclerosis

demonstrates that there is a similar risk for PTSD with a devastating chronic illness (Chalfant et al., 2004; Esposito, 2016).

There are also many areas where future research could explore more specifics about the experience of trauma from cancer. An example would be how economic and racial minorities may be more at risk for trauma since previous research suggests that people of color are more at risk for depression due to chronic illness than Whites (Nobles et al., 2016). Future studies that would broaden our understanding of this phenomenon could focus on a larger sample size with a more heterogeneous participant pool. Research could also focus on the experience of cancer for people of color, people who are uninsured, and/or people who are from a lower socioeconomic class, as these factors may impact the cancer experience.

The role of gender in the cancer experience is a subject that could use more illumination. In this study there was lack of male participants due to a difficulty recruiting them. This may have been a result of men not wanting to talk about their emotional journey of cancer or an indication that trauma is less common for men than women. Regardless, future studies could work to uncover more around this gender discrepancy, as this study is too small to make any inferences.

An unanticipated finding of this study was the role that fertility and intimacy played in the cancer experience, which is an area that future research could focus more on. Another specific area that could be further explored is the impact of past sexual assault on those who have been diagnosed with gynecological cancer and how this affects trauma from cancer. In this small sample, two participants were women who had been sexually assaulted prior to dealing with gynecological cancer, and they felt that the assault had an impact on their experiences. This study also uncovered the multi-layered impact trauma has on identity. There is limited research

on this aspect, and a previous study by Banou (2009) called for future research on how illness impacts identity and self-esteem. In general, future research should continue to uncover more data around this topic as well as new research questions and problems surrounding the psychological impact of cancer and other diseases.

### **Implications for Practice**

#### **Social Emotional Awareness**

An important result in this study was the unanimous finding of all participants who reported experiencing anxiety and fear of the future. This characteristic of future oriented fear is a cornerstone of the cancer experience for young adults as well as a key aspect of the alternative model to PTSD of medical traumatic stress. For many young adults, cancer causes a developmental dilemma where their future goes from bright and full of potential to a more ominous unknown, causing ongoing distress in anticipating a relapse.

For this population there are also numerous hidden triggers that were highlighted in the study, such as concerns about fertility, intimacy, vocation, physical activity, social life, and countless other potential factors that will continue to come up in the life of cancer survivors. Because cancer affects so many life domains there is little left untouched in survivors lives such that they could be easily triggered and reminded of the ongoing limitations imposed by cancer well after they end treatment. This experience can also be very isolating as described by some participants in this study who talked about how people in their lives were unable to understand what they were going through. This emphasizes the importance of providers in both medical and mental health settings to have knowledge and insight into the developmental challenge of cancer for young adults and help both them and their families in getting the support they need.

#### **Screenings and Interventions**

One of the most important clinical implications of this study is simply the awareness that young cancer patients experience traumatic stress and understanding the importance of screening them early in their diagnoses so they can obtain mental health resources from the beginning. Several studies listed in their implications a call for more screening for PTSD and psychological symptoms in medical settings (Arnaboldi et al., 2017; Banou, 2009; Gesi et al., 2017; Mehnert et al., 2010). These findings substantiate that traumatization in newly diagnosed patients is a reality that needs more attention within the medical community. Providers should offer preventative screenings and routinely assess newly diagnosed patients as research demonstrates that PTSD can interfere with medical care and has long-lasting effects on quality of life, cognitive status, and adjustment mechanisms (Arnaboldi et al., 2017). Medical staff also need more training and competencies to deal with traumatized patients in their care.

Potential screenings for medical trauma must also account for crucial risk and protective factors, such as prior trauma history and social support. The important role of prior trauma history, prior psychiatric history, and recent life events in patients' adjustment to cancer have implications for their screening, treatment, and psychosocial assessment of patients (Cordova et al., 2017; Green et al., 2000). Nipp et al. (2018) urged for more interventions to address patients' PTSD symptoms at diagnosis in order to address physical and psychological symptom burdens. More continuity policies are required for current healthcare systems to accommodate this need. For instance, there are better psychological outcomes when mental health and medical providers communicate across systems (Ungar et al., 2013). This is a significant takeaway for future research to focus on: providing more enhanced coordinated care for those with physical ailments to receive mental healthcare in tandem to help them cope.

A study by Li et al. (2017) developed a psychological intervention program aimed to reduce anxiety for people diagnosed with laryngeal cancer and found a significant difference in outcomes compared to controls. The study concluded that offering psychological interventions to newly diagnosed cancer patients is beneficial and can improve quality of life. These findings contribute to the growing body of research that suggests psychological interventions should be available to cancer patients in tandem with their medical care.

An important distinction between medical trauma and other traumas is that we understand the where, how, and why it occurs, and since we can anticipate the trauma, we can plan for prevention and intervention (Hall & Hall, 2013). In anticipating that anyone given a cancer diagnosis is at risk for medical traumatic stress, we can then be prepared to encounter this phenomenon clinically and act accordingly. The relational trauma model outlined by Saakvitne (2017) provides a description of the kind of therapeutic holding space that could be built into a larger therapeutic model for treating medical traumatic stress clinically. This was also addressed by Stolorow (2015), who emphasized the importance of context and holding painful feelings and emotions in a context of human understanding such that they can gradually become more bearable. In the case of medical trauma this is likely why several participants found some benefit from socializing with other cancer survivors because the survivors understood their struggles and were able to empathize from personal experience rather than speculation. Another clinical implication of this study was the impact of past trauma history on cancer patients. This need is best stated by a participant:

I wish there could have been counseling specifically for people going through gynecological cancers who have a history of sexual trauma. That this group of people

[be] approached in a different way by the doctors, somehow, to make the experience feel less horrific, less likely to bring back old memories of the body being violated. (S2)

This is a specific instance where a participant wished she had had more support around being a sexual assault survivor who was facing gynecological cancer. Other areas where counselors could provide more specialized support concern the impact of cancer on fertility and intimacy for survivors. Counseling around cancer must acknowledge the *all-encompassing nature of cancer* in its impact on all life domains and how different survivors carry different needs and challenges.

Lastly, some participants gave very specific feedback around the lack of survivorship options, and these resource gaps inform implications for clinical practice. Most larger hospitals provide some form of support groups for cancer patients, although these are often limited to people with specific types of cancer and for people actively in treatment. However, many participants felt as though they had nowhere to go to talk about their struggles as cancer survivors once they were in remission. This is a service that hospitals and agencies could focus more on providing when considering ongoing resources.

### **Counselor Considerations and Relational Bedside Manner**

The cancer experience is complex and different for each patient. How we view cancer impacts how we treat cancer. It is important to acknowledge that cancer is often not just an acute disease but a chronic condition, as survivors may never fully feel free of the illness regardless of their prognosis. Counselors working with oncology patients and cancer survivors should have some understanding around how this population often faces a loss of assumed health and a need for identity renegotiation in the wake of cancer. Some patients may need more trauma-focused counseling, while others may benefit from more holistic counseling that recognizes the mind-body connection.

Previous studies discussed in the literature review suggested various clinical and practical implications that are important to note about what might be done to better support disease survivors who suffer from traumatic stress. Much of the awareness that is needed is within the medical community where disease survivors receive the majority of their care. This awareness includes screening for traumatic stress, improving bedside manner, and integrating both medical and mental health care systems for better continuity of care.

Using the relational lens to understand and treat medical trauma, healthcare providers can build more awareness and reframe the pathologizing stance of *what's wrong with you?* to a relational stance of *what's happened to you?* (Bloom, 1999; Saakvitne, 2017). This sets the stage for a safe space in which people can be held and seen for their experience of traumatic stress. Bloom (1999) addresses the human need for safety that expands beyond physical safety into psychological, social, and moral safety as well, stating how providers must “radically shift our perspective on ourselves and others, moving us towards a position of compassion and understanding and away from blame and criticism” (p. 15). To acknowledge medical trauma is to affirm the lived experience of those who suffer psychologically by carrying the burden of an often times invisible disability.

A fundamental shift is needed in our current healthcare systems for medical providers to be given the training and language around psychological trauma in order to provide relational care that emphasizes compassion and empathy towards patients who are in crisis. Providers need to develop new models that give more time to patient interaction so that healing relationships can develop for patients who are struggling physically and mentally. Several studies implicated the importance of medical providers taking mental health issues into account by treating patients with consideration within the healthcare systems (Kulaksizoglu, 2007; Scott et al, 2017; Tutton



et al., 2012). Rather than ignore or blame patients for their psychological distress, providers must acknowledge the mind-body connection that is innate within all of us. If medical providers can better understand the psychological distress of their patients as being a normal reaction to medical illness, then they can provide better bedside manner around comorbid medical and mental health issues.

### **Integrated Healthcare Model**

Several studies implied that a prevention model for medical trauma would involve the integration of physical healthcare with mental healthcare (Banou et al., 2009; Hall & Hall, 2013; Mystakidou et al., 2012). Hall and Hall (2013) discussed the importance of the integration of physical and mental healthcare where counselors can have access to patients from the moment of diagnosis onwards. Ideally, cancer patients should have access to counseling, psychiatry, support groups, peer mentors, and survivorship programs concurrently with their cancer treatment.

This integrative approach calls for medical settings to provide in-house mental health services, screenings, and referrals to mitigate the disconnect between systems of care. Not addressing mental health in medical settings, as if they were not intertwined, is detrimental to patients. We also need to rethink the invisible disability of chronic illness and “approach disability from an integrative frame that treats both the medical and psychological components of disabling conditions” (Esposito, 2016, p. 8). By changing the narrative around medical trauma, there can be more awareness of the traumatic stress that results from a chronic illness diagnosis and the need to develop a plan for how systems can have better wrap around care for patients in distress.

A prevention model for medical trauma would involve screenings for traumatic stress in healthcare settings where patients receive their medical diagnoses. In order to ensure continuity

of care, there should be automatic referrals for mental health support for those given a new medical diagnosis. A more integrated model would allow for patients to receive both medical and mental healthcare in the same site. Lastly, medical caregivers need to improve their awareness and language around trauma so as to provide a relational bedside manner that can support the disease survivor both physically and emotionally.

### **Social Justice Implications**

The chronicity of illnesses like cancer is in itself a social justice issue. This study uncovered the complexity of the cancer experience for young adults facing social issues such as ableism, financial distress, and vocational challenges. Notably, participants in this study were largely White, middle class, and had some form of health insurance, yet they still faced injustices caused by their illness. This reality brings to light how those living without insurance and financial stability are that much more vulnerable.

In the United States, where healthcare is not a right, people living with cancer and other chronic illnesses face ongoing challenges with access to the care they need to survive. There is no lack of medical or mental health expertise in this country. In fact, this is home to some of the best hospitals, physicians, and researchers in the world. What is lacking is access to this care in a medical system that is largely insurance-mandated and profit driven. If healthcare were treated as a basic human right, then this would eliminate the current barriers to treatment that many people continue to face.

### **Importance of Topic to Counseling and Psychology**

Illuminating the traumatic nature of life-threatening disease allows for more general awareness around the mental health repercussions of a cancer diagnosis. Gaining this insight and knowledge into the experience of young adults grappling with a new cancer diagnosis can have

clinical implications for how they could best be supported in our field. An example would be a better referral system for people given a new diagnosis, so they can receive the emotional support they need that is concurrent with their medical treatment.

Such research can also offer suggestions as to how traumatic stress should be dealt with in medical settings to ensure continuity of care. An example of a notable improvement that could be made is screening patients in medical settings for traumatic stress symptoms. Currently, our healthcare system in the United States is not integrative, and in most clinical settings medical and mental health are addressed separately. However, patients would be better served if they could be assessed for their adjustment to a new diagnosis and offered referrals and resources for mental health support that are accessible.

A more insidious issue is that the medical community does not consistently recognize the psychological distress of a major medical diagnosis as a normal reaction to an abnormal event. Because many healthcare providers routinely interact with patients, they may become desensitized to the traumatic stress caused by medical events for individuals. Therefore, this research can bring to light the fact that the experience of traumatic stress is in fact a normal and reasonable reaction to a cancer diagnosis. Providers will need to increase their awareness of the mental health of their patients in order to ensure better care. Injecting empathy into the medical model is a call for more integrative and holistic care of patients.

### **Reflections as Researcher**

As the researcher, I feel this study has illuminated my understanding of the emotional and physical journey cancer survivors endure. I found that their experiences often mirrored each other, as well as my own experience as a disease survivor. This process has been both cathartic

and validating, as it has confirmed and expanded upon the experience of traumatic stress from disease and illuminated the importance of this topic.

I have felt validation not just in completing the study that I set out to perform but in the unsolicited feedback I received from some of the participants. For instance, one participant stated, “I really appreciated this experience and I am going to bring this survey to my counselor next week to explain some of the feelings I have” (S2). Another offered, “Your study has been really helpful to me in processing my thoughts/feelings about my diagnosis” (S4). Still another stated, “Thank you for including my thoughts. It feels nice to have some good come out of something so awful, you know!” (S7). These sentiments were reassuring signs that the study did no harm to participants and instead may have provided some positive benefits.

What I also learned is that being a researcher is an entirely different role from that of the counselor I am used to. As anticipated, I had to suppress the urge to comfort some of my participants as if I were their counselor when they cried or shared difficult stories. I feel incredibly grateful to them for opening up about such difficult and vulnerable information to a perfect stranger and allowing me to bear witness to their pain. In that sense, I feel obligated to do my best in sharing these findings and working to increase awareness around this phenomenon.

What has been most challenging about this process is balancing my own personal life and mental health with my academic and professional goals. Raising two small children while completing a dissertation has been an adventure. I sometimes feel all my energy goes into my family, school, and work, which can result in minimal self-care. There was a point in this process where I felt my mental health was suffering from the stress. I also found my own trauma surrounding illness surfacing while constantly reading and writing about the topic. I went back

into counseling in order to create a place to hold my emotions and frustrations and to further process my trauma. I feel that this decision was critical in completing this dissertation.

This topic is really important to me both personally and professionally, and I hope to contribute to the body of work surrounding traumatic stress caused by illness. If given the opportunity, I hope to continue my research on this topic in an academic setting as I believe there is much more to uncover in the phenomenon of traumatic stress caused by major diseases. I shared my research in a course I teach on stress and trauma and plan to present it in upcoming conferences. I believe that this topic has become and will continue to be a specialty of mine that I can further explore both clinically and academically.

### **Overall Conclusions**

This study set out to describe the phenomenon of psychological distress from cancer in order to build a model of medical traumatic stress. Twelve participants shared stories of their lived experiences battling cancer both physically and emotionally. Several new categories, themes, and subthemes emerged from the data collected in initial interviews. Participants were then given a follow-up questionnaire asking them to describe their experience of medical traumatic stress and identify which themes generated from the interviews were most salient for them. In this way, the study was able to address the research goal of having young adults describe their experiences of psychological distress caused by a cancer diagnosis and treatment. The concept of medical traumatic stress has been described here and is a starting place for further study and discussion on this phenomenon.

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## References

- Adler, J.M. (2012). Living into the story. Agency and coherence in a longitudinal study of narrative identity development and mental health over the course of psychotherapy. *Journal of Personality and Social Psychology, 102*, 267-389.  
doi: 10.1037/a0025289
- Agee, J. (2009). Developing qualitative research questions: A reflective process. *International Journal of Qualitative Studies in Education, 22*(4), 431-444.
- Ainsworth, M.D. & Bell, S.M. (1970). Attachment, exploration, and separation: Illustrated by the behavior of one-year-olds in a strange situation. *Child Development, 41*, 49-67.  
doi:10.2307/1127388
- Alonzo, A. (2000). The experience of chronic illness and post-traumatic stress disorder: The consequences of cumulative adversity. *Social Science & Medicine, 50*, 1475-1484.  
doi:10.1016/S0277-9536(99)00399-8
- Alter, C. et al. (1996). Identification of PTSD in cancer survivors. *Psychosomatics, 37*(2), 137-147. doi:10.1016/S0033-3182(96)71580-3
- American Cancer Society. (n.d.). Cancer that develops in young adults. Retrieved from <https://www.cancer.org/cancer/cancer-in-young-adults/cancers-in-young-adults.html>
- American Psychiatric Association. (1987). Diagnostic and statistical manual of mental disorders (3<sup>rd</sup> ed., revised). Washington, DC.
- American Psychiatric Association. (1994). Diagnostic and statistical manual of mental disorders (4<sup>th</sup> ed.). Washington, DC.
- American Psychiatric Association. (2000). Diagnostic and statistical manual of mental disorders (4<sup>th</sup> ed., text rev.). Washington, DC.

- American Psychiatric Association. (2013). *Diagnostic and statistical manual of mental disorders* (5<sup>th</sup> ed.). Washington, DC.
- Arnaboldi, P., Riva, S., Crico, C. & Pravettoni, G. (2017). A systematic literature review exploring the prevalence of post-traumatic stress disorder and the role played by stress and traumatic stress in breast cancer diagnosis and trajectory. *Breast Cancer- Targets and Therapy*, 9, 473-485. doi:10.2147/BCTT.S111101
- Auerback, C.F., Salick, E. & Fine, J. (2006). Using grounded theory to develop treatment strategies for multicontextual trauma. *Professional Psychology: Research and Practice*, 37(4), 367-373. doi:10.1037/0735-7028.37.4.367
- Banks, M. (2014). *Women with visible and invisible disabilities: Multiple intersections, multiple issues, multiple therapies*. Hoboken, NJ: Taylor and Francis.
- Banou, E., Hobfoll, S. & Trochelman, D.R. (2009). Loss of resources as mediators between interpersonal trauma and traumatic and depressive symptoms among women with cancer. *Journal of Health Psychology*, 14(2), 200-214. doi: 10.1177/1359105308100204
- Bloom, S. (1997). *Creating sanctuary: Toward the evolution of sane societies*. New York, NY: Routledge.
- Bloom, S. (1999). *Trauma theory abbreviated*. From the Final Action Plan: A Coordinated Community Response to Family Violence, Attorney General of Pennsylvania's Family Violence Task Force.
- Boss, P. (1999). *Ambiguous loss: Learning to live with unresolved grief*. Cambridge, MA: Harvard University Press.
- Bronfenbrenner, U. (1979). *The ecology of human development*. Cambridge, MA: Harvard University Press.

- Bronfenbrenner, U. & Ceci, S.J. (1994). Nature-nurture reconceptualized in developmental perspective: A biological model. *Psychological Review*, *101*, 568-586.
- Carletto, S., Borghi, M., Scavelli, F., Francone, D., Perucchini, M.L., Cavallo, M., Pagnini, F., Bertolotto, A., Oliva, F. & Ostacoli, L. (2018). Prevalence of posttraumatic stress disorder in patients with multiple sclerosis. *The Journal of Nervous and Mental Disease*, *206*(2), 149-153. doi: 10.1097/NMD.0000000000000780
- Carspeken, P.H. (1996). *Critical Ethnography in Education Research*. New York, NY: Routledge.
- Chalfant, A.M., Bryant, R.A. & Fulcher, G. (2004). Posttraumatic stress disorder following diagnosis of multiple sclerosis. *Journal of Traumatic Stress*, *17*(5), 423-428.  
doi:10.1023/B:JOTS.0000048955.65891.4c
- Cordova, M.J., Riba, M.B. & Spiegel, D. (2017). Post-traumatic stress disorder and cancer. *Comorbid PTSD*, *4*(4), 330-338. doi: 10.1016/S2215-0366(17)30014-7
- Creswell, J.W. (2014). *Research design: Qualitative, quantitative, and mixed methods approaches* (4<sup>th</sup> ed.). Thousand Oaks, CA: Sage.
- Denney, R.M., Aten, J.D. & Leavell, K. (2011). Posttraumatic spiritual growth: A phenomenological study of cancer survivors. *Mental Health, Religion & Culture*, *14*(4), 371-391. doi: 10.1080/13674671003758667
- Devlin, R. F., & Pothier, D. (2006). *Critical disability theory: Essays in philosophy, politics, policy, and law*. Vancouver: UBC Press.
- Dirth, T.P. & Branscombe, N.R. (2018). The social identity approach to disability: Bridging disability studies and psychological science. *Psychological Bulletin*. *144*(12), 1300-1324.  
doi:10.1037/bul0000156



- Doka, K. J. (Ed.). (1989). *Disenfranchised grief: Recognizing hidden sorrow*. Lexington, MA, England: Lexington Books/D. C. Heath and Com.
- Dzul-Church, V., Cimino, J.W., Adler, S.R., Wong, P. & Anderson, W.G. (2010). "I'm sitting here by myself...": Experiences of patients with serious illness at an urban public hospital. *Journal of Palliative Medicine, 13(6)*, 695-701. doi: 10.1089/jpm.2009.0352
- Esposito, J. (2016). *Understanding unpredictable chronic illness and its links to posttraumatic stress and growth: The case of multiple sclerosis*. Unpublished doctoral dissertation. Columbia University, New York.
- Fullilove, M.T., Lown, E.A., & Fullilove, R.E., III. (1992). Crack 'hos and skeezers: Traumatic experiences of women crack users. *Journal of Sex Research, 29(2)*, 275-287.  
doi:10.1080/00224499209551647
- Gadamer, H. (2004). *Truth and method*. New York, NY: Continuum Publishing Group.
- Gauntlett-Gilbert, J., Rodham, K., Jordan, A. & Brook, P. (2015). Emergency department staff attitudes towards people presenting in chronic pain: A qualitative study. *Pain Medicine, 16*, 2065-2074. doi: 10.1111/pme.12844
- Gergen, K.J., Josselson, R., & Freeman, M. (2015). The promises of qualitative inquiry. *American Psychology, 70(1)*, 1-9.
- Gesi, C., Carmassi, C., Sancassiani, F., Gadducci, A. & Dell'Osso, L. (2017). Post-traumatic stress disorder in patients with ovarian cancer. *International Review of Psychiatry, 29(5)*, 403-408.
- Gilligan, C. (2015). The Listening Guide method of psychological inquiry. *Qualitative Psychology, 2(1)*, 69-77.
- Gilligan, C., Spencer, R., Weinberg, K., & Bertsch, T. (2003). On the *Listening Guide*: A voice-

- centered relational model. In P.M. Camic, J.E. Rhodes, & L. Yardley, (Eds.), *Qualitative research in psychology: Expanding perspectives in methodology and design*, (pp.157-172). Washington, DC: American Psychological Association.
- Giorgi, A. (2009). *The Descriptive Phenomenological Method in Psychology: A Modified Husserlian Approach*. Duquesne University Press.
- Grassi, L., Spiegel, D. & Riba, M. (2017). Advancing psychosocial care in cancer patients. *F1000 Research*, 6: 2083. doi: 10.12688/f1000research.11902.1
- Green, B.L., Epstein, S.A., Krupnick, J.L., & Rowland, J.H. (1997). Trauma and medical illness: Assessing trauma-related disorders in medical settings. In J.P. Wilson & T.M. Keane (Eds.), *Assessing psychological trauma and PTSD* (pp. 160-191). New York, NY: Guilford Press.
- Green, B.L., Krupnick, J.L., Rowland J., Epstein, S.A., Stockton, P., Spertus, I. & Stern, N. (2000). Trauma history as a predictor of psychological symptoms in women with breast cancer. *Journal of Clinical Oncology*, 18(5), 1084-1093.  
doi:10.1200/JCO.2000.18.5.1084
- Groleau, J.M., Calhoun, L.G., Cann, A. & Tedeschi, R.G. (2013). The role of centrality of events in posttraumatic distress and posttraumatic growth. *Psychological Trauma, Research, Practice, and Policy*, 5(5), 477-483. doi:10.1037/a0028809
- Hahn, H. (1985). Disability policy and the problem of discrimination. *American Behavioral Scientist*, 28, 293-318. doi:10.1177/000276485028003002
- Hall, M. & Hall, S. (2013). *When treatment becomes trauma: Defining, preventing, and transforming medical trauma*. Paper based on program presented at the ACA Conference, Cincinnati, OH.

- Hefferon, K. Greal, M. & Mutrie, N. (2009). Post-traumatic growth and life threatening physical illness: A systemic review of the qualitative literature. *British Journal of Health Psychology, 14*, 343-378. doi: 10.1348/135910708X332936
- Heidegger, M. (1927/2011). *Being and Time* (J. Macquarrie & E. Robinson, Trans.). New York, NY: Harper & Row.
- Herman, J. (1997). *Trauma and Recovery (2<sup>nd</sup> ed)*. New York, NY: Basic Books.
- Hottensen, D. (2010). Anticipatory **grief** in patients with cancer. *Clinical Journal of Oncology Nursing, 14(1)*, 106-107. doi: 10.1188/10.CJON.106-107
- Hunt, M.R., Chan, L.S. & Mehta, A. (2011). Transitioning from clinical to qualitative research interviewing. *International Journal of Qualitative Methods, 10(3)*, 191-201.
- Iacoviello, B.M. & Charney, D.S. (2014). Psychosocial facets of resilience: Implications for preventing posttrauma psychopathology, treating trauma survivors, and enhancing community resilience. *European Journal of Psychotraumatology, 5*, 1-10.  
doi: 10.3402/ejpt.v5.23970
- Janoff-Bulman, R. (1992). *Shattered assumptions: Towards a new psychology of trauma*. New York, NY: Free Press.
- Josselson, R. (2013). *Interviewing for qualitative inquiry: A relational approach*. New York, NY, US: The Guilford Press.
- Kangas, M., Henry, J. & Bryant, A. (2002). Posttraumatic stress disorder following cancer: A conceptual and empirical review. *Clinical Psychology Review, 22(4)*, 499-524.  
doi: 10.1016/S0272-7358(01)00118-0
- Kass, J.D. (2017). *A person-centered approach to psychospiritual maturation: Mentoring*

- psychological resilience and inclusive community in higher education*. New York, NY: Palgrave Macmillan. doi 10.1007/978-3-319-57919-1
- Kilpatrick, D.G., Resnick, H.S., Milanak, M.E., Miller, M.W., Keyes, K.M. & Friedman, M.J. (2013). National estimates of exposure to traumatic events and PTSD prevalence using DSM-IV and DSM-5 criteria: DSM-5 PTSD prevalence. *Journal of Traumatic Stress*, 26, 537–547. doi: 10.1002/jts.21848
- Kreidler, M. & Kurzawa, C. (2009). Trauma spectrum disorders. *Journal of Psychosocial Nursing and Mental Health Service*, 47(11), 26-33.
- Kroger, J. (2007). *Identity development: Adolescence through adulthood* (2nd ed.). Thousand Oaks, CA, US: Sage Publications, Inc.
- Kubler-Ross, E. (1969). *On death and dying*. New York: The Macmillian Company.
- Kulaksizoglu, I.B. (2007). Mood and anxiety disorders in patients with myasthenia gravis. *Therapy in Practice, CNS Drugs*, 21(6), 473-481. doi: 10.2165/00023210-200721060-00004
- Laranjerira, C., Leao, P.P. & Leal, I. (2013). Meaning of life after cancer: An existential-phenomenological approach to female cancer survival. *Women's Studies International Forum*, 40, 132-143. doi: 0.1016/j.wsif.2013.05.015
- Leano, A., Korman, M.B., Goldberg, L. & Ellis, J. (2019). Are we missing PTSD in our cancer patients? *Canadian Oncology Nursing Journal*, 29(2), 141-146.
- Lefebvre, H. & Levert, M.J. (2006). Sudden and unexpected health situation: From suffering to resilience. *Illness, Crisis & Loss*, 14(4), 337-354.

- Li, X., Li, J., Shi, Y., Wang, T., Zhang, A., Shao, N. & Wang, Z. (2017). Psychological intervention improves life quality of patients with laryngeal cancer. *Patient Preferences and Adherence*, *11*, 1723-1727. doi: 10.2147/PPA.S147205
- Little, M., Jordens, C., Paul, K. & Sayers, E. (2001). *Surviving survival: Life after cancer*. Marrickville NSW: Choice Books.
- Luttrell, W. (2000). "Good enough" methods for ethnographic research. *Harvard Educational Review*, *70*(4), 499-523
- Marshall, C., & Rossman, G. B. (2015). *Designing qualitative research* (6th ed.). Thousand Oaks, CA: Sage.
- Massey, S.G. & Barreras, R.E. (2013). Introducing "Impact Validity." *Journal of Social Issues*, *69*(4), 615-632.
- McCann, L. & Pearlman, L. (1990). *Psychological trauma and the adult survivor: Theory, therapy and transformation*. New York, NY: Brunner/Hazel.
- Mehnert, A. & Koch, U. (2007). Prevalence of acute and post-traumatic stress disorder and comorbid mental disorders in breast cancer patients during primary cancer care: A prospective study. *Psychooncology*, *16*(3), 181-188. doi: 10.1002/pon.1057
- Mehnert, A., Lehmann, C., Graefen, M., Huland, H. & Koch, U. (2010). Depression, anxiety, post-traumatic stress disorder and health-related quality of life and its association with social support in ambulatory prostate cancer patients. *European Journal of Cancer Care*, *19*, 736-745. doi:10.1111/j.1365-2354.2009.01117.x.
- Morris, B.A., Shakespeare-Finch, J. & Scott, J.L. (2012). Posttraumatic growth after cancer: The importance of health-related benefits and newfound compassion for others. *Support Care Cancer*, *20*, 749-756. doi: 10.1007/s00520-011-1143-7

- Morris, B.A., Wilson, B. & Chambers, S.K. (2013). Newfound compassion after prostate cancer: a psychometric evaluation of additional items in the Posttraumatic Growth Inventory. *Support Care Cancer, 21*, 3371-3378. doi: 10.1007/s00520-013-1903-7
- Morrow, S.L. (2005). Quality and trustworthiness in qualitative research in counseling psychology. *Journal of Counseling Psychology, 52*(2), 250-260
- Morrow, S.L. (2007). Qualitative research in counseling psychology: Conceptual foundations. *The Counseling Psychologist, 35*, 209-235.
- Myers, H., Wyatt, G., Ullman, J., Loeb, T., Chin, D., Prause, N., Zhang, M., Williams, J., Slavich, G. & Liu, H. (2015). Cumulative burden of lifetime adversities: Trauma and mental health in low-SES African Americans and Latino/as. *Psychological Trauma, 7*(3), 243-251. doi: 10.1037/a0039077
- Mystakidou, K., Parpa, E., Tsilika, E.L., Panagiotou, I., Roumeliotou, A., Galanos, A. & Gourliamos, A. (2012). Traumatic experiences of patients with advanced cancer. *Journal of Loss and Trauma, 17*(20), 125-136. doi:10.1080/15325024.2011.595296
- National Cancer Institute. Adolescents and young adults with cancer. January 31, 2018, from <https://www.cancer.gov/types/aya>
- Nipp, R.D. et al. (2018). *Cancer, 124*(16), 3445-3453. doi: 10.1002/cncr.31576.
- Nobles, C., Valentine, S., Borba, C., Gerber, M., Shtasel, D. & Marques, L. (2015). Black-white disparities in the association between posttraumatic stress disorder and chronic illness. *Journal of Psychosomatic Research, 85*, 19-25. doi: 10.1016/j.jpsychores.2016.03.126
- Pai, A., Suris, A. & North, C.S. (2017). Posttraumatic stress disorder in the DSM-5: Controversy, change, and conceptual considerations. *Behavioral Sciences, 7*(7), 1-7. doi:10.3390/bs7010007

- Ponterotto, J.G. (2005). Qualitative research in counseling psychology: A primer on research paradigms and philosophy of science. *Journal of Counseling Psychology, 52*(2), 126-136.
- Porges, S. (2011). *The Polyvagal Theory: Neurophysiological Foundations of Emotions, Attachment, Communication, Self-Regulation*. New York, NY: W.W. Norton & Company.
- Pranjic, N., Bajraktarevic, A., & Ramic, E. (2016). Distress and PTSD in patients with cancer: cohort study case. *Materia Sociomedica, 28*(1), 12-16.
- Saakvitne, K.W. (2017). Relational theory: The cornerstone of integrative trauma practice. *APA Handbook of Trauma Psychology: Trauma Practice, 2*, 117-142.
- Salick, E.C. (2004). *Post-traumatic Growth Following Physical Disability and Chronic Illness*. Unpublished doctoral dissertation. Yeshiva University, New York.
- Salick, E.C. & Auerback, C. (2006). From devastation to integration: Adjusting to and growing from medical trauma. *Qualitative Health Research, 16*(8):1021-1037.  
doi: 10.1177/1049732306292166
- Scott, J.G., Warber, S.L., Dieppe, P., Jones, D. & Stange, K.C. (2017). Healing journey: a qualitative analysis of the healing experiences of Americans suffering from trauma and illness. *BMJ Open, 7*, 1-8. doi:10.1136/bmjopen-2017-016771
- Scott, M.J. & Stradling, S.G. (1992). *Counseling for posttraumatic stress disorder*. London, UK: Sage Publications.
- Scott, M.J. & Stradling, S.G. (1994). Post-traumatic stress disorder without the trauma. *British Journal of Clinical Psychology, 33*(1), 71-74.

- Sigmund, J.A. (2003). Spirituality and trauma: The role of clergy in the treatment of posttraumatic stress disorder. *Journal of Religion and Health, 42*(3), 221-230.  
doi: 10.1023/A:1024839601896
- Smith, L., Chambers, D.A. & Bratini, L. (2009). When oppression is the pathogen: The participatory development of socially just mental health practice. *American Journal of Orthopsychiatry, 79*(2), 159-168. doi:10.1037/a0015353
- Sorsoli, L., & Tolman, D. L. (2008). Hearing voices: Listening for multiplicity and movement in interview data. In S. N. Hesse-Biber & P. Leavy (Eds.), *Handbook of emergent methods* (pp. 495–515). New York, NY: Guilford Press.
- Stolorow, R.D. (2015). A phenomenological-contextual, existential, and ethical perspective on emotional trauma. *Psychoanalytic Review, 102*(1), 123-138.  
doi:10.1521/prev.2015.102.1.123
- Suzuki, L.A., Ahluwalia, M.K., Arora, A.K., & Mattis, J.S. (2007). The pond you fish in determines the fish you catch: Exploring strategies for qualitative data collection. *The Counseling Psychologist, 35*, 295-327.
- Swain, J., French, S., Barnes, C. & Thomas, C. (2004). *Disabling barriers- enabling environments* (2<sup>nd</sup> ed.). Thousand Oaks, CA: Sage Publications.
- Swartzmann, S., Booth, J.N., Munro, A. & Sani, F. (2017). Posttraumatic stress disorder after cancer diagnosis in adults: A meta-analysis. *Depression and Anxiety, 34*(4), 327-339.  
doi: 10.1002/da.22542
- Tedeschi, R.G. & Calhoun, L.G. (1996). The Posttraumatic Growth Inventory: Measuring the positive legacy of trauma. *Journal of Traumatic Stress, 9*, 455–472.  
doi:10.1002/jts.2490090305



- Timm, M. (2015). Creating a preferred counselor identity in supervision: A new application of Bernard's discrimination model. *The Clinical Supervisor, 34*, 115-125.  
doi: 10.1080/07325223.2015.1021499
- Tobin, S. (2004). Disability as masquerade. *Literature and Medicine, 23(1)*, 1-22.  
doi: 10.1353/lm.2004.0010
- Trost, Z., Scott, W., Guck, A., Agtarap, S., Driver, S., Roden-Foreman, K., Reynolds, M., Foreman, M.L. & Warren, A.M. (2015). Perceived injustice after traumatic injury: Associations with pain, psychological distress, and quality of life outcomes 12 months after injury. *Rehabilitation Psychology, 60(3)*, 213-221. doi: 10.1037/rep0000043
- Turner & Lloyd (1995). Lifetime traumas and mental health: The significance of cumulative adversity. *Journal of Health and Social Behavior, 36*, 360-376. doi: 10.2307/2137325
- Tutton, E., Seers, K. & Langstaff, D. (2012). Hope in orthopedic trauma: A qualitative study. *International Journal of Nursing Studies, 49*, 872-879.  
doi:10.1016/j.ijnurstu.2012.01.013
- Ungar, M., Ghazinour, M. & Richter, J. (2013). Annual research review: What is resilience within the social ecology of human development? *Journal of Child Psychology and Psychiatry, 54(4)*, 348-366. doi: 10.1111/jcpp.12025
- Vachon, M. (2001). The meaning of illness to a long-term survivor. *Seminars in Oncology Nursing, 17(4)*, 279-284. doi: 10.1053/sonu.2001.27926
- Van der Kolk, B.A. (2003). Post-traumatic stress disorder and the nature of trauma. In M.F. Solomon, D.J. Siegel (Eds.), *Healing trauma: Attachment, mind, body, and brain* (pp. 168-195). New York, NY: Norton.

- Van der Kolk, B. A. (2014). *The body keeps the score: Brain, mind, and body in the healing of trauma*. New York: Viking.
- Wade, D.M., Brewin, C.R., Howell, D.C., White, E., Mythen, M.G. & Weinman, J.A. (2015). Intrusive memories of hallucinations and delusions in traumatized intensive care patients: An interview study. *British Journal of Health Psychology*, 20, 613-631.  
doi: 10.1111/bjhp.12109
- Wakefield, J.C. (1997). Diagnosing DSM-IV – Part I: DSM-IV and the concept of disorder. *Behaviour Research and Therapy*, 35, 633– 649. doi: 10.1016/S0005-7967(97)00018-1
- Wertz, F.J. (2005). Phenomenological research methods of counseling psychology. *Journal of Counseling Psychology*, 52(2), 167-177.
- Wertz, F. J., Charmaz, K., McMullen, L. M., Josselson, R., Anderson, R., & McSpadden, E. (2011). *Five ways of doing qualitative analysis: Phenomenological psychology, grounded theory, discourse analysis, narrative research, and intuitive inquiry*. New York, NY: Guilford.
- Yalom, I. (1980). *Existential Psychotherapy*. New York, NY: Basic Books.
- Zola, I.K. (1989). Toward the necessary universalizing of a disability policy. *The Milbank Quarterly*, 67(2), 401-428. doi: 10.2307/3350151

## APPENDIX A

**Informed Consent**

This is an informed consent to participate in a qualitative research study at Lesley University. In order to participate, it is necessary that you give your informed consent. By signing this informed consent statement, you are indicating that you understand the nature of this project and agree to participate in this research. Please consider the following points before signing:

- I understand that I am participating in a 60 to 90-minute interview, which will be audio recorded and transcribed. I will also be asked to participate in a follow up questionnaire, although this portion is an optional part of the study. Participants in this study are younger adults who have been diagnosed with cancer and identify as having experienced psychological distress as a result. I will be asked questions around my emotional response to illness and how I have experienced grief, loss, and changes in identity. The purpose of this study is to better understand the phenomenon of psychological distress from cancer. I understand that talking about this subject may cause negative emotions and that I may decline to answer any of the questions, take a break or withdraw from the study at any time.
- I understand that my identity will not be linked with my data, and that all information I provide will remain confidential. Data will be stored in a locked file cabinet and on a password protected computer.
- I understand that participation in research is not required, is voluntary, and that I may withdraw my participation in the study for any reason and at any time without penalty.
- There is a Standing Committee for Human Subjects in Research at Lesley University to which complaints or problems concerning any research project may, and should, be reported if they arise. Contact the Committee Chairperson at [irb@lesley.edu](mailto:irb@lesley.edu)

By signing this form, I am stating that I am over 18 years of age, and that I understand the above information and consent to participate in this academic research at Lesley University.

Signature: \_\_\_\_\_ Today's Date: \_\_\_\_\_ Print name: \_\_\_\_\_  
(of participant)

Signature: \_\_\_\_\_ Today's Date: \_\_\_\_\_  
(of researcher)

If you have any additional questions or concerns about this study, please contact the principal researcher or the faculty advisor:

Researcher: Audrey Ryan, LMHC      aryan4@lesley.edu      cell: 617-320-0538

Faculty Advisor: Susan Gere, Ph.D.      sgere@lesley.edu      617-349-8342

### Informed Consent

This is an informed consent to participate in a qualitative research study at Lesley University. In order to participate, it is necessary that you give your informed consent. By signing this informed consent statement, you are indicating that you understand the nature of this project and agree to participate in this research. Please consider the following points before signing:

- I understand that I am participating in an email questionnaire distributed through a secure email. My questionnaire will be linked with my original interview transcript and my identity will be kept confidentially. The questionnaire will address psychological distress related to cancer asking for qualitative responses to questions in written form.
- I understand that all information I provide will remain confidential. Data will be stored in a locked file cabinet and on a password protected computer. The data will be destroyed after five years.
- I understand that participation in research is not required, is voluntary, and that I may withdraw my participation in the study for any reason and at any time without penalty.
- There is a Standing Committee for Human Subjects in Research at Lesley University to which complaints or problems concerning any research project may, and should, be reported if they arise. Contact the Committee Chairperson at [irb@lesley.edu](mailto:irb@lesley.edu)

By signing this form, I am stating that I am over 18 years of age, and that I understand the above information and consent to participate in this academic research at Lesley University.

Signature: \_\_\_\_\_ Today's Date: \_\_\_\_\_ Print name: \_\_\_\_\_  
(of participant)

Signature: \_\_\_\_\_ Today's Date: \_\_\_\_\_  
(of researcher)

If you have any additional questions or concerns about this study, please contact the principal researcher or the faculty advisor:

Researcher:            Audrey Ryan, LMHC            aryan4@lesley.edu    cell: 617-320-0538

Faculty Advisor:     Susan Gere, Ph.D.            sgere@lesley.edu    617-349-8342

## APPENDIX B

**Information Sheet**

**Study Title:** *Injecting Empathy into the Medical Model: Understanding Psychological Distress from a Cancer Diagnosis.*

Researcher: Audrey Ryan, LMHC      aryan4@lesley.edu      cell: 617-320-0538  
Faculty Advisor: Susan Gere, Ph.D.      sgere@lesley.edu      617-349-8342

**Why are you doing this study?**

The purpose of this study is to better understand the lived experience of psychological distress in younger adults diagnosed with cancer. This is a qualitative phenomenological study for a dissertation in counseling psychology with the goal of building a model of this phenomenon.

**What will I be asked to do in this study?**

Participants will be asked to explore their experience of psychological distress in relation to their cancer diagnosis. All of the questions will be open-ended and revolve around the lived experience of having cancer and its impact on mental health and life stressors.

**What are the possible risks or discomforts?**

Due to this research digging into the experience of psychological distress from cancer there is a high likelihood of participants sharing negative emotions surrounding their illness that could be potentially distressing. To account for potential negative emotional responses, resources for counseling will be provided as well as a clinician on call to speak with.

**What are the possible benefits?**

The potential benefit for participants will be creating a safe space to share their emotional journey with cancer and have their voices heard. The interview could potentially have some cathartic benefit for participants.

**How will you protect the information you collect, and how will that information be shared?**

Results of this study may be used in a dissertation, publications, and presentations. Pseudonyms will be used for all participants and named parties, and for locations shared during the interview. All paper copies of transcripts will be kept in a secure location and separate from pseudonym codes. All digital information will be encrypted and stored on a password-protected device. Upon completion of this study, data will be permanently deleted from the digital device and all paper materials will be shredded. All information disclosed in this interview will remain confidential.

**Financial Information**

Participants will be compensated with a \$25 gift certificate for participation in the interview. They will be compensated \$20 for participation in a follow up questionnaire.

**What are my rights as a research participant?**

Participation in this study is voluntary. Participants may withdraw from this study at any time - they will not be penalized in any way or lose any sort of benefits for deciding to stop participation.

If a participant decides to withdraw from this study, the researcher will ask if the information already collected can be used.

**Who can I contact if I have questions or concerns about this research study?**

If participant have any questions, they may contact the researcher at:

Audrey Ryan  
617-320-0538  
[aryan4@lesley.edu](mailto:aryan4@lesley.edu)

Those who have any questions about participating in this research can contact the Institutional Review Board at Lesley University via [irb@lesley.edu](mailto:irb@lesley.edu).

## APPENDIX C

**RESEARCH STUDY****Investigating the lived experience of  
Psychological Distress from Cancer**

*Seeking research participants for a qualitative  
study on psychological distress in reaction to a  
cancer diagnosis.*

- Inclusion criteria: 18-39 years old  
Cancer diagnosis within past 5 years
- Procedures involved: Interview (in person or online)  
Follow-up questionnaire (optional)
- Time commitment: 60-90 minutes
- Compensation: \$25 for interview; \$20 for follow-up questionnaire
- Location: Interviews can take place at your home, the researcher's  
office in Kenmore Square, or Lesley University.
- Contact Information: Researcher- Audrey Ryan, LMHC, Ph.D. student  
464 Commonwealth Ave., Boston, MA  
audreyryanlmhc@gmail.com  
617-320-0538
- University affiliation: Lesley University, Cambridge MA  
Counseling & Psychology Department

**APPENDIX D     Research Question Protocol- Semi-Structured Interview****A. Diagnosis:    How did you experience your cancer diagnosis?**

*(Follow up questions: How long did it take for clinicians to make the diagnosis? Was the diagnosis made incidentally or after symptoms? Was it expected or unexpected?)*

**B. Bedside manner: How did you experience bedside manner of your providers?**

*(Follow up question: Did the physician delivering the news offer support and empathy or was he/she matter-of-fact?)*

**C. Treatment and Procedures: How did you experience any medical procedures and/or treatments for your cancer?**

*(Follow up questions: Are there specific memories of medical procedures or treatment that have stuck with you? Have you experienced thoughts of reenactment or ruminations? (Define terms.)*

**D. Identity/Grief/Loss: How have you experienced grief and loss with respect to cancer?**

*(Follow up questions: How has your relationship with your body changed since being diagnosed? Do you feel that your body is a safe space? Do you feel you've experienced identity (define?) changes with respect to having had cancer?*

**E. Future: In your experience, how has cancer changed your thoughts about the future?**

*(Follow up questions: To what extent do you worry about the future, your prognosis, longevity? How has time passing affected your experience of living with cancer?)*



**F. Existential: Did your diagnosis begin a process of re-evaluation of life goals?**

*(Follow up questions: How have you tried to make sense of the diagnosis existentially (define)?*

*An existential crisis? A search for spirituality?)*

### **Debriefing**

How has this experience been for you?

Do you have any questions for me?

Thank you so much for talking to me today about such a difficult topic. My hope is that these interviews will help me to gain more insight into the psychological effects of cancer and building a model of medical traumatic stress. I really appreciate you taking the time to talk with me today and I would be happy to share with you my results if you are interested. There is also an optional follow up questionnaire to the interview, if you are interested in participating we can keep in touch. Thank you again for your time.

Here is a list of local and national resources for cancer support groups and programs. If you would like a referral for a therapist I am also happy to provide you with a list of clinicians.

## RESOURCES

### **Dana Farber**

Young Adult Program (YAP)

617-632-3301

[amanda\\_bryant@dfci.harvard.edu](mailto:amanda_bryant@dfci.harvard.edu)

<https://www.dana-farber.org/for-patients-and-families/care-and-treatment/support-services-and-amenities/young-adult-program/>

<https://www.facebook.com/YAPatDFCI>

### **Facing Cancer Together**

410 Washington Street

Brighton, MA

[ngaulin@facing-cancer.org](mailto:ngaulin@facing-cancer.org)

617-332-5777

<https://facing-cancer.org>

### **Stupid Cancer**

Facebook support group:

<https://www.facebook.com/stupidcancer/>

<https://www.facebook.com/groups/scnortheast/>

## APPENDIX E

**Follow up Questionnaire**

**DEFINITION of Medical Traumatic Stress:** *1) Traumatic event caused by an internal stressor; the body attacking itself. 2) Typically involves future oriented concerns of prognosis, functionality, and morbidity. 3) The body no longer feels safe, survivor may feel betrayed by their body.*

1. How do you identify with this definition of medical traumatic stress from your experiences?
  
  2. What symptoms have you experienced more prominently as part of this traumatic stress?
  
  3. What part of your experience of cancer was most traumatic for you: diagnosis, treatment, bedside manner of medical providers, procedures, or prognosis?
  
  4. Which aspects were and were not what you would consider to be traumatic?
  
  5. What are your challenges living with cancer day-to-day?
  
  6. How has your cancer affected home life and work life?
  
  7. How have you obtained support?
  
  8. Have factors of race, class, gender, or sexuality affected your experience of having cancer?  
Access to services (healthcare)? Sociocultural stressors? Have you experienced any stigma?
-