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Amy Tindall Willson
“If I told you what was going
to happen, you wouldn’t do
it”: The Breast Cancer
Survivor’s Experience of
Chemotherapy

ABSTRACT

Chemotherapy is a concept that strikes a chord inside many people, conjuring images of nausea, hair loss, and pain. It is synonymous with cancer. The impact of undergoing treatment for a life-threatening diagnosis like cancer can have both seen and unseen impacts on the person, their families, and their loved ones. The effects can reverberate through a person’s life, affecting not only their health status, but also their relationships, careers, sense of self, worldview, and spirituality. This study looks more closely at the experiences of women who have undergone chemotherapy for the treatment of breast cancer and considers the full range of experiences to better understand the effects it has on people’s lives. Specifically, the purpose of this study is to lay the groundwork for the understanding of the impact of chemotherapy on breast cancer survivors. Through 11 one-to-one interviews with women who have been treated with chemotherapy for breast cancer, this study will focus in-depth on what the experience of chemotherapy was like for these women and how it changed their lives.

Major findings in this study include significant experiences of positive life changes in the realms of sense of self, relationships, and spirituality following chemotherapy. This study can be broadened to include people undergoing many different invasive treatment procedures and affect how mental health professionals interact with and treat these populations.

“IF I TOLD YOU WHAT WAS GOING TO HAPPEN, YOU WOULDN’T DO IT”:
THE BREAST CANCER SURVIVOR’S EXPERIENCE OF CHEMOTHERAPY

A project based upon an independent investigation,
submitted in partial fulfillment of the requirements
for the degree of Master of Social Work.

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2008

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This thesis is dedicated to the millions of women and men who have been touched by breast cancer. To those who have survived, those who have passed, and those who continue to fight, this study is done in your name.

This study would not have been possible without the love, support, understanding, and tears of many. First and foremost to my mother, Susan, for always supporting me in all my foibles- you are my inspiration. To Betty Clark, though you are no longer with us your spirit and grace remain. To my dad, John, my brothers, Andy and Matt, and my sister-in-law, Kara, I certainly wouldn't be here without a lot of your sweat and heavy lifting. To my best friend, Erin Jorgenson, without whom I would be lost. To all my Smith girls- you are too numerous to name, but rest assured each and every one of you has a special place in my heart. To my thesis advisor Jill Clemence- your patience, understanding, and guidance have been invaluable to me during this process. I could not have done it without you. And last, but certainly not least, to all the women who invited me into their lives for a brief moment to share their experiences- I have been touched and humbled by all of you.

Thank you, thank you. A million times, thank you all.

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CHAPTER I

INTRODUCTION

Chemotherapy is a concept that strikes a chord inside many people, conjuring images of nausea, hair loss, and pain. It is synonymous with cancer. The impact of undergoing treatment for a life-threatening diagnosis like cancer can have both seen and unseen impacts on the person, their families, and their loved ones. The effects can reverberate through a person's life, affecting not only their health status, but also their relationships, careers, sense of self, worldview, and spirituality. When chemotherapy is chosen as a method of treatment, this impacts the person's experience of the illness as it can cause a myriad of side effects that range from mild to life threatening, in and of themselves. These can lead to an array of responses that range from mild discomfort to symptoms of trauma (Stewart, Bielajew, Collins, Parkinson, and Tomiak, 2006, Mehnert and Koch, 2007, and Rabin, Leventhal, and Goodin, 2004). For many, chemotherapy changes the landscapes of their lives and is often regarded as being worse than the cancer (Docherty, Sandelowski, and Preisser, 2006). The DSM-IV-TR includes "being diagnosed with a life-threatening illness" as a traumatic event that can lead to the symptoms and diagnosis of Posttraumatic Stress Disorder (PTSD) (DSM-IV-TR, 2000, p. 462). This study proposes to closely examine the specific stressors that can arise from chemotherapy as it is considered independently from cancer. Previous research has found that individuals undergoing chemotherapy experience changes in quality of life (e.g. Zebrack, Yi, Petersen, and Ganz, 2007, Hurria, A., Rosen, Hudis, Zuckerman, Panageas,

Lachs, Witmer, van Gorp, Fournier, D'Andrea, Moasser, Dang, Van Poznak, Hurria, and Holland, 2006, and Carver, Smith, Petronis, and Antoni, 2006), anticipatory nausea (e.g. Montgomery, Bovbjerg, 2003, and Montgomery, Bovbjerg, 2001), cognitive impairment (e.g. Falletti, Sanfilippo, Maruff, Weih, and Phillips, 2005, and Bender, Sereika, Berga, Vogel, Brufsky, Paraska, and Ryan, 2006), depression and anxiety (e.g. Reddick, Nanda, Campbell, Ryman, and Gaston-Johansson, 2005, and Deshields, Tibbs, Fan, and Taylor, 2006), and fatigue (e.g. Jacobsen, Hann, Azzarello, Horton, Balducci, and Lyman, 1999, and Mills, Parker, Dimsdale, Sadler, and Ancoli-Israel, 2005). None of these studies, however, have looked at how these chemotherapy side effects have affected the realms of spirituality, sense of self, and worldview as this study does.

What is it like when the treatment for the illness is what many consider to be the worst part? What about effects that aren't considered to be traumatic, but still impact one's life? This study looks more closely at the experiences of women who have undergone chemotherapy for the treatment of breast cancer and considers the full range of experiences to better understand the effects it has on people's lives. Specifically, the purpose of this study is to lay the groundwork for the understanding of the impact of chemotherapy on breast cancer survivors. However, the implications of the findings of this study can be broadened and generalized to other cancers that have a chemotherapy protocol as well. These findings can be translated into ways to provide more emotional, physical, spiritual, and mental support for patients undergoing chemotherapy and allow for a better understanding of what happens when someone undergoes a life-threatening treatment. While the chemotherapy experience may not be explicitly traumatic, it is

possible that it is on a spectrum that includes its own set of psychologically distressing symptoms that need to be addressed in the field of mental health.

Through one-to-one interviews with women who have been treated for breast cancer, this study will focus in-depth on what the experience of chemotherapy was like for these women and how it changed their lives, for good, bad, or not at all. This kind of information can lead to a better understanding of what is needed by cancer patients before, during, and after chemotherapy. Are their mental health needs being met? Are their relationships being strained? Has it raised questions regarding their faith? Do they regret the decision? All of these are important factors to consider when treating a person as a whole and should not be overlooked by the medical and mental health communities.

CHAPTER II

LITERATURE REVIEW

A 2006 case study examined the reactions of a teenage girl, Abby, undergoing chemotherapy for the treatment of Hodgkin's Lymphoma (Docherty, Sandelowski, and Preisser, 2006). What the authors observed was the young woman "fighting the treatment, as opposed to fighting the cancer. (Her) response to her symptoms frightened her, and she felt that she might not be up to the challenge" (Docherty et al., 2006, p.305). Abby wrote in her journal "(w)ell, it's a feeling that I had for awhile with this. It didn't seem right. It just didn't make any sense to me that for my body to get better, I have to completely break it down and get sick and just, and just so I can get better. It just didn't seem right" (Docherty et al., 2006, p.304). In a 1997 case study, Flemons followed a woman, Judith Shulimson, through her treatment for breast cancer and included segments from her journal in his case study. She wrote that "(t)he cure is worse than the disease, especially since the disease hasn't really caused me any problems so far; it's the treatment that has made me so sick....The first chance I get to think about continuing with chemotherapy I start thinking of running away....Chemotherapy: metaphors of aggression, destruction, violence, warfare" (Flemons and Shulimson, 1997, p.182). The irony of the cure being worse than the disease is hardly a novel idea and is certainly not limited to chemotherapy. Around 100 BC, Greek philosopher Publilius Syrus stated that "(t)here are some remedies worse than the disease." This idea seems to be especially highlighted in the use of chemotherapy to treat cancer. The side effects can result in

myriad changes that people may experience for the rest of their lives, or at least long after treatment for their cancer has ended. For women with breast cancer this can be especially poignant as they are already wrestling with a sickness that has struck in a place that, for many, is an important part of their identity and sexuality. When chemotherapy ends it does not necessarily denote the end of its impact.

Co-Morbids

Multiple studies have found that chemotherapy has been associated with high co-morbidities of both a physical and psychological nature (Maguire, Faulkner, Booth, Elliot, and Hillier, 1996, Wilkinson, 1991, and Watson, Meyer, Thomson, and Osofsky, 1998). The psychological co-morbidities looked at in this study are Posttraumatic Stress Disorder, Anxiety Disorders, and Depression, as well as general feelings of lowered emotional and affective functioning caused by side effects.

Posttraumatic stress disorder (PTSD)

The DSM-IV-TR explains PTSD, in part, as the development of certain “symptoms following exposure to an extreme traumatic stressor involving direct personal experience of an event that involves actual or threatened death or serious injury, or a threat to one’s physical integrity” (American Psychiatric Association (APA), 2000, p.463). It goes on to include “being diagnosed with a life-threatening illness” (APA, 2000, p.464) as one of these traumatic stressors. With these criteria in mind, chemotherapy certainly seems to fit this bill, as well as the diagnosis of cancer itself. With its dramatic side effects and reputation for being worse than the cancer, chemotherapy appears to fit the bill of being a “traumatic stressor” (APA, 2000, p.463).

Much of the current research regarding PTSD symptoms and breast cancer is focused on the diagnosis (Tjemmland, Soreide, & Malt, 1996) or the overall experience itself (Rabin, Leventhal, & Goodin, 2004, Mehnert & Koch, 2007, and Amir & Ramati, 2002). Much of the findings from these studies highlight the fact that “(t)here is evidence that a number of patients develop cancer- or treatment-related PTSD” (Mehnert & Koch, 2007, p.186). However, the findings also supported the strong link between patients’ understandings about the cancer and the treatment and subsequent symptoms of PTSD. According to Rabin et al. (2004), the emotional reactions of most patients to their illness are due in large part to their beliefs about the disease, not medical information. This underscores the importance of a patient’s state of mind and beliefs while undergoing chemotherapy in determining how the treatment will effect them post-treatment. Amir and Ramati (2002) found a correlation between women receiving chemotherapy with a low-disease stage and a higher risk for developing PTSD-like symptoms. A possible theory behind their finding is “that the coping style of suppression in a supposedly healthy woman (low disease stage), combined with difficult chemotherapy, creates the most fertile ground for the development of PTSD symptoms” (Amir & Ramati, 2002, p.204) thus underscoring the profound impact of chemotherapy and the associated beliefs a patient may have with it in determining its long-term effects in survivors.

Taieb, Moro, Baubet, Revah-Levy, and Flament (2003) looked at PTSD symptoms in young survivors of childhood cancer and their parents. They found that “it is both the diagnosis of cancer (an acute event of life threat) and its treatment (a long-lasting or repetitive threat to both life and physical integrity), which are experienced as the traumatic events by children and their parents” (Taieb et al., 2003, p.262).

Tjemsland et al. (1996) conducted a study in which they focused solely on the experience of being diagnosed with breast cancer and the time leading up to initial surgery. They found that “nearly half of the patients reported a high level of intrusive thoughts during the days immediately following diagnosis” (Tjemsland et al., 1996, p.6). Could some of these intrusive thoughts be related to anticipation anxiety for what the patients may assume to be a treatment protocol that may include chemotherapy? Certainly it’s hard to separate the concept of cancer from its most high-profile treatment.

Psychological distress including depression, anxiety, and cognitive functioning

Several studies have cited psychological distress (including depression, anxiety, emotional expression, and neuropsychological effects) as a phenomenon commonly associated with breast cancer and its treatment. Pieterse, van Dooren, Seynaeve, Bartels, Rijnsburger, de Koning, Klijn, van Elderen, Tibben, & Duivendoorn (2007) related coping styles with psychological distress measurements. They found that “(a)pproach coping (trying to do something about the stressor) for instance, was found to be more beneficial than avoidant coping (trying to avoid the stressor)” (Pieterse et al., 2007, p.851). Moreover, Pieterse et al. found that when a patient either sought out, or had in place, strong social support this could decrease levels of psychological distress and was in line with the results associated with active coping styles. A study by Manne, Glassman, and Du Hamel (2000) found that a decline in physical abilities in women with cancer predicted maladaptive coping strategies more often in those with lower-stage cancer than those with a higher stage. This would seem to imply that the psychological distress experienced by healthier seeming women is greater and more drastic than that of women who may be sicker. Reddick, Nanda, Campbell, Ryman, & Gaston-Johansson

(2005) had findings that were consistent with this hypothesis and also found that “coping plays a significant role in the process of psychosocial adaptation to breast cancer” (Reddick et al., 2005, p.151). Again, this underscores the connection between the impact of cancer and chemotherapy and women’s self-views. It also speaks to the idea that women with better coping strategies may find that previously held personal beliefs are less affected by treatment. Shapiro, Boggs, Rodrigue, Urry, Algina, Hellman, and Ewen (1996) studied differences in various coping styles and found that side effects were less profound in women with a confrontive coping style, that is, women who sought out information and were willing to talk about cancer both in and out of the treatment setting, as well as women who reported higher levels of optimism. “(C)oping patterns were significant predictors of physical, psychological, and total side effects in women with stage II breast cancer receiving adjuvant chemotherapy” (Shapiro et al., 1996, p.152). As to optimism having an effect on long-term psychological well-being, Tartaro, Roberts, Nosarti, Crayford, Luecken, and David (2005) wanted to know what consequences and outcomes, if any, women saw who were able to find some benefit in their course of illness and treatment. What they found in this study was that prior to diagnosis, while seeking treatment for their symptoms, the women who reported higher levels of distress were the same women who were able to find benefit in their cancer and treatment experience, thus plummeting their distress scores during their course of treatment. However, two-and-a-half years following the end of treatment, women who had found benefit and women who had not, were equal in levels of distress in quality of life (QOL) and adjustment. One notable difference was that spiritual well-being was reported as higher by the women who felt they had found some meaning in their cancer than those

who did not (Tartaro et al., 2005). Whether this is caused by the cancer diagnosis alone, or is on part due to the course of chemotherapy, is what this study aims to look at.

Lam, Chan, Ka, and Fielding (2007) looked at treatment decisions made post-surgery by Chinese women and found that those who had difficulties deciding on a course of treatment, and had experienced distress during the early post-operative period, “were at greater risk of persistent psychological morbidity” (Lam et al., 2007, p.910). “(P)sychological morbidity is not just a transient reaction to diagnosis and treatment of breast cancer, with 49% reporting psychological morbidity lasting at least 8-months” (Lam et al., 2007, p.910). This statistic, when compared with the rate of psychological morbidity in Caucasian women, was significantly higher. Interestingly enough, the authors noted that this discrepancy may have more to do with the younger average age of their participants, 51.2, than with their ethnicity, as they were being compared to women in western studies with the average age of 59.4. This correlates with studies about younger women having more adverse reactions to chemotherapy, as discussed in a later section.

While depression is not a statistically likely response to breast cancer treatment, when it *is* a factor it can have over-arching consequences that can lower perceived QOL (Desields, Tibbs, Fan, & Taylor, 2006). “Depressive symptoms can affect interpersonal relationships, occupational performance, perceptions of health, and physical symptoms” (Desields et al., 2006, p.404). According to other studies, a third of people with cancer will develop a depressive illness and/or an anxiety disorder (Derogatis, Morrow, Fetting, Penman, Piasetsky, and Schmale, 1983, and Parle, Jones, and Maguire, 1996). As cited in Chan, Ho, and Chan (2007), “Zebrack concluded that ‘quality of life outcomes partially

may be a function of the cognitive frame or meaning that survivors attribute to their experience” (Chan et al., 1999, p.847). Certainly, if a person is suffering from depressive symptoms this framework would be significantly affected and thus their feelings regarding identity and self-view, among other things. In a study comparing depressive symptoms immediately following treatment and again 2 years after diagnosis, Sharpley and Christie (2007) found that women’s initial self-reports were higher than those subsequent. “(T)hey placed less weight upon the somatic symptoms as time went by and instead emphasized more their lack of ability to cope with demands of having cancer, their mental confusion and their feelings of hopelessness and loss of previously valued activities” (Sharpley & Christie, 2007, pps.759-760). This finding begs the question about how many of these symptoms were due to anxiety and fear proceeding the start of chemotherapy and then morphed into concerns about quality of life and loss of cognitive functioning following the end of treatment.

A meta-analysis of studies conducted by Stewart, Bielajew, Collins, Parkinson, and Tomiak (2006) found significant results linking cognitive decline with adjuvant chemotherapy for breast cancer. “It has been suggested that these changes are a consequence of chemotherapy-related neurotoxicity” (Stewart et al., 2006, p.77). In this study a decline in visual memory, attention, visuospatial functioning, learning, speed of processing, and verbal learning were linked with women who had undergone chemotherapy for the treatment of their breast cancer (Stewart et al.). A meta-analysis of six studies on the subject found that “chemotherapy may give rise to some generalized cognitive impairment” (Falleti, Sanfilippo, Maruff, Weih, & Phillips, 2005, p.66). Yet another study also found declines in verbal memory but not visual memory, however, this

study also found that “perceptions of cognitive impairments were evident immediately following the conclusion of chemotherapy. Thus, the subjective reports of cognitive impairment preceded declines detected by the objective measures” (Bender, Sereika, Berga, Vogel, Brufsky, Paraska, & Ryan, 2006, p.428). A perceived cognitive decline that occurs before an objectively measurable one could be argued to be due, at least in part, to previously held beliefs about chemotherapy and its side effects as understood in our culture. Such beliefs could weigh heavily in the impact such a treatment has. One could speculate that any deterioration in such significant areas of cognitive functioning would most assuredly have some impact on a patient’s sense of identity.

A study by Farrell, Heaven, Beaver, and Maguire (2005) looked at women undergoing in-patient chemotherapy and how responsive their caregivers were to their needs, including psychological needs. They found that nurses in the ward identified about 20% of the actual concerns of patients and “were least likely to identify concerns about the future and psychological concerns” (Farrell et al., 2005, p.74). This is an interesting phenomenon in that it may have a profound effect on a woman’s experience of chemotherapy if she feels that her caregivers are not in-tune with many of her needs. If psychological needs go unaddressed in treatment, such as feelings of sadness or anxiety, then it can’t be assumed that they will go away once treatment is concluded and not remain as an ongoing concern.

A study by Alder and Bitzer (2003) looked at which stages of treatment women experienced positively and which were more negative. The stages were broken down into diagnosis, in-patient treatment, chemotherapy, radiotherapy, and after-care and the survey was given to women who were within 5 years of being diagnosed with breast cancer.

What they found was that “the first diagnostic phase and the phase of chemotherapy represented the most strainful” (Alder & Bitzer, 2003, p.93). They found that the significance of patients having a negative experience during chemo- or radiotherapy had higher depression and anxiety scores at the time of the survey. Women who reported having had an overall negative experience with the medical system also showed higher anxiety and depression scores (Alder & Bitzer, 2003). The implications of this study suggest that a possibly mitigating influence during chemotherapy could be the interactions with healthcare workers. It is possible that these types of encounters could help ease feelings of anxiety and depression brought on by the side effects and psychological impact of undergoing chemotherapy, thus making its impact less profound.

Last to note, “(l)iving through the cancer of a close family member...could contribute to a learning history that vividly equates cancer with extremely noxious outcomes. This could leave women in a heightened state of fear and anxiety over the consequences of personally experiencing cancer” (Badger, Segrin, Meek, Lopez, & Bonham, 2005, p.96). Is it the cancer itself, the fears related to treatment, or a combination of both that create these “noxious outcomes”?

Nausea

Perhaps one of the most common side effects traditionally associated with chemotherapy is nausea. Anticipatory nausea has been studied (Montgomery & Bovbjerg, 1996) to determine factors associated with expectations of nausea, time nausea begins in relation to infusion, and change in pattern as treatment progresses. Results indicate that as patients progress in their treatment their anticipatory nausea becomes based on real-life experience of it and not just previously held beliefs (Montgomery & Bovbjerg, 2001). A

third study by Montgomery and Bovbjerg (2003) showed a correlation between emotional distress and anticipatory nausea before the first infusion and with no prior history of receiving chemotherapy. The fact that anticipatory nausea can happen even before the first infusion of chemotherapy goes to show how deeply ingrained in our cultural awareness this side effect is and raises questions about how this affects a patient's overall experience of the treatment and their own role within it.

It's not only anticipatory nausea that is a side effect of chemotherapy, but delayed nausea as well. "(D)elayed nausea and vomiting (i.e. nausea and vomiting occurring more than 24 h post-chemotherapy) was a considerable problem. Delayed nausea was present for 5 days and vomiting for 3 days post-chemotherapy" (Molassiotis, 2000, p.233). Such an intense side effect is not without its consequences, especially when considered in the context of receiving multiple infusions over the course of treatment.

Fatigue

Similar to nausea, fatigue is one of the most common side effects experienced by people undergoing chemotherapy. According to Servaes, Verhagen, and Bleijenbergh (2002) it is, in fact, the most common side effect. Bovbjerg, Montgomery, and Raptis (2005) considered whether or not fatigue could be considered to be a conditioned response to chemotherapy. Their results indicate that there is a significant relationship between the two, even going so far as to speculate that the results may last well past the end of treatment. As Cameron, Cella, Herndon, Kornblith, Zuckerman, Henderson, Weiss, Cooper, Silver, Leone, Canellos, Peterson, and Holland (2001) found, it's not uncommon for patients to re-experience nausea when returning to the clinic long after their treatment has ended. Another notable effect of this possibly conditioned response,

similar to the data on nausea, is that of anticipatory fatigue (Bovbjerg et al., 2005). As with anticipatory nausea, the researchers in this study noted a certain number of subjects that appeared to suffer from fatigue before even their first infusion of chemotherapy. Considering the possible psychological impact of a conditioned response of either nausea or fatigue, or both, it is significant to note that sometimes the symptom occurs *before* the stimulus has even been introduced. Can it be that the possible side effects of chemotherapy are so commonly known that they can actually happen when chemotherapy is just anticipated? This would seem to indicate a rather strong reaction to the treatment, outside of its physical effects. A third common side effect, stress, has also been studied as an anticipatory phenomenon (Lekander, 2001). “The present pattern of data indicates that immune variables change as a function of anticipation when cancer patients report to the treatment-associated milieu” (Lekander, 2001, p.36). Lekander goes on to speculate that this reaction can be due to either the conditioned response, or, in the case of patients who have yet to undergo their first infusion, “higher mental functions” (Lekander, 2001, p.37). If the stimulus is coming from the patient’s imagination, than it is a powerful force, indeed.

This finding proves to be even more significant in light of the research by Mills, Parker, Dimsdale, Sadler, and Ancoli-Israel (2005) who found that “the increased ratings of depressed mood in response to chemotherapy were best predicted by pre-treatment ratings of depressed mood and by fatigue in response to chemotherapy” (Mills et al., 2005, p.92). Anticipatory responses have the potential to have a great impact on post-treatment reactions. When fatigue is elevated, women tended to report that it “interfered to a greater extent with their general activity, ability to bathe and dress, normal work

activity, ability to concentrate, relations with others, enjoyment of life, and mood” (Jacobsen, Hann, Azzarello, Horton, Balducci, and Lyman, 1999, p.239). Alterations to one’s lifestyle of this magnitude, from a combination of real and perceived possible side effects, have the potential to drastically impact many beliefs held by the person experiencing them. Self-view, identity, sexual identity, and spirituality are all likely to be considered during such a painful period.

Quality of Life/Identity

Quality of life

Quality of life (QOL) includes such realms as physical and emotional functioning and health, social functioning, vitality, sleep quality (Stein, Jacobsen, Hann, Greenberg, and Lyman, 2000), body image, future perspective, and sexual functioning/enjoyment (Janz, Mujahid, Lantz, Fagerlin, Salem, Morrow, Deapen, and Katz, 2005) among other things. Irwin, Arnold, Whelan, Reyno, and Cranton (1999) found in their research on subjects who got to choose between a more aggressive and shorter course of chemotherapy versus a longer course with fewer side effects, that “quality of life is subjective and can only be defined by the individual based upon what he/she believes matters most” (Irwin et al., 1999, p.290). There have been many studies on the realm of how disease affects people’s perceived quality of life, particularly in breast cancer research. This research relates to the current study in that the specific role that chemotherapy plays in that process is being examined. It is interesting to note that many of the following studies show an initial decrease in QOL during treatment, and a return to previous levels in the months following treatment completion.

In a study by Buick, Petrie, Booth, Probert, Benjamin, and Harvey (2000), the researchers sought to compare the change in affect and function between women referred for chemotherapy and those referred for radiotherapy for breast cancer. What they found is that “(r)adiotherapy and chemotherapy produce low to moderate psychological distress and functional impairment” (Buick et al., 2000, p.54). However, when the two groups were directly impaired, they found that the women referred for chemotherapy experienced more functional impairment and negative affect than did those referred for radiotherapy, as well as more disturbance to their sleep and managing within the home. Overall, they found that “(r)eferral for chemotherapy as opposed to radiotherapy appears to produce an 8% to 25% increase in impairment of everyday activities” (Buick et al., 2000, p.55). In other words, before treatment has even begun, many women experience a negative daily impact in their lives for just having been referred for chemotherapy. The final factor these researchers considered was the impact of the side effects of chemotherapy on subjects’ affect and functioning levels. Hair loss, bladder infections, and nausea “are not conducive to maintaining one’s social, vocational, and domestic responsibilities and interpersonal relationships. Psychosocial disruption associated with chemotherapy may affect patients’ perception of their ability to meet role demands and personal expectations” (Buick et al., 2000, p.56). This shift in perception has the potential to greatly affect a person’s sense of mastery and autonomy, and thus their overall self-image. The ways in which a woman copes with these stressors could be integral for how she feels about herself when treatment is completed.

One side effect of chemotherapy in particular, hot flashes, has been estimated to occur in about 40% of women in chemotherapy treatment for breast cancer (Stein et al.,

2000). Stein et al. also found that 58% of those women found them to be somewhat to very distressing. “(W)omen with hot flashes experienced poorer sleep quality, higher levels of fatigue, and poorer physical health compared to women without hot flashes” (Stein et al., 2000, p.443). This same study also found a significant relationship between hot flashes and poorer quality of life. As an exclusive symptom of chemotherapy, hot flashes are unique in that they can provide reasonable evidence as to the potential impact that this treatment alone can have on women.

The Janz et al. (2005) study found evidence to suggest “that adjuvant chemotherapy had a greater impact on QOL than which surgical procedure was performed. While the largest QOL differences were found in areas of body image and future perspective, meaningful differences were also observed in social well-being and fatigue” (Janz et al., 2005, p.1477). Also interesting to note, this same study found that these QOL impacts had more of a detrimental effect of younger versus older women. It can be speculated that this could, in part, be due to the side effects producing more of a disturbance in the lives of younger women who may be working more, caring for a young family, and possibly never having dealt with any prior major health issues. Janz et al noted in this study that there did not appear to be any discrepancies across race when testing for QOL changes, but did note that “chemotherapy had a disproportionately greater impact on women with lower levels of education... (i)n this study women who reported having less than a high school diploma were also more likely to be minority, of lower income, and unemployed” (Janz et al., 2005, p.1477). This finding can have implications on the types of support networks these women have and, similar to the results found for young women, have more of a profound impact on their day-to-day

functioning. Daily functioning includes not only being financially secure enough to miss work, but also the toll that fatigue and all the other symptoms can take on women who may have to do more active and hands-on jobs. Carver, Smith, Petronis, and Antoni (2006) had slightly different findings in their study on QOL. They found that “Hispanic women reported more frequent negative feelings, more social avoidance, more distress about their family’s future, and more distress about the possibility of recurrence than did other women” (Carver et al., 2006, p.756). Spencer, Lehman, Wynings, Arena, Carver, Antoni, Derhagopian, Ironson, and Love (1999) said that “(a)lthough differences emerged between age and ethnic groups in profiles of concerns felt and distress levels experienced, associations among the variables did not vary significantly by subgroup” (Spencer et al., 1999, p.167). Spencer et al. (1999) also found no correlation between these differences and socioeconomic status and went on to infer that the reason Hispanic women reported higher levels of distress may be due to cultural factors, such as acknowledgement of feelings being appropriate for them culturally. In contrast, Spencer et al. found that African American women reported much less concern regarding pain and sexuality. Again, the researchers speculated as to whether or not this was due to culturally maintaining a strong image.

As previously mentioned, several studies have found that in the long term, chemotherapy does not result in significant declines in QOL. While Schou, Ekeberg, Sandvik, Hjermsstad, and Ruland (2005) found this to be the case in their study, which looked at health-related QOL predictors, they also found that QOL did decline immediately following cessation of treatment for some populations. “(P)oorer social functioning was associated with chemotherapy at three months and younger age at three-

and 12-months” (Schou et al., 2005, p.1820). Contrary to evidence from previously cited studies, Schou et al. found no correlation between chemotherapy and cognitive functioning. Winer, Lindley, Hardee, Sawyer, Brunatti, Borstelmann, and Peters (1999) in their study state that “QOL was significantly better in patients who were disease-free at the time of the interview compared to patients with evidence of recurring disease” (Winer et al., 1999, pps.171-172). Said interview was conducted 12 months post-treatment for all subjects. These results indicate with what relief people may once again to experience their lives once their course of treatment has ceased, and with what dread those who have to go through it again still feel. While the current study suggests that chemotherapy has profound effects on women who undergo it, particularly with identity and QOL, the idea that life can take on a new and positive meaning and level of enjoyment once treatment is over is in line with this hypothesis. “An improvement in overall quality of life and emotional well-being was demonstrated from before to 6 months after chemotherapy. This is likely related to completion of chemotherapy treatment, resolution of chemotherapy-related side effects, and return to normal living” (Hurria, Rosen, Hudis, Zuckerman, Panageas, Lachs, Witmer, van Gorp, Fournier, D’Andrea, Moasser, Dang, Van Poznak, Hurria, and Holland, 2006, p.929). Having once experienced such a profound regiment of treatment it isn’t unusual to see many people seek to find enjoyment in life, even if it is under a globally new way of thinking.

Finally, Zebrack, Yi, Petersen, and Ganz (2007) looked at how several different factors prior to treatment affected long-term QOL. In regard to age, they found that “older individuals may not be faced with concurrent demands of work and childrearing, which may complicate adaptation in younger individuals and lead to more distress and

poorer QOL” (Zebrack et al., 2007, unknown page #). Other demographic factors also influenced QOL, including income level and comorbidities (Zebrack et al.).

Sex

Sexual functioning and enjoyment is an area of QOL that bears consideration as it is also affected by chemotherapy. Winer et al. (1999) found that a “large proportion of patients reported decreased sexual interest and activity, as well as pain or difficulty with intercourse, at the time of the interview” (Winer et al., 1999, p.172). They also acknowledge that “(f)urther research is needed to determine if changes in sexual function are related to hormonal changes that occur as a consequence of high dose chemotherapy, are representative of physiological sequelae of serious illness, or are due to some other combination of factors” (Winer et al., 1999, p.172). In a 2006 study by Archibald, Lemieux, Byers, Tamlyn, and Worth, the researchers looked specifically at the symptoms of chemically-induced menopause (prompted by chemotherapy) and women’s sexual functioning. “During interviews, 21 participants (70%) described experiencing one or more negative changes in their sexual functioning associated with CIM (chemically-induced menopause)” (Archibald et al., 2006). This decrease in sexual functioning “was a negative and meaningful experience for the majority of the breast cancer survivors in this study. For many of the women, negative changes in sexual functioning introduced a sense of guilt, frustration or anger, or led to worries about their future well-being or their relationship with their partner. Often changes in sexual functioning were closely tied to how breast cancer survivors viewed themselves as women or sexual beings” (Archibald et al., 2006, p.100). Sexual functioning and identity are considered to be integral parts of QOL for most people. The impact of chemotherapy on this realm of identity for many

women is profound and can lead to new and different thinking about sexual identity, functioning, and desire for a long time following the end of active treatment. Taylor, Lamdan, Siegel, Shelby, Hrywna, and Moran-Klimi (2002) did a more specific study and looked at how breast cancer and its treatments affected African American women and their sense of sexual attractiveness. They “conceptualized sexual attractiveness as a construct that is related to body image and thus expected to find results similar to earlier studies of body image that were conducted with largely Caucasian samples” (Taylor et al., 2002, p.513). The results that they found were that “addressing concerns about body image and sexual attractiveness received low priority” (Taylor et al., 2002, p.514) for African American women when discussed in a group therapy setting. This could be due to either the nature of the issue, the nature of the setting in which it was being discussed, or some combination of the two, for the women. Regardless, the researchers “found that it was the women who had chemotherapy in combination with a lumpectomy who reported the greatest difficulties regarding feelings of sexual attractiveness” (Taylor et al., 2002, p.513). They attributed this, in part, to the side effects of chemotherapy, including loss of hair, discoloration of the skin, and weight gain. Whatever the severity, area, or personal impact chemotherapy has on sexual functioning and attractiveness, it is a factor in identity and this makes it worth further consideration.

Treatment Decisions

The potential for being affected by chemotherapy doesn't just begin when a woman is diagnosed with breast cancer. Rather, its implications and side effects are in mind for many women during cancer screenings, such as mammograms. One study found that women with locally advanced breast cancer had delayed screening due in part to the

fear of side effects of treatment (Mohamed, Williams, Tamburrino, Wryobeck, and Carter, 2005). These women “denied having yearly mammograms or performing monthly breast self-exams” (Mohamed et al., 2005, p.403). Within this same study, these women, when compared with the control group, showed no difference between education, employment, marital status, or awareness of preventative health guidelines. Additionally, both groups reported the same percentages of those with health insurance. A possible conclusion from this could be that there is a segment of women in the population who wind up with locally advanced breast cancer that is due in part to their fear of chemotherapy and its side effects.

In a very different study from the previous one, Muir, Meiser, Tucker, Andrews, Tucker, K., and Friedlander (2004) looked at women in a high-risk group for breast cancer and their willingness to participate in chemoprevention. Chemoprevention is used as a means of reducing the risk of breast cancer in high-risk women by using drugs such as tamoxifen, an estrogen suppressor (Muir et al., 2004). The study found that around half of the women interviewed would be willing to participate in clinical trials of chemoprevention with the other half citing that they would not be willing to participate for “fear of side effects” (Muir et al., 2004, p.43). While participating in such a measure to maybe prevent the possible development of breast cancer may seem extreme, some women may view it as a way to avoid later, and possibly worse, side effects from actual chemotherapy. For these women it is a price they are willing to pay, which is a factor that cannot be ignored.

The end of treatment is a time during which women can experience very ambivalent feelings about chemotherapy. Despite its numerous side effects, many women

perceive some courses of chemotherapy with high rates of side effects, such as adriamycin, as being more effective and aggressive than other courses of chemotherapy with fewer side effects (Irwin et al., 1999). With this in mind, it should come as no surprise that for many women the end of chemotherapy, and cancer treatment as a whole, represents a time of crisis and worry (Arnold, 1999). Fear of recurrence may emerge as a large concern for many women, particularly those who acknowledge that while they were in chemotherapy they felt like they were actively fighting their cancer. A subject in the study by Arnold (1999) said “I guess having medical people taking charge of your life and body makes me feel more secure and being on treatment made me feel that at least I had something in my body fighting to kill the cancer....To be honest, it scares the hell out of me sometimes not having that ‘safety net’ of treatment” (Arnold, 1999, p.27). As Arnold states in her summation of this statement: “(t)reatment may be an anxiety-provoking unpleasant experience, but it is a proactive process that gives many women the comfort that they are ‘doing something’ instead of waiting to see what the future holds” (Arnold, 1999, p.27). The expectations of others also weigh heavily during this time, as one subject reported, “(p)eople on the outside assume that once you are ‘cured’ and ready to return to whatever you did before with the full vim and vigor of the ‘before’ cancer you- as if nothing happened” (Arnold, 1999, p.29). What “happened” for these women was that they underwent intensive chemotherapy and many of them will be dealing with the after effects and consequences of this for an undetermined amount of time. They grapple with both the fear of the unknown future, and integrating their treatment experiences into what they know about themselves and the world. “Before my last chemo, I loved being alone in the house when my husband and daughter were out of

town, but now I hate being alone and fear choking to death while eating alone, or getting very ill in the middle of the night when I'm alone" (Arnold, 1999, p.32). Fear of the future, both recurrence and the unknown, is a valid fear for many of these women. Supporting these findings, Chantler, Podbilewicz-Schuller, and Mortimer (2005) found that "participants in our focus groups reported exaggerated fear of cancer recurrence and death from breast cancer. Fear began with the diagnosis, abated while on active therapy, and worsened as active treatment was completed and contact with health professional(s) decreased" (Chantler et al., 2005, p.75). There is a balance needed between understanding the benefits of chemotherapy and truly being in touch with its potentially life-altering consequences.

Partners/Caretakers

The role of caretakers and partners is an important one during chemotherapy. They spend the most time with the women and often witness many of the chemotherapy's side effects firsthand. A study by Segrin, Badger, Dorros, Meek, and Lopez (2007) found "emotional contagion on anxiety, emanating from partners to the women with breast cancer, but not vice versa" (Segrin et al., 2007, pps.639-640). This indicates yet another realm in which women may have to face symptoms from their chemotherapy: the distress that it is causing their partner to watch them undergo treatment. Additionally, this study found that women's anxiety and depression were closely associated with their partner's levels in these realms. "(P)artners' anxiety was positively associated with depression, symptom distress, mental fatigue, and physical fatigue, and negatively associated with symptom management among women with breast cancer" (Segrin et al., 2007, p.640). Thus, it would seem that a partner's management of his/her anxiety and depression is

critical to the woman's ability to cope with her own psychological side effects.

Similarities in feelings experienced by partners to women also was found in the study by Mohamed et al. (2005). This was a study that examined treatment decisions made by women with locally advanced breast cancer. They found "significantly greater depression and active religious surrender than the control partners" (Mohamed et al., 2005, p.403) which correlated with the "(g)reater active religious surrender" (Mohamed et al., 2005, p.403) seen in the women with locally advanced breast cancer. In the study by Chantler et al. (2005), the authors found that women with male partners tended to report that the "men were less 'emotionally available' than women" (Chantler et al., 2005, p.76).

Overall, "(m)en were effective in providing verbal statements of encouragement and optimism. Although this support was viewed as being extremely helpful at the point of diagnosis, women became frustrated when they requested support by discussing less optimistic aspects of their disease" (Chantler et al., 2005, p.76). It may be that when a husband is vicariously experiencing the effects of his wife's chemotherapy he is less likely to be able to provide the kind of psychological support that she may feel she needs. Harrison, Maguire, and Pitceathly (1995) found that it can be especially difficult for men watching their wives undergo treatment as she is usually the person to whom they are closest emotionally, thus making it harder for them to burden her with their own feelings. This could be true for all caretakers in that they may find it difficult to manage their own emotional reactions to seeing their loved one go through chemotherapy and subsequently have a hard time providing the kind of support the woman needs. There are many ways in which this could affect the woman, but this has yet to be studied. It has been shown that it's common for couples to draw on their mutual bond "to develop their confidence in

their ability to deal with the issues associated with the disease (dealing with the unknown, the threat of loss, the uncertainties and changes, and organization of the support network) and to transform this experience of suffering into a meaningful and constructive life experience personally and conjugally” (Picard, Dumont, Gagnon, & Lessard, 2005, p.132). However, this same study also confirmed that in order for these more positive outcomes to happen, it was important that “love existed before the disease” (Picard et al., 2005, p.132). Ideally this would be the case in all relationships but sadly, is not. Many women undergo chemotherapy and other treatments without the emotional, psychological, mental, and physical support of a loving partner. “(F)eelings of fighting the battle of cancer alone may be frightening and contribute to a diminished sense of well-being” (Arnold, 1999, p.31). Sense of self and worldview may be just two schemas that could be affected by such an experience.

The end of treatment marks another time of transition for women and their support networks. In Arnold’s study one respondent remarked that “(o)nce treatment is over, you have no one to talk to” (Arnold, 1999, p.30). This feeling may result, at least in part, from the woman’s own internal struggle to incorporate new thoughts and beliefs into her existing schemas. She may feel alien in the world in which she previously operated.

Conclusion

There is still a lot to be learned about the effects of chemotherapy and how they affect survivors. Once faced with a treatment regimen that many consider to be worse than the disease, it doesn't seem unexpected that many people experience a shift in some of their previously held beliefs and views. Sense of self, worldview, sexuality, and religion are a few examples of realms that may be influenced. As the literature has

shown, chemotherapy has many side effects, not all of them physical. This study seeks to find out more about the consequences, expected and unexpected, positive and negative, that women experience as a result of their having been through this arduous treatment.

CHAPTER III

METHODOLOGY

This study is an exploratory look into the types of quality of life changes women may experience after receiving chemotherapy for the treatment of breast cancer. It is based on the premise that facing such a serious and potentially dangerous treatment may have profound and lasting effects on sense of self, spirituality, relationships, and worldview. The study was designed using content analysis to code for themes that emerge across participants. Through an hour long, one-on-one interview, participants were asked to reflect back on the nature of their chemotherapy experience. The interview questions centered on the physical, emotional, mental, and spiritual areas of identity. The open-ended structure of the questions was designed to prompt further exploration of the topics through narration, and as such, were specific to this study. “Available instruments are not generally used because this would defeat the basic purpose of the research: to learn inductively about a phenomenon that was previously unknown or poorly understood” (Anastas, 1999, p.354). The goal was to invite participants to evaluate the ways in which they perceived themselves to be different than they were prior to breast cancer, and process what changes, if any, were due to the chemotherapy experience. The questions were developed and set through intuition and collaboration with the thesis advisor and were designed to allow subjects to evaluate if they felt an area of identity had been affected. Questions were not based on the literature as such, as this is a preliminary and exploratory look at whether or not areas of identity were affected. Questions were

open-ended with the intention of inviting subjects to explore the topic further. The questions were not asked according to category, rather a brief summary of the course of treatment was requested and subjects were then asked to give narrative responses around areas of identity, concerns, and side effects. At times, clarifying follow-up questions were asked based on answers given, but the script was strongly adhered to.

The interview guide (see Appendix D) was based on flexible method research and was intended to garner as much information as possible, which included direct observations and context.

The researcher, the people and phenomena studied, and the inferences made about them are seen as part of an open, interactive, potentially fluid situation. The credibility of the findings of flexible method studies often flows directly from this inclusion of context, of everyday social and psychological complexities, in the picture. (Anastas, p.61).

Themes, concepts, and words from the answers provided were later identified and coded and used for content analysis. The sample was obtained using a volunteer, snowball method in which participants often referred other eligible survivors into the study.

Sample

There were 11 participants in this study. All were women who had undergone chemotherapy for the treatment of breast cancer. These women were required to be between six months and five years past the end of chemotherapy and 18 years of age or older. Recruitment took place via the nonprobability method of snowballing.

This technique is used either with convenience or purposive samples when there is initial access only to a very limited number of identifiable sample members. These few people who meet the sampling criteria are recruited, and they in turn are requested to identify other people like themselves who would be eligible to participate in the study. (Anastas, p.289).

The exploratory nature of the study allowed for this method of recruitment as a basis for beginning to gather initial data. There were no additional age or race requirements, however, the participants were all female, which lent some homogeneity to the sample. Selection procedures were only random in that all participants who were contacted through the network, met the requirements, and agreed to participate, were included. There was no selection bias based on initial conversations with the researcher as to the nature of the participant's chemotherapy experience, thus allowing for any possible "negative cases" (Anastas, p.61). At the end of each interview, each participant was asked if she was aware of any others who would be willing to be interviewed and was welcomed to provide the researcher's contact information to them. Initial subjects were recruited through friends of acquaintances known to the researcher. This allowed for at least two degrees of separation between each participant and the researcher. Demographic information including age, date of diagnosis and stage of cancer, family history of cancer, race/ethnicity, occupation, marital status, and religious affiliation were gathered in order to consider data in terms of support networks, lifestyle, and beliefs and to compare the data both within the group and to the larger population (see Appendix C). This information was gathered via a brief questionnaire that participants filled out immediately preceding the interview and after signing the Informed Consent. In the case of phone interviews it was mailed out to participants prior to scheduling the interview, along with a stamped and addressed return envelope. Interviews were set-up upon return receipt of both the Demographic Information Data and Informed Consent forms.

Four of the interviews were conducted over the phone and seven were done in person. All participants were Caucasian and the age range was 34 to 69 years old with the

average age being 55. Eight participants were from Colorado, one from New York, one from Georgia, and one from Utah. Date from diagnosis ranged from 10 months to 5 years, with an average of a little over 2 years.

Risks and benefits were discussed with each interviewee prior to the start of the recording process. They were verbally informed that the primary risk of participating in the study was that they may experience some degree of emotional stress or trigger and that discussing an experience like chemotherapy can be upsetting and make them feel vulnerable. They were reassured that they could stop the interview at any time.

Additionally, the women were provided with a list of mental health professionals, clinics, and hotlines that were local to them in the event that they felt the need to talk to someone following the interview. This information was researched and gathered by the researcher prior to each interview and was on hand in case it was needed. Participants were also reassured that all information gathered would be held in confidence by myself and that my thesis advisor would only have access to it once all identifying information had been removed. It was explained that their names would not be used in the study, they would be randomly assigned a number, and identifying characteristics, such as age, would be minimal.

A primary benefit of participating in this study was explained as being the participant's knowledge that her experience and sharing of it could potentially lead to a better understanding and system of care for others who have to undergo similarly invasive and traumatizing protocols. It was also explained that the chance to process the experience and share it with another may provide new understanding about it for the participant and may help her to think of it in previously unconsidered terms.

Data Collection

Data was collected through a one hour interview with each participant (see Appendix D). Each subject received, reviewed, and signed a copy of the Informed Consent (see Appendix B) form prior to the start of the interview and was given a copy to retain for their records. A Smith College Human Subjects Review (HSR) committee approved the study and all of its materials prior to the first interview (see Appendix A). Included in the Informed Consent was information about the nature and approval of the HSR, contact information for both the researcher and the HSR committee, and information about protecting confidentiality in line with federal guidelines. Additionally, information was provided about local resources for participants to contact if they experienced any harmful side effects triggered from the interview.

Quality of life variables including relationships, religion/spirituality, sense of self, and worldview were addressed in the open-ended interview. Questions around topics such as concerns about chemotherapy before, during, and after treatment, side effects and their emotional effects, and any changes noticed emotionally, mentally, or physically were included. Face-to-face interviews were conducted in the homes of the participants, and over-the-phone interviews were conducted from the home of the researcher. Interviews were audio-recorded using a small taping device and later transcribed by the researcher. In the case of phone interviews, the interviewee was put on speaker phone and recorded using the same device as used with in-person interviews. Each sample was blinded by the assignment of a random number to the interview and the removal of all identifying information, including names, from the interview transcriptions. The

randomly assigned number was given by the researcher, and all information was coded according to the number assigned to each interview.

Data Analysis

Data content was analyzed for themes with coding based on these themes and then contrasted and compared with all of the information as a whole. Themes such as emotions, worldview, change in spirituality, and type of symptoms were color-coded and charted. As the study progressed and new or unexpected information was gathered, it helped to inform other areas to explore with new participants. The complete transcription of each interview allowed for the re-reading of the interviews, and further examination and comparison of the data. Potential researcher-bias due to previous experiences with chemotherapy was addressed through the non-leading and open-ended nature of the questions.

Themes were assigned different colors for analysis and were highlighted accordingly as they emerged in each interview. The themes included emotional effects/coping/support, other effects/changes, side effects, sense of self, relationships, spirituality, worldview, concerns, and causes of the changes. A master list was kept of the color assigned to each theme, and each interview was reviewed and coded according to these themes and colors by underlining the responses. Each theme was reviewed and responses and quotes were recorded on a separate sheet of paper with similarities and differences noted in patterns and responses.

CHAPTER IV

FINDINGS

This chapter contains the findings from interviews conducted with 11 female breast cancer survivors who have undergone chemotherapy. The structure of the interview was designed to elicit narrative responses that reflected on the changes, if any, the participants felt they had undergone as a result of receiving chemotherapy. Areas of change included emotions that were affected, physical changes, relationships, worldview, sense of self, and spirituality. To gain additional information around these topics, participants were asked to reflect back on their chemotherapy experience and to discuss topics such as side effects, support networks, and concerns. At the end of the structured interview, participants were asked if there was additional information they wished to share about the nature of their experience with chemotherapy.

The data from these interviews are presented in the following order: demographic information of participants, side effects, emotional/coping/support networks, physical and mental changes, sense of self, relationships, spirituality, worldview, concerns, and causes.

Participant Demographics

The sample size for this study was 11, all female. All participants (n=11) identified as Caucasian. Christian (n=7), Jewish (n=2), and not affiliated (n=2) were selected as religious/spiritual affiliation. The women identified as married (n=7), divorced (n=1), single (n=2), and widowed (n=1). Most of the participants (n=9) reported that they are still working, while the others (n=2) are retired. Several of the women (n=5)

reported no family history of cancer, a few (n=3) reported a family history that included breast cancer, and some (n=3) reported a family history of cancer that did not include breast cancer. One participant, (n=1) did not report the stage of cancer with which she had been diagnosed, a couple (n=2) were diagnosed stage 1, the majority (n=6) were diagnosed with stage 2, and a couple (n=2) were diagnosed with stage 3 breast cancer. Participants were between 6 months and 5 years from completion of chemotherapy.

Side Effects

Participants described a myriad of side effects that they attributed to the chemotherapy. All participants (n=11) reported losing their hair, which was the only side effect that all 11 had in common. There were varying emotional responses to this loss, but all agreed for the most part that, as one participant put it, “it turned out to be a much messier process than I would have anticipated. It comes out in clumps. It’s worse than having a shedding pet.” Most subjects (n=9) described overwhelming fatigue, which one woman described as:

Profound fatigue where you literally feel like, if you’ve ever had weights from working out, like ankle-weights that you carry, felt literally, it was so hard just to put one foot in front of the other. It just washes over you. Like, 3 or 4 o’clock in the afternoon it’s like you run into a brick wall. You are so dead. You are gone.

Another subject described the fatigue as:

Your get up and go definitely got up and went. There isn’t anything that isn’t sapping of your strength. And there were really days where I felt like I couldn’t crawl out of the bed. I mean, you do, because you think ‘if I don’t get out I won’t be able to.’

Other participants (n=3) reported insomnia. Most of the subjects (n=8) struggled with nausea, but only a few (n=3) actually vomited. One woman stated that her nausea was so “horrific...I had, basically from the day I got my first chemo until three weeks (after the

last), just constant nausea and puking.” As a result, a few (n=5) described some weight loss and (n=6) stated that their sense of taste was negatively altered. One participant stated that “anything sweet was really disgusting tasting, it tasted just like I was crunching on a sugar bowl.” Another stated “the food was terrible!” while a different subject simply declared that “things didn’t taste the way they normally do.” Mouth sores were reported by several women (n=4), which one described as “trench mouth” as well as dry mouth (n=2). One woman stated:

As far as I can tell you, I forced myself to eat, I drank this rinse called ‘Magic Rinse’ to deaden my mouth and throat so the sores would not prevent me from eating. I continued to eat whether I liked it or not.

For one participant, she recalled her mouth sores as a sort of fluke:

My first infusion, they did not tell me to suck on ice cubes, so I lost the skin on the inside of my mouth and I had pustules all over my face. I was miserable, just miserable. My second infusion, the nurse came and hugged me and was almost in tears and she said ‘I forgot to tell you to chew on ice. But the day I had you as my patient my 93-year old mother slipped and fell, I was late for work. Please forgive me.’ So I chewed ice during the orange infusion and I chewed on ice during that whole infusion and I never got sores in my mouth again.

Four respondents reported having significant issues with neuropathy, which included pain and tingling in their feet, arms, and hands.

And as a matter of fact, the doctors were like ‘If you start feeling tingling in your fingers you need to take a week off’ because it can cause permanent nerve damage. And my fingers started tingling but I was like ‘I don’t want to take a week off, I want to be done.’ So now my fingers tingle. But whatever. If I had taken a week off I don’t know if I would have gone back.

Another more common side effect experienced by several women (n=4) was described as “chemo brain” or memory and cognitive impairment. All four also stated that the effects had lasted to some degree post-chemotherapy. One woman said “I had what I would call ‘chemo brain’ it made my mind foggy, so it was hard to keep my train

of thought or my focus.” Another woman summed it up by saying “I would have a thought come into my head and it would just exit.” Another frequent side effect was varying forms of pain (n=5). This included joint and bone aches, headaches, and generalized pain, which, for some, continued past the end of treatment. “I have a lot of pain that I don’t tell anybody about, but I’m kind of sick of it.” Another described the actual pain of the infusion:

I didn’t have a port because the drugs I was given were brand new and they were not toxic to the skin. So I didn’t have to have the port. So it was just like touching a hot oven. You knew, they’re putting in the saline, they’re putting in the other bags of drugs, and as soon as the chemo hit you knew it because my arm was literally on fire. Like you literally, you were fighting back the pain. So that was the sensation during. And you were always cold, very cold. You could feel it was ice cold and burning at the same time. So it was very contradictory in terms of the senses.

Depression and sadness were another side effect listed by several (n=3) women which one attributed to her “listlessness” of not being able to engage fully in her life. Dizziness was described by a few (n=3) and one stated that she still struggled when rolling over in bed. One woman developed a sore on the bottom of her foot that her surgeon “scooped out” while another developed pustules on her face. Another woman described her skin peeling so badly that she was afraid “if it keeps going my bone’s going to show through.” Two women reported the loss of all of their nails while another one simply stated that they had become extremely brittle. Dry eyes, runny nose, skin color change, and diarrhea were each described by one woman as minor inconveniences.

Some less common side effects included one woman’s hallucination-like visuals of orange and purple spots in front of her face, slurred speech, and listing gait while walking, none of which she felt her doctor was able to explain to her. Sexual side effects

were reported by two women, with one of them stating that “the drugs dry you up, everything. So that has been really, really annoying. That was a side effect I never knew about. It affects your sexuality.”

Side effects led to more serious problems for two of the women. While one woman reported that she was initially thought to have a blood clot that turned out to be nothing, another actually did get one, due to her port:

It was in my arm, my hand turned purple, you know, big swollen, like an elephant arm. I was at work at it was pretty scary. They thought it was arterial at first. Then they said ‘ICU’ and I thought ‘this is bad and that could kill me.’ I was more scared with that than I was actually with the chemo. So it was a result of the chemo, but it was more tangible for me to see that this was a potentially deadly problem.

This same subject went on to say that:

I made it through chemo and then I developed a gall bladder problem and had to have my gall bladder out, and I got an ulcer as a result of the chemo and developed Gastritis.

One other subject experienced a rather serious side effect related to her already present condition of Super Ventricle Tachycardia:

And that means every once in a while my heart starts beating very quickly, and if I take a deep breath and sit down, it goes away. However, when you have chemo, you get your Tachycardia, and you can’t get rid of it. So you end up in the emergency room, where they stop and start your heart, you know, within a second, in order to make it stop. I had to do that three times.

Emotional/Coping/Support Networks

Despite the disparity in marital status, all respondents (n=11) reported feeling that they had an adequate emotional and physical support network. What this network looked like for each of them, however, varied greatly. One woman stated that her husband was:

Just so wonderful and precious and kind and just helped me get through it so much more, and I have wonderful friends from my church who decided on their

own, when I started chemo, they came every Tuesday morning. So I was here at home with our family, our daughters and granddaughters and grandsons.

Like most of the participants (n=9) this woman never drove herself to one of her infusions, rather, she always had a ride from a friend, family member, or neighbor. In contrast, two women drove themselves to every treatment and sat alone during them.

This was a journey I was making by myself. I'm a widow, I do have two sisters and an 86-year old mother who doesn't understand why I'm sick. And both my sisters have spouses and children and grandchildren and they both work full time. It wasn't like they were there holding your hand.

The other woman who went through it alone stated that:

I thought this is like a new experience cause I'm learning all this different stuff. I thought 'I hate to be the guinea pig' but someone's gotta do it, you know? And I felt that it was better that I got it than some young mother with children, like that. I thought, cause I'm single, I've always been single. I've got brothers and sisters and if something were to happen to me it would be no big deal. Well, it would be a big deal, but you know, not like a family.

Despite going through each infusion on her own, each of these two women expressed that they absolutely felt that they were emotionally supported by family members and friends throughout the treatment. "My family members and friends were absolutely awesome, including my neighbors. Everybody was very supportive. I never went to a chemo appointment by myself." All of the married women (n=7) stated that their husbands drove them most of the time and sat with them, and friends drive them the other times.

My husband was distressed just generally over the whole situation, I don't think men deal with, particularly if it's a female-oriented problem, and he was just scared to death about what was going to happen and he was going to wake up some morning and I wasn't going to be there.

One woman made a cross country move halfway through her course of chemotherapy. Her husband was her "100% caretaker" before the move, but due to work conflicts, she found herself driving herself to treatments in their new home state. Despite the

overwhelming amount of support that all women felt they received during treatment, one said that:

I remember feeling really alone, even though I had tons of friends, and my husband and my family were really supportive. I just felt like no one knew exactly what I was going through.

Emotional effects experienced from the impact of undergoing chemotherapy were expressed by most of the women (n=9) and two of the women described it as not being an emotional time for them. One stated that “you really don’t know what you’re getting into, so ignorance truly is bliss.” Another woman said both that “I can’t imagine not doing it” and “well, you know, emotionally it’s terrifying. I mean, you, if you think about it too much you’d be in a padded room.” Many women expressed the trauma of the experience, with one stating “it is a traumatic time, no matter what you say or do, it’s traumatic.”

When asked specifically what the side effects had been like emotionally for her, one respondent said:

Most of them were pretty scary, like when I had at least three different anti-nausea treatments, and it was the third treatment and none of them were working, and I, plus I did lose my appetite. So I hadn’t eaten much, and I couldn’t even tolerate drinking any water at that point, so that was pretty scary. I didn’t want to have to go to the hospital because I was throwing up from chemo.

Two of the women found the loss of their hair to be among the most difficult side effects for them emotionally. One woman said:

If anyone had ever said, you know, five years ago before I had breast cancer, that it would be harder for me to lose my hair than it would be to lose my breast, I would have told them ‘you’re absolutely crazy.’ I can honestly tell you that it was harder for me to lose my hair than it was for me to lose my breast.

When asked why this was such a traumatic side effect, another woman put it this way:

You’re never really, in my opinion, emotionally prepared for that. Why your hair? Because, in my mind set, it is the physical attribute that you’re sick. Nobody knows by looking at you ‘oh, you’re sick.’ No hair? Cancer.

When asked if she felt this was directly related to the chemotherapy she replied:

Exactly. Because if you have radiation that would not be the case, or if you had cancer and didn't have either one, that would not be the case. Correct. That is absolutely correct. So it is the only outward physical attribute and it was literally coming out in clumps. And I was horrified. That was the only time I cried.

Despite varying reasons as to why, and to what extent, the chemotherapy elicited an emotional reaction, the majority (n=9) of the women solidly agreed that there had, in fact, been emotional consequences related to the treatment.

Universally all (n=11) of the women agreed that they had made the correct decision and did not regret undergoing chemotherapy. "I think I would be a nutcase (if I hadn't had it). I think I would be wondering every single day, did they get it all out? Is it floating around in me?" One woman reported having had such inconsequential side effects that she had questioned at one point whether or not she had ever really had cancer. The others (n=10) however, definitely noticed they were affected. One woman who did not report having any emotional changes or struggles stated that:

It was not exactly a party, but I had zero fear sitting there. I was not afraid of what was going into my body. I have a friend who was afraid that all the drugs were going to kill her. And if you want to look at it that way, you are taking poison, and I would expect that you would be a freaking, nervous wreck. But I just pictured it as my get-well juice. You have to if you're going to take that junk...or you would not be able to sit in that chair, it would be like a lethal injection.

All of the women (n=11) also agreed with each other in that they felt they had all chosen the most aggressive form of treatment available and had done all that they could to ensure that it would not return, despite concerns they may have had about the chemotherapy. "I wanted automatically the best chance to live. You know, I have three kids at home."

Another said "well, I really didn't want to do it, but when he (the oncologist) told me that was the treatment that he would suggest, I didn't really think twice." Another put it as

doing it “for me and my own emotional wellbeing, I had to do everything that was possible.” One participant had a dramatic moment that had a profound impact on her, yet she never wavered in her commitment to continuing:

The Adriamycin/Cytosan, they call it the Red Devil because it’s actually red. When the nurse came to inject it into my IV, she had to put on, basically, chemical gear. Two pairs of gloves, the mask, and the extra gown. For me, my husband and I went ‘this is not good.’ She has to put all this stuff on because it can’t touch her, but she’s going to inject it into me.

One woman had a distinct moment of wanting to quit treatment, but agreed to continue after discussing it with her husband:

It hit me that this was real and it’s not going away and it’s a long haul. And I didn’t want to do it. And I told my husband I didn’t want to do it anymore, and we kind of had a deal, cause I had always said ‘if I ever got cancer I would never do chemo, that’s my outlook, that’s my fate, blah blah blah.’ So when I agreed that if I was going to do it all, we kind of contracted in a way that I was doing it for him. So, then, four weeks later I was like ‘there’s no way I’m doing this again. This is ridiculous’ and so he said ‘let’s go back to the doctor and see if there’s more stuff they can give you for the nausea, try it one more time and if it’s this bad or worse we can decide what we’re going to do.

As for coping with the emotional side effects of going through chemotherapy, the women reported a range of skills and resources. All of them (n=11) reported that while actually receiving the infusion, they had no interest in being social with people in the room outside of their support network. Many (n=8) reported that they slept through most of the infusions as there was Benadryl added to their cocktails. One woman reported that it was a nice time for her to catch up on her reading. “I came (alone) because I wanted to read my book. I never have time to read, now’s a good time to read. I don’t need a bunch of people around watching me get this, you know?” A few women (n=3) felt that it was important and helpful for them to maintain an exercise regimen to help them cope.

Lingering emotional side effects remain for most (n=9) of the women. These range from the sentiment that they are “done” and will not ever do chemotherapy again, to the “voice of paranoia” that most (n=7) of them described as being ever present in the back of their heads. These women hope that someday they will not attribute every ache and pain to a possible reoccurrence of cancer. Two of the women also described lingering emotional effects upon seeing the chemotherapy room again during subsequent doctor’s appointments. “Now when I go to my doctor’s and I catch a glimpse of that room, it makes you feel funny. I think my husband, too.” The other woman stated that “I can remember the smell of the chemo room and I can remember the smell of walking into the hospital. I don’t remember going home.”

Finally, several women (n=4) talked about the difficulties and emotional impact of not feeling like their doctors were forthcoming with information. One said that “what I resented the most was my oncologist and my nurse not saying to me how hard it would really be.” Another said, “I will tell you one thing, there’s not enough information given to chemo patients, I don’t feel, by their doctors. The doctors are very bad about giving you information.” Another expressed anger about this, saying:

I’m angry about that because I know I’m not alone in this. And they give you this song and dance when you’re a deer in headlights. You really don’t know a darn thing about what they’re talking about. I think that needs a great deal of re-vamping.

The fourth woman explained this lack of information from another angle, saying that:

I think that one of the things is that they don’t tell you a lot of the things that are going to happen. And there’s a good reason for it. The doctor said ‘I’ll be honest with you, if I told you what was going to happen, you wouldn’t do it.’ I think, it’s a very viable point of view. It’s not pleasant. I would have done it, but I know other people who wouldn’t.

While all the women agreed that they had made the best possible decision for themselves at the time, the emotional consequences and repercussions were different for each of them.

Physical and Mental Effects

All of the participants (n=11) reported some kinds of physical consequences from the chemotherapy. Most of the women (n=7) stated that while they felt slowed down by the chemotherapy, they didn't feel overwhelmingly terrible.

I pretty quickly realized I could work and maybe school, or maybe a little exercise. It put limits on me and made me re-prioritize what activities I wanted to get done everyday and that sort of thing. But I've definitely seen people way worse off.

One participant said that she "wasn't really fatigued until it was kind of all over. And I was thinking, 'I don't know if I'm fatigued or just lazy now.'" Another said she felt she "has less stamina now" and that "I feel like I've aged more than I would have if I had not had (chemo)." One of the younger women said she had told her doctor "I think I was born at 100 and now I'm 68 because I have a lot more in common with 68 year olds" due to the physical consequences of the chemotherapy.

The remaining women (n=4) reported more severe and persistent physical effects from the chemotherapy. These four women also reported much more difficulty with treatment. One described it as:

Well, physically it was kind of like crawling out of a hole everyday. Um, you know, once you got up on level ground it seemed a little bit better. But the idea of lying in bed and you think 'well, I have to get up and take a shower.' It was almost kind of more than I can bear thinking about. But once you'd gotten yourself out of bed and you'd turn the water on and you get in there and think 'ok, this is gonna make me feel better.' There's a lot of talking to yourself and kind of self-motivating. I'm not one too...I don't do sick well.

When asked about negative physical changes that had resulted from chemotherapy, one woman declared, “you know, you get negatives, but they become very trivial compared to going through chemo.”

Exercise was a primary coping strategy for dealing with the side effects for a few (n=5) of the participants. One told a story about a local radio show talk host who had been diagnosed with breast cancer shortly before she had been and how she had worked out everyday and had still managed to do her daily radio show.

Before that I don't think I realized that you could keep up a pretty decent level of activity and then since then I've read that it can really help you tolerate the whole experience better, if you can even just go for walks, or some physical activity.

She found this example to be very inspiring for her and it helped motivate her to keep up with her own exercise program, which she credits with keeping her side effects from being much worse. Another said that her perspective on exercise was “it could have been worse, maybe I could have been a lot sicker.” She maintained a schedule of running everyday that she was able and skiing as often as she could. A younger participant was an aerobics instructor and said she simply reduced her teaching schedule to three classes a week while undergoing treatment. She felt that this helped her cope physically and emotionally, however, she also believed that she was still suffering from some of the fatigue-like side effects:

Our lives are crazy busy normally, but I definitely feel like there's a big rock on my back. I still go 100 miles an hour, but I'm just like dead tired every night. So I guess this is my new normal, but I can't remember what my old normal was.

The women who maintained their exercise schedules (n=5) all agreed that this was a great help to them. One of the non-exercising women admitted “I don't exercise, I never have, I never will. But I would have people come over and walk with me because walking is so

good for you, and I hated that more than life.” In addition to exercise, nutrition was also cited by several ladies (n=4) as being a way for them to cope with chemotherapy. One said, “I forced myself to eat more nutritiously than anyone you’ve heard of in your entire life. Spinach, collards, all kinds of really good things, everything I know to be nutritiously good for the body.” These four women all agreed that food became a main way for them to respond to the treatment. One put it this way:

I read everything on the Internet, got as much info as I could cause I think when you have info you don’t worry as much about that type of thing. So I looked at what chemo does to your body, about physical therapy, about food, diet supplements, I just looked up everything. And then I felt ok about it.

Being mindful of eating healthfully and nutritiously was a way in which these four women maintained a sense of control about what was happening to their bodies.

One of the most persistent side effects reported by several (n=5) participants was a change in cognitive functioning, or “chemo brain.” While not all of the women mentioned these effects, and several (n=3) specifically stated that they had not noticed any cognitive changes, ‘chemo brain’ was a term recognized by all of the women (n=11). One woman cited her continuing issues with memory, processing, and “lack of clear-headedness” as affecting her job and relationships with her co-workers. Another said, “I definitely feel slower. I have to pay attention to what I’m doing or I get scatter-brained.” One of the younger women said, “I always say, even now, I have chemo moments like brain farts or early Alzheimer’s. I’ve noticed that I never used to have them.” Another described how it affected her daily:

I really don’t feel that I’m back mentally 100%. My short-term memory is coming back little by little but it’s not as sharp as it used to be. Sometimes I can’t get the right vocabulary words out, I misused a lot of words right after. There are a lot of words that just sort of slipped through my head and it really bothered me. I’d

explain to people ‘I’ve got chemo brain and I’m not really thinking correctly.’ If I forget an occasion I just send a card late and say ‘sorry, it didn’t register with my chemo brain.’

The three women who reported no cognitive side effects all agreed with one another that they had, at some point during treatment, feared that they might experience it.

For five of the women, hair loss was identified as one of the most troubling physical side effects. One woman said that when she lost her hair two days prior to when her doctor told her she would that it was the only time of her entire illness that she cried. Another woman felt it was hard for her because, “for a woman it’s a hard thing when all your hair comes out. Cause when you have a husband or a family, or a boyfriend, you know, you just, it’s a hard thing.” Another woman described the loss of her hair being the outward sign to the world that she was sick:

I could sort of maybe say ‘it’s not that bad, it’s not that bad.’ But when I lost my hair I had to say to myself ‘this is bad, this is really bad. You’re sick and this is life threatening.’ You know, all the things I already knew, but maybe that hair loss made it all that much clearer.

Another put it this way:

Well, I guess, while I still had my hair no one knew so I could fake it. But once your hair falls out you’re a totally different person cause everybody knows, they wonder or they look at you differently.

When talking about deciding to shave her head, another participant said:

I went one day, shaved my head, and that was kind of liberating for me. And that was just kind of getting over that hump of ‘you’re gonna lose your hair, you’re kind of losing it, now it looks horrible’ and then you just shave it and it’s done.

While all (n=11) of the women lost their hair during chemotherapy, several (n=6) said that it had re-grown in a different way that they didn’t like. One described it as “crazy curly” while another said:

I came back with chemo curl, I'm part of the 70% where your hair comes back like, different. I hate it, I hate it short, I hate it curly. It came back bronze, black, platinum, white. I've been blonde for almost 60 years, I didn't know who I was in the mirror.

One participant looked at the loss of her hair in a more positive light and said, "I got upset when I knew I was gonna lose my hair. But my hair was so bad anyways, I thought maybe I'll get some new!" One of the younger women was upset not so much at the loss of her hair, but at the hormonal changes that resulted from the chemotherapy and led to "random hairs and adult acne."

Two women specifically mentioned that they felt they had sexual side effects that they had been unprepared for. One felt that her "sex drive is a lot lower" and the other said:

Everything hurts, and that is just something that nobody tells you. And I have, they just say that you atrophy in that area, and I believe it. The drugs dry you up, everything. So that has been really, really annoying. That was a side effect I never knew about. It affects your sexuality.

Both felt that this particular side effect was a direct result of the chemotherapy.

Finally, several (n=3) of the women felt that there was no reason for them to have gotten breast cancer based on their healthy lifestyles. While two of them recognized that their good health going into chemotherapy had probably made the treatments more tolerable for them, all three were angry and confused at having to get it.

You know, statistically, I shouldn't have had breast cancer. You know, I didn't smoke, I didn't drink, I was not overweight, there was no history in my family. I shouldn't have had it. But I got it.

Another said:

I kinda went through the stages of grief, just like they tell you, you will, I was shocked, anger, I mean, I couldn't believe it was me cause I've run, like, ten marathons before. I mean, I like cookies, but...cookies shouldn't give you cancer.

For these women, having to go through chemotherapy was particularly hard in that it seriously affected their belief that they had been living lives that protected them from such harsh realities.

Sense of Self

Sense of self was explained to the participants as including the way in which they view themselves and their identity. The most significant response given by the participants was that most of them (n=7) felt that priorities had become even more important to them in their lives. One described this as feeling like “things closer to home have become more important” and another said:

I did come out of this realizing, one thing I have done and I will continue to do, is we don't put things off. Like if we talk about doing something, going somewhere or doing something, if we can afford it and can find the time to do it, we do it. We don't say 'we'll do it in two years.' We don't tend to do that anymore. Life has become very precious.

Another put it as:

Your whole outlook on life changes. The little things in life become very important, like seeing the flowers and the trees, the birds singing and all that. Grandchildren smiling.

One of the younger participants felt like it had helped to see a new perspective on her life:

I always really appreciated life and I always knew that tomorrow could be different, I always had a respect for the fragileness of life, it did reinforce and help me become clearer on what I want out of life. But it does make you struggle with that a bit, too. It seems like 'how do I prioritize all these really important things and make sure that happens?'

One woman felt that her perspective on herself had changed in such a way that she felt the importance of becoming a more giving person in order to lead a more meaningful life.

She said, “life is not all about me. It's about what you give back and if I was to die

tomorrow, would I have made a difference?” Several of the women (n=5) also described part of the changes in their self-identities following chemotherapy included them actually liking themselves better. One woman said:

I think I'm definitely a different person. You have empathy now. I was probably one of those people who would stare at the lady who's hair was falling out, and now I when I see them I have not sympathy, but empathy. I've been there and done that, and it's not just the hair, it's everything that goes with it. But I think I am much more attuned to other people than I ever was. Maybe I'm just finally growing up...but it definitely gave me perspective.

Another woman came right out and said, “I probably like myself better because a lot of the things that are kind of superfluous that meant something before, it doesn't matter. It's just another day.” A woman who had particularly bad side effects and had said that “if you had asked me five years ago ‘would you have chemo?’ I would have said ‘oh no, that stuff will really poison you’” went on to describe herself as being “tough as nails” in the face of her treatment and side effects and attributes much of her progress to this positive attitude about herself. Several (n=4) of the women specifically described themselves as being “strong” during treatment and one said that as a result of that strength she realized “it's quite incredible what you can get through.”

Some of the participants (n=5) really felt like their sense of self and identity was really shaken or different as a result of their chemotherapy experiences. One said, “I think I was shaken for awhile” while another described her sense in a bit more detail:

It's definitely been affected, but I think more, the lasting effects of the chemo I would say are, it's my frustrations with my memory and being frustrated that my brain doesn't work as efficiently as it used to. But, so that affects my sense of self. I don't think I'm as articulate as I was.

When asked who one woman considered herself to be in lieu of having undergone chemotherapy, she responded by saying, “I don't want it. I don't want to be a part of it, I

don't want it to be a part of me. Leave me, go away." Three of the women also described distinctively negative consequences that they felt and attributed to the chemotherapy. One said "we have cancer, we will always have cancer. There's no guarantee that there's no cell in our bodies that still exists." Another phrased it as, "people comment continuously, you must be normal and you want to scream cause you're like 'I'm not normal!' The new me. And I've read about it, but you can't tell anybody." This same woman described these feelings in relation to her hair growing back and people assuming that was a sign of her recovery and completion with the effects of chemotherapy. Part of the fear related to changes in self had to do with the concern related to the chemotherapy not having worked 100%. One of the younger women talked about how she and her husband had always planned to adopt a child someday:

The other piece is that I don't know if in good conscience now I should adopt, because I don't know what...and I found myself struggling with that. I certainly wouldn't want to adopt a child and then die.

In contrast, four of the interviewees felt that very little, if anything had changed about their self-identities. When asked about possible changes, one said, "not at all. Not even slightly. As a matter of fact, if anything, I realize I have more self-confidence because I realize that I am not a breast." Another attributed the lack of change to her tremendous sense of self-worth, saying, "I have an, I must have a gigantic ego. It was 'this is what is happening to me, I'm still who I am. It's not happening to my spirit.'"

All of the women were very sure in their feelings of whether or not undergoing a treatment as intense as chemotherapy had affected who they thought themselves to be. Despite full agreement from all of them that they would not have changed their decision, not all agreed that they had made it through unscathed.

Relationships

Most of the participants (n=6) felt that they had relationships that had grown stronger or deeper as a result of them having gone through treatment. One of them expressed that her relationship with her mother was the most profoundly affected by her experience. She said:

I said to someone once, ‘man, if I had to go through that again now with my mom being how she is now, I might do it again!’ She comes to visit and she’s helpful and pleasant. My relationship with her has definitely gotten closer.

Another felt that her relationship with her husband had grown much closer since her chemotherapy, “my husband and I have always had a wonderful marriage and been close, but we’re even closer now.” Others expressed the change in their relationships by comparing them to the people they felt they were no longer close to:

I think that by and large it brought me closer to most people. There are a few people, some people just cannot handle the illness thing. And the obvious problems that you have from it, it’s more than they can...but no one close to me was like that.

Another described it as:

I’ve probably embraced the relationships with the people who gave me positive energy and kinda let go a little bit of the people who had negative energy. So, the positive relationships have gotten stronger and the negative ones I’ve tried to get rid of.

Another woman felt that the experience had brought her much closer to her kids and that had improved their relationships significantly. One woman saw her experience as being a positive one for her relationship with her husband due to the fact that he was scheduled to deploy to Iraq and instead received a compassionate reassignment back home. She said:

It’s so funny, we kid with each other, I say ‘if I had to do it all over again I would if it meant you didn’t have to go to Iraq’ and he says ‘I’d go to Iraq if it meant you didn’t have to go through it.’

Some of the women (n=3) felt that there had been no real significant changes in any of their relationships. While one described this as being the case, she also felt at the same time that “I don’t know if it deepened it, but it made me more aware of none of us know how much time we have left, so make sure you connect.” In general, these three women felt that their relationships had proceeded through their treatments without many effects. One participant reported that this was mainly due to the fact that she had adopted an attitude of her treatment being a “non-event” and that she would not allow it to affect her loved ones.

Finally, three of the women agreed that they had negative consequences in some of their relationships during and following treatment. One of these women was one who felt she had grown closer to her kids, but at the same time felt it had strained the relationship with her boyfriend. She said, “my boyfriend says I’ve changed. He says that definitely I’ve changed since going through all that. I don’t know that it’s a positive thing in his eyes.” She indicated that she had much more uncertainty in her relationship with him than she had prior to treatment. She went on to describe a time when she had almost been hospitalized for a serious side effect and:

I remember that night, particularly, my boyfriend was watching the news to see what the weather was like the next day so he could play golf and I, that was disturbing to me. I thought, ‘I don’t even know if I’m going to wake up tomorrow and you’re worried about the weather so you can play golf.’

Another woman said that her fiancé had actually broken up with her before her treatment began. She said, “he just left. He brought me home from the hospital and just left.” She felt that this was due to his discomfort at seeing her go through chemotherapy and face all the potential side effects. The third woman who felt that chemotherapy had negatively

affected her relationships felt that her development of “chemo brain” had adversely affected her performance in the workplace, and thus also her rapport with her colleagues. She said, “I would say, it affected my relationships with a couple of people I work with in a negative way.” She went on to explain how this had made her workplace a more uncomfortable place for her to be.

For the most part, the women’s relationships were not harmed in any way, and many were described as “deeper”, “stronger”, and “closer” as a result of the chemotherapy experience.

Spirituality

The women in the study varied from Christian (n=7), Jewish (n=2), spiritual (n=1), and atheist (n=1). All but one of the women (n=10) felt that religion played some part in their chemotherapy experience in helping them to cope and process. Eight of the women stated specifically that religion or spirituality were a great support for them and helped them manage their treatments better than they would have otherwise. When talking about whether or not her relationship with God had affected her during treatment, she said:

I think it made all the difference, it really did. I so often thought ‘if there was someone who couldn’t turn to God in a time like this, how could they possibly come through it without a lot of emotional problems? I think I would have felt lost, I would have been afraid, I think I would have had extreme fear.

Another woman just expressed it as, “in terms of recovery it helped me to know that there was some greater being that your thoughts could turn to.” One participant talked specifically about how her religious beliefs helped her during her infusions:

I got a (feeling) of totally being levitated by God. I have a very strong religious background, so I had absolutely zero fear whatsoever going into the infusion, zero

fear while I was there, and zero fear during the time frame. No fear. I just felt that God was lifting me up. I sat in a chair, if I started to get nervous I just said a prayer, 'Jesus be with me, comfort me, let me feel your arms around me.' And that got me through.

Another woman simply stated that "I probably believe more now than ever that God has a plan and regardless of what you do His plan is gonna follow through." For these eight women, religion and spirituality were seen as absolutely crucial in their journey through chemotherapy.

Two of the women felt that their spirituality increased while undergoing treatment, while just one of them saw this as being integral to her recovery. One said, "I think it increased my recognition for the need for some kind of spirituality" while the other started attending church regularly. She said:

I definitely felt a connection, more than I had, I just really identified and the things that the pastor said and does continue to affect me more I think than they used to. I think I needed that spirituality at the time, I think I still do, you know, to understand it.

One woman expressed that she felt that it had made her more "thoughtful" about religion and spirituality. She said, "I haven't really decided how I'm going to take it and where I'm going, I do find myself thinking about it much more than I did before." The woman who identified as atheist said, "I actually don't believe in God, but I didn't believe in God 20 years ago, so it has nothing to do with this. I didn't look for help anywhere but right here." All of the women used their spirituality, or lack thereof, as a way of coping and processing their experiences. To each, it was a topic that bore at least some thought.

Worldview

Worldview was defined in the interview as having to do with one's sense of safety and place in the world, view of world events, and level of interest in happenings around them. All but two (n=9) of the participants agreed that their worldviews had at least been affected by their experience of undergoing chemotherapy, but there was a great divergence in what ways it was affected. Four of the women felt that they had grown more interested or sensitive to world events. One stated this simply as being "more interested in what's going on in the world, instead of less" and another put it as being "a lot more sensitive to other people's needs now." The other two of these four women felt that it had increased the level of their interest in finding a cure for cancer. One said:

I think I appreciate more than ever how much time and money the drug companies have put into research. And I'm grateful there is such a vocal breast cancer lobby, because I do think that has an effect on how much time and money and research gets focused on breast cancer. I've always appreciated the research and development aspect of the drug companies and universities, but that appreciation definitely increased.

Of the remaining women (n=5) who felt their worldviews had been affected, one felt that she now worried less about issues like politics than before, saying, "I might have dwelled on it more before, and I do not dwell on it anymore." One woman felt it had given her a "sense of a loss of, I don't know if safety is the word, but you get a sense of your own vulnerability." Another woman found herself questioning humanity and peoples' actions more than she had before. She said:

I think that you look at the way the world is and you really, I found myself wondering why people were actually trying to kill one another when there are so many things that can kill them. Why work so hard? It just doesn't make much sense to me.

Another woman felt her worldview change in that she was more able to let things go than she had been able to before. She felt that “at some point I had to say ‘gotta let go, gotta let go’ and let these things take place.” Finally, of the five women who felt their worldviews had been affected by chemotherapy, the last woman said that “the way my worldview was when I was sick was about me” and when asked if it was different since completing treatment, she responded, “oh God, yes. I’m back to me.” This last woman did not feel like her change in worldview had a lasting effect and that she was able to return to the way in which she had previously understood the world.

Two of the women felt that their worldviews had not changed at all as a result of going through chemotherapy. One simply said it is “pretty much the same” and the other felt that “it has helped me be even more empathic, and I always thought I was pretty empathetic. I think it’s just reinforced that worldview.” For the majority, there was at least a small shift in how they thought about the world in some ways. For the others, it either reinforced or didn’t affect these views.

Concerns Before, During, and After Chemotherapy

Participants were asked about their concerns about chemotherapy in a three-part question. Concerns they had before their first infusion, during their course of chemotherapy, and since the completion of chemotherapy were discussed in the interviews. The women expressed a range of responses for all three of these time periods.

Before

The most common (n=3) concern before the beginning of treatment was how family and loved ones would respond to it. One participant said her concern was “how to take care of my husband. I wasn’t worried about me, I told him I was going to be fine. I

was so worried about my husband and family.” Another woman was worried about how it was going to affect her children while the third identified worry about her children and about what the effects of the chemotherapy would be on her body. This third woman, plus a couple of more (n=3) were concerned with how the treatments would make them feel. One was concerned that “I would be throwing up around the clock and that it would probably kill me” and another focused on not wanting “to wind up in the hospital” due to sickness. Uncertainty and not knowing about what was going to happen were identified by two of the women as their greatest concern. One said, “I didn’t have any idea what it was going to do to me, or how I was going to feel” and the other stated that it was “the uncertainty of it.” This latter woman also expressed concern about having to delay the onset of chemotherapy due to a cold she had gotten and felt anxiety at the thought of having to delay treatment and remain in a state of not knowing.

One woman was very candid in her admission that her greatest concern before the onset of treatment was “hair loss. I mean, I was certainly concerned about how I was going to feel, but that wasn’t my biggest concern. I would have to say that it was hair loss.” Another participant worried that the treatment “wasn’t gonna work” and the remaining women (n=2) felt that they had no concerns before the onset of chemotherapy. One of them said, “honestly, I didn’t have any concerns about the chemo, I just felt like it was something I needed to do and I would just go with it.”

During

Concerns that arose during the course of chemotherapy also ranged among the women. Two women were worried about the pain and sickness they were experiencing. One of these women found it very difficult to manage her nausea during the treatment

which caused anxiety for her. The other woman said that the pain of the infusion itself was so intense that she described it as “a horrible burning sensation.” Two more of the participants said that one of their biggest concerns during their infusions was that they could keep going and continue the course of treatment. One put it as “keeping my head above water, keep going, day-to-day” and the other woman said to herself “alright, suck it up and go do it because you have to do it and it’s the right thing to do.” Another woman said that, while she only had four infusions and none were particularly bad, she was worried each time that the next one was going to be the one that had a negative effect on her. She said, “I was worried that maybe the first one wasn’t bad, if that’s all there is to it then no problem. Then I thought, well maybe the second one, maybe they’ll get worse each time.” Another participant found herself most concerned about “what it might be doing to my body, it might be damaging my heart, so I was careful.” Another woman was primarily concerned with fatigue during her course of treatment, saying that it was “the kind of fatigue I’ve never experienced.” For another woman, her biggest concern was that the chemotherapy “wasn’t gonna work” and she would have to face the problem again. One woman expressed great concern over her family, saying, “they were so worried about me. I hated that.” However, two of the women said that they felt they had no concerns during the course of their chemotherapies. One said:

I really, you’re so focused on, sometimes the moment, I didn’t really have that many concerns, and I actually would tell people, through a lot of it, there was a lot of peacefulness to it because you didn’t really think about all the trivial things you normally think about. I was in the here and now, in a strange sort of way it was a very peaceful sort of experience.

Overall, most of the women struggled with at least one concern during the course of their treatments.

After

Concerns following the end of treatment were on a much shorter range than those preceding and during. The great majority (n=8) of the women expressed some fear since the end of chemotherapy of a recurrence. One woman put it as “when’s it going to come back” rather than ‘if.’ There was a general understanding amongst all of the women that if their breast cancer returned, it would be metastasized and prove much more difficult to treat than the original occurrence. When talking about whether the chemotherapy had really worked, one who had already had a recurrence said, “I pray daily that it did. It’s the kind of thing where you really don’t want to think that there’s a possibility.” Another woman had already experienced a recurrence and felt that “my biggest concerns have shifted, before I’m sure I worried about a recurrence. And now, it’s highly unlikely to recur (just) as breast cancer. Just a recurrence. Anywhere.” One woman said that the thought of recurrence “plays into everything,” particularly around doctor visits. Another woman put her concern as:

That it didn’t work, that it will come back. I think it worked, it served its purpose for the round that I’ve been through, but did it kill everything and is there any still floating around that’s going to show up at some point?

For two of the women, recurrence was not their main concern. One was struggling with how her hair was going to look as it grew back in, while the other woman was struggling with the thought that ‘chemo brain’ might come on in a delayed fashion for her and affect her job performance. Only one woman said that she had no future concerns. She said simply, “I don’t have any. I’m done. I swear to God.”

Causes

Towards the end of the interviews, the women were asked to reflect back on their experiences and evaluate what they felt had caused most of the changes and effects that they had discussed. Two of the women very clearly felt that the chemotherapy itself had the most profound impact on them. One felt that “categorically” she could isolate the chemotherapy as the cause of all of her struggles, mainly because it was the thing making her sick. She said:

For me, it was a continuum, you don't like pretty much everything being done to you. In my case they all just kind of came together, but it was the ups and downs that would give you back your life for awhile. And you might find that is what is good about chemo, you're not locked away for six months in despair and pain, and whatever. That instead you are able to be back in the world and everything. I really, the chemo part of it, I can isolate it easily, it was so isolatable.

Four of the women felt that the diagnosis of breast cancer was the cause of most of their distress and the psychological and emotional impact. One felt that it was the diagnosis “because it came completely out of left field.” For these women it was the moment of being told they had a life threatening illness that had the most profound impact. Their courses of treatment were secondary to this moment and its meaning.

Five of the women felt that it was a combination of both the diagnosis and the chemotherapy that had the greatest impact on them. One said, “I don't necessarily think you can isolate them out. It just becomes so complicated.” Another said “I can't say that chemo itself was the reason why I look and think a little bit differently and why I tend to be impatient with people who focus on minutiae. I do feel it's a function of the entire process.” For another woman, the diagnosis led to an emotional reaction, but the effects

of the chemotherapy had so many physical side effects that she felt herself have a strong emotional reaction to it as well, making it impossible to distinguish between the two.

Summary

This chapter has presented the findings from 11 interviews conducted with women who completed a course of chemotherapy for the treatment of breast cancer. There were many themes that emerged in several areas, while in others, many of the women described very unique experiences. Universally, participants agreed that chemotherapy was the correct course of treatment to undergo in their treating protocols. Not one of the women stated that she wished she had not undergone it, although many expressed great concern at its effectiveness. All agreed that they felt they would be either terminally ill or dead if they had not undergone chemotherapy.

CHAPTER V

DISCUSSION

The objective of this qualitative and exploratory study was to look at possible links between the experience of undergoing chemotherapy for the treatment of breast cancer and subsequent psychological, emotional, and physical changes. This study attempted to draw a distinction between the experience of breast cancer as a whole and the process of undergoing chemotherapy. These elements were explored through interviews with breast cancer survivors who had undergone chemotherapy. This chapter presents the findings in the following order: 1) key findings, 2) implications, 3) limitations, and 4) conclusion.

Key Findings

In the findings regarding side effects, the vast majority of the women reported side effects that were in accordance with the literature. These included fatigue (Servaes, Verhagen, and Bleijenberg, 2002), nausea (Molassiotis, 2000), hair loss (Buick, Petrie, Booth, Probert, Benjamin, and Harvey, 2000), sleep disturbance (Buick et al., 2000), neuropathy, vomiting (Molassiotis, 2000), and cognitive changes (Stewart, Bielajew, Collins, Parkinson, and Tomiak, 2006), among others. Side effects that were not mentioned in the literature include a blood clot, visual spots, and exacerbation of Super Ventricle Tachycardia. It cannot be said that these side effects were caused solely by the chemotherapy and not influenced in some way by existing factors. However, all of these

side effects had further implications regarding the emotional, physical, and psychological well-being of all of the women.

The findings regarding emotional changes, coping, and support networks were supported by the literature in that the women with strong support networks and active coping skills felt that they handled the experience well emotionally (Pieterse, van Dooren, Seynaeve, Bartels, Rijnsburger, de Koning, Klijn, van Elderen, Tibben, & Duivenvoorden, 2007). What was not mentioned in any of the literature was the general agreement among the women that they had gained something positive in their lives after having gone through chemotherapy. For some (n=7) it was the recognition and greater appreciation of their relationships, some (n=7) felt they had re-evaluated their life's priorities, and others (n=5) even felt that they liked themselves better. These findings imply more than just negative or neutral changes that take place during the process of undergoing chemotherapy.

The findings about physical and mental changes were also in accordance with the literature (Stewart et al., 2006), with several women (n=5) experiencing 'chemo brain' as a negative occurrence and most (n=9) stating that they had suffered from physical fatigue. These effects were closely linked with emotional changes such as depression, depressive symptoms like crying, and irritation for eight of the women. One woman reported going on anti-depressants during her chemotherapy due to her difficulty in dealing with the physical side effects and how that was causing her great emotional distress. Two of the women felt that their inability to exercise at their previous levels due to fatigue caused them great sadness and frustration.

Sense of self was affected for all but four of the women (n=7) in at least a minimal way. What was interesting to note was that seven of the women reported liking themselves better, while three of these same women also reported negative consequences to their self-image. For one this included difficulties that had subsequently arisen in her romantic relationship due to her becoming more assertive. This created a dilemma for her in determining her ongoing status with this partner, to whom she was not married. Previous literature does address improvement in emotional well-being (Hurria, Rosen, Hudis, Zuckerman, Panageas, Lachs, Witmer, van Gorp, Fournier, D'Andrea, Moasser, Dang, Van Poznak, Hurria, and Holland, 2006), but does not address the issue of overall positive life changes experienced by women who have undergone chemotherapy.

Relationships were affected for eight of the women, with three noting negative changes. Many of these changes were linked by the women with changes in self and emotion. Several of the women stated that going through a process as harrowing and difficult as chemotherapy helped them to realize who their true friends were, the people they felt would stay by them through thick and thin. For some, the identity of these people was a surprise. All of the married women reported tremendous support from their husbands, while two of the single women struggled in their relationships with their boyfriends/fiancés. One of the women in particular, who felt her relationship with her boyfriend had been negatively affected, felt that it was related to the fact that he was as committed to her as a husband would have been. She remarked on the fact that he was free to leave at any point, as one woman's fiancé did, which led her to have many ambivalent feelings about having him in her life and led to him being inconsistent in his

support of her. The woman whose fiancé left her after bringing her home from surgery simply remarked that, “it could have been worse. We could have been married.”

Spirituality remained fairly constant in most of the women, with only one participant self-identifying as atheist. Two of the women felt it had increased their levels of spirituality as it helped them to cope with the treatment. Women who maintained high levels of spirituality throughout the process attributed much of their progress to God, in accordance with the literature and felt they coped well (Tartaro, Roberts, Nosarti, Crayford, Luecken, and David, 2005).

Two of the women felt that their worldview was unaffected by the process and maintained their previous perspectives. For the other nine women, responses ranged from worrying less to worrying more to changing for a time and then going back to previously held beliefs post-treatment. This latter example indicates a shift in worldview used as a means to cope and process and then a move away from these beliefs in an effort to distance herself from her ‘sick’ identity. Interestingly, this was the one woman who identified as having no spiritual or religious beliefs and described herself as having a “tremendous ego,” perhaps thereby explaining her need to return to her more ‘normal’ state of being.

There were many concerns expressed through the three stages of before, during, and after treatment. What is interesting to note is that none of the women at any time expressed a fear or concern with death. Rather, main focuses were on how to keep going, concerns with whether the treatment was doing what it ought to, and loved ones. While recurrence was a main concern for many (n=8) of the women, it was discussed more in terms of future treatment implications than in terms of possible fatality.

The findings around causes for these changes and effects indicate that the diagnosis of cancer and the treatment of chemotherapy are quite wrapped up in one another. The experience was described as one woman as “being on a continuum” and described the diagnosis as having so much meaning, partly because of its implication of chemotherapy, that it was impossible to distinguish the two from each other. Five of the women felt it was not possible to distinguish one from the other, two felt that the chemotherapy was the cause of their changes, and four felt that the diagnosis alone had the most impact on them.

Implications

The implications of these findings for the field of social work include several different factors. The purpose of this study was to raise awareness between the possible links between a life-threatening treatment for a life-threatening disease and possible emotional and psychological side effects that should be addressed by the mental health community. This study has shown that undergoing chemotherapy for the treatment of breast cancer does, in fact, have at least a minimal effect on the emotional well-being of survivors. Mental health professionals should be prepared to identify and discuss chemotherapy-related issues independently of the greater cancer experience.

Another implication from this study is the tremendous positive response that many of the participants reported having had. Further research on this angle of the process would be interesting in assessing how life-threatening situations can profoundly affect people in life re-evaluating ways. Consistency of responses and reactions from this subset of women indicate that this is an area that may have far-reaching implications.

Differences between married versus non-married women as related to support networks and changes in self-identity is another area that bears the need for more research as there are implications here about how relationship status can have profound meaning and consequences. Is there a difference in level of support when there is a legal commitment to another? This theory would be supported by the example of the woman whose fiancé left her right before the beginning of treatment while none of the husbands did the same. Is this commitment culturally reinforced, and if so, how? This also has implications for how single women may have been treated differently by their medical team than married women. What alternative support systems do single women have, and to what extent do they feel they can reliably count on these networks?

Another common sentiment during the course of the interviews was women feeling like their doctors had not provided them with enough information about their course of treatment. Perhaps a need for more information about side effects, emotional and psychological impacts, and resources for coping need to be more openly shared by doctors with their patients. One woman suggested that having a person on her treating team who's sole purpose was to help her understand the medical jargon and the side effects would have been extremely helpful. A study around how much information provided to patients is helpful, and how much is too much, could be a very useful tool for the cancer community. Admittedly, there is a fine line between knowing too little and too much. One woman reported that she immediately found that she had to stop looking at the Internet as it was overwhelming her with information. Still, a balance between helpful knowledge around what is happening, and a certain amount of ignorance may prove to be

key in helping women manage their symptoms and experiences and maintain a sense of control.

Limitations

One of the main limitations of this study is that it was done on a subset of greatly similar women. All identified as Caucasian, all but one as spiritual or religious, and all with an adequate support network. It was also difficult to ascertain causes for effects and changes experienced by the women by having them focus solely on their memories and retrospectively. Possibly doing a study in which women are interviewed both before and after chemotherapy could yield more conclusiveness in the distinction between the cancer experience as a whole, and the chemotherapy effects.

Another limitation is that all of the women in relationships were with men. There was no consideration in this study for same-sex couples and the implications of a partner undergoing chemotherapy. All women in this sample were also self-selecting in their decision to participate. Since they were recruited via word-of-mouth there is an implied web of relatedness, both among themselves, and with the interviewer.

Conclusion

The current study provides useful data on changes that occur during and following the use of chemotherapy to treat breast cancer. While many themes did emerge, each woman's narrative and story was uniquely her own. Each had a very private experience of going through treatment and felt that she had gained something within herself or her life that led her to want to participate in this study. No one experience, relayed during the course of a single interview, can express the tremendous courage with which each of these women, and all those who undergo the daunting rigors of such a treatment, faced

their mortality. As one woman put it, and as each expressed in her own way, “it’s life changing.”

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Appendix A

Human Subjects Review Application and Approval Letter

Investigator Name: Amy Willson

Project Title: The Breast Cancer Survivor's Experience of Undergoing Chemotherapy

Project Purpose and Design

Chemotherapy is a concept that strikes a chord inside many people, conjuring images of nausea, hair loss, and pain. It is synonymous with cancer. The impact of undergoing treatment for a life-threatening diagnosis like cancer can have both seen and unseen impacts on the person, their families, and their loved ones. The effects can reverberate through a person's life, affecting not only their health status, but also their relationships, careers, sense of self, worldview, and spirituality. When chemotherapy is chosen as a method of treatment this impacts the person's experience of the illness as it can cause a myriad of side effects that range from mild to life threatening, in and of themselves. These can lead to an array of responses that range from mild discomfort to symptoms of trauma (Stewart, Bielajew, Collins, Parkinson, and Tomiak, 2006, Mehnert and Koch, 2007, and Rabin, Leventhal, and Goodin, 2004). For many, chemotherapy changes the landscapes of their lives and is often regarded as being worse than the cancer (Docherty, Sandelowski, and Preisser, 2006). The DSM-IV-TR includes "being diagnosed with a life-threatening illness" as a traumatic event that can lead to the symptoms and diagnosis of Posttraumatic Stress Disorder (PTSD) (DSM-IV-TR, 2000, p. 462). To the best of my knowledge, this is the first study that proposes to closely examine the specific stressors that can arise from chemotherapy as it is considered independently from cancer. Previous research has found that individuals undergoing

chemotherapy experience changes in quality of life (e.g. Zebrack, Yi, Petersen, and Ganz, 2007, Hurria, A., Rosen, Hudis, Zuckerman, Panageas, Lachs, Witmer, van Gorp, Fournier, D'Andrea, Moasser, Dang, Van Poznak, Hurria, and Holland, 2006, and Carver, Smith, Petronis, and Antoni, 2006), anticipatory nausea (e.g. Montgomery, Bovbjerg, 2003, and Montgomery, Bovbjerg, 2001), cognitive impairment (e.g. Falletti, Sanfilippo, Maruff, Weih, and Phillips, 2005, and Bender, Sereika, Berga, Vogel, Brufsky, Paraska, and Ryan, 2006), depression and anxiety (e.g. Reddick, Nanda, Campbell, Ryman, and Gaston-Johansson, 2005, and Deshields, Tibbs, Fan, and Taylor, 2006), and fatigue (e.g. Jacobsen, Hann, Azzarello, Horton, Balducci, and Lyman, 1999, and Mills, Parker, Dimsdale, Sadler, and Ancoli-Israel, 2005). None of these studies, however, have looked at how these chemotherapy side effects have affected the realms of spirituality, sense of self, world view, and sexuality, as this study plans to do.

What is it like when the treatment for the illness is what many consider to be the worst part? What about effects that aren't considered to be traumatic, but still impact one's life? This study will look more closely at the experiences of women who have undergone chemotherapy for the treatment of breast cancer and will consider the full range of experiences to better understand the effects it has on people's lives. Specifically, the purpose of this study is to lay the groundwork for the understanding of the impact of chemotherapy on breast cancer survivors. However, the implications of the findings of this study can be broadened and generalized to other cancers that have a chemotherapy protocol as well. These findings can be translated into ways to provide more emotional, physical, spiritual, and mental support for patients undergoing chemotherapy and allow for a better understanding of what happens when someone

undergoes a life-threatening treatment. While the chemotherapy experience may not be explicitly traumatic, it is possible that it is on a spectrum that includes its own set of psychologically distressing symptoms that need to be addressed in the field of mental health.

Through one-to-one interviews with women who have been treated for breast cancer, I plan to focus in-depth on what the experience of chemotherapy was like for these women and how it changed their lives, for good, bad, or not at all. This kind of information can lead to a better understanding of what is needed by cancer patients before, during, and after chemotherapy. Are their mental health needs being met? Are their relationships being strained? Has it raised questions regarding their faith? Do they regret the decision? All of these are important factors to consider when treating a person as a whole and should not be overlooked by the medical and mental health communities.

According to Boyatzis, the purpose of analyses of data in social work studies is to summarize and describe the meaning and content of the answers (Anastas, 1999). The interviews will start with an explanation from me about the purpose of the study and an invitation to the participant to describe in as much detail as they feel comfortable, what chemotherapy was like for them, including the context of their life when it began. The purpose of conducting the interviews in such an open-ended manner is to allow the participants to connect with their material in their own way and to describe the situation in a totally subjective manner.

It is possible that questions designed to illicit a deeper response may be used in some instances, such as “What did you think about while you were in the chair getting chemo?” and “What was it like for your family and loved ones?” Interviews will be

audio recorded, and I will also take notes during them noting affect and anything else of significance. These field notes will be correlated with each interview during the transcription process and similarities and discrepancies will be noted in the analysis. I will analyze the data using the grounded theory method that is “explicitly designed for ‘the discovery of theory from data systematically obtained and analyzed in social research’” (Anastas, 1999, p.61).

The research from this study will be used in my MSW thesis for the Smith College School for Social Work where it will be presented to my peers and colleagues in partial fulfillment of my graduation requirements. This research will be used for possible presentation and publication and a copy of it will remain in the Smith library.

The Characteristics of the Participants

Participants in this study must be women 18 and older, fluent in English, who have undergone chemotherapy specifically for the treatment of breast cancer. They must be between six months and five years from the end of chemotherapy. There are no specific exclusionary characteristics if the women fall into these categories. I would like to have a broad range of age, race, religion, socioeconomic status, and marital status. A sample size of 12 to 15 women is ideal.

The Recruitment Process

The recruitment will take place in Denver, Colorado and will take place through word of mouth initially beginning through connections and associates of my mother, herself a breast cancer survivor. Through my mother and her friends and colleagues eligible participants will be identified and given my contact information with which to follow-up. For participants who may be known to me, they will receive a brief

description of the study, its requirements, and my contact information. If they chose to contact me a phone interview will follow and at no time will I be informed of their names or addresses. For others, they will also receive my contact information and I will also receive theirs through our mutual contact. These interviews may happen over the phone or in person, at the participant's discretion. This open method of recruitment will allow for the most diverse sample to be obtained in that a broad range of possible participants will be notified through my mother and her contacts.

The Nature of Participation

Interviews will be expected to last no more than an hour. Participants need only show up and be willing to have the interview tape recorded. Participants will have the option of deciding where they would like to conduct the face-to-face interviews. Interviews will be conducted in a private room at a local library, which I will obtain permission to use ahead of time. If a phone interview is indicated, if I know the participant or they are more comfortable with this format, this will be arranged in lieu of a face-to-face interview. Phone interviews will be recorded using a recording device designed for this purpose. Demographic data, including age, age at diagnosis, stage of cancer, and family history of cancer, race, religion, occupation, and marital status will be collected to ensure a broad range of experiences and ensure diversity. A form will be provided to subjects, either through mail or email, to fill out prior to the interview, as well as the Informed Consent form. For phone interviews these forms will not be required, instead a copy of the Informed Consent will be provided to them prior to the interview by our mutual contact. This will also include a stamped envelope addressed to

myself. Verbal consent also will be obtained over the phone and demographic data will be collected verbally. All interviews will be transcribed by myself.

Risks of Participation

The primary risk of participating in this study is that interviewees may experience some degree of emotional stress or trigger. Discussing an experience like chemotherapy can be upsetting and make the participant feel vulnerable. These risks will be discussed openly and participants reassured that they may stop the interview at any time. The women will be provided with a list of local mental health professionals, clinics, and hotlines in the event that they feel they need to talk to someone following the interview. They will also be reassured that all information gathered will be held in confidence by myself. My thesis advisor will only have access to their information once all identifying information has been removed. Names will not be used in the study and identifying characteristics will be minimal.

Benefits of Participation

A primary benefit of participating in this study will be the participant's knowledge that her experience and sharing of it can potentially lead to a better understanding and system of care for others who have to undergo similarly invasive and traumatizing protocols. Additionally, the chance to process the experience and share it with another may provide new understanding about it for the participant and may help her to think of it in previously unconsidered terms.

Informed Consent Procedures

Informed Consent forms will be mailed to participants at least a week before the interview is to take place as a way to give participants a chance to read it and think of any

questions or concerns ahead of time. This will include a stamped return envelope if they chose to mail it back to me rather than bring it to the interview. I will bring extra copies as well in the event that a participant forgets to bring hers. I will collect a signed copy from each participant and also provide a blank copy for each subject to retain for her own records. In the case of a phone interview, the Informed Consent form need to have been returned to me prior to the interview, by mail. Two copies of the Informed Consent will be provided to them prior to the interview by our mutual contact, one to sign and return, and one to keep for their records. I will also include a stamped envelope addressed to myself in which to return the consent form.

Precautions Taken to Safeguard Confidentiality and Identifiable Information

Confidentiality will be protected in this study by not including any personally identifying information in the interviews beyond previously mentioned demographic data, and keeping responses in a locked box. I will blind all data by referring to subjects by a randomly assigned number instead of using their name to track participation and data collection. Data used in quotations and vignettes will also be disguised. Any questions may be skipped and not answered and participants may drop out of the study at *any* time during the data collection process or after, up until April 30, 2008. All information will be shared with my thesis advisor only after all identifying characteristics have been removed or disguised. All data collected, including notes, transcripts, tapes, etc., will be kept for 3 years in a secure location, as per federal guidelines. If materials are needed longer they will continue to be stored securely and will be securely destroyed when no longer needed. I will make available the names and numbers of organizations offering support to cancer survivors as well as the names and numbers of practicing

clinicians in their areas. All areas of concern are addressed in the Informed Consent and any additional questions or concerns that may arise may be addressed to me via phone or email at any time.

Investigator's Signature: ___Amy Willson_____ Date: __1/26/08_____

Advisor's Signature: _____ Date: _____

February 27, 2008

Amy Willson

Dear Amy,

Your second set of revisions has been reviewed and all is now in order. We are therefore glad to give final approval to your study.

Please note the following requirements:

Consent Forms: All subjects should be given a copy of the consent form.

Maintaining Data: You must retain signed consent documents for at least three (3) years past completion of the research activity.

In addition, these requirements may also be applicable:

Amendments: If you wish to change any aspect of the study (such as design, procedures, consent forms or subject population), please submit these changes to the Committee.

Renewal: You are required to apply for renewal of approval every year for as long as the study is active.

Completion: You are required to notify the Chair of the Human Subjects Review Committee when your study is completed (data collection finished). This requirement is met by completion of the thesis project during the Third Summer.

Good luck with your project.

Sincerely,

Ann Hartman, D.S.W.
Chair, Human Subjects Review Committee

CC: Jill Clemence, Research Advisor

Appendix B

Informed Consent Form

Dear Participant,

My name is Amy Willson. I am conducting a research study of breast cancer survivors to learn more about the experience of chemotherapy and its effect on identity, self, worldview, and other areas of change. The purpose of this is to learn more about possible additional supports that could be put into place for such a population. The study is being conducted for my thesis in the Master of Social Work program at the Smith College School for Social Work and may be presented and used for publication.

I am interested in exploring the experiences and life changes, if any, experienced by women who have been treated with a chemotherapy protocol for breast cancer. You are being asked to participate in this study if (a) you are over the age of eighteen (18), (b) you have had chemotherapy for breast cancer and (c) you are between six (6) months and five (5) years past treatment. As a participant in this study you will be asked to participate in a face-to-face interview, or a phone interview. Face-to-face interviews will be conducted in a private room of a local library, to be arranged ahead of time by me, to ensure confidentiality. Questions will focus on your experience while undergoing chemotherapy. The interview will take between 45 to 60 minutes. Interviews will be audio recorded and tapes will be transcribed and coded numerically by myself to ensure your confidentiality. Tapes will be destroyed after three (3) years, along with all other study material. All interviews will be transcribed by myself. You will also be asked to fill out a brief demographic questionnaire at the beginning of the interview to collect background data for the study.

The potential risks of participating in this study are the possibility that you might feel strong or uncomfortable emotions while talking about your experiences. In case you feel the need for additional support after participating in this study, you will be given a list of resources for mental health services in your area.

Your participation in this study is completely voluntary. You will receive no financial benefit for your participation in this study. You may benefit from knowing that you have contributed to the knowledge of mental health treatment of cancer patients undergoing chemotherapy. It is my hope that this study will help social workers have a better understanding of how to work more effectively with those diagnosed with breast cancer. You may also benefit from being able to tell your story and having your perspective heard.

Strict confidentiality will be maintained, as consistent with Federal regulations and the mandates of the social work profession. Coding the information and storing the data in a locked file for a minimum of 3 years will protect confidentiality. Should I need the materials beyond the 3 year period they will continue to be kept in a secure location

and will be destroyed when no longer needed. Your identity will be protected, as names will be changed in the analysis of the data. Your name will never be associated with the information you provide in the questionnaire or the interview, but your demographic information will be used. The data may be used in other educational activities as well as in the preparation for my Master's thesis and may be seen by my thesis advisor once identifying information has been removed. When my thesis is presented the data will be presented as a whole and when brief illustrative quotes or vignettes are used they will be carefully disguised. Any concerns regarding confidentiality may be further discussed with me before the interview commences.

This study is completely voluntary. You are free to refuse to answer specific questions and to withdraw from the interview at any time. If you decide to withdraw, all data describing you will be immediately destroyed. If you decide to withdraw wholly from the study you may do so by notifying me by April 30, 2008. You may reach me at any time via phone or email at the number below, to discuss concerns or questions and you may contact the Smith College School for Social Work Human Subjects Review Committee at 413-585-7974.

YOUR SIGNATURE INDICATES THAT YOU HAVE READ AND UNDERSTAND THE ABOVE INFORMATION AND THAT YOU HAVE HAD THE OPPORTUNITY TO ASK QUESTIONS ABOUT THE STUDY, YOUR PARTICIPATION, AND YOUR RIGHTS AND THAT YOU AGREE TO PARTICIPATE IN THE STUDY.

SIGNATURE OF PARTICIPANT

SIGNATURE OF RESEARCHER

DATE

DATE

If you have any questions or wish to withdraw your consent, please contact: Amy Willson. Please keep a copy of this consent for your own records.

Sincerely,

Amy Willson

Appendix C

Demographic Information Form

Birthdate and age:

Date diagnosed with breast cancer:

Stage of cancer with which you were diagnosed:

Family history of cancer:

Race/ethnicity:

Occupation:

Marital status:

Religious affiliation:

(for researcher to assign) Number:

Appendix D

Interview Guide

- 1) What was going on in your life when you were receiving chemotherapy? What was the context? This may include other treatments you may have previously received.
- 2) When were you diagnosed? What factors contributed to your decision to undergo chemotherapy? Family? Family history? Friends? What did your doctor tell you about it and how did they present it to you?
- 3) How did you explain the decision to yourself? Your family?
- 4) Who supported you during the process? Sat with you? Drove you?
- 5) What was your biggest concern before the protocol began? During? After?
- 6) What did you think about while you were receiving the chemotherapy? (For those who received it via I.V.) Did you visualize what was happening in your body? If so, how?
- 7) What side effects, if any, did you experience? How well did you tolerate it? What was that like for you emotionally? Physically?
- 8) Did you decide to continue/not continue with chemotherapy? Why or why not?
- 9) What changed for you during the treatment emotionally? Mentally? Physically? Were there any positive changes in your life? Negative changes? What's different now? What's the same?
- 10) Did it affect your worldview? Spirituality? Relationships? Sense of self?
- 11) What would it have been like if you hadn't decided to get chemotherapy?

12) Do you feel your reaction was due to the chemotherapy or to the diagnosis of cancer itself, or both?

13) Is there anything you would like to add? Any questions for me?