# LOOKING AT THE SILVER LINING: POSTTRAUMATIC GROWTH IN YOUNG BREAST CANCER SURVIVORS

by

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#### **ABSTRACT**

KELLI NICOLE TRIPLETT. Looking at the silver lining: Posttraumatic growth in young breast cancer survivors. (Under the direction of DR. RICHARD G. TEDESCHI).

This study examined negative and positive experiences reported by a sample of young breast cancer survivors (N = 87; ages 25-45) at approximately 12 months postdiagnosis. Qualitative and quantitative analyses were conducted including utilization of Linguistic Inquiry and Word Count (LIWC) software to explore relationships between psychosocial variables and positive and negative emotion words used in response to open-ended items. Multiple themes of negative experiences emerged indicating that young breast cancer survivors struggle with issues related to side effects/treatment, concern for the future, relationship/interpersonal issues, difficulty coping, appearance/self-esteem issues, employment, parenting, and other general life events. Responses to an open-ended item regarding positive aspects of the breast cancer experience revealed themes of posttraumatic growth (PTG), improved self-care, and adaptive coping efforts. A Total Negative Experiences Score and Total Positive Experiences Score were calculated based upon open-ended item responses and compared with measures of PTG, depression, coping, quality of life, and social support. Results indicate that participants reporting a greater number of negative experiences reported greater depression, pain, and cognitive problems. Greater usage of negative emotion words as calculated by LIWC software was related to greater depression, pain, cognitive difficulties, negative feelings, and fewer positive feelings. Greater number of reported positive experiences was related to higher levels of PTG, positive reappraisal, religious coping, active coping, and less denial. Greater usage of positive emotion words was

related to lower levels of reported social avoidance, cognitive difficulties, and negative feelings. Implications for future research are discussed.

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# **DEDICATION**

I dedicate my dissertation to my grandmother, Agnes Cole, who battled and survived breast cancer with grace and poise. I am so lucky to have learned from you. This work was completed in loving memory of her brother, Clayton Moore, who recently lost his own battle with breast cancer.

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# LIST OF ABBREVIATIONS

HRQOL health-related quality of life

LIWC linguistic inquiry and word count software

PTG posttraumatic growth

PTGI posttraumatic growth inventory

PTSS posttraumatic stress symptoms

QOL quality of life

TNES total negative experiences score

TPES total positive experiences score

#### CHAPTER 1: INTRODUCTION

In 2013 in the United States alone, approximately 296,980 new cases of breast cancer will be diagnosed with 39,620 deaths attributed to the disease (American Cancer Society, 2013). With the possibility of death due to breast cancer, a diagnosis with the disease and subsequent treatments can force patients to grapple with their own mortality. According to the American Psychiatric Association (DSM-IV-TR), a traumatic event is defined as one in which "...the person experienced, witnessed, or was confronted with an event or events that involved actual or threatened death or serious injury, or a threat to the physical integrity of self or others..." (2000, p. 426). Using these criteria as a guide, breast cancer (including the diagnosis, treatment, progression, and recurrence) can be considered a traumatic event.

## Cancer as a Traumatic Stressor

Hearing the words, "You have cancer" can be devastating. A cancer diagnosis is often unexpected and can involve a variety of difficult treatments including chemotherapy, radiation, and/or surgery. Gurevich, Devins, and Rodin (2002) have outlined three main factors that differentiate cancer from other traumatic stressors: (1) the chronicity of threat; (2) the uncertainty, intangibility, and anticipatory nature of threat; (3) the internality of threat. In terms of the chronicity of the cancer threat, breast cancer patients are repeatedly exposed to treatments and pain that cause stress as they battle the disease. Once treatment has ended, cancer can still cause stress as many patients fear the recurrence of the disease (Gurevich, Devins, & Rodin, 2002) and/or feel uncertain about

their future. Gurevich and colleagues (2002) liken the cyclical nature of the cancer experience to other traumatic events such as "war, family violence, and incest" (p. 260) where survivors are repeatedly exposed to traumatic events.

The cancer experience includes a pervasive sense of uncertainty. Cancer patients experience stress due to such uncertainty even prior to diagnosis as they undergo diagnostic tests and wait for results (Gurevich, Devins, & Rodin, 2002). Once the diagnosis is certain, treatment outcomes and the progression of the disease remain uncertain. Gurevich, Devins, and Rodin (2002) note this type of "anticipatory stress" is not characteristic of all traumatic events, but is a key component of the cancer experience. Often, fear and anxiety related to test results, procedures, and the threat of death are the most salient stressors for cancer patients (Gurevich, Devins, & Rodin, 2002).

The internality of cancer is another feature that separates it from many other events that can be classified as "traumatic" by the DSM-IV definition. Cancer comes from within one's body and is therefore inescapable and cannot be avoided (Gurevich, Devins, & Rodin, 2002). Pain, scars from treatment, and bodily changes can be persistent reminders of the presence of the disease or reminders that the disease could recur.

The recognition of breast cancer as a potentially traumatic stressor prompted researchers to examine the incidence of posttraumatic stress disorder (PTSD) in breast cancer patients currently undergoing treatment as well as breast cancer survivors who have completed treatment. Estimates of PTSD have varied from 3% (Green et al., 1998) to 35% (Mundy et al., 2000). Gurevich, Devins, and Rodin (2002) note in their review of

existing studies of PTSD in breast cancer patients and survivors that inconsistencies in measures of PTSD as well as variability in study designs make it difficult to accurately determine the incidence of PTSD in breast cancer patients. Despite the variability in incidence, it is likely that some breast cancer patients at least experience posttraumatic stress symptoms (PTSS) even if they do not meet the criteria for PTSD.

In addition to the DSM-IV definition of trauma, a more general definition of a traumatic event is an experience in which survivors' assumptions and core beliefs about the world are shaken or, even worse, shattered (Janoff-Bulman, 1992). These potentially "shattered" beliefs include previously held ideas that the world is benevolent, life is fair, and the individual is deserving of good things – these ideas may not seem quite as true to many people post-trauma. Following a traumatic event such as breast cancer, survivors may search for meaning in the event, and many are forced to either develop schemas that accommodate the event or construct new views regarding the self, others, and the world (Janoff-Bulman, 1992). It is through the cognitive work related to the shattering of assumptions and new schema development that Calhoun and Tedeschi have posited posttraumatic growth (PTG), positive change experienced as a result of the struggle with a traumatic event, occurs (Calhoun & Tedeschi, 1999, 2004, 2006; Tedeschi & Calhoun, 1995, 1996, 2004).

#### Posttraumatic Growth

In studies discussed later in this chapter, research has consistently revealed that some people experiencing potentially traumatic events such as breast cancer report positive ways in which they have grown psychologically or emotionally from the experience (Bellizzi & Blank, 2006; Bellizzi et al., 2010; Bozo, Gündoğdu, &

Büyükaşik-Çolak, 2009; Brunet, McDonough, Hadd, Crocker, & Sabiston, 2010; Bussell & Naus, 2010; Chan, Ho, Tedeschi, & Leung, 2011; Cordova, Cunningham, Carlson, & Andrykowski, 2001; Cordova et al., 2007; Gall, Charbonneau, & Florack, 2011; Hefferon, Grealy, & Mutrie, 2010; Ho, Chan, Yau, & Yeung, 2011; Lelorain, Bonnaud-Antignac, & Florin, 2010; Manne et al., 2004; Mols, Vingerhoets, Coebergh, & van de Poll-Franse, 2009; Morrill et al., 2008; Sadler-Gerhardt, Reynolds, Britten, & Kruse, 2010; Sears, Stanton, & Danoff-Burg, 2003; Weiss, 2002, 2004). In general, these studies demonstrate that some breast cancer patients (persons currently undergoing treatment) as well as post-treatment survivors sometimes report PTG.

#### Dimensions of Posttraumatic Growth

In developing the Posttraumatic Growth Inventory (PTGI), Tedeschi and Calhoun (1996) identified five domains in which PTG tends to occur: spiritual change, new possibilities in life, feeling stronger as a person, having a greater appreciation for life, and positive changes in the way survivors relate to others. The five-factor structure of the PTGI has been supported in a recent study of survivors of various traumas (Taku, Cann, Calhoun, & Tedeschi, 2010) as well as in a recent study of breast cancer survivors (Brunet et al., 2010). The five dimensions of PTG as they relate to the breast cancer experience will be discussed in more detail in the following section.

As previously mentioned, researchers have identified five domains in which PTG may occur. For one, people often report growth in the area of *personal strength*. Trauma survivors are exposed to situations and events that they never imagined they would experience and, not surprisingly, some survivors may feel a sense of accomplishment for surviving. Survivors may feel that if they can handle and survive a traumatic event, they

can handle anything. Tedeschi and Calhoun (2004) note that an increased sense of personal strength is often associated with a sense of vulnerability. Specifically, survivors may come to realize the world can be dangerous and thus feel more "vulnerable" to stressful events. Although they recognize that they are vulnerable to other difficult situations, some survivors report feeling that they are better equipped to handle other difficult situations that might arise (Calhoun & Tedeschi, 2006). In a qualitative study of breast cancer survivors, one participant reported feeling "...stronger in that if a challenge were to come my way I could take on that challenge. I'm not so insecure...I feel I am stronger," (Sadler-Gerhardt, 2007, p. 146). Breast cancer survivors experiencing PTG may view the world as less predictable post-diagnosis but might also believe that if they can handle a breast cancer diagnosis, treatments, and side-effects, they can handle anything.

In addition, survivors often report that they have *new possibilities* in life due to their traumatic experiences. Just as traumatic events are often unexpected themselves, they can lead to unexpected positive changes such as shifting interests or new life paths, meeting new people, and/or engaging in new activities (Calhoun & Tedeschi, 2006). For example, survivors may decide to change careers, may develop new friendships, or may have access to better resources due to their traumatic experience. In general, opportunities may develop for survivors that otherwise would not have been available (Tedeschi & Calhoun, 1996). In a qualitative interview, one breast cancer survivor discussed new possibilities in her life such as adopting a child and moving to a large city to be near her son (Sadler-Gerhardt, 2007). Overall, it appears that an illness such as breast cancer can influence survivors to embark on a new life direction.

Survivors may also notice positive changes in the way they relate to others such as feeling more compassion for others, developing stronger relationships with loved ones, and feeling more connected with people in general (Calhoun & Tedeschi, 2006). In their qualitative study of eight breast cancer survivors, Sadler-Gerhardt and colleagues (2010) found, "Nearly all the women described stronger, closer, and better relationships with loved ones" (p. 274). One breast cancer survivor specifically discussed her changed relationship with her husband by saying, "We took our vows, you know, in sickness or in health...and we just don't take each other for granted," (Sadler-Gerhardt, 2007, p. 148). Although survivors may have taken their loved ones for granted before their traumatic experience, it appears that some survivors do not do the same post-trauma.

Trauma survivors often report a greater appreciation of life which has been described as not taking life for granted and shifting priorities such as spending more time with family and less time at work (Calhoun & Tedeschi, 2006). For example, one breast cancer survivor stated, "Having had cancer kind of puts everything into perspective and because my mother died from cancer, so it's like what's important? Is it important if someone has that last bag of chips or if I don't mop the floor...important is living..."

(Morris, Campbell, Dwyer, Dunn, & Chambers, 2011, p. 670). Another survivor reported,

"Right away, one of the things that happened is all of the little junk fell away - your main priorities come into focus so clearly...All those little things that seemed so, so important have gone away...I go out in my garden in the morning and I think, I am so lucky - look, I am here and the birds are chirping, the flowers are growing..." (Sadler-Gerhardt et al., 2010, p. 274).

With many trauma survivors, it appears as though the possibility of death brings into focus the fragility of life. Survivors enter a state of "mortal time" (McQuellon & Cowan, 2000) where they are faced with the stark reality of human mortality. Entering this state may be a catalyst for change in survivors as they better appreciate life and shift their priorities.

Spiritual growth is another area in which many survivors report positive change. Some of the positive spiritual changes include a closer relationship with God, stronger faith, and a greater sense of meaning in life (Calhoun & Tedeschi, 2006), with survivors endorsing statements such as "I have a stronger religious faith" and/or "I have a better understanding of spiritual matters" (Tedeschi & Calhoun, 1996). For example, one breast cancer survivor noted, "I truly understand what it means to give up control to a higher power and to rely on God in your faith," (Sadler-Gerhardt, 2007, p. 151). It appears that some breast cancer survivors believe their spirituality has deepened due to their experience with the disease.

## Model of Posttraumatic Growth: Distress

Tedeschi and Calhoun's model of posttraumatic growth (1995, 1996, 2004) includes multiple factors that influence the development of growth following a potentially traumatic event (see Appendix A). The model has been updated and revised as research findings related to the process of PTG have emerged. With any discussion of the model of PTG, it is important to note Calhoun and Tedeschi have recognized PTG may co-occur with negative trauma responses such as emotional distress, dysfunctional thinking, hyperarousal, and nightmares related to the event (Calhoun & Tedeschi, 1998; Tedeschi & Calhoun, 2004). In fact, it appears a curvilinear relationship between PTG

and distress exists where survivors reporting moderate levels of distress also report higher levels of PTG than survivors reporting no or high levels of distress (Dekel, Mandl, & Solomon, 2011; Solomon & Dekel, 2007). If distress is very high, it may be difficult for PTG to occur. Additionally, if distress is very low, it is likely the event did not "shake" a survivor's assumptions about the world. Thus, there would be no need for one to examine core beliefs and no chance for PTG to occur.

## Model of Posttraumatic Growth: Rumination

Many people whose previously held beliefs (e.g., the world is benevolent and good things happen to good people) are disrupted posttrauma may struggle to understand why and how a traumatic event might have occurred. Specific to breast cancer, patients might grapple with having tests conducted and waiting for results, the actual cancer diagnosis, frightening procedures, or even end-of-treatment issues such as no longer having ongoing contact with healthcare providers. Thus, they might engage in cognitive work to better understand the event (or multiple events) and to rebuild their beliefs (Cann et al., 2010). This type of event-related cognitive work has been referred to as "rumination" with two types of rumination currently included in the PTG model: intrusive and deliberate rumination (Cann et al., 2010). Initial event-related rumination appears to be mainly intrusive. This type of rumination includes uninvited thoughts about the traumatic event that can be stressful in nature and is referred to by Watkins (2008) as "unconstructive" because it can be upsetting to have repetitive thoughts about the event. Later, deliberate rumination may develop which involves intentionally thinking about the event and can include attempts to make sense of or find meaning in the event. Such rumination is referred to by Watkins (2008) as "constructive." Studies of PTG have found intrusive rumination to be associated with distress whereas deliberate rumination has been associated with PTG (Cann et al., 2010; Calhoun, Cann, Tedeschi, & McMillan, 2000; Cann, Calhoun, Tedeschi, & Solomon, 2010; Taku et al., 2008). Additionally, intrusive rumination has played an indirect role in the PTG process via its relationship with deliberate rumination (Triplett, Tedeschi, Cann, Calhoun, & Reeve, 2012). It appears that intrusive thoughts can lead to more deliberate thinking in an attempt to make sense of traumatic event and/or the ability to eliminate intrusive thoughts.

Based on the cognitive work described above, PTG does not automatically occur - it takes time to rebuild assumptions and ruminate about the meaning of the traumatic event. Thus, it would be expected that some time since diagnosis must pass for PTG to occur. Some studies of breast cancer survivors have found a positive relationship so that a longer passage of time yielded higher levels of PTG (Cordova et al., 2001, M = 1.96years post-treatment completion; Sears et al., 2003, M = 7.12 months post-diagnosis). In contrast, Weiss (2004) found less PTG was reported as more time passed since the diagnosis of breast cancer (M = 3.23 years post-diagnosis). Other studies have found no association between time since diagnosis and PTG (Bellizzi et al., 2010, M = 6.1 months post-diagnosis; Bellizzi & Blank, 2006, 1 to 4 years post-diagnosis (mean not reported); Cordova et al., 2007, M = 9.4 months post-diagnosis; Lelorain et al., 2010, M = 10 years post-diagnosis; Morrill et al., 2008, M = 4 years post-diagnosis; Mystakidou et al., 2008, M time = 6.11 years post-diagnosis). Cross-sectional studies assessing PTG at only one time point are likely not the best way to investigate the relationship between PTG and time. Longitudinal studies measuring PTG soon after a traumatic event and over the years would help to clarify the relationship. For example, Manne et al. (2004) assessed PTG in

breast cancer survivors (M = 4.5 months post-diagnosis) and their partners at 3 time points over 1.5 years and found PTG to increase for both partners over time.

It is also important to note discrepancies in the literature regarding PTG as an outcome of coping with a stressful event (Schaefer & Moos, 1998; Tedeschi & Calhoun, 1995) versus a coping process (Davis, Nolen-Hoeksema, & Larson, 1998; Park & Folkman, 1997). Based on Tedeschi and Calhoun's current model (2004), PTG is considered both a process and an outcome. The cognitive work that takes place (intrusive and deliberate rumination) is necessary in order to rebuild assumptions about the world and this struggle with the traumatic event is a *process* that may occur at different rates (or not at all) in different people. In many survivors, an outcome of this cognitive struggle is that that they report feeling as though their lives have changed for the better and, in these cases, PTG is considered an outcome.

Model of Posttraumatic Growth: Distal and Proximate Cultural Elements
Other key elements of the PTG model include distal and proximate cultural
elements (Calhoun & Tedeschi, 2006). Calhoun and Tedeschi (2004) refer to distal
cultural elements as broad cultural themes in larger societies/geographic areas. The
development of PTG following a traumatic event might be influenced distally by
narrative frameworks related to "religious themes and perhaps themes of optimism and
self-reliance..." (Calhoun & Tedeschi, 2006, p. 12). It is likely that proximate cultural
elements, social networks with which a person interacts, might offer a more direct
influence on the development of PTG than distal elements (Calhoun & Tedeschi, 2006).

The primary reference group, persons with whom the survivor interacts regularly, is an important proximate cultural element. Calhoun and Tedeschi (2006) have identified

three components of the proximate social world that are particularly relevant to the development of PTG: responses of important others to trauma-related disclosures, congruence between the survivor's ruminations and thoughts of significant others about the situation, and whether the concept of PTG is present within the survivor's primary reference group. Survivors who self-disclose about traumatic experiences and receive a supportive response, perhaps engaging in discussions about growth, would be more likely to experience PTG than survivors who receive negative responses to their disclosure or who do not discuss their experience with others. Discussing the traumatic experience with others might not only help the survivor manage distressing emotions, but survivors might talk to others who offer new perspectives that aid in new schema development and facilitates PTG (Taku, Tedeschi, Cann, & Calhoun, 2009). Further, discussing traumatic experiences with close others may lead to a heightened sense of intimacy and closeness (Tedeschi & Calhoun, 2004).

Model of Posttraumatic Growth: Characteristics of the Survivor Characteristics of the survivor also appear important in the development of PTG (Calhoun & Tedeschi, 2006). When examining PTG and various traumatic stressors, research indicates that females tend to report higher levels of PTG than males. A recent meta-analysis of 70 studies measuring PTG found women to report significantly more PTG than men (g = .27, 95% CI = .21 - .32; Vishnevsky, Cann, Calhoun, Tedeschi, & Demakis, 2010). The meta-analysis results revealed a small to moderate gender difference with higher PTG reported by women even when data from unpublished studies were included.

In addition, younger survivors of traumatic experiences tend to report higher levels of PTG than older survivors (Bellizzi & Blank, 2006; Bellizzi et al., 2009; Cordova et al., 2001; Lechner et al., 2003; Manne et al., 2004; Milam, Ritt-Olson, & Unger, 2004; Morris, Shakespeare-Finch, & Scott, 2007; Polatinsky & Esprey, 2000; Widows, Jacobsen, Booth-Jones, & Fields, 2005). Specific to breast cancer, being confronted with a life-threatening illness at a younger age appears to be more threatening than a diagnosis when older (Morris & Shakespeare-Finch, 2011). Based on the model of PTG, perceiving the event as more threatening is more likely to lead to the cognitive processes required to experience PTG. Differences in the breast cancer experience based on age will be discussed next.

# Breast Cancer and Age

Approximately 25% of breast cancer survivors are younger than 50 years old, but most studies have been conducted with older, postmenopausal survivors (Wong-Kim & Bloom, 2005). Thus, results from many breast cancer studies may not be generalizable to younger survivors (Thewes, Butow, Girgis, & Pendlebury, 2004). Young breast cancer survivors appear to have a different set of stressors than older survivors partially because breast cancer is less expected at a younger age and the diagnosis might be more shocking to younger women. Other stressors in younger breast cancer survivors include issues related to reproduction and sexuality post-treatment (Avis, Crawford, & Manuel, 2004; Casso, Buist, & Taplin, 2004; Gorman, Malcarne, Roesch, Madlensky, & Pierce, 2010; Schover, 1994; Thewes et al., 2004; Partridge et al., 2004) as well as work-related issues (Avis et al., 2004; Thewes et al., 2004), which might increase their risk for distress. For instance, young breast cancer survivors might be more likely to be employed full-time at

diagnosis and would have to figure out how to navigate treatments and side-effects while working or how to deal with a financial loss in addition to medical costs. Young breast cancer survivors are more likely to have young children to take care of while being treated and recovering from surgeries. In addition to the stress of parenting, young survivors might have concerns regarding what would happen to their children if they did not survive. Younger survivors are more likely than older survivors to desire reproduction in the future and would be faced with the stress of potential fertility problems due to treatments.

With these issues in mind, it is not surprising that multiple studies have found younger breast cancer survivors tend to show greater psychological morbidity than older survivors (Bardwell et al., 2006; Bloom & Kessler, 1994; Christensen et al., 2009; Cordova et al., 1995; Epping-Jordan et al., 1999; Ganz, Greendale, Petersen, Kahn, & Bower, 2003; Gorman et al., 2010; Harrison and Maguire, 1995; Vinokur, Threatt, Vinokur-Kaplan, & Satariano, 1990). Further, younger survivors tend to report a lower quality of life (QOL) than older survivors due to effects of treatment such as premature menopause, early ovarian decline, and sudden onset of hot flashes (Avis et al., 2005a). Additionally, the 5-year survival rate tends to be lower among women diagnosed with breast cancer before age 40 (84%) when compared to women diagnosed at age 40 or older (90%) (Anders et al., 2008; Goldhirsch et al., 2001). Research has found that tumors diagnosed at younger ages tend to be more aggressive and/or less responsive to treatment (Anders et al., 2008; Goldhirsch et al., 2001), which may be a source of great distress in younger patients.

## The Current Study

With breast cancer mortality rates declining (American Cancer Society, 2013), young women diagnosed with breast cancer are now more likely to become long-term survivors. Thus, it is important to understand how younger women deal with a breast cancer diagnosis and subsequent treatment. The current study aimed to explore PTG in a young sample of female breast cancer survivors (ages 25 to 45) via qualitative data as well as quantitative responses on the PTGI. Although PTG has been previously examined in breast cancer patients (Bellizzi & Blank, 2006; Bellizzi et al., 2010; Bozo et al., 2009; Brunet et al., 2010; Bussell & Naus, 2010; Chan et al., 2011; Cordova et al., 2001; Cordova et al., 2007; Gall et al., 2011; Hefferon et al., 2010; Ho et al., 2011; Koutrouli, Anagnostopoulos, & Potamianos, 2012; Lelorain et al., 2010; Luszczynska et al., 2012; Manne et al., 2004; Mols et al., 2009; Morrill et al., 2008; Sadler-Gerhardt et al., 2010; Sears, Stanton, & Danoff-Burg, 2003; Silva, Crespo, & Canavarro, 2012; Silva, Moreira, & Canavarro, 2012; Svetina & Nastran, 2012; Weiss, 2002, 2004), no published studies with a young breast cancer sample appear to exist. In fact, the lowest mean age of the studies mentioned above, 46.28 years (Bozo et al., 2009), is greater than the oldest participant in the current study. Thus, the current study adds to existing PTG research by examining the phenomenon in the youngest breast cancer sample to date. Additionally, the current study aimed to examine the relationship between the qualitative data and quantitative measures of coping, depression, social support, health behaviors, and QOL.

A literature search was conducted via the PsycINFO and PubMed search engines to examine findings regarding PTG in breast cancer survivors via the key words "posttraumatic growth and breast cancer." The search returned 61 results via PsycINFO

and 36 results via PubMed. Articles were omitted from the current review if they did not use the PTGI to measure growth or did not report PTGI scores specifically for breast cancer patients; did not examine variables relevant to the current study; examined PTG following support programs, sport programs, interventions or activities designed to promote PTG; examined PTG only in children or partners of breast cancer survivors; were dissertations with the same sample used in a published manuscript; or were not published in English. The exclusion of the previous articles (and duplicate articles located by both search engines) resulted in a sample of 31 articles, two of which were qualitative in nature.

Although some researchers have used the terms "posttraumatic growth" and "benefit-finding" (Tennen & Affleck, 2002) interchangeably, researchers have noted the conceptual differences between these terms. Specifically, PTG involves a personal transformation where philosophies about the world and/or self are revised (Aspinwall & Tedeschi, 2010). This transformation involves surpassing what was present before a traumatic event – going beyond the previous status quo – and reflects an improvement versus a return to baseline (Tedeschi & Calhoun, 2004). In contrast, benefit-finding lacks being "transformed" and involves the identification of positive aspects post-trauma such as improvement in family and social relationships, life priorities, sense of spirituality, career goals, self-control, and the ability to accept circumstances (Urcuyo, Boyers, Carver, & Antoni, 2005). Clearly, some of the benefits overlap with PTG, but others do not fit into the five dimensional model of growth. Studies comparing the two constructs have concluded that benefit-finding and PTG are related, but distinct constructs (Mols et al., 2009; Sears et al., 2003). Additionally, benefit-finding often occurs very soon after a

traumatic event (Burt & Katz, 1987; Frazier, Conlon, & Glaser, 2001; Fromm,
Andrykowski, & Hunt, 1996; McMillen, Smith, & Fisher, 1997) since the recognition of
benefits can occur almost immediately; more time is needed for the process of developing
PTG where a personal transformation occurs. Despite the conceptual differences, it is
important to recognize findings from studies of benefit-finding in breast cancer samples
since they might offer useful information related to the process of PTG. Thus, studies of
benefit-finding that include variables related to the current study are included in the
following literature review.

# Qualitative Studies of PTG in Breast Cancer Survivors

Consistent with many qualitative studies, the qualitative studies of PTG with breast cancer survivors used small samples that allowed for the collection of in-depth, rich data related to the breast cancer experience. Sadler-Gerhardt and colleagues (2010) conducted qualitative interviews with eight breast cancer survivors and Hefferon and colleagues (2010) conducted interviews with ten survivors. Both studies utilized a phenomenological paradigm where the participant is considered the "expert" and no preconceived hypotheses are developed (Hefferon et al., 2010, p. 228). Hefferon and colleagues (2010) focused their investigation of PTG around a key question, "What does finding positive benefits from your trauma mean to you," (p. 230) with follow-up questions developing based on participants' responses. Sadler-Gerhardt and colleagues (2010) did not develop one key question, but instead asked multiple open-ended questions related to, "...change, cancer, chronic illness, posttraumatic stress, and posttraumatic growth," (p. 269). In both studies, the interviews were transcribed verbatim and common themes were identified.

Hefferon and colleagues (2010) discovered eight main themes in their analysis of participants' interviews: the body, exercise class (participants were part of a larger study where they took part in an exercise program), existential reevaluation, self-identity, philosophy change, society, lack of rumination, and impact of trauma. However, the only published manuscript thus far (Hefferon et al., 2010) provides information related to the theme of "the body" with other themes to be discussed in future publications. Subthemes related to the body emerged such as fear of new body, negative effects of chemotherapy on the body and reconnection with the body with all ten women experiencing PTG to some extent. The data indicated that participants, in general, reported a better QOL and greater appreciation for life after their diagnosis with breast cancer. Further, participants' bodies and bodily changes due to the cancer and treatments were perceived by most participants to be an important piece of self-identity.

The authors noted a sequential process described by some participants where they first felt a negative relationship with the changes in their bodies such as hair loss and loss of breasts, but eventually developed a positive relationship with their new bodies. For example, one participant stated:

"Your eyes look flat, there's no sparkle in them, and all the rest of it. When the chemotherapy stopped, and things started to grow back again, like my hair ...Um (pauses) it was like spring...because everything was just, you know, bursting out! My hair...the hair on my head was so strong. My eyelashes were just...crazy and I really began to feel so much better. I suppose, once that stuff filters out of your system. I just felt really great," (p. 237).

The authors concluded that as survivors became physically strong again, they began to feel mentally stronger than before which reflects growth on the PTG dimension of personal strength.

Sadler-Gerhardt and colleagues (2010) found several common themes shared by participants including post-surgical recovery, adjuvant treatment side effects, relational upheavals, and fears of recurrence. Unique contextual themes were also identified such as one participant who had experienced breast cancer previously and minimized the seriousness of the disease or two participants of child-bearing age who were concerned with infertility. In addition to identifying themes, researchers conducted a narrative analysis of the interviews and noted the occurrence of two meta-narratives: Change and Meaning.

Three common themes emerged related to the meta-narrative of change: chronic illness changes, negative changes, and posttraumatic growth. In terms of the chronic illness theme, most participants did not feel "chronically ill" even though they recognized the toll the disease had taken on their bodies. Some of the negative changes reported by participants were changes in mood, sexual difficulties, disappointing relationships, a lack of understanding or support from others, and a loss of voice to ask for help from others. Two women reported a weakening of faith or anger at God.

Despite the negative changes women discussed, all participants provided evidence that they experienced PTG. Participants unanimously reported instances of PTG in the areas of "new possibilities, interests, or a changed life direction, discovery of what one believes is important in life, and more appreciation for intangibles," (p. 273). Two participants reported feeling like a better person or proud of themselves after dealing with

breast cancer. Most of the women reported a strengthening of relationships and some reported greater compassion for others as evidenced by volunteer work. Additionally, some women reported feeling closer to God and engaging in prayer and/or going to church more often.

Both of the qualitative studies discussed above provide support for the occurrence of PTG following a breast cancer diagnosis and subsequent treatments. Although not specific to breast cancer, two additional qualitative studies of cancer survivors and positive changes similar to PTG have been conducted (Fromm et al., 1996; Steel, Gamblin & Carr, 2008). These studies will be briefly discussed as well as recommendations made by the authors for future qualitative studies of PTG specifically in cancer survivors.

In their study of adult bone marrow transplantation survivors (n = 90), Fromm and colleagues (1996) asked participants the following questions: "Has your transplant had any negative effect upon your family life or upon other members of your family? Has your transplant had any positive effect upon your family life or any other members of your family? Have you noticed any changes in your relationships with other people since your transplant? Have you noticed any changes in your outlook on life since your transplant," (pp. 226-227). Participants who answered "yes" to any of the questions were prompted to describe the changes they experienced. Three major categories emerged (changes related to the self, the family, and others) and each category was classified as both positive and negative. Subcategories were identified under each of the six major categories and changes related to the five PTG dimensions were: 59% of participants reported a new philosophy of life, 47% reported a greater appreciation of life, 29%

reported increased empathy for others, 27% reported a positive change in life priorities, 54% reported a positive change in personal attributes, 52% reported improved family relationships, and 9% reported increased spirituality.

Total positive change and total negative change scores were calculated for each participant by counting the number of individual positive and negative subcategories reported (M positive change = 10, SD = 4.8; M negative change= 9, SD = 4.9). Seven predictor variables including gender, age at transplant, marital status, education, time post-transplant at interview, bone marrow transplant type, and degree of transplant risk for each participant were force-entered into a regression model at a single step for both total positive and total negative change scores. The predictors accounted for 10% of the variance in negative change and 16% of the variance in positive change. Degree of transplant risk and time post-transplant were significant predictors for total positive change indicating participants with a higher transplant risk and less time since treatment reported more positive changes.

Steel and colleagues (2008) asked the following questions to participants (*N* = 120) who had been diagnosed with hepatobiliary (liver and bile ducts) cancer (*M* age = 63, *SD* = not reported): "Have you changed your life in any way as a result of being diagnosed with cancer? If yes, how? Did the way you changed happen mostly in the way you think, feel, or behave? If you have experienced a change, when did it occur?" (p. 645). A content analysis was conducted to examine participants' responses to these questions. Participants also completed the PTGI, and researchers compared participants' responses on the open-ended questions with the PTGI to see whether responses matched items on the PTGI. Results demonstrated the PTGI captured many of the areas of growth

mentioned by participants. However, they also found that many participants reported health behavior changes such as smoking and drinking less that the PTGI did not capture. Although the authors suggest more qualitative research is needed assess whether additional items on the PTGI would better capture PTG in survivors with cancer, health behavior changes are not areas of PTG as defined by Calhoun and Tedeschi.

Quantitative Studies of PTG in Breast Cancer Survivors

Studies of PTG in breast cancer survivors have examined a wide variety of potential correlates of growth such as coping (Bellizzi & Blank, 2006; Bussell & Naus, 2010; Lelorain et al., 2010; Manne et al., 2004; Sears et al., 2003; Silva, Crespo, & Canavarro, 2012; Svetina & Nastran, 2012), optimism (Bellizzi & Blank, 2006; Bellizzi et al., 2010; Bozo et al., 2009; Sears et al., 2003), religiosity (Bellizzi et al., 2010; Gall et al., 2011), social support (Bozo et al., 2009; Cordova et al., 2001; Sears et al., 2003; Weiss, 2004), depression (Bussell & Naus, 2010; Cordova et al., 2001; Luszczynska et al., 2012; Morrill et al., 2008), posttraumatic stress (Cordova et al., 2001; Cordova et al., 2007; Koutrouli, Anagnostopoulos, & Potamianos, 2012; Ho et al., 2011; Morrill et al., 2008), QOL (Bellizzi et al., 2010; Lelorain et al., 2010; Morrill et al., 2008; Sears et al., 2003; Silva, Moreira, & Canavarro, 2012), marital satisfaction (Manne et al., 2004; Weiss, 2004) and positive affect (Chan et al., 2011; Lelorain et al., 2010). The current study aims to provide additional information on the relationship between PTG as measured by the PTGI and coping, depression, QOL, and social support. Results from previous studies of PTG and breast cancer survivors with these variables will next be discussed.

## Coping

Breast cancer patients coping with the disease have been described as "lone warriors" engaging in "hand-to-hand combat" with the "enemy" (Arthur McDonald, 2009, p. 2). A large part of the breast cancer battle includes efforts made to relieve suffering and anxiety caused by the disease. Coping has been defined as cognitive and behavioral efforts to reduce demands of the disease that are appraised by the survivors as having exceeded their resources (Folkman, Lazarus, Gruen, & DeLongis, 1986). In their theory of cognitive coping with stressful events, Lazarus and Folkman (1984) describe two types of coping: emotion-focused (regulating emotions) and problem-focused (dealing with the problem that is causing the distress). Examples of emotion-focused coping include distancing (trying to forget about the problem), avoiding the problem, seeking social support, positive reappraisal, self-controlling, and accepting responsibility (Folkman et al., 1986). Problem-focused forms of coping include efforts to problem solve as well as interpersonal efforts to alter the situation (Folkman et al., 1986).

Coping research with young breast cancer survivors has found that a form of emotion-focused coping where efforts are made to recognize the good even in the face of the breast cancer experience (referred to as positive reframing and/or positive reappraisal) is a frequently used coping mechanism (Avis et al., 2005a; Manuel et al., 2007). Two studies found that young breast cancer survivors who used positive cognitive restructuring also reported a higher QOL (Avis et al., 2005a; Danhauer, Crawford, Farmer, & Avis, 2009). In their examination of open-ended coping questions, Manuel and colleagues (2007) found that young breast cancer survivors reported positive reappraisal as a helpful way of dealing with their concerns about the future. Several studies of PTG

in breast cancer survivors have also examined coping responses including active coping, religious coping, humor, acceptance and others discussed below. Unfortunately, the coping literature uses a wide range of coping terminology and assessments, making it confusing to compare across studies (Skinner, Edge, Altman, & Sherwood, 2003). However, studies of breast cancer survivors, PTG (and benefit-finding), and coping have consistently utilized either the COPE (Carver, Scheier, & Weintraub, 1989) or Brief COPE (Carver, 1997) to measure coping (both of which were developed based on Lazarus and Folkman's concept of coping) which helps with ease of comparison across studies.

Bellizzi and Blank (2006) used the Brief COPE to investigate the relationship between coping and three PTG factors: relating to others, purpose in life, and appreciation of life. Results from their study of 224 breast cancer survivors (M age = 60; SD = 12.01) demonstrated that adaptive coping (comprised of the subscales of self-distraction, active coping, seeking emotional and instrumental support, venting, positive reappraisal, planning, acceptance, and religion) was significantly positively correlated with relating to others, new possibilities, and appreciation of life. Maladaptive coping strategies (substance abuse, denial, behavioral disengagement, and mental disengagement) were not significantly associated with PTG.

Similarly, Bussell and Naus (2010) used the Brief COPE in their study of 59 breast cancer survivors (M age = 50; SD = not reported). The results indicated that religious coping, positive reappraisal, using instrumental support and using emotional support to cope were significantly correlated with total PTGI scores. Lelorain and colleagues (2010) also utilized the Brief COPE and found that adaptive coping in the

form of active coping, positive reappraisal, relational coping, and religious coping all predicted total PTG in their sample (N = 307; M age = 62.4; SD = 7.9).

Silva, Crespo, and Canavarro (2012) used the Brief COPE and examined the relationship between "cognitive coping" (positive reappraisal, humor, acceptance, planning) and "social support seeking" (emotional and instrumental support) with PTG. This study included a sample of 50 breast cancer survivors (M age = 52.1 years, SD =8.3) followed from time of surgery, during treatment (e.g., chemotherapy, radiation therapy), and 6 months post-treatment. To measure PTG, the Portuguese version of the PTGI was utilized (Silva et al., 2009) which yields a total score, but only 4 dimensions (as factor analysis yielded 4 strong factors); personal resources and skills, new possibilities and life appreciation, strengthening of social relationships, and spiritual development. Results indicated that cognitive coping at time of surgery was significantly positively corelated with quality of life post-treatment and one dimension of PTG during treatment: personal resources and skills. The use of social support seeking at time of surgery was significantly positively correlated with three dimensions of PTG during treatment: personal resources and skills, new possibilities and life appreciation, and strengthening of social relationships. Also, the use of coginity coping and support seeking at time of surgery indirectly influenced depression (as measured by the HADS) and psychological quality of life (as measured by the World Health Organization Quality of Life – Bref) post-treatment via PTG (specifically, the personal resources and skills dimension). The authors suggest that cognitive and support seeking coping might promote self-efficacy around personal resources (e.g., "feeling stronger") and may promote better psychological adjustment post-treatment.

In a study of benefit-finding and coping, Urcuyo and colleagues (2005) utilized the Brief COPE and found, as hypothesized, benefit-finding in breast cancer survivors (M age = 53.45; SD = 12.34) to be strongly related to positive reappraisal and religious coping. Other weaker relationships included active coping, substance use, and acceptance.

Both Manne and colleagues (2004) and Sears and colleagues (2003) specifically examined the positive reappraisal subscale of the COPE. Manne et al. (2004) found positive reappraisal was not a significant predictor of PTG via growth curve modeling over 1.5 years since diagnosis (correlations were not reported) in their study of 162 breast cancer survivors (M age = 49; SD = not reported). In contrast, Sears et al. (2003) found PTG to be significantly positively correlated with positive reappraisal at 12 months (N =60; M age = 51.57; SD = 10.33) with positive reappraisal adding to the prediction of PTG (change  $R^2 = .08$ ). A meta-analysis of benefit finding and PTG (Helgeson, Reynolds, & Tomich, 2006) also examined positive reappraisal and its effect size was larger than any of the other variables examined. Lastly, although they did not use the COPE or Brief COPE to examine coping in their sample of breast cancer survivors, Svetina and Nastran (2012) explored PTG and coping via the Coping Response Inventory (Moss, 1993). In their sample of 190 women aged 31 to 83 (M age = 61.7, SD = 9.7), positive reassessment, a variable similar to positive reappraisal that accounts for cognitive strategies used to reconstruct problems and find positive aspects of distress, was significantly positively related to PTG. Not only was positive reassessment significantly correlated with total PTGI score, it significantly predicted PTG. Other coping variables

were also related to PTG, but exhibited weaker relationships including: logical analysis, support seeking, and problem solving.

Sears and colleagues (2003) also examined benefit-finding via the question, "Have there been any benefits that have resulted from your experience with breast cancer?" and recorded the number of benefits and identification of at least one benefit. Additionally, responses were coded and categories emerged that closely matched the 5 dimensions of the PTGI with the addition of health benefits which the PTGI does not capture. Positive reappraisal was related to the number of benefits, but not identification of at least one benefit. When predictors of number of benefits, positive reappraisal, and PTG were examined, higher education and optimism predicted number of benefits at 3 months, hope predicted positive reappraisal at 3 months, and time since diagnosis and perceived cancer stress predicted PTG at 12 months. These findings provide support that positive reappraisal, benefit-finding, and PTG are related constructs, but explain unique variance. These findings also provide support for the PTG model that the event must be perceived as traumatic enough to shake a person's core beliefs so they engage in cognitive work (rumination) to rebuild assumptions. It is through this cognitive work that PTG occurs and the process takes time. Thus, it is not surprising that PTG was correlated with both severity of the event and time since the event.

Overall, results from these studies suggest that adaptive coping such as active coping efforts, religious coping, and using emotional and instrumental support to deal with problems might be related to more positive adjustment to breast cancer and greater reports of PTG. With the exception of Manne and colleagues (2004), the above studies consistently found various forms of adaptive coping to be related to PTG. As previously

mentioned, studies with young breast cancer survivors have reported positive reappraisal to be a useful tool and it has been related to better QOL (Avis et al., 2005a). Because positive reappraisal involves actively identifying positive aspects of stressful situations, it is not surprising that survivors who use this coping skill would actually report more benefits or PTG.

### Quality of Life

Quality of life is an overarching term used to describe domains such as functional status, self-care activities, mobility, physical activities, work or household responsibilities, disease and treatment-related symptoms, psychological functioning, and social functioning (Ganz et al., 1993). With breast cancer treatments including surgery, radiation, chemotherapy, and hormone therapy, patients often must deal with pain, swelling, sexual side effects, and hot flashes (Casso et al., 2004) that can cause QOL to suffer. As previously mentioned, the variety of stressors that young breast cancer survivors face appears to place them at an increased risk for poorer QOL than older breast cancer survivors (Avis et al., 2005a).

Studies of PTG have sought to examine its relationship with QOL. Morrill and colleagues (2008) examined PTG and QOL in a sample of 161 breast cancer survivors (*M* age = 59; *SD* = 10.6) via the Functional Assessment of Cancer Therapy Scale – Breast; FACT-B; Brady et al., 1997. The FACT-B includes ten breast cancer specific items such as "I am able to feel like a woman," "One or both of my arms are swollen or tender," and "I am self-conscious about the way I dress," etc. Examination of correlations revealed that PTG was significantly correlated with QOL. Upon further examination, PTG was found to moderate the relationship between PTSS and QOL. Similarly, Silva and

colleagues (2012) found that PTG (as measured by the Portuguese version of the PTGI) buffered the effect of perceived impact of breast cancer on psychological and social QOL (as measured by the Portuguese version of the World Health Organization QoL-Bref) in their study of 78 breast cancer survivors (M age = 52.08, SD = 8.86). This finding suggests when higher levels of PTG are reported, people with higher levels of distress (e.g., posttraumatic stress or greater perceived negative impact of breast cancer on life) report a better QOL. Thus, PTG may act as a buffer of sorts against negative consequences of posttraumatic stress and could potentially be described as "stress-buffering."

Sears and colleagues (2003) measured QOL via the Functional Assessment of Cancer Therapy (FACT; Cella et al., 1993) in their study of 92 breast cancer survivors at 3 and 12 months post-treatment (M age = 51.57; SD = 10.33). The FACT is identical to the FACT-B except it lacks the ten breast cancer specific items. In this study, the PTGI and FACT total scores were not significantly correlated.

Bellizzi and colleagues (2010) measured health-related quality of life (HRQOL) via the Short Form-36 Health Survey (SF – 36; Ware, Snow, Kosinski, & Gandek, 1993). The SF-36 includes two component scores: Mental Component Score (social functioning, vitality, mental health, role-emotional) and Physical Component Score (physical function, role-physical, bodily pain, general health). They utilized a large sample of 802 breast cancer survivors (M age = 57.2; SD = 10.1). A multiple regression with total PTGI score entered at the last step indicated PTG accounted for an additional 6% of the variance and significantly predicted the Mental Component Score. However, PTG did not significantly predict the Physical Component Score. Interestingly, the relationship between PTG and

QOL was contrary to the researchers' prediction – more growth was associated with lower mental HRQOL. The authors hypothesized this inverse relationship might be explained by distress and PTG co-occurring. Their hypothesis fits the model of PTG in that survivors must experience a certain level of distress for assumptions about the world to be shaken and necessitate rebuilding.

Lelorain and colleagues (2010) also used the SF-36 to measure QOL in a sample of 307 (M age = 62.4; SD = 7.9) long-term breast cancer survivors (Mean time since diagnosis = 10 years), but did not examine the Physical Component Score. Although PTGI total score and PTGI dimensions of appreciation of life and new possibilities were not significantly correlated with the Mental Component Score, the PTGI dimensions of relation to others and personal strength were significant. This finding suggests survivors reporting PTG in relationships with others and personal strength many years after their diagnosis might reap some benefit and report a higher QOL in the area of mental health or vice versa.

The findings related to the QOL and PTG relationship are inconsistent. One study found no relationship (Sears et al., 2003), two studies found QOL and PTG were significantly positively correlated and PTG acted as a moderator of QOL (Morrill et al., 2008; Silva et al., 2012), one study found total PTG to be related to *lower* scores on Mental Component Score of the FACT-B (Bellizzi et al., 2010), and one study found only the dimensions of relationships with others and personal strength to be positively related to the Mental Component Score (Lelorain et al., 2010). Examining time since diagnosis does not aid in untangling the findings – Bellizzi et al. (2010) at 6.1 months since diagnosis found the inverse relationship, Sears et al. (2003) at 7 months since

diagnosis found no relationship, Morrill et al. (2008) at 4 years and Silva et al. (2012) at 6 months since diagnosis found the moderating effect of PTG, and Lelorain et al. (2010) at 10 years since diagnosis found the Mental Component Score significantly related to two PTG dimensions. The samples were similar on all other demographic and medical variables. Perhaps the FACT (with its lack of the ten breast cancer specific items) and SF-36 Physical Component Score were not sensitive enough to the QOL of breast cancer survivors for a relationship to be detected. Thus, the significant relationships were found using the FACT-B, Mental Component Score of the SF-36, and psychological and social QOL as measured by the Portuguese version of the World Health Organization QoL-Bref.

Although the findings are inconsistent, it does appear that PTG is related to QOL in some manner, perhaps indirectly. It is also important to consider that these findings were from studies with older survivors (≥ 51.57 years) so findings from the current study with survivors 45 years old and younger might vary since younger survivors might be more sensitive to the effects of trauma than older survivors.

#### Depression

In 2006, Helgeson and colleagues conducted a meta-analysis of PTG and benefit-finding and specifically examined their relationship with depression. Because studies measuring both benefit-finding and PTG were examined together, it is impossible to determine the relationship between depression and PTG alone from these results. However, the analysis examined 20 studies which utilized the PTGI and 22 studies which used open-ended items to measure benefit-finding/PTG both of which are relevant to the current study. The effect size for depression, r = -.09 (p < .001), led the authors to

suggest PTG (and benefit-finding) are associated with better mental health outcomes.

This finding was based on a variety of traumatic events; the studies discussed below are specific to breast cancer.

Based on previous studies, Chen and colleagues (2009) estimated 1.5 to 55% of women diagnosed with breast cancer will become depressed within the first 6 months of diagnosis. However, Tedeschi and Calhoun (1996) have noted that positive consequences of stressful events such as PTG can co-exist with negative psychosocial responses. Thus, some researchers have been interested in the relationship between negative aspects of the breast cancer experience such as depression and positive aspects of the breast cancer experience such as PTG (Cordova et al., 2001; Morrill et al., 2008). As previously mentioned, young breast cancer survivors appear to have an increased risk for psychological morbidity (Bardwell et al., 2006; Bloom & Kessler, 1994; Christensen et al., 2009; Cordova et al., 1995; Ganz et al., 2003; Gorman et al., 2010; Harrison & Maguire, 1995; Vinokur et al., 1990). Therefore, examining depression in the current sample can yield useful information regarding participants' increased risk for depression and potential for higher levels of PTG (both likely due to their younger age). The following five studies of depression and PTG were conducted with a general sample of breast cancer survivors with an overall average mean age of 57.3 years.

Mystakidou and colleagues (2008) used the Greek version of the Hospital Depression and Anxiety Scale (G-HADS) to measure depression in their sample of 100 breast cancer survivors (M age = 58.2; SD = 11.9). A significant negative correlation emerged between the new possibilities subscale of the PTGI and the G-HADS total score

indicating survivors who reported higher levels of new possibilities reported lower levels of depression. No other relationships between depression and PTG were significant.

Cordova and colleagues (2001) examined depression via the Center for Epidemiologic Studies—Depression Scale (CES-D; Radloff, 1977) in breast cancer survivors (N = 70; M age = 54.7; SD = 12.1) and age and education matched healthy comparison women. Results demonstrated breast cancer survivors did not differ from the control group in terms of depression, but they did report higher levels of PTG. Additionally, PTG was not significantly related to depression. Urcuyo and colleagues (2005) also used the CES-D to examine the relationship between benefit-finding and depression. A significant relationship emerged with higher levels of benefit-finding associated with lower levels of depression (beta = -.23, p < .01).

Consistent with the findings of Sears et al. (2003), Morrill and colleagues (2008) also used the CES-D and found depression was not significantly correlated with PTG scores. However, PTG moderated the relationship between posttraumatic stress symptoms and depression, indicating that when higher levels of PTG are reported, lower levels of depression are reported by people with high levels of posttraumatic stress. Silva and colleagues (2012) also found that PTG and depression were not significantly correlated, but that PTG approached significance as a moderator (p = .06) to buffer the effects of participants' negative perceptions of breast cancer on symptoms of depression.

An additional study of two PTG dimensions, personal strength and spiritual growth, in 164 breast cancer survivors (M age = 49.99, SD = 11.62) briefly examined depression utilizing the CES-D (Luszczynska et al., 2012). The authors created a "cumulative index of PTG" using the personal strength and spiritual growth dimensions

from the PTGI and found the index to be significantly positively correlated with depression. As the depression-PTG relationship was not a focus of the study, this finding was not discussed by the authors. However, they did recognize their lack of inclusion of all PTG dimensions as a weakness.

Findings from these studies suggest that even though depression and PTG might not be directly related, PTG might act as a buffer by reducing the deleterious effects posttraumatic stress symptoms and/or negative perception of breast cancer has on depression. More investigation into the relationship between PTG and depression (especially in young breast cancer survivors) is warranted.

### Social Support

In the area of health research, social support has consistently been related to psychological adaptation following a cancer diagnosis (Bloom & Spiegel, 1984; Neuling & Winefield, 1988; Bloom, 1990). Social support is a multidimensional construct that has led to a multitude of different social support measures that make it difficult to compare results across studies (Weiss, 2004). Many researchers categorize social support in two distinct categories: emotional support where a person is emotionally available such as providing comfort in times of distress and instrumental support where a person is physically available such as providing transportation to medical appointments (Bloom, Stewart, Johnston, Banks, & Fobair, 2001). In their study of breast cancer survivors 50 years old or younger (N = 336), Bloom and colleagues (2001) found a larger social network was related to greater emotional and instrumental support. Further, greater emotional support was related to greater mental well-being. Greater instrumental support was related to poorer physical health which is not surprising considering women with the

poorest physical health might need the most instrumental support. A more recent study of social support in breast cancer survivors who had been diagnosed at age 40 or younger (N = 131; M age = 53.3; SD = not reported) found participants who reported less social support also reported higher levels of depression (Gorman et al., 2010).

In their study of 104 breast cancer survivors (*M* age = 46.28 years; SD = 9.23), Bozo and colleagues (2009) found perceived social support predicted PTG. Further, PTG was significantly correlated with global social support, social support from family, friends, and a significant other. These findings are in contrast to findings from Cordova and colleagues (2001) where the relationship between social support and PTG was not significant. Sears and colleagues (2003) measured emotional support via three items and found the total score from these items was positively correlated with PTG, but was not significant. However, emotional support was significantly correlated with positive reappraisal which predicted more positive mood and better health at 3 and 12 months post-study enrollment as well as PTG (measured only at 12 months). Thus, emotional support might influence PTG indirectly through positive reapprasisal.

Finally, Weiss (2004) specifically examined social support in her study of 72 breast cancer survivors (M age = 54.2; SD = 8.6) and found higher levels of PTG were reported by women who felt their husbands were supportive. Additionally, women who had contact with another breast cancer survivor who reported benefits from the experience reported higher levels of PTG. Contrary to the study hypothesis, scores from a measure of general social support were not associated with PTG, but they did approach significance (p = .15).

These findings suggest that several paths to PTG via social support might exist. In some cases, social support might lead to positive reappraisal which might be related to PTG. For example, talking to a person who has been through breast cancer and found benefits from the experience might lead to positive cognitive restructuring and ultimately, PTG. For some people, simply having others physically present to help during the breast cancer experience might bring them closer together and lead to reports of PTG on the "relating to others" dimension (no positive reappraisal needed in this case). As with the other variables discussed in this review of the PTG-breast cancer literature, further examination is needed into the relationship between PTG and social support.

#### Health Behaviors

With advances in detection and treatments leading to more breast cancer survivors surviving the disease, health behaviors have important implications for survivors' recovery as well as the potential for recurrence and general health (Park & Gaffey, 2007). In addition, health behaviors appear to be related to QOL with survivors who exercise more often reporting better emotional and physical well-being (Blanchard et al., 2003; Courneya, 2003; Pinto & Trunzo, 2005). It appears that a cancer diagnosis can prompt survivors to alter health behaviors in a positive manner (Andrykowski, Beacham, Schmidt, & Harper, 2006), but it is unclear how these changes relate to PTG or whether PTG relates to healthy habits in general. It makes sense that if one reports a greater appreciation of life post-cancer, changes might be made to improve health so life will last longer. As previously discussed, Steel and colleagues (2008) found that reported positive health behavior change was a positive consequence of the cancer experience. Kurtz, Wyatt, and Kurtz (1995) examined aspects of positive change in females post-cancer

(changes in philosophy, desire to support others, and sexual satisfaction) as well as health habits. Results demonstrated that positive changes were significantly positively correlated with adaptive changes in health behavior (assessed by a summary measure). Other studies of PTG or benefit-finding and healthy behaviors could not be located. It might be that making changes to improve health after breast cancer is another benefit of the cancer experience. On the other hand, positive health behaviors might be an outcome of PTG. The current study aims to provide more information in this area.

### **Summary and Conclusions**

Although there has been a recent increase in research regarding PTG in breast cancer survivors, multiple questions still remain. The relationship between PTG and a variety of factors such as coping, QOL, depression, and social support remains unclear. Young breast cancer survivors have been investigated less than older survivors, making the relationships between the above-mentioned variables even less clear in the younger population.

## Statement of Purpose

The goal of the current study was to examine PTG and coping, QOL, depression, and social support in a sample of young breast cancer survivors. An investigation of survivors' responses to the following two open-ended questions was conducted: "What major challenges have you faced since your diagnosis," and "What positive experiences have you had?" Responses to the second question were compared to the PTGI to see if new areas of growth not captured by the PTGI emerge in the data. Further, a content analysis of the open-ended items was conducted to examine their relationship with

coping, depression, QOL, social support, and PTG scores. A final goal was to examine whether PTG predicts healthy behaviors. The study hypotheses include:

# Hypotheses

- 1. Survivors will report positive changes in the areas of personal strength, relating to others, appreciation of life, new possibilities and spiritual growth consistent with the PTGI. Additionally, survivors will report positive changes related to health behaviors.
- 2. Survivors reporting a higher number of negative experiences will report higher levels of depression and distress and lower levels of PTG. Survivors reporting a higher number of positive experiences will report higher levels of PTG, adaptive coping, and QOL.
- 3. Survivors reporting a high number of negative experiences and low number of positive experiences will report lower levels of PTG and higher levels of depression than survivors reporting a high number of positive experiences and low number of negative experiences.
- 4. Survivors reporting higher levels of emotional social support, adaptive coping, and QOL at baseline, 6 months, and 12 months will report more positive changes on the open-ended items at 12 months as these methods of coping appear likely to produce positive experiences (baseline, 6 months) and it is likely that people who are coping well will continue to recognize positive experiences (12 months).
- 5. Survivors reporting higher levels of PTG at 6 months will report a higher number of healthy behaviors on the open-ended items and as measured by the personal habits form at 12 months.

#### **CHAPTER 2: METHODS**

### **Participants**

Participants in the current study (N = 87) were recruited to be a part of a larger multicenter, longitudinal study of breast cancer survivors assessing menstrual cycle maintenance and QOL after breast cancer treatment (N = 836). The initial sample size of the current study was thought to be 143 (with 133 responding to the open-ended items), but upon data analysis, it was realized that 46 participants from a different study had inadvertently received open-ended items and their data were unable to be used for the purposes of the current study. Participants of the current study were female patients who were within the age range of 18 to 45 years old who had been diagnosed with stages I to III invasive breast cancer within the previous eight months. Participants were excluded if they had prior or concurrent diagnoses of cancer, excluding basal or squamous cell skin carcinoma and/or stage 0 cervical cancer. Because participants were required to have regular menstrual cycles at diagnosis, women who had a previous hysterectomy were ineligible for the study.

### Design and Procedure

Recruitment to the current study began in January 1998 and ended in December 2005. Patients were identified using tumor or surgical registries and patient or physician referrals and were recruited through two sites: Memorial Sloan-Kettering Cancer Center in New York City, NY and M.D. Anderson Cancer Center in Houston, TX. The current study was approved by the institutional review board of each hospital as well as the US

Department of Defense Human Subjects Committee. In addition, IRB approval was obtained at UNC-Charlotte for the purpose of this project.

At each institution, patients' oncologists or surgeons were contacted by clinic staff to obtain approval to approach them and obtain patients' next scheduled clinic appointment. If the physician approved, patients were approached at the clinic site, (if scheduled for a follow-up or treatment visit) or sent a letter describing the purpose of the study, which was followed by a telephone call. The clinic staff person screened patients to ensure that they met eligibility criteria and asked patients to participate if eligible. Participants were also identified by the clinical centers' participating investigators, oncologists, surgeons, and radiologists, who were informed of the study protocol. These patients were referred by the physicians to the study coordinators, who then screened and enrolled eligible patients. Refusal rate for the current study was low with 9% of eligible women declining to participate.

If patients were screened while in clinic, they signed the informed consent form and medical record release, and completed the baseline study questionnaires at that time. Patients who were initially screened over the telephone were asked to come to the clinic for a baseline visit to complete these forms. These visits were scheduled to coincide with patients' next scheduled clinic appointment and to accommodate the their schedules. Participants who were post-treatment or not scheduled to be in clinic within the next 4-6 weeks had the option of completing the informed consent and questionnaires through the mail. When the latter procedure was used, the clinic coordinator scheduled a telephone call with the participants to go through the consent form, the medical release, and the study questionnaires. Patients who agreed to participate via phone completed the forms

and mailed them back to the clinic coordinator. The clinic coordinator then reviewed the forms to make sure they were completed correctly and called the patients with any questions. If the forms were in order, the clinic coordinator completed a registration form on each participant and mailed the baseline forms and signed consent form, via courier mail service, to the project manager at the Wake Forest School of Medicine, which was the coordinating center for this study. All follow-up data collection was conducted by mail through the study coordinating center.

Several adherence, retention, and incentive strategies were implemented for the current study to keep women interested in participating. For example, all participants were sent holiday cards in December as well as cards on their birthdays. A newsletter was published 2-3 times per year, providing participants with updates on the number and state of residence of the participants, information about literature related to breast cancer, information about the staff at the participating centers, recipes and information shared by the participants. In addition, a quarterly drawing was held for gift certificates to Wal-Mart, Home Depot, and Lowe's Home Improvement Centers for participants who returned their forms within the designated time frames. A toll free 800 number also existed for women to call and ask questions about their forms or the study protocol.

Participants enrolled in the current study were followed at 3, 6, 12, and 18 months post-baseline (See Table 1 for timeline of administration of measures). At each follow-up, they completed various QOL and psychosocial measures and updated their family and medical history. Data collection during the follow-up period was centralized in that all follow-up forms were mailed to participants, along with a self-addressed stamped envelope, by staff at the coordinating center at the Wake Forest School of Medicine.

Procedures were developed to contact participants if questionnaires were not returned to the coordinating center in a timely manner (i.e., within 21 days of the date the forms were mailed). The questionnaire completion time at follow-up was approximately 25-35 minutes. When the follow-up questionnaires were received by the coordinating center, the project managers examined each returned follow-up questionnaire for completeness. Participants with greater than 10% missing data on any of the study forms were telephoned in order to reduce the occurrence of missing data.

#### Measures

Medical Chart Review. Clinical staff conducted a medical chart review on enrolled patients within 6 weeks of the baseline clinic visit. The information obtained included: time since diagnosis, stage and grade, size and number of positive lymph nodes, estrogen and progesterone receptors (positive and negative), treatment prescribed (e.g., surgery, radiation, and/or chemotherapy; adjuvant therapy), whether immediate reconstructive surgery was performed, current medications, comorbid conditions, and patients' height and weight.

Participants enrolled in the current study completed the following measures:

Demographic Information. Participants completed basic demographic information including age, marital status, educational level, employment status, and income.

Open-ended Items. Participants completed two open-ended items at 12 months: "What major challenges have you faced since your diagnosis," and "What positive experiences have you had?"

Posttraumatic Growth. Participants completed the Posttraumatic Growth Inventory (PTGI; Tedeschi & Calhoun, 1996) at baseline, 6, 12, and 18 months. The PTGI includes 21 items examining the extent to which survivors have grown positively from the traumatic experience. Scoring for the PTGI consists of a total score and scores on each on the five dimensions: spiritual change, new possibilities in life, feeling stronger as a person, having a greater appreciation for life, and positive changes in the way survivors relate to others. The scale ranges from 0 (I did not experience this change) to 5 (I experienced this change to a great deal) with a possible total score ranging from 0 to 105. The PTGI has appropriate internal consistency (alpha = .90) and test-retest reliability over a two-month interval (r = .71).

Coping. Coping was assessed at baseline, 3, 6, 12 and 18 months with the 28-item Brief COPE scale (Carver, 1997). This measure assesses 14 coping reactions (two items per subscale) and is based on the longer COPE inventory (Carver et al., 1989). The subscales include active coping, planning, suppression of competing activities, restraint coping, seeking instrumental social support, seeking emotional social support, positive reappraisal, acceptance, turning to religion, focus on venting of emotions, denial, behavioral disengagement, mental disengagement, and alcohol and drug use. Participants rate the extent to which each response was used in trying to deal with stresses associated with their cancer diagnosis and treatment. A total coping score is not calculated for the Brief COPE. Options are to examine each scale separately in relation to other variables or to create second-order factors from among the scales and use the factors as predictors. The current study examined the 14 subscales separately. Cronbach's alpha for individual scales ranged from .50 to .90 in the original validation sample (Carver, 1997).

Depression. Depression was assessed at baseline, 3, 6, 12 and 18 months with the Beck Depression Inventory (BDI; Beck & Steer, 1987). The BDI is a 21-item measure of

depression that yields a total score and has been used with a variety of clinical and nonclinical populations and has been validated as a reliable screening tool for depression. Internal consistency for the BDI tends to be high (alpha = .85) (Ambrosini, Metz, Bianchi, Rabinovich, & Undie, 1991). Additionally, the BDI includes an item assessing suicidal ideation – no participants in the current study endorsed feeling as though they would like to kill themselves or planning to kill themselves if they had the chance.

Quality of Life. The current study used 3 measures of quality of life:

- 1. The SF-36 Health Status Questionnaire (Ware & Sherbourne, 1992) was administered at baseline, 3, 6, 12, and 18 months. The SF-36 is one of the most widely used measures of health status consisting of 36 items measuring eight domains. These eight domains form two component scores: the Mental Component Score (MCS) consists of vitality, mental health, role limitations due to emotional health, and social functioning. The Physical Component Score (PCS) consists of general health, physical functioning, bodily pain, and role limitations due to physical health. The SF-36 has a mean of 50 and SD of 10 with Cronbach's alpha of the domains ranging from .73 to .96 (Ware et al., 1993).
- 2. The Functional Assessment of Cancer Therapy Breast (FACT-B; Brady et al., 1997) was administered at baseline, 3, 6, 12 and 18 months. The FACT-B is a 44-item self-report measure which yields a total score and the following subscales: physical wellbeing, social/family well-being, emotional well-being, functional well-being, and breast cancer concerns. Cronbach's Alpha for the FACT-B total score in the original validation sample was .90 with subscales ranging from .63 to .86 (Brady et al., 1997).

3. The Quality of Life in Adult Cancer Survivors (QLACS; Avis et al., 2005b) was administered at 18 months. The QLACS was developed specifically for cancer survivors who are no longer in the midst of treatment. The measure includes five cancerspecific domains (appearance concerns, financial problems, distress over recurrence, family-related distress, and benefits of cancer) as well as 7 generic QOL domains (negative feelings, positive feelings, cognitive problems, sexual problems, physical pain, fatigue, and social avoidance). The QLACS consists of 47 items with domain scores ranging from 4 to 28. 4 items comprise the benefits of cancer domain: "You appreciated life more because of having had cancer," "You realized that having had cancer helps you cope better with problems now," "You felt that cancer helped you to recognize what is important in life," and "You felt better able to deal with stress because of having had cancer." Further, a Generic Summary Score difficulties score was created by the measure authors to assess for difficulties such as negative feelings, positive feelings (reversescored), cognitive problems, pain, sexual problems, social avoidance, and fatigue). Cronbach's alpha was .72 or higher for each domain in the validation sample.

Health Behaviors. Health behaviors were assessed at baseline, 6, 12, and 18 months via 7 items related to exercise, smoking, and drinking. Participants indicating they smoke and drink also indicated how many cigarettes they smoke per day and how many beverages they consumed per month. Participants indicated how often they engaged in each of the following: walking, strenuous or very hard exercise, moderate exercise, and mild exercise.

Social Support. Social support was assessed at baseline, 3, 6, 12 and 18 months with the Medical Outcomes Study (MOS) Social Support Survey (Sherbourne & Stewart,

1991). The MOS measured respondents' evaluation of the functions and resources provided by their social network. The scale measures four aspects of support: emotional support, tangible support, affection, and social interaction and also includes a total support score (average of the four subscale scores). Cronbach's alpha was .91 and higher for all categories and the overall score in the validation sample (Sherbourne & Stewart, 1991).

Measures were administered in the following order for all participants: demographic items, SF-36, FACT-B, BDI, Brief COPE, PTGI, MOS, Health Behavior Items, QLACS, and the open-ended items.

#### **CHAPTER 3: DATA ANALYSIS**

The study consisted of a mixed-methods approach using both qualitative and quantitative methods. Because the current study was a secondary data analysis of an existing study, variables relevant to the current study were requested from the Wake Forest Baptist Health biostatistician familiar with the larger study. Quantitative analyses were then conducted in Statistical Package for the Social Sciences version 20.0. A coded data agreement was approved by the Wake Forest Institutional Review Board prior to assistance with data analyses from the UNCC Charlotte dissertation committee and student coder.

### Qualitative Methods

Participants' responses to the open-ended items questions were analyzed according to Lincoln and Guba's constant comparative method (1985) which is a component of Glaser and Strauss' grounded theory (1967). The first step of the constant comparative method required participants' responses to be divided into chunks of meaning called "units." These units contained sections of the responses that were the smallest amounts of text not requiring additional text to explain the meaning. The process continued as new units were formed and grouped with units similar in meaning (forming categories) or the unit was chosen to stand alone (awaiting other units of similar meaning). Categories were compared within and between participants' responses and then revised as needed to avoid redundancies and to ensure data were not being forced to

To check the reliability of the themes, a second researcher unfamiliar with the specifics of the study (another UNC Charlotte Health Psychology graduate student) analyzed the units and assigned existing codes via the codebook. For item 1, no new themes were developed based on the second coder's analysis of units. However, descriptions of several themes within the codebook were expanded upon based on 23 units which the second coder experienced difficulty distinguishing between 2 possible themes. After themes were more clearly defined, they were resent to the second coder for forced choice. The percentage of agreement between coders was 86.74% with disagreement in theme for 37 out of 279 units. Coders discussed the 40 discrepant themes to determine the best assignment and one theme, "adjustment to life after cancer" was dropped and collapsed into various other categories. Two additional themes, "death of a loved one" and "health problem of close other" were collapsed into the theme of "general life event/stressor not explicitly related to cancer" (see Chapter 4 for more details related to themes).

For item 2, the percentage of agreement between coders was 88.36% with disagreement in theme for 32 out of 275 units. Based on the second coder's feedback, 3 units were separated into smaller units and recoded. Coders discussed the discrepant themes to determine the best assignment and one theme "improved self-esteem" was collapsed into the theme of "personal strength."

Additionally, responses were prepared for entry into the Linguistic Inquiry and Word Count software 2007 (LIWC; Pennebaker, Booth, & Francis, 2007). Preparation of responses included correction of all misspellings, spelling out abbreviations (e.g. "chemo" became "chemotherapy"), adding spaces between hyphens so LIWC did not

count sentence breaks as single words and spelling out words when symbols were used (e.g., "and" instead of "&" or "+"). After responses were uploaded into the program, LIWC compared each word of a participant's response to several dozen categories of psychologically-relevant words such as affect, cognitive processes, social processes (Owen, Hanson, Preddy, & Bantum, 2011). Specifically, LIWC calculated the percentage of total words that were positive emotion words (e.g., "happy"; "exciting") and negative emotion words (e.g., negative emotions such as "sad"; generally negative words such as "ugly"). Scores were calculated utilizing the LIWC software and based on responses to both open-ended items combined as some participants discussed positive experiences in response to the challenges question and others discussed negative events in response to the positive experiences question. In total, two LIWC scores were calculated for each participant (negative emotion score and positive emotion score) based on percentages of emotion words across both open-ended items. Additionally, a total word count score (total number of words used to answer open-ended items 1 and 2) was calculated to ensure that the amount of text written by each participant did not differ by education level.

# Hypothesis 1

To test Hypothesis 1, that survivors will report positive changes in areas consistent with the PTGI as well as healthy behaviors, themes discussed by women on the positive experience question (open-ended item #2) were compared to the five dimensions of PTG as measured by the PTGI. Responses were also compared to the benefit-finding scale of the QLACS as the other QOL measures do not assess benefit-finding. Positive experience themes emerging from open-ended #2 that are not measured

by the PTGI or the QLACS were also explored. Percentages and frequencies were calculated to reflect the number of women who discussed positive changes for each PTG dimension as well as changes not captured by the PTG dimensions.

### Hypothesis 2

The BDI, PTGI, and QLACS were analyzed to determine whether survivors reporting more negative experiences report higher levels of depression (as measured by the BDI), higher levels of negative feelings, cognitive problems, social avoidance, financial problems, family distress, recurrence distress, and appearance difficulties (as measured by the QLACS) and lower levels of PTG (as measured by the PTGI). A total negative experiences score (TNES) for each participant was calculated (total number of negative experiences mentioned) based on themes from the first open-ended item.

Although the wording of the item prompted participants to discuss "major challenges" experienced, participants tended to write about negative experiences (assuming that not all "challenges" are negative). Thus, the TNES was created by counting the number of negative experiences reported by participants. Positive or neutral statements made in response to the question were not included in the calculation of the TNES.

The TNES was correlated with the PTGI and BDI at 12 months and relevant QLACS domains at 12 months. Additionally, the total negative emotion score for each participant as calculated by the LIWC software was correlated with PTGI, and BDI scores at 12 months and QLACS domains at 12 months.

The second part of hypothesis 2, that survivors reporting a higher number of positive experiences will report higher levels of PTG, adaptive coping (religious coping, positive reappraisal, using instrumental support and using emotional support) as

measured by the Brief COPE, and QOL (SF-36, FACT-B, QLACS) was examined via Pearson correlations. A total positive experiences score (TPES) for each participant was calculated (total number of positive experiences mentioned) based on themes from the second open-ended item. Negative or neutral statements in response to the question were not included in the calculation of the TPES. The TPES was then correlated with PTGI, Brief COPE, and relevant QOL scores at 12 months. Further, a linear regression analysis was conducted to determine whether TPES predicts PTG at 18 months. Additionally, the LIWC total positive emotion score for each participant was correlated with QOL and PTGI scores at 12 months.

# Hypothesis 3

To test the third hypothesis that survivors reporting a higher number of negative experiences and lower number of positive experiences will report lower levels of PTG at 12 months than survivors reporting a higher number of positive experiences and lower number of negative experiences, a multiple regression was conducted with PTGI total score as the dependent variable and TNES and TPES as independent variables and the interaction effect was examined. Additionally, to test the hypothesis that participants reporting a higher number of positive experiences and lower number of negative experiences would report lower levels of depression than participants reporting a higher number of negative experiences and fewer positive experiences, a multiple regression was conducted with 12-month BDI total score as the dependent variable and TNES and TPES as independent variables and the interaction effect was be examined.

# Hypothesis 4

To test the fourth hypothesis that social support (emotional support and total score), adaptive coping (religious coping, positive reappraisal, using instrumental support and using emotional support), QOL at baseline, 6 months, and 12 months will be related to positive changes on the open-ended items at 12 months, correlations between the variables with the TPES were examined at each time point.

# Hypothesis 5

To test the final hypothesis that survivors reporting higher PTGI scores at baseline and 6 months will report a higher number of healthy behaviors on the open-ended items at 12 months, a healthy behaviors score was calculated for each participant based on their responses (number of health behavior changes) to the positive experience open-ended question (with participants dichotomized as yes - reported healthy changes or no - healthy changes not reported). Linear regressions were conducted with baseline and 6 month PTGI scores as predictors and the healthy behaviors score as the dependent variable to determine whether PTG at baseline predicts healthy behaviors reported at 12 months and whether PTG at 6 months predicts healthy behaviors at 12 months.

To test the second part of this hypothesis, that participants reporting higher PTGI scores at 6 months will report better health behaviors at 12 months, three groups were created based on number of alcoholic beverages consumed per month and coded as 0 (no drinking), 1 (low drinking), 2 (high drinking). An analysis of variance (ANOVA) was conducted to detect group differences in 6-month PTGI scores based on drinking. Further, participants were grouped based on reports of exercise as 0 (no exercise), 1 (walking), 2 (mild exercise), 3 (moderate exercise), and 4 (strenuous exercise) and one

analysis of variance (ANOVA) was conducted to detect group differences in 6-month PTGI scores based on exercise.

#### **CHAPTER 4: RESULTS**

# Demographics

All 143 participants within the 18 to 45 year old age range received open-ended items as part of their 12-month follow-up questionnaire. Eighty-seven participants responded to the open-ended items. Thirty-three participants did not to respond to the open-ended items administered at 12 months. Additionally, 2 participants had died by 12 months, 2 participants reported that they were too overwhelmed to participate, 3 reported that they were not interested in continuing, 2 were lost to follow up and 14 did not fill out the forms at the prescribed intervals (but did complete some subsequent forms for follow-up outside of the study time frame of 18 months). Of note, a total of 3 participants died by the 18-month follow up, 1 of whom completed the 12 month measures.

The following analyses are based on the sample of 87 participants who completed the open-ended items and corresponding quantitative measures. Participants ranged in age from 25.21 to 45.71 years old at time of diagnosis (M = 38.08 years, SD = 5.26). Time since diagnosis at completion of baseline measures ranged from 22 to 186 days (M = 125.16 days, SD = 45.06). Participants were predominantly white (93.10%), highly educated (84.4% with an undergraduate college degree or above), married (70.1%), and with family incomes of at least \$75,000 per year (70.1%) (See Table 2).

Characteristics of the two groups (those who completed the items (N = 87) and those who did not (N = 33)) were examined for between-group differences. These groups will henceforth be referred to as responders or non-responders. There were no significant

differences in age between responders (M age = 38.08, SD = 5.26) and non-responders (M age = 39.65, SD = 4.22) as evidenced by an Independent samples t-test, t(118) = -1.54, p = .13. Both samples were predominantly white (93.10% of responders vs. 87.88% of non-responders). Comparison of BDI 12-month total score was not significantly different between groups, t(118) = -.44, p = .66. However, differences between PTGI total score approached significance, t(118) = 1.89, p = .06, with responders reporting higher levels of PTG (M = 63.39, SD = 19.02) than non-responders (M = 55.93, SD = 20.53).

# PTG, Demographic, and Medical Variables

Although age at diagnosis was not significantly correlated with 12-month PTGI total score, it approached significance with older participants reporting lower PTGI scores (r = -.19, p = .08). Time since diagnosis was not significantly correlated with PTGI total score (r = -.07, p = .50). Demographic variables such as marital status, F(5, 85) = .61, p = .69, education, F(7, 78) = .79, p = .60, and income, F(6, 78) = 1.33, p = .26 were examined via one-way ANOVA and were not significantly related to PTGI scores at 12-months. However, participants who received chemotherapy (N = 74) reported significantly higher PTG total scores (M = 64.78, SD = 19.19) than participants who did not receive chemo (N = 12) (M = 53.00, SD = 14.59), t(84) = -2.03, p = .05. Other medical variables were not significantly related to PTG (See Table 3). See Table 4 for psychosocial characteristics of the study sample by survey time point.

#### Qualitative Results

Qualitative analysis of open-ended item 1: Challenges faced since breast cancer diagnosis

Of 87 participants, 4 participants did not respond to item 1 (response rate of 95.40%). Qualitative analysis of Item 1 revealed 12 themes reflective of challenges faced since diagnosis including: side effects/treatment issues, concern for the future, relationship/interpersonal issues, difficulty coping, general life event/stressor not explicitly related to cancer, appearance/self-esteem issues, parenting/caregiver stress, employment issues, financial difficulties, adjustment to life after treatment, adaptive coping efforts, and educating the self about cancer/treatment options (See Table 5). Additional themes included: positive statements in response to the question and an "other" category for statements that did not fit within other themes. Further details about themes are described below.

### Side Effects and Issues Surrounding Treatment

Side effects and issues surrounding treatment were the most commonly reported difficulties by participants (N = 38). While the majority of these responses were specific to side effects (86.30%), other responses reflected issues surrounding treatment such as getting to appointments, getting used to different doctors, and decisions related to treatment. Other participants reported the difficulty of dealing with frightening tests and the anticipation of test results. Sample responses include: "My sex interest/arousal has decreased a lot," "Getting BRCA1 and result and making decisions, plus informing family members that they may be affected," "Can't find time or energy to exercise and lose this post-chemo weight," "Facing my first mammogram and ultrasound was kind of scary..." "Becoming infertile and the emotions of not having another child," "The hot flashes have taken over my every day existence (I'm cold, hot, cold, hot)," and "Coming

to terms with losing my hair was the greatest challenge. As trivial as it may sound, it was pretty traumatic."

#### Concern for the Future

Concern for the future was the second most frequently reported response (*N* = 18). The majority of responses reflecting concern for the future were expressions of fears surrounding cancer recurrence (61.54%). Additional concerns included the growth of new cancers, the ability to have children, and being around for family in the future. Sample responses include: "I still have a conflict with the future. I want to build a new home, but don't want to impose this upon my family if I won't be here, for example," "I wish I could have a baby, but I'm menopausal now and don't know if that will ever happen," "Dealing with the nagging 1% of my brain that wonders when (not so much if) the cancer will return," "My biggest challenge is fear of recurrence - every odd ache and pain scares me, especially since my close friend recently died a painful death due to liver cancer," and "Because I continue to watch and monitor a lump in 1 breast, I have had continual fears and anxiety about recurrence."

#### Relationship/Interpersonal Issues

Relationship difficulties and interpersonal issues were also reported frequently (N = 17). The majority of interpersonal difficulties centered on issues with family and friends, although some statements were reflective of difficulties with people in general. Specifically, some participants discussed difficulties in their marriages (N = 7) and others felt as though no one could understand what they were going through or could not support them appropriately (N = 7). Sample responses include: "My husband has not been loving and supportive through last year's treatment," "Adjusting to the realization

that my parents are not capable of emotionally supporting me," "Sometimes I find it difficult to relate to my friends," "The major challenge I face every day is people's ignorance," "Getting people to stop "babying" me," and "It's been difficult to have patience for people and occurrences that seem to dwell on the unimportant and trivial."

# Difficulty Coping

Difficulties coping with cancer including strong negative emotions and rumination were common negative experiences reported by participants (N = 16). Sample responses include: "I'm not sure what to do or where I belong now," "I am sad," "Lately, I have been feeling more depressed/anxious," "In this journey over the past year I often behaved as if my body belonged to someone else, and split from the reality of what was happening to me," "Dealing with it on a daily basis -I don't understand why I still think about it and all its ramifications every day," and "Some days I just want to run away."

General Life Event or Stressor not Explicitly Related to Cancer

Participants (N = 15) reported a number of challenges since diagnosis that appeared unrelated to the cancer experience and reflected of general life events (e.g., moving, a loved one experiencing health problems, death of a loved one, getting married, attending school). Sample responses include: "Worried about mother's surgery," "My husband was out of work," "Completing my doctorate dissertation," "Recently hurting my knee has been tough and seems like a big setback since I cannot exercise," and "Oldest son mugged while on vacation,"

#### Positive Statements

Interestingly, some participants (N = 11) included responses to the question about challenges that were positive in nature. Although most of these participants recognized

difficulties (N = 10), they also included positive statements in their responses such as: "I don't really mind my distorted body because at least I have a body," "I am fortunate," "I want to figure out how I can help other women going through this process," "Marriage is better than ever now," and "I am getting stronger every day and I feel like I can get close to my old self in the near future."

# Appearance/Self-esteem Issues

Difficulties related to changed appearance or decreased self-esteem due to cancer and treatments were reported by some participants (N = 11). Sample responses included: "I am somewhat self-conscious of the breast area where I had my mastectomy," "To awake one day and see a mutilated, bloated, and bald person where once had been the 'me' I rejoiced in, was the cruelest of all," "My self-esteem has been greatly lowered. I am not confident in my self-image," "Reconstruction is not as good as we hoped for," and "Since losing my breast I look in the mirror and it just isn't very attractive to me."

# Parenting/Caregiver Stress

Some participants (N = 10) reported stress related to parenting or caregiving directly related to the cancer experience: "I feel as if I'm letting them (the children) down somewhat and they're being forced to grow up faster than they should," "Taking care of our child (1 year old at diagnosis) during treatment," and "Physical challenges of taking care of 3 small children while going through treatment." Other participants discussed general parenting/caregiver stress: "I'm a single mother with three children," and "My 17 year old daughter began sneaking out of the house, telling me she did not like me, etc."

#### **Employment Issues**

Some participants (N = 9) reported issues related to employment due to cancer and subsequent treatment. Sample responses include: "It's been a challenge to go to work every day even though I'm tired and lack energy." "I experienced a very tough time with my supervisor at work giving me a very hard time about doctor appointments and so forth," "I believe prospective employers don't want to hire me because I might have more days off due to Dr.'s appointments and illness and they're afraid I won't be a good employee," and "I was diagnosed my first 3 months in the job and was on disability for year after that."

### Adjustment to Life after Treatment

Participants who reported that adjusting to life after treatment was a challenge (*N* = 9), discussed issues such as attempting reestablishing schedules and attempts to get life back to the way it was before being diagnosed with cancer. Specific responses were related to returning to previous activities such as working, dating, or exercising. Sample responses include: "My greatest challenge has been getting back into a consistent workout schedule," "I am dealing with life post-mastectomy," "Trying to get back into a work habit," and "Having a hard time dating again."

### Adaptive Coping Efforts

In contrast to reported coping difficulties (e.g., rumination, strong negative emotions), some participants (N = 8) described their attempts to deal with cancer challenges. Sample responses include: "But moving back into that ruined shell - cleaning house as it were, and adjusting to the changes in a loving way that acknowledges all the trauma and its lessons- that has been the greatest hurdle," "Not being afraid to ask for

help or support from others," "...accept that my life as I knew it had changed forever," and "Keep moving with life, even with my little hic-up (sic)."

#### Additional Themes

As previously mentioned, more infrequent themes included: financial difficulties (e.g., "The cost of this disease in money"), educating the self about cancer/treatment options ("Selecting a doctor and learning about and understanding treatment options"), and "other" where the response lacked enough information to code it within another theme ("Sex.").

Qualitative analysis of open-ended item 2: Positive experiences

All 87 participants responded to item 2 (response rate of 100%). Qualitative analysis of item 2 revealed 7 themes reflective of positive experiences including: positive change in relating to others, personal strength, greater appreciation of life, new possibilities, coping, self-care, and spiritual growth (See Table 6). Additional themes include: difficulties related to cancer experience, no positive change attributed to cancer, and an "other" category for statements that did not fit within other themes or did not contain enough information to fully understand the meaning of statement. As hypothesized, themes emerged that were consistent with the five dimensions of PTG: relating to others, personal strength, appreciation of life, new possibilities, and spiritual growth. However, the hypothesis that participants would report positive changes in health behaviors was only partially supported. Although a theme representative of improved self-care in general emerged, only 4 participants reported specific health behavior improvements (e.g., quitting smoking, improved nutrition, improved sleep). Additional details about themes are described below.

# Positive Change in Relating to Others

Changes in relating to others was the most commonly reported positive experience with more than half of participants (N = 54) reporting such an experience. This theme was consistent with the PTG dimension of relating to others in that participants reported that the cancer experience provided them with clarity in their relationships (who their friends are, how strong family members are, how supportive family members are), that they felt closer to family and/or friends, developed greater compassion for others, and improved their communication with others. Sample responses include: "I'm not as scared to share my fears and I feel that my relationship with my husband, parents, sisters and best friends has grown. They have seen me at my worst and we communicate better now," "Experiencing cancer taught me compassion and interest in other people's misfortunes," "The biggest positive during this was realizing the caliber of friendships in my life. I did not know I had so many people that would go over and above for me. My friends and family have been incredibly supportive," and "I try to be more tolerant and less judgmental about people and decisions made."

## Personal Strength

Some participants (N = 34) reported that they viewed themselves as stronger or more confident through their experience with cancer. As previously mentioned, this theme was consistent with the PTG dimension of personal strength as participants appeared to realize their vulnerability yet reported feeling stronger and more confident as a result of their illness and subsequent treatments. Additionally, two participants reported feeling that a positive aspect of their cancer experience was an improvement in self-esteem and/or self-worth. Sample responses include: "I've learned that I may be a

stronger person than I thought I was previously, doing things I thought I could never do, such as going to the hospital for tests in surgeries that were frightening, staying overnight at the hospital, etc.," "I learned that I am worth a lot," "I can do/endure more than I thought," "I have realized what a brave, strong woman I am," and "I have the 'I can do this - I can do anything' attitude!"

## Greater Appreciation of Life

This theme reflects participants' (N = 28) reports that cancer influenced them to change their outlook on life and to change their priorities (e.g., enjoyment of more things, not sweating the small stuff). Participants' responses were consistent with the PTG dimension of greater appreciation of life in that participants reported no longer taking their lives for granted and shifting their perspective on life in general. Sample responses include: "I live each day to the fullest," "I finally understand what it means not to sweat the small stuff. Never could understand that," "I thought I was appreciative and grateful before my bout with cancer, but I have experienced a deeper well of joy and gratitude than I thought possible," and "TAKE NOTHING and NO MOMENT for granted! You don't know if you have tomorrow."

# New Possibilities

Responses comprising this theme were reflective of new opportunities experienced by participants (N = 19) as a result of their cancer diagnosis and/or treatment. Examples of such opportunities are meeting new people or friends that they otherwise would not have met and/or accomplishing new things. This theme was consistent with the PTG dimension of new possibilities in that a traumatic experience (cancer, in this case) can lead to new life paths and opportunities for survivors. Sample

responses include: "I've changed my career path from being in the legal profession to returning to school to become a nurse to either work in oncology for children or become a research monitor," "I have met a wonderful group of young survivors," "I was able to raise over \$15,000 for breast cancer research. I am going to participate again in 2006 and hope to raise even more with the help of my family and friends," and "As silly as it sounds, my new hair has been a positive experience! I had straight hair my entire life and now it is curly; no more curling iron!"

# Coping

Some participants (N = 18) responded to item 2 by discussing various means of coping with their illness such as relying on others for emotional support and asking for help, keeping their sense of humor, having a positive attitude, and/or religious coping (e.g., prayer, trust in God). Participants tended to view these efforts as positive aspects of the cancer experience. Sample responses include: "I learned to laugh at myself and make light of my cancer, it helped me to cope with my fears of being bald, being sick, and worrying about dying," "I kept a positive attitude throughout my entire experience with breast cancer," "That you cope better if you keep your sense of humor," "I trust God will get me and these kids through this," and "I believe in making lemonade out of lemons - always look at the silver lining."

### Self-care

As previously mentioned, improvements in self-care were noted by some participants (N = 13). Although it was hypothesized that participants would report specific improvements in health behaviors after being diagnosed with cancer (e.g., quitting smoking, eating better, improvements in exercise regimen), only 4 participants

actually reported specific health behavior improvements. The majority of responses reflected survivors' improved efforts to take care of themselves in general. Sample responses include: "I realized how important your health is and how important it is to take care of your body," "I've learned a great deal about nutrition and exercise and how it can help your body work more efficiently," "I have started an exercise program and am very healthy and want to be in shape to do things with my daughter," and "Quit smoking!"

# Spiritual growth

A small number of participants (N = 5) reported that they grew spiritually as a result of their experience with cancer. This theme was predicted to emerge in response to item 2 as PTG research has demonstrated that trauma survivors often report developing a closer relationship with God, stronger faith, and a greater sense of meaning in life. Sample responses include: "I have a totally different outlook on life - My faith is a lot stronger than before," "I learned that God is truly real," and "I've learned that my faith in God does make all things doable...good or bad."

#### Additional Themes

Three additional themes emerged including difficulties related to cancer experience, no positive change attributed to cancer, and other. Of reported difficulties related to cancer (N = 8), 61.54% of the statements were reflective of negative experiences in relating to others such as: "I also learned that not all people are comfortable being around sick people nor are they supportive, in fact I was shunned by some family and friends who just didn't 'feel right' around me." Sample responses of other reported difficulties include: "To me, having had this disease has been like a death."

Other participants (N = 2) reported that cancer did not lead to any positive change via statements such as: "I have always had a great family and friends. Nothing has changed." Lastly, responses by participants (N = 16) included in the "other" category lacked enough information to code it within another theme and/or it was unclear whether the positive experience was due to cancer, time, or another variable ("Finishing doctorate program").

# Hypothesis 1

To test the first hypothesis that survivors would report positive change in areas consistent with the PTGI, themes on the positive experience question were compared to the five dimensions of PTG as measured by the PTGI. As previously discussed, all five dimensions of PTG emerged as themes in response to open-ended item 2 with relating to others as the most popular theme (62.07% of participants reported changes in this area) and spiritual change as the most infrequently reported dimension (5.75% of participants reported change in this area). Themes were also compared to the benefit-finding scale of the QLACS. Of the four items comprising the benefit-finding scale of the QLACS, responses similar to two of the items, "You appreciated life more because of having had cancer," and "You felt that cancer helped you to recognize what is important in life" comprised the greater appreciation of life theme and overlapped with the greater appreciation of life dimension as measured by the PTGI. The hypothesis that a theme would emerge related to the other two QLACS items, "You realized that having had cancer helps you cope better with problems now", and "You felt better able to deal with stress because of having had cancer" was not directly supported. Although a coping theme emerged, statements tended to reflect participants' ability to cope specifically with cancer and did not transfer to coping with life problems in general.

A positive change discussed by women that was not captured by PTGI dimensions was improved self-care (N = 13). Some women discussed how they now aim to take better care of themselves. This benefit to the cancer experience is not captured by any of the five dimensions of PTG.

Interestingly, some participants (N = 11) included positive statements in their responses to open-ended item 1 with one of these participants responding with a positive statement only: "...focus on making my life better." In general, these positive statements varied (e.g., relationships, rediscovering the self, feeling of survival) and did not reflect psychological growth or transformation due to cancer. However, the fact that these women put a positive spin on their responses to the challenges of cancer may reflect differences in coping style and/or PTG and requires further examination.

### Hypothesis 2

#### TNES results

To test the second hypothesis that survivors reporting a higher number of negative experiences would report higher levels of depression and distress and lower levels of PTG, a Total Negative Experiences Score (TNES) was calculated based on responses to open-ended item 1 (e.g., "Another big challenge is facing that I will likely never be able to give birth"). The TNES ranged from 0 to 9 (M = 2.97, SD = 1.97) with 79.1% of participants reporting 4 or fewer. As hypothesized, the BDI total score at 12 months was significantly correlated with the TNES (r = .28, p < .01), indicating that participants who reported more negative experiences reported higher levels of depression. Although the TNES was not significantly correlated with all hypothesized QLACS domains at 12 months (higher level of negative feelings, social avoidance, financial problems, family

distress, distress about cancer recurrence, and appearance concerns), significant correlations did exist between TNES and cognitive problems (r = .27, p < .05) and pain (r = .24, p < .05). These correlations indicate that participants who reported more negative experiences also reported higher levels of cognitive problems (e.g., difficulty concentrating, short attention span, trouble remembering things) as well as greater difficulties related to pain (e.g., pain that got in the way of doing things such as social activities, mood disrupted by pain).

Correlations between the TNES and 12-month PTGI domains and total score (N = 86) were not significant. Because little variability existed in the number of negative experiences reported, participants were grouped ( $1 = \text{TNES of } 0 - 3 \ (N = 57)$ ; 2 = TNES of  $4 - 8 \ (N = 29)$ ) to compare PTGI means via Independent Samples T-Test. No significant differences between means on PTGI dimensions or PTGI total score existed between TNES groups.

## TPES results

To test the second part of hypothesis 2, that survivors reporting a higher number of positive experiences will score higher on the PTGI, adaptive coping dimensions (religious coping, positive reappraisal, using instrumental support and using emotional support) as measured by the Brief COPE, and report greater QOL, relationships with the TPES were examined. The TPES ranged from 0 to 10 (M = 3.00, SD = 1.92) with 81.6% of participants reporting 4 or fewer positive experiences. Of note, the TNES and TPES were significantly positively correlated (r = .38, p < .01) indicating that participants reporting more negative experiences were more likely to report more positive experiences. As predicted, the TPES was significantly correlated with PTG domains at 12

months including personal strength (r = .31, p < .01), spiritual change (r = .27, p < .05), greater appreciation of life (r = .23, p < .05), new possibilities (r = .28, p < .01) and PTGI total score (r = .29, p < .01). Scores on the relating to others dimension of the PTGI and the TPES were not significantly correlated (r = .09, p = .41). A simple linear regression was conducted to determine whether TPES predicted PTGI total score at 18 months and yielded significant results, F(1, 70) = 7.81, p < .01, with a medium effect size (r = .30).

As hypothesized, the TPES was significantly correlated with the active coping (r = .22, p < .05) and positive reappraisal (r = .31, p < .01) scales of the Brief COPE. However, hypotheses that significant positive correlations would exist between the TPES and use of instrumental support (r = .10, p = .34) and use of emotional support (r = .11, p = .31), as measured by the Brief COPE, were not supported.

In terms of quality of life, the TPES was significantly correlated with the QLACS benefits of cancer domain at 12 months ( $r = .23 \ p < .05$ ) indicating that participants who reported more positive experiences identified greater number of benefits as assessed by the QLACS (e.g., cancer helped to recognize what is important in life, deal with stress better because of having had cancer). Relationships between the TPES and other QLACS domains were not significant. Additionally, relationships between the TPES and other quality of life measures such as the SF-36 (PCS r = -.13, p = .23; MCS r = .13, p = .22) and Fact-B (r = .04, p = .73), were not significant suggesting that participants who reported a greater number of positive experiences did not report better quality of life.

### LIWC results

The LIWC negative emotion score ranged from 0 to 8.33 (M = 2.40, SD = 2.09) and the LIWC positive emotion score ranged from 0 to 36.36 (M = 6.54, SD = 5.24).

Total word count mean of 86.01 (SD = 58.24), did not differ by education level, F(7,79) = 1.33, p = .25. Correlations between PTGI dimensions and total PTGI score at 12 months with the LIWC positive and negative emotion scores were not significant. However, the BDI total score at 12 months and LIWC negative emotion score were significantly correlated (r = .25, p < .05) indicating that participants using a higher percentage of negative emotion words in response to the open-ended items reported higher levels of depression. The LIWC positive emotion score and BDI total score were not significantly correlated although the negative relationship did approach significance (r = ..18, p = .08).

Several QLACS domains were significantly correlated with the LIWC negative emotion score including: pain (r=.24, p<.05), cognitive difficulties (r=.27, p<.05), negative feelings (r=.25, p<.05), and positive feelings (r=.24, p<.05) (See Table 7). The negative emotion score was also significantly correlated with the QLACS generic summary score which is comprised of QLACS negative feelings, positive feelings (reverse-scored), cognitive problems, pain, sexual problems, social avoidance, and fatigue (r=.28, p<.05), These results indicate that participants who reported greater difficulty due to pain, greater cognitive difficulties, greater negative feelings (e.g., feeling depressed, worrying), fewer positive feelings (e.g., feeling happy, enjoying life), and a higher generic summary score also used a higher percentage of negatively valenced words in response to the open-ended items. In contrast, the LIWC positive emotion score was significantly correlated with the following QLACS domains: social avoidance (r=.24, p<.05), cognitive difficulties (r=.28, p<.01), positive feelings (r=.22, p<.05), and negative feelings (r=.29, p<.01). The LIWC positive emotion score was also

significantly correlated with the QLACS generic summary score which is comprised of QLACS negative feelings, positive feelings (reverse-scored), cognitive problems, pain, sexual problems, social avoidance, and fatigue (r = -.28, p < .01). These results indicate that participants who utilized a greater percentage of positively valenced words in response to the open-ended items also reported that they were less likely to avoid social situations/interactions, experienced fewer cognitive difficulties, and experienced more positive feelings and less negative feelings.

# Hypothesis 3

The third hypothesis, that survivors reporting a higher number of negative experiences and lower number of positive experiences would report lower levels of PTG at 12 months was tested by conducting a multiple regression with PTG as the dependent variable and TNES and TPES as independent variables. The model was significant, F(2, 83) = 5.02, p < .01, with TNES and TPES accounting for 11% of the variance in total PTG (See Table 8). Although the overall model was significant, TNES was not a significant predictor (p = .12) of PTG. These findings suggest that a higher number of reported positive experiences, regardless of levels of TNES, were associated with greater PTG. To test for the existence of an interaction effect, a product term was computed (TNESxTPES) and a hierarchical regression was conducted with TNES and TPES entered at Step 1 and the product term entered at Step 2. Although the overall model was significant, F(3, 82) = 3.44, p < .05, the interaction effect was not significant ( $R^2$  change = .004, p = .55).

To test the second part of hypothesis 3, that survivors reporting a lower number of negative experiences and higher number of positive experiences would report lower

levels of depression at 12 months, a multiple regression was conducted with BDI total score as the independent variable and TNES and TPES as independent variables. The model was significant, F(2, 84) = 3.77, p < .05, with TNES and TPES accounting for 8% of the variance in BDI total score. Although the overall model was significant, TPES was not significant (p = .63). These findings suggest that a higher number of reported negative experiences, regardless of levels of TPES, were associated with greater depression. Next, a product term was computed to test for the existence of an interaction effect (TNESxTPES) and a hierarchical regression was conducted with TNES and TPES entered at Step 1 and the product term entered at Step 2. Although the overall model was not significant, it did approach significance, F(3, 83) = 2.65, p = .054. However, the interaction effect was not significant ( $R^2$  change = .005, p = .50).

# Hypothesis 4

To test the hypothesis that participants reporting greater emotional social support, adaptive coping, and QOL at baseline, 6 months, and 12 months would report more positive experiences (as measured by open-ended item 2) at 12 months, Pearson Correlation Coefficients were calculated between TPES and psychosocial variables.

### Positive Experiences and Baseline Variables

No significant correlations existed between the TPES score and baseline measures: MOS emotional support (r = -.08, p = .49), MOS total support (r = -.11, p = .30), Brief COPE positive reappraisal (r = .10, p = .36), Brief COPE religious coping (r = .15, p = .16), Brief COPE use of instrumental support (r = .01, p = .92), Brief COPE use of emotional support(r = -.15, p = .17), FACT-B physical QOL (r = -.08, p = .49), FACT-B social QOL (r = -.11, p = .32), FACT-B emotional QOL (r = .06, p = .56), FACT-B

functional QOL (r = -.14, p = .20), FACT-B total QOL (r = -.09, p = .40), SF-36 PCS (r = .07, p = .55), and SF-36 MCS (r = -.05, p = .68).

# Positive Experiences and 6-month Variables

As predicted, the TPES score was significantly positively correlated with positive reappraisal (r=.22, p<.05) and religious coping (r=.22, p<.05) as measured by the Brief COPE at 6 months. Another significant correlation emerged that was not predicted, as greater TPES scores were associated with less denial (r=-.23, p<.05). Other hypothesized relationships were not significant: MOS emotional support (r=-.01, p=.94), MOS total support (r=-.06, p=.57), Brief COPE use of instrumental support (r=-.07, p=.50), Brief COPE use of emotional support(r=-.04, p=.74), FACT-B physical QOL (r=-.09, p=.41), FACT-B social QOL (r=-.11, p=.31), FACT-B emotional QOL (r=-.09, p=.40), FACT-B functional QOL (r=-.08, p=.49), FACT-B total QOL (r=-.05, p=.64), SF-36 PCS (r=-.03, p=.76), and SF-36 MCS (r=.07, p=.51).

### Positive Experiences and 12-month Variables

As predicted, the TPES score was significantly positively correlated with positive reappraisal (r = .31, p < .01) and active coping (r = .22, p < .05) as measured by the Brief COPE at 12 months. Brief COPE religious coping approached a significantly positive relationship with TPES (r = .20, p < .06). Other hypothesized relationships were not significant: MOS emotional support (r = .004, p = .97), MOS total support (r = .03, p = .77), Brief COPE use of instrumental support (r = .10, p = .34), Brief COPE use of emotional support(r = .11, p = .31), FACT-B physical QOL (r = .06, p = .54), FACT-B social QOL (r = .10, p = .35), FACT-B emotional QOL (r = .10, p = .38), FACT-B

functional QOL (r = .01, p = .92), FACT-B total QOL (r = .04, p = .73), SF-36 PCS (r = .13, p = .23), and SF-36 MCS (r = .13, p = .22).

## Hypothesis 5

The fifth hypothesis, that survivors reporting higher levels of PTG at 6 months will report a higher number of healthy behaviors on the open-ended items and as measured by the personal habits form at 12 months, was only able to be partially tested. Unfortunately, only 4 participants discussed healthy behaviors as assessed by open-ended item 2 and due to the low number of responses, participants were unable to be grouped based on healthy behaviors. Another difficulty with this hypothesis was the small number of smokers (N=3) as assessed by the 12-month personal habits form. As the sample of smokers was too small to compare PTGI means to non-smokers, only alcohol users were compared to non-users in terms of PTG. Alcohol users (N = 58) reported a number of drinks consumed per month ranging from 1 to 120 with a mean of 16.43 drinks (SD =21.09). Participants were assigned to one of the following groups: no drinking, low drinking ( $\leq$  9 drinks per month), and high drinking ( $\geq$  10 drinks per month). An analysis of variance (ANOVA) was conducted and total PTGI scores did not differ significantly between groups, F(2, 82) = .66, p = .52. Means of PTGI dimensions also did not differ significantly between groups: Relating to Others, F(2, 82) = .22, p = .80, New Possibilities, F(2, 82) = .92, p = .40, Personal Strength, F(2, 82) = -.60, p = .55, Spiritual Change, F(2, 82) = -.55, p = .59, and Appreciation of Life, F(2, 82) = -.06, p = .06.95.

Yet another difficulty occurred when attempting to examine the relationship between PTG and exercise. The planned analysis was to group exercisers in the following manner: 0 (no exercise), 1 (walking), 2 (mild exercise), 3 (moderate exercise), and 4 (strenuous exercise). However, only 5 participants reported that they did not exercise. In fact, the majority of participants reported that they engaged in strenuous exercise at least once per month (N = 47). Thus, an Independent Samples T-test was conducted to compare PTGI scores of strenuous exercisers to more moderate exercisers/non-exercisers and the results were not significant, t(83) = -1.30, p = .20.

#### CHAPTER 5: DISCUSSION

The current study utilized a subset of young breast cancer survivors (M age = 38.08 years) from a larger study to examine negative experiences of breast cancer as well as positive experiences including PTG. The goal of the current study was to examine PTG specifically in young breast cancer survivors using both qualitative and quantitative methods. Based on a review of PTG and breast cancer literature, five major hypotheses were developed and it was expected that: 1) The five dimensions of PTG would emerge as themes in response to an open-ended item about positive experiences since diagnosis. It was also predicted that participants reporting more positive experiences would be more likely to engage in improved health behaviors; 2) A higher number of negative experiences reported would be related to greater depression and lower levels of PTG. A higher number of positive experiences would be related to higher levels of PTG, adaptive coping, and OOL; 3) A high number of negative experiences in combination with a low number of positive experiences would yield lower levels of PTG and higher levels of depression; 4) Greater emotional social support, adaptive coping, and QOL at all time points would be significantly related to a greater number of positive experiences reported at 12 months; 5) Higher levels of PTG at 6 months would be positively correlated with healthy behaviors at 12 months. Although not all hypotheses were supported, the results offer new information about the breast cancer experience in what appears to be the youngest sample to date.

# Hypothesis 1

As predicted, the five dimensions of PTG emerged as themes in response to the positive experiences open-ended item. Of these themes, positive change in relating to others was the most frequently discussed dimension (62.07% of participants) followed by personal strength (39.05%), greater appreciation on life (32.18%), new possibilities (22.84%) and with spiritual growth as the least frequently reported (5.75%). These results were consistent with other qualitative studies of cancer survivors where PTG emerged thematically (Fromm et al., 1996, Hefferon, 2010, Sadler-Gerhardt et al., 2010, Steel et al., 2008). Fromm and colleagues (1996) reported frequencies of PTG domains with results similar to the current study including improved family relationships as the most commonly reported change (52%) and spiritual change as the least commonly reported (9%). Although specific frequencies were not reported, Sadler-Gerhardt and colleagues (2010) found that all participants (N = 8) reported new possibilities/greater appreciation of life, "nearly all" all participants reported improved relationships with others, examples of personal strength were discussed in 2 participants, and "several" participants reported spiritual growth. The current study provides further support that cancer patients tend to frequently report all dimensions of PTG with spiritual growth as the least commonly reported dimension. Results also provide further validity data for PTG.

In analyzing responses to the positive experiences open-ended item, one theme not captured by PTGI emerged: better self-care (N = 13). Included in this theme were specific health behaviors reported by participants (N = 4). Based on previous research suggesting that a cancer diagnosis can prompt patients to alter health behaviors in a positive manner (Andrykowski, Beacham, Schmidt, & Harper, 2006), it was anticipated

that more participants would have reported positive changes in this area. Specifically, it was expected that healthy behaviors and appreciation of life would be positively related as participants reporting a greater appreciation of life post-cancer might make changes to improve their health so their lives would potentially last longer. However, due to the small number of participants reporting positive health behaviors, the relationship between reported health behavior change and appreciation of life was unable to be examined.

The finding of an additional theme not captured by the PTGI is in line with a critique of the PTG model that it does not consider health benefits following trauma and that the PTGI does not assess for positive health habits (Hefferon et al., 2010). However, very few participants in the current study actually reported positive changes in health behaviors in response to the positive experiences question, indicating that health behaviors may not be one of the most salient issues in the young breast cancer survivor population Based upon the quantitative health behavior items, the participants were already fairly healthy (e.g., very few smokers, very few non-exercisers, very few heavy drinkers) leaving little room for growth in health behavior change in these areas.

Although participants may have improved their health behaviors in other areas, the nature of the questions used to assess health behavior change in the current study may not have afforded them the opportunity to discuss such changes. Further, one could argue that a change in health behaviors represents an identified benefit post-trauma and is not necessarily reflective of the transformation necessary to qualify as PTG.

# Hypothesis 2

As previously discussed, a Total Negative Experiences Score (TNES) and Total

Positive Experiences Score (TPES) were created by counting the number of negative and

positive experiences reported by each participant at 12 months. Before discussing findings related to these composite scores, it is important to recognize their limitations. These scores were created based on written responses to open-ended items that occurred at the end of lengthy questionnaires. Thus, participants might have been exhausted and refrained from listing every possible negative or positive experience. It is assumed then that participants listed the most salient negative and/or positive experiences, but the responses may not be representative of all of the experiences of young breast cancer survivors. Additionally, a thorough analysis typical of qualitative studies where in-depth interviews are conducted and follow-up questions are asked for clarification was unable to be conducted in the current study.

As predicted, the TNES was significantly positively correlated with BDI total score at 12 months. The most obvious explanation for the positive correlation between number of negative experiences and depression is that breast cancer survivors experiencing more negative experiences also experience greater symptoms of depression and vice versa. Further, in a state of depressed mood, negative experiences that might usually seem trivial could be perceived as major struggles which could have influenced a greater number of reported negative experiences in patients experiencing greater severe symptoms of depression. Participants experiencing greater distress may have taken the time to write in more detail about their negative experiences in response to the questions, thus resulting in a higher TNES. It is also important to note that participants did not respond to the open-ended item with negative experiences only specific to the cancer experience. They mentioned other general life stressors such as moving or stressors related to work. Thus, the finding suggests that the greater the number of stressors related

to breast cancer *or* to life in general, the higher reported the level of depression in breast cancer survivors.

Other significant relationships emerged between the TNES, pain and cognitive problems as measured by the QLACS. As many participants (N = 38) reported negative experiences related to side effects and issues surrounding treatment with 86.30% of units (chunks of meaning) reflecting specific side effect issues (e.g., general pain, pain due to due reconstruction, pain during sexual intercourse, memory loss), it is not surprising that associations between these variables existed (as the TNES was comprised mainly of reported side effects). Other hypothesized relationships between the QLACS and TNES (e.g., higher level of negative feelings, social avoidance, financial problems, family distress, distress about cancer recurrence, and appearance concerns) were not significant, which may be accounted for in that they were reported less frequently by participants and were not as large of a component of the TNES as side effects.

Additionally, the hypothesis that the TNES and PTG would be significantly negatively correlated was not supported. This lack of relationship might be accounted for by the idea that whereas some trauma survivors might need more negative experiences (e.g., greater number) to achieve PTG, others might need a *meaningful* negative experience. Despite the relationship between TNES and BDI score, a limitation to the TNES is that it lacks any incorporation of the severity of reported negative experiences. For instance, a negative experience such as "Dealing with people's ignorance" contributed to the development of the TNES as equally as "Another big challenge is facing that I will likely never be able to give birth." While the former could be considered a nuisance challenge, the latter could be considered as more of a life-altering experience.

However, perception of severity may vary from person to person. The quality/severity of negative experiences was unable to be assessed by the TNES and is likely an area for future studies.

As predicted, participants who recognized a greater number of positive experiences as measured by the Total Positive Experiences Score (TPES), reported higher levels of PTG at 12 months as well as greater change in the dimensions of personal strength, spiritual change, greater appreciation of life, and new possibilities. These findings make sense in that individuals who had experienced greater PTG by 12 months post-diagnosis would be more likely to discuss PTG in response to the positive experiences open-ended item and/or were more likely to recall positive experiences with ease and to report a greater number of these experiences. Also, the significant finding that TPES predicted PTGI total score at 18 months suggests that participants recognizing more positive changes in their lives at 12 months were more likely to report PTG six months later. Surprisingly, the TPES was not significantly correlated with the relating to others dimension of the PTG at 12 months. As the most commonly reported theme in response to the positive experiences question was positive change in relating to others, it is difficult to discern why this relationship did not exist.

In terms of coping, the TPES was significantly correlated with the positive reappraisal and active coping scales of the Brief COPE, as predicted. As the TPES was comprised primarily of statements related to PTG (200 out of 275 units), and previous research has found positive reappraisal (Bellizzi & Blank, 2006; Bussell & Naus, 2010; Lelorain et al., 2010; Sears et al., 2003) and active coping (Bellizzi & Blank, 2006; Lelorain et al., 2010) to be significantly related to PTG, these findings are not surprising.

These relationships can also be explained by the presence of the "coping" theme which emerged in response to the positive experiences open-ended questions and partially comprised the TPES. Contrary to predictions, hypotheses that significant positive correlations would exist between the TPES and use of instrumental and emotional support were not supported. This finding suggests that total number of positive experiences reported was not influenced by emotional support or instrumental support although a causal relationship could not be explored. As findings from previous research of social support and PTG have been mixed with significant relationships emerging in some studies (Bozo et al., 2009; Weiss, 2004), but not others (Cordova et al., 2001; Sears et al., 2003), it appears that a more in depth examination of this relationship is necessary and was unable to be explored within the current study.

The TPES was significantly correlated with the QLACS benefits of cancer domain at 12 months, but not with other QLACS domains as was predicted. As previous research has indicated similarities between PTG and benefit-finding (e.g., although separate constructs, both involve recognition of positive experiences), it follows that participants reporting a greater number of positive experiences also reported greater PTG as well as a greater number of benefits. The TPES was not significantly related to other QLACS domains or additional quality of life measures such as the SF-36 and FACT-B. However, PTG scores in the current study were also unrelated to QOL variables. As discussed in chapter 1, findings related to the QOL and PTG relationship are inconsistent. Based on results from the current study, it appears that young breast cancer survivors who reported a greater number of positive experiences or reported greater PTG did not

report better quality of life above and beyond recognizing benefits of the cancer experience.

Another portion of hypothesis 2 involved the examination of participants' responses to the open-ended items via the LIWC software. Based on an analysis of the positive and negative emotion totals calculated by combining responses from both openended items, it appears as though word choice (or at least positive and negative emotions words) can give us insight into how participants were experiencing the world at 12 months post breast cancer diagnosis. According to Tausczik and Pennebaker (2010), how people react to events (or in the case of the current study, describe events), offers information about how they are coping with the event. In the current study, participants' word choice via responses to the open-ended items can be viewed as a proxy for overall adjustment/reaction to breast cancer. Participants' word choice offers further insight into their feelings of depression and quality of life. Examination of negative emotion word utilization revealed that the higher the percentage of negative emotion words, the greater reported depression and QLACS dimensions such as pain, cognitive difficulties, negative feelings, and the generic summary score (greater negative feelings, fewer positive feelings, greater cognitive problems, pain, sexual problems, social avoidance, and fatigue) at 12 months. Higher percentage of negatively valenced words was also related to fewer positive feelings as measured by the QLACS. These results are in line with previous studies utilizing the LIWC software that found negative emotion word use to indicative of the presence of distress (Manne, 2002).

Examination of the positive emotion words revealed increased usage was related to lower levels of reported social avoidance, cognitive difficulties, negative feelings, and

QLCAS generic summary score. Additionally, greater positive feelings were reported on the QLACS when participants used a higher percentage of positive emotions words in response to the open ended items. If the use of positive emotions words generally indicates that a participant is viewing an event in a more positive manner or coping more positively with the event that other participants, then it follows that the participant would be experiencing more positive feelings in general and have fewer QOL difficulties such as social avoidance, cognitive difficulties, etc. Conversely, it is possible that participants experiencing fewer QOL difficulties would view their experience with breast cancer in a more positive manner that participants struggling with QOL, and would then use more positive emotion words when writing about it. Unfortunately, the cross-sectional nature of the current analysis does not allow for further information about causality related to participants' positive emotion word usage.

# Hypothesis 3

The prediction that participants reporting a higher number of positive experiences and lower number of negative experiences would report greater PTG was only partially supported. Based upon a linear regression analysis of PTG total score with TPES and TNES as predictors, 11% of the variance in PTG was accounted for by these variables with TPES as the only significant predictor. This finding indicates that participants who recognized positive experiences, regardless of the negative experiences they reported, experienced greater PTG. This finding makes sense given the idea that trauma survivors need some amount of distress to have their core beliefs shaken and to begin the cognitive work necessary for PTG to occur. However, too many negative experiences can be perceived as overwhelming and more likely to lead to great distress or PTSD. If the

TNES is considered to be a proxy for distress and if research that a curvilinear relationship between PTG and distress exists is considered (Dekel, Mandl, & Solomon, 2011; Solomon & Dekel, 2007), then it is not surprising that a significant linear relationship did not exist between PTG and the TNES.

Additionally, the prediction that participants reporting a higher number of positive experiences and lower number of negative experiences would report lower levels of depression was also only partially supported. Based upon a linear regression analysis of BDI total score with TPES and TNES as predictors, 8% of the variance in BDI score was accounted for by these variables with TNES as the only significant predictor. This finding indicates that participants who recognized more negative experiences, regardless of the positive experiences they reported, experienced greater symptoms of depression. Again, if the TNES is considered to be a proxy for distress and the BDI measures a form of distress – depression – then one would expect a significant relationship between the two variables.

Overall, hypothesis 3 assumed that an interaction between TPES and TNES would exist and contribute to the prediction of PTG and BDI scores. However, an interaction between the two variables did not significantly contribute to the prediction of either PTG or BDI. For greater PTG, it appears more important that participants recognized more positive experiences and the number of negative experiences was less important (or possibly not linear in nature). For lower levels of depression, it appears more important that participants recognized fewer negative experiences and positive experiences were less important.

# Hypothesis 4

Based upon previous research, it was predicted that participants reporting more positive experiences on the positive experiences open-ended item would also report greater emotional social support, adaptive coping, and QOL (as measured by FACT-B and SF-36) across time points. In terms of social support, participants' reports of emotional support across time points were not significantly correlated with the TPES. This finding is similar to Hypothesis 2 findings where coping in the form of emotional support and/or instrumental support were not significantly related to the TPES. These findings suggest that both participants' reported use of emotional support as a coping mechanism and participants' perceptions of emotional support received did not influence the number of positive experiences reported by participants (or vice versa). Again, these results are not surprising given the mixed nature of findings related to social support and PTG in previous studies (Bozo et al., 2009; Cordova et al., 2001; Weiss, 2004; Sears et al., 2003). However, it does appear that a ceiling effect could have created difficulty in examining the relationship between social support and TPES as the majority of participants (N = 56) reported feeling supported "most" or "all of the time."

At 6 and 12 months, the hypothesis was partially supported with significant positive correlations between positive reappraisal (a form of adaptive coping) and the TPES. Across the literature examining breast cancer and PTG, positive reappraisal has consistently been found to be significantly positively correlated to PTG alone (Bussell & Naus, 2010; Sears et al. 2003; Svetina and Nastran, 2012), and as part of an adaptive coping summary score (Bellizi & Blank, 2006; Lelorain et al., 2010; Silva, Crespo, & Canavarro, 2012). Although other significant relationships with coping techniques have

varied across studies, positive reappraisal appears to be consistently related. Further, although the TPES is not a direct measure of PTG, it was significantly correlated with PTG and also predicted PTG at 12 months, thus it is not surprising that positive reappraisal would be related to both the TPES and PTG. From a qualitative standpoint, participants did appear to be utilizing positive reappraisal (e.g., trying to see breast cancer in a different light, to make it seem more positive) as they responded to the positive experiences open-ended item.

Similar to findings with positive reappraisal, religious coping was also significantly positively correlated with the TPES at 6 months and approached significance at 12 months. This finding is in line with previous studies examining religious coping where it was found to be significantly positively correlated with PTG alone (Bussell & Naus, 2010) and as part of an adaptive coping summary score (Bellizzi & Blank, 2006). Religious coping has also been found to be significantly positively correlated with benefit-finding (Urcuyo et al., 2005). Again, it was expected that the TPES would be significantly correlated with forms of adaptive coping (such as religious coping) as PTG literature has consistently discussed this relationship. Although spiritual change was the most infrequently reported dimension of PTG on open-ended item 2, several participants did report religious coping ("I pray a lot") that does not necessarily reflect growth, but was perceived to be a positive aspect of their breast cancer experience.

A final significant correlation emerged that was not predicted at 6 months: greater TPES scores were associated with less denial. As denial is not typically viewed as an "adaptive" coping mechanism, no predictions were made about this form of coping. However, it may be considered adaptive that participants reporting more positive

experiences were less likely to deny their diagnosis with breast cancer (e.g., pretending that it is not happening) at 6 months and more likely to embrace both positive and negative experiences.

Lastly, health-related quality of life was not significantly correlated with the TPES across time points suggesting that better quality of life does not necessarily lead to a greater number of positive experiences (and vice versa). However, this study provides insight into the OOL struggles experienced by young breast cancer survivors such as treatment side effects, issues with reconstruction and appearance, etc. as they were areas commonly discussed by participants. Further, issues related to side effects appeared to trickle into other areas of patient's lives such as parenting ("My toddler and young child don't always understand if I'm not up to some activities"). As research has found younger breast cancer patients to report poorer QOL than older patients (Avis et al., 2005a) and many participants reported that at least one side effect was challenging to them at 12 months (45.78%), it is possible that QOL in the current sample was generally lower than in a sample of older breast cancer survivors (which comprises the majority of the literature) and the range may have been restricted. Clearly, further research in the area of quality of life and how it is related to challenges and positive aspects of the breast cancer experience in young breast cancer survivors is warranted.

# Hypothesis 5

As previously discussed, difficulties were encountered when attempting to test the fifth hypothesis, that survivors reporting higher levels of PTG at 6 months would report a higher number of healthy behaviors. Unfortunately for the purposes of the current study, most participants were non-smokers engaged in moderate exercise and moderate levels of

alcohol consumption. Outside of the confines of this research study, it is promising that young breast cancer survivors are engaged in healthy behaviors approximately 12 months post-diagnosis in the "real world." Given these findings, a comparison of activity levels between younger and older survivors might yield interesting differences due to general ability level and/or older survivors experiencing more difficulty "bouncing back" to their previous state of health post-treatment.

#### Limitations

There are several limitations to the current study. For one, this study was designed with the assumption that usable open-ended item data existed for 133 participants. Unfortunately, it was discovered during data analysis that a portion of participants who completed the open-ended items were actually from a separate study and their responses were unable to be explored. Although the current study's sample size (N = 87) is appropriate for a qualitative study, the reduction in size reduced the statistical power to detect significant relationships between variables. Additionally, this small sample size means that the results may not be generalizable to a larger population of breast cancer survivors. Further, participants were primarily white, educated women with above average income who represent only a small subset of breast cancer survivors yet comprise the majority of women in most breast cancer studies.

Another potential study flaw was the design of the open-ended items. These items were at the end of an already lengthy questionnaire and presented to participants on the same page with half a page of room to write their responses. Additionally, this method did not allow for follow-up questions to assist in clarifying some participants' responses that were grouped in the "other" theme due to lack of information of lack of clarity

regarding meaning. Participants may have been too tired to handwrite all of their difficulties or all of their positive experiences. Some chose not to respond at all (N = 33). Overall, this method of eliciting qualitative data might have led to little variation in number of responses with TNES and TPES because many participants may have offered fewer details about their experiences due to haste, feeling as though the set-up on the page did not call for lengthy responses, or both.

An additional limitation of the current study is the cross-sectional nature of analyses which limits the understanding of causal relationships between variables. This is especially disappointing given that the study involves the use of longitudinal data across 18-months (although the data were analyzed in a cross-sectional manner). As this sample has been included in another study examining PTG and correlates over time (Danhauer et al., in press), more sophisticated analyses have already been conducted and would have been redundant for the purposes of the current study.

Finally, although this writer and second coders attempted to remain unbiased in analyzing qualitative data, it is important to note that all are members of the PTG research team at UNCC. Although attempts were made to allow themes to emerge from the data without imposing PTG themes onto open-ended responses, it is possible that our familiarity with PTG could have influenced our analysis.

### Strengths

Despite study limitations, findings from the current study appear to be generally commensurate with the previous studies of PTG and breast cancer survivors and can add to the rapidly growing PTG literature. Although sophisticated data analyses using longitudinal data were not conducted in the current study, the study utilized qualitative

and quantitative data to gain a richer understanding of participants. Multiple time points were also examined and even if analyses were not longitudinal in nature, analyses were able to be conducted at varying steps of the breast cancer process (e.g., from soon after diagnosis to off treatment). Further, the utilization of the LIWC software provided a unique view of participants' use of positive and negative emotions words and their relationships with psychosocial variables.

Additionally, the study utilized what appears to be the youngest sample of breast cancer survivors to date and provides new information about the breast cancer experience through the eyes of such young survivors. As results from many breast cancer studies may not be generalizable to younger patients (Thewes et al., 2004), results from the current study offers insight into challenges they may experience (e.g., treatment side effects, concern for the future, employment and parenting issues, etc.) as well as positive experiences (PTG, improved self-care, etc.).

#### Future Directions

The current study indicates that a higher number of reported negative events across a wide range of issues including side effects, parenting and relationship stressors, and general life stressors are likely related to symptoms of depression in breast cancer survivors. The highly stressful (and potentially traumatic for some) nature of a diagnosis with breast cancer is difficult enough, but the additional challenges of navigating treatment and functioning as a *young, active* patient can also be traumatic. Although many studies with breast cancer survivors examine QOL, the negative events discussed by women in the current study appear to cut across a wider range of issues (e.g., employment and financial difficulties, relationship and parenting issues, etc.) that QOL

measures do not capture. Not only is it important for researchers to recognize and measure a wider variety of negative events since QOL measures appear to miss these challenges, it is important for clinicians to explore negative events with and assist patients in coping in an effort to prevent the development of symptoms of depression.

In regard to coping with breast cancer, Silva and colleagues (2012), note that patients and survivors may benefit from assistance with cognitive-emotional processing of the cancer experience. In relation to the PTG model, clinicians could assist patients in engaging in deliberate rumination to promote the positive reappraisal of their situation when possible. As social support in the current study of young breast cancer survivors was not related to PTG, but positive and negatively-valenced word choices were, encouragement of coping with breast cancer via writing might be a helpful approach and might encourage the development of PTG. Studies examining benefits of the promotion of positive reappraisal and the development of PTG in breast cancer survivors should be pursued.

Additionally, the currently study employed a grounded theory approach to better understand the experiences of the young breast cancer population. This type of bottom-up or "emic" approach allows themes and patterns to emerge from the data. Further qualitative analysis of the data could provide insight into the beliefs and behaviors of survivors that can be applied across cultures. Future analyses of the data using a top-down or "etic" approach would allow for the researcher to group responses based on more broad concepts and categories that would allow for cross-cultural comparisons.

The current study provides further support that PTG exists in young breast cancer survivors as evidenced by qualitative analysis at 12 months post-diagnosis and at multiple

time points via the PGTI. In response to qualitative items, participants spontaneously responded with PTG-themed statements when asked to discuss positive experiences in general. Further, PTGI results indicated that PTG scores increased over time: baseline mean = 60.09, 6-months mean = 62.40, 12-months mean = 63.14, 18-months mean = 64.91. For an in-depth analysis of PTG over time utilizing the current sample as part of a larger breast cancer study, please see Danhauer and colleagues (in press). Reports of PTG in this study are in line with previous studies that have documented the existence of PTG in breast cancer patients and survivors (Bellizzi & Blank, 2006; Bellizzi et al., 2010; Bozo et al., 2009; Brunet et al., 2010; Bussell & Naus, 2010; Chan et al., 2011; Cordova et al., 2001; Cordova et al., 2007; Gall et al., 2011; Hefferon et al., 2010; Ho et al., 2011; Koutrouli, Anagnostopoulos, & Potamianos, 2012; Lelorain et al., 2010; Luszczynska et al., 2012; Manne et al., 2004; Mols et al., 2009; Morrill et al., 2008; Sadler-Gerhardt et al., 2010; Sears, Stanton, & Danoff-Burg, 2003; Silva, Crespo, & Canavarro, 2012; Silva, Moreira, & Canavarro, 2012; Svetina & Nastran, 2012; Weiss, 2002, 2004). It is encouraging that despite the multiple negative events experienced by participants, they were able to recognize areas of their lives in which they had grown. To quote a participant from the current study, it appears as though breast cancer survivors are able to make "lemonade out of lemons" and to "look at the silver lining" of the breast cancer experience.

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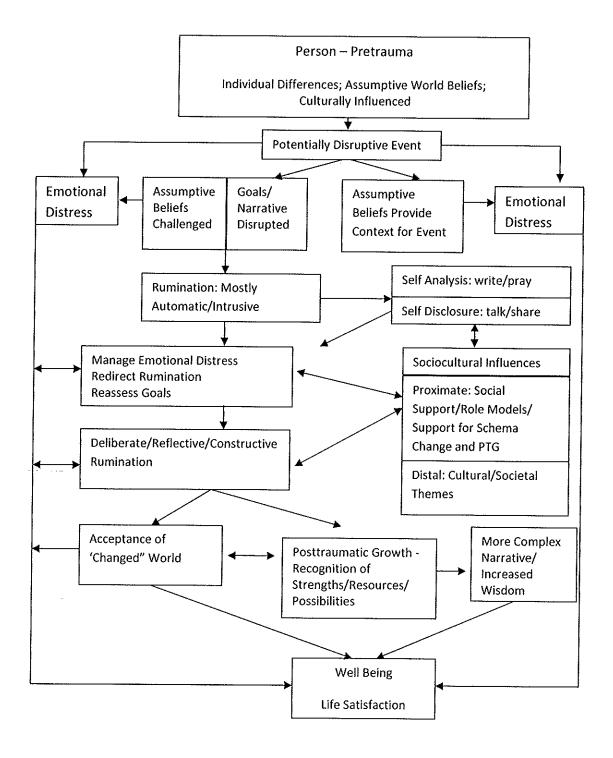
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### APPENDIX A: MODEL OF POSTTRAUMATIC GROWTH



#### APPENDIX B: STUDY MEASURES

### Post Traumatic Growth Inventory

1 = I experienced this change to a very small degree as a result of my cancer.
2 = I experienced this change to a small degree as a result of my cancer.

Indicate for each of the statements below the degree to which this change occurred in your life as a result of your cancer, using the following scale:

0 = I did not experience this change as a result of my cancer.

4 :	= I experienc	ed this change	to a great degre	ee as a result of	It of my cancer. my cancer. alt of my cancer.
1. I chang 0	ged my priori 1	ties about what 2	is important in	life. 4	5
2. I have a	a greater appi	reciation for the	value of my o	wn life.	
0	1	2	3	4	5
3. I develo	oped new into	erests. 2	3	4	5
4. I have a	ı greater feeli	ng of self-relia	nce.		
0	1	2	3	4	5
5. I have a	ı better under	standing of spir	ritual matters.		
0	1	2	3	4	5
6. I more	clearly see th	at I can count o	n people in tim	nes of trouble.	
0	1	2	3	4	5
7. I establi	shed a new p	oath for my life.			
0	1	2	3	4	5
8. I have a	greater sense	e of closeness v	vith others.		
0	1	2	3	4	5
	ore willing to	express my em			
0	1	2	3	4	5

10. I know be 0	tter that I can h 1	andle difficulti 2	es. 3	4	5
11. I am able	to do better thin	ngs with my life 2	e. 3	4	5
12. I am better	r able to accept	the way things	work out.	4	5
13. I can bette	r appreciate ea 1	ch day. 2	3	4	5
14. New oppo 0	rtunities are av 1	ailable which v 2	wouldn't have b	een otherwise.	5
15. I have moi 0	re compassion	for others.	3	4	5
16. I put more 0	effort into my	relationships.	3	4	5
17. I am more 0	likely to try to 1	change things	which need cha	nnging. 4	5
18. I have a str 0	ronger religiou: 1	s faith. 2	3	4	5
19. I discovere 0	ed that I'm stroi 1	nger than I thou 2	ight I was. 3	4	5
20. I learned a 0	great deal about	ut how wonders	ful people are.	4	5
21. I better acc	cept needing of	hers. 2	3	4	5

#### **Brief COPE**

These items deal with ways you've been coping with your diagnosis of breast cancer. There are many ways to try to deal with problems. These items ask what you've been doing to cope with this one.

Obviously, different people deal with things in different ways, but we are interested in how you've tried to deal with it. Each item says something about a particular way of coping. We want to know to what extent you've been doing what the item says. How much or how frequently. Do not answer on the basis of whether it seems to be working or not just whether or not you're doing it. Use these response choices. Try to rate each item separately in your mind from the others. Make your answers as true FOR YOU as you can.

	Not doing at all	Doing a little bit	Doing a medium amount	Doing a lot
1. I've been turning to work or other activities to take my mind off things	1	2	3	4
2. I've been concentrating my efforts on doing something about the situation I'm in	1	2	3	4
3. I've been saying to myself "this isn't re	al" l	2	3	4
4. I've been using alcohol or other drugs to make myself feel better	1	2	3	4
5. I've been getting emotional support from others	1	2	3	4
6. I've been giving up trying to deal with i	it 1	2	3	4
7. I've been taking action to try to make the situation feel better	1	2	3	4

	Not doing at all	Doing a little bit	Doing a medium amount	Doing a lot
8. I've been refusing to believe that it has happened	1	2	3	4
9. I've been saying things to let my unpleasant feelings escape	1	2	3	4
10. I've been getting help and advice from other people	1	2	3	4
11. I've been using alcohol or other drugs help me get through it	to 1	2	3	4
12. I've been trying to see it in a different to make it seem more positive	light, 1	2	3	4
13. I've been criticizing myself	1	2	3	4
14. I've been trying to come up with a stra about what to do	tegy 1	2	3	4
15. I've been getting comfort and understanding from someone	1	2	3	4
16. I've been giving up the attempt to cope	: 1	2	3	4
17. I've been looking for something good is what is happening	in 1	2	3	4
18. I've been making jokes about it	1	2	3	4

	Not doing at all	Doing a little bit	Doing a medium amount	Doing a lot
19. I've been doing something to think about It less, such as going to movies, watching reading, daydreaming, sleeping, or shoppi	TV,	2	3	4
20. I've been accepting the reality of the fait has happened	act that 1	2	3	4
21. I've been expressing my negative feeli	ngs 1	2	3	4
22. I've been trying to find comfort in my religion or spiritual beliefs	1	2	3	4
23. I've been trying to get advice or help for other people about what to do	rom 1	2	3	4
24. I've been learning to live with it	1	2	3	4
25. I've been thinking hard about what steps to take	1	2	3	4
26. I've been blaming myself for things that happened	1	2	3	4
27. I've been praying or meditating	1	2	3	4
28. I've been making fun of the situation	1	2	3	4
29. I've tried to keep my feelings to mysel	f 1	2	3	4

	Not doing at all	Doing a little bit	Doing a medium amount	Doing a lot
30. I've kept others from knowing how bac things were	1 1	2	3	4
31. I've wished that the situation would go away or somehow be over with	1	2	3	4
32. I've had fantasies or wishes about how things might turn out	1	2	3	4

### **Beck Depression Inventory**

The following questions consist of groups of statements. After reading each group of statements carefully, chose the one statement in each group which best describes the way you have been feeling the past week, including today. Be sure to read all the statements in each group before making your choice.

1. I do not feel sad.

I feel sad.

I am sad all the time and I can't snap out of it.

I am so sad or unhappy that I can't stand it.

2. I am not particularly discouraged about the future.

I feel discouraged about the future.

I feel I have nothing to look forward to.

I feel that the future is hopeless and that things cannot improve.

3. I do not feel like a failure.

I feel I have failed more than the average person.

As I look back on my life, all I can see is a lot of failures.

I feel I am a complete failure as a person.

4. I get as much satisfaction out of things as I used to.

I don't enjoy things the way I used to.

I don't get real satisfaction out of anything anymore.

I am dissatisfied or bored with everything.

5. I don't feel particularly guilty.

I feel guilty a good part of the time.

I feel quite guilty most of the time.

I feel guilty all of the time.

6. I don't feel I am being punished.

I feel I may be punished.

I expect to be punished.

I feel I am being punished.

7. I don't feel disappointed in myself.

I am disappointed in myself.

I am disgusted with myself.

I hate myself.

8. I don't feel I am any worse than anybody else.

I am critical of myself for my weaknesses or mistakes.

I blame myself all the time for my faults.

I blame myself for everything bad that happens.

9. I don't have any thoughts of killing myself.

I have thoughts of killing myself, but I would not carry them out.

I would like to kill myself.

I would kill myself if I had the chance.

10. I don't cry anymore than usual.

I cry more now than I used to.

I cry all the time now.

I used to be able to cry, but now I can't cry even though I want to.

11. I am no more irritated now than I ever am.

I get annoyed or irritated more easily than usual.

I feel irritated all the time now.

I don't get irritated at all by the things that used to irritate me.

12. I have not lost interest in other people.

I am less interested in other people than I used to be.

I have lost most of my interest in other people.

I have lost all of my interest in other people.

13. I make decisions about as well as I ever could.

I put off making decisions more than I used to.

I have greater difficulty in making decisions than before.

I can't make decisions at all anymore.

14. I don't feel I look any worse than I used to.

I am worried that I am looking old or unattractive.

I feel that there are permanent changes in my appearance that make me look unattractive.

I believe that I look ugly.

15. I can work about as well as before.

It takes an extra effort to get started at doing something.

I have to push myself very hard to do anything.

I can't do any work at all.

16. I can sleep as well as usual.

I don't sleep as well as I used to.

I wake up 1-2 hours earlier than usual and find it hard to get back to sleep.

I wake up several hours earlier than I used to and cannot get back to sleep.

17. I don't get more tired than usual.

I get tired more easily than I used to.

I get tired from doing almost anything.

I am too tired to do anything.

18. My appetite is no worse than usual.

My appetite is not as good as it used to be.

My appetite is much worse now.

I have no appetite at all anymore.

19. I haven't lost much weight, if any, lately.

I have lost more than five (5) pounds.

I have lost more than ten (10) pounds.

I have lost more than fifteen (15) pounds.

20. I am no more worried about my health than usual.

I am worried about physical problems such as aches and pains; or upset stomach or constipation.

I am very worried about physical problems, and it's hard to think of much else.

I am so worried about my physical problems that I cannot think about anything else.

21. I have not noticed any recent change in my interest in sex.

I am less interested in sex than I used to be.

I am much less interested in sex now.

I have lost interest in sex completely.

FACT-B

Below is a list of statements that other people with your illness have said are important. Please circle or mark one number per line to indicate your response as it applies to the <u>past 7 days</u>.

	Not at All	A little Bit	Somewhat	Quite a Bit	Very Much
PHYSICAL WELL-BEING					
I have a lack of energy	0	1	2	3	4
I have nausea	0	1	2	3	4
Because of my physical condition, I have trouble meeting the needs of my family	0	1	2	3	4
I have pain	0	1	2	3	4
I am bothered by side effects of treatment	nt 0	1	2	3	4
I feel ill	0	1	2	3	4
I am forced to spend time in bed	0	1	2	3	4
SOCIAL/FAMILY WELL-BEING I feel close to my friends	0	1	2	3	4
I get emotional support from my family	0	1	2	3	4
I get support from my friends	0	1	2	3	4
My family has accepted my illness	0	1	2	3	4
I am satisfied with family communication about my illness	on O	1	2	3	4
I feel close to my partner (or the person who is my main support)	0	1	2	3	4

	Not at All	A little Bit	Somewhat	Quite a Bit	Very Much
Regardless of your current level of sexu. If you prefer not to answer it, please mo					
I am satisfied with my sex life	0	1	2	3	4
Please circle or mark one number per the past 7 days.	r line to in	ndicate yo	ur response :	as it app	lies to
	Not at All	A little Bit	Somewhat	Quite a Bit	Very Much
EMOTIONAL WELL-BEING					
I feel sad	0	1	2	3	4
I am satisfied with how I am coping with my illness	0	1	2	3	4
I am losing hope in the fight against my illness	0	1	2	3	4
I feel nervous	0	1	2	3	4
I worry about dying	0	1	2	3	4
I worry that my condition will get	0	1	2	3	4

worse

	Not at All	A little Bit	Somewhat	Quite a Bit	Very Much
ADDITIONAL CONCERNS					
I have been short of breath	0	****	2	3	4
I am self-conscious about the way I dress	0	1	2	3	4
One or both of my arms are swollen or tender	0	1	2	3	4
I feel sexually attractive	0	1	2	3	4
I am bothered by hair loss	0	1	2	3	4
I worry that other members of my family might someday get the same illness I have	0	1	2	3	4
I worry about the effect of stress on my illness	0	1	2	3	4
I am bothered by a change in weight	0	1	2	3	4
I am able to feel like a woman	0	1	2	3	4
I have certain parts of my body wher I experience pain	e 0	1	2	3	4

1.	Overall, ho	ow would	you rate	your qua	ality of lif	e? (Chec	k one bo	x below.	)
1	2	3	4	5	6	7	8	9	10
No. of the control of	As bad o							Best q of life	uality
2.	How satisf	ied are yo	ou with yo	ur curre	ent quality	of life?	(Check o	one box	below.)
1	2	3	4	5	6	7	8	9	10
	Not at all happy with quality of life now Very happy with quality of life now								
3.	In general	would yo	u say you	r health	is: (Cheo	ek one bo	ox.)		
	Excellen	t V	ery good		Good		Fair		Poor
<ul><li>4. Compared to one year ago, how would you rate your health in general now?</li><li>(Check one box.)</li></ul>									
	Mu	ch better	now than	1 year a	go				
	Somewhat better now than 1 year ago								
	Abo	out the sa	me						
	Sor	newhat w	orse now	than 1 y	ear ago				
	Mu	ch worse	than 1 yea	ar ago					

The following are questions about a typical (or usual) day's activities. **Does your health** now limit you in these activities, and if so, how much? (Check one box for each question.)

5. heavy	Vigorous activities, such as running, lifting objects, or strenuous sports	Yes, limited a lot	Yes, limited a little	No, not limited at all				
6. vacuu	Moderate activities, such as moving a table, ming, bowling or golfing							
7.	Lifting or carrying groceries							
8.	Climbing several flights of stairs							
9.	Climbing one flight of stairs							
10.	Bending, kneeling, stooping							
11.	Walking more than a mile							
12.	Walking several blocks							
13.	Walking one block							
14.	Bathing or dressing yourself							
During the <u>past 4 weeks</u> , have you had any of the following problems with your work or other regular daily activities as a result of your <u>physical health</u> ?								
15. other a	Cut down on the <b>amount of time</b> you spent on activities	work or	Y	es No				
16.	Accomplished less than you would have liked							

		Yes	No					
17.	Were limited in the kind of work or other activities you did							
18. (it too	Had <b>difficulty</b> performing work or other activities k extra effort)							
other i	g the <u>past 4 weeks</u> , have you had any of the following problems with regular daily activities as a result of any <u>emotional</u> problems (such a seed or anxious)?	•						
		Yes	No					
19. or othe	You cut down on the amount of time spent on work er activities							
20.	You accomplished less than you would have liked							
21.	1. You did work or other things less carefully than usual							
22. During the <u>past 4 weeks</u> , to what extent has your <u>physical health or emotional</u> <u>problems</u> interfered with your normal social activities with family, neighbors, friends, or groups? (Check one box.)								
	Not at Slightly Moderately Quite Extreme	ely						

23.	During the past 4	<u>weeks,</u> ho	w much <u>b</u>	<u>ody pain</u> ha	ve you had	d? (Check	one box.)
	None	Very Mild	Mild	Mod (Med		Severe	Very Severe
24. (inclu	During the <b>past 4</b> diding both work outsi	·		-		•	work
past 4	Not at all questions are about less weeks. (For each que to have been feeling	estion, ple		n) a b w things har	it ] <u>ve been</u> w	•	_
How	much of the time <u>du</u>	ring the p	ast 4 wee	<u>ks</u>			
		All of the time	Most of the time	A good bit of the time	Some of the time	A little of the time	None of the time
25.	Did you feel full of	pep?					
26.	Have you been a ve	ry nervous	s person?				
27.	Have you felt so do		dumps tha	t			
	nothing could cheer	you up?					

		All of the time	Most of the time	A good bit of the time	Some of the time	A little of the time	None of the time
28.	Have you felt calm	m and peacef	ul?				
29.	Did you have a lo	t of energy?					
30.	Have you felt dow	nhearted and	d blue?				
31.	Did you feel worn	out?					
32.	Have you been a h	nappy person	.?				
33.	Did you feel tired	?					
34. emotion	During the past 4 onal problems interfees)?						
	All of the time	Most of the time	Some o		tle of time	None of the time	

# How TRUE or FALSE is each of the following statements for you?

		Definitely true	Mostly true	Don't know	Mostly false	Definitely false
35.	I seem to get sick a littl	e easier than	other peopl	e		
36.	I am as healthy as anybo	ody I know				
37.	I expect my health to ge	et worse				
38.	My health is excellent					

# MOS Social Support Form

# The following are questions about the support that is available to you.

	esent time, about how many close friends and close relatives do you have at ease with and can talk to about what is on your mind)? (Please write boxes below.)
Currently, how o	Number of close friends and close relatives s look to others for companionship, assistance, or other types of support. ften is each of the following kinds of support available to you if you one box for each statement.)

	None of the time	A little of the time	Some of the time	Most of the time	All of the time
2. Someone to help you if you were confined to bed.					
3. Someone you can count on to listen to you when you need to talk.					
4. Someone to give you good advice about a crisis.					
5. Someone to take you to the doctor if you needed it.					
<ol><li>Someone who shows you love and affection.</li></ol>					
7. Someone to have a good time with.					
8. Someone to give you information to help you understand a situation.					
<ol><li>Someone to confide in or talk to about yourself or your problems.</li></ol>					

	None of the time	A little of the time	Some of the time	Most of the time	All of the time
10. Someone who hugs you.					
11. Someone to get together with for relaxation.					
12. Someone to prepare your meals if you were unable to do it yourself.					
13. Someone whose advice you really want.					
14. Someone to do things with to help you get your mind off things.					
15. Someone to help with daily chores if you were sick.					
16. Someone to share your most private worries and fears with.					
17. Someone to turn to for suggestions about how to deal with a personal problem.					
18. Someone to do something enjoyable with.					
19. Someone who understands your problems.					
20. Someone to love you and make you feel wanted.					

For the following questions, please check the box that is the most true for you at the present time. (Check only one box for each statement.)

### Of the people who are important to you, how many:

	None	One	Some	Most	All
21. Don't understand you.					
22. Get on your nerves.					
23. Ask too much of you.					
24. Argue with you.					
25. Don't include you.					
26. Show that they don't like you.					·
27. Boss you.					
28. Try to get you to do things you don't want to do.					

### **QLACS**

INSTRUCTIONS: We'd like to ask you about some things that can affect the quality of people's lives. Some of these questions may sound similar, but please be sure to answer each one. Below is a scale ranging from "never" to "always". Please indicate how often each of these statements has been true for you in <a href="the past 4 weeks">the past 4 weeks</a>. Please try to answer the sexual activity questions even if you do not currently have a partner. (Circle one answer for EACH question)

In th	e past 4 weeks	Never	Seldom		About as often as not	Fre- quent- ly	_	Always
1. the th	You had the energy to do ings you wanted to do	1	2	3	4	5	6	7
2. activi	You had difficulty doing ties that require concentrating	1	2	3	4	5	6	7
3. a shor	You were bothered by having attention span	1	2	3	4	5	6	7
4.	You had trouble remembering things	3 1	2	3 .	4	5	6	7
5.	You felt fatigued	1	2	3	4	5	6	7
6.	You felt happy	1	2	3	4	5	6	7
7.	You felt blue or depressed	1	2	3	4	5	6	7
8.	You enjoyed life	1	2	3	4	5	6	7
9.	You worried about little things	<b>*****</b>	2	3	4	5	6	7
10. unable	You were bothered by being to function sexually	1	2	3	4	5	6	7
11. do the	You didn't have energy to things you wanted to do	1	2	3	4	5	6	7

		Never	Seldom		About as often as not			Always
12.	You were dissatisfied with your sex life	1	2	3	4	5	6	7
13.	You were bothered by pain that kept you from doing the things you wanted to do	e 1	2	3	4	5	6	7
14.	You felt tired a lot	1	2	3	4	5	6	7
15.	You were reluctant to start relationships	new 1	2	3	4	5	6	7
16.	You lacked interest in sex	1	2	3	4	5	6	7
17.	Your mood was disrupted by pain or its treatment	1	2	3	4	5	6	7
18.	You avoided social gathering	gs 1	2	3	4	5	6	7
19.	You were bothered by mood swings	1	2	3	4	5	6	7
20.	You avoided your friends	1	2	3	4	5	6	7
21.	You had aches or pains	1	2	3	4	5	6	7
22.	You had a positive outlook on life	1	2	3	4	5	6	7
23.	You were bothered by forget what you started to do	tting 1	2	3	4	5	6	7
24.	You felt anxious	1	2	3	4	5	6	7
25.	You were reluctant to meet new people	1	2	3	4	5	6	7
26.	You avoided sexual activity	1	2	3	4	5	6	7

		Never Se	ldom		About as often as not		Very often	Always
27.	Pain or its treatment interfer with your social activities	ered 1	2	3	4	5	6	7
28.	You were content with you	ır life 1	2	3	4	5	6	7
29.	You appreciated life more of having had cancer	because 1	2	3	4	5	6	7
30.	You had financial problems of the cost of cancer surger							
	treatment	1	2	3	4	5	6	7
31.	You worried that your family were at risk of getting cance	•	ers 2	3	4	5	6	7
32.	You realized that having ca helps you cope better with problems now	incer 1	2	3	4	5	6	7
33.	You were self conscious ab way you look because of yo cancer or its treatment		2	3	4	5	6	7
34.	You worried about whether family members might have causing genes	-	2	3	4	5	6	7
35.	You felt unattractive because your cancer or its treatment		2	3	4	5	6	7
36.	You worried about dying fr	rom 1	2	3	4	5	6	7
37.	You had problems with insubecause of cancer	urance 1	2	3	4	5	6	7
38.	You were bothered by hair cancer treatment	loss from 1	2	3	4	5	6	7
39.	You worried about cancer c back	coming 1	2	3	4	5	6	7

		Never	Seldom	Some- times	About as often as not	Fre- quent- ly	-	Always
40.	You felt that cancer helped to recognize what is import	•			. 90	10.0004		
	in life	1	2	3	4	5	6	7
41.	You felt better able to deal stress because of having ha	ad						
	cancer	1	2	3	4	5	6	7
42.	You worried about whethe family members should ha							
	genetic tests for cancer	1	2	3	4	5	6	7
43.	You had money problems because you had cancer	that aros 1	se 2	3	4	5	6	7
44.	You felt people treated you differently because of chan to your appearance due to yourcancer or its treatment	ges	2	3	4	5	6	7
45.	You have financial problem due to a loss of income as							
	a result of cancer	1	2	3	4	5	6	7
46.	Whenever you felt a pain, y that it might be cancer again		ried 2	3	4	5	6	7
47.	You were preoccupied with about cancer		ns 2	3	4	5	6	7
18.	Finally, is there anything el of life that has not been cov	se that y	ou wisl these qu	h to add	l that is i s?	mporta	nt to y	our quality
		NO	)		YES			
	If "YES, please explain:							

#### Health Behavior Items

These questions are about habits that may affect your health (smoking, alcohol use, weight, and exercise). Please answer each question as accurately as possible.

1. Do you smoke currently?

Yes No

If <u>yes</u>, how many cigarettes do you smoke per day? (1 pack = 20 cigarettes)

I smoke occasionally

0-5 cigarettes a day

6-20 cigarettes a day

21 – 30 cigarettes as day

31 - 40 cigarettes a day

More than 40 cigarettes a day

2. Do you currently drink alcoholic beverages?

Yes No

If yes, how many alcoholic beverages (beer, wine, or mixed drinks) do you currently drink in an average month?

\_\_\_\_\_Beverages per month

3. What is your current weight?

The following questions are about your usual physical activity and exercise. This includes walking and sports.

4. Think about the walking you do outside the home. In the past month, how often did you walk outside the home for more than 10 minutes without stopping? (Mark only one).

Rarely or never (Go to question 5)

1-3 times each month (Go to question 4a)

1 time each week (Go to question 4a)

2-3 times each week (Go to question 4a)

4-6 times each week (Go to question 4a)

7 or more times each week (Go to question 4a)

4a. When you walked outside the home for more than 10 minutes without stopping how many minutes did you usually walk?

Less than 20 minutes

20-39 minutes

40-59 minutes

1 hour or more

#### 4b. What was your usual speed?

Casual strolling or walking (less than 2 miles an hour)
Average or normal (2-3 miles an hour)
Fairly fast (3-4 miles an hour)
Very fast (more than 4 miles an hour)
Don't know

Following are three categories of exercise, (strenuous, moderate, and mild). Not including walking outside the home, how often each week (7 days) do you usually do the following strenuous, moderate, and mild types of exercise?

5. STRENUOUS OR VERY HARD EXERCISE. (You work up a sweat and your heart beats fast). For example, aerobics, aerobic dancing, jogging, tennis, swimming laps.

None (Go to question 6)

- 1 day per week (Go to question 5a)
- 2 days per week (Go to question 5a)
- 3 days per week (Go to question 5a)
- 4 days per week (Go to question 5a)
- 5 or more days per week (Go to question 5a)

5a. How long do you usually exercise like this at one time?

Less than 20 minutes 20-39 minutes 40-59 minutes 1 hour or more

6. MODERATE EXERCISE. (Not exhausting). For example, biking outdoors, using an exercise machine (like a stationary bike or treadmill), calisthenics, easy swimming, popular or folk dancing.

None (Go to question 7)

- 1 day per week (Go to question 6a)
- 2 days per week (Go to question 6a)
- 3 days per week (Go to question 6a)
- 4 days per week (Go to question 6a)
- 5 or more days per week (Go to question 6a)

6a. How long do you usually exercise like this at one time?

Less than 20 minutes 20-39 minutes 40-59 minutes

#### 1 hour or more

7. MILD EXERCISE. For example, slow dancing, bowling, golf.

### None

- 1 day per week (Go to question 7a) 2 days per week (Go to question 7a)
- 3 days per week (Go to question 7a)
- 4 days per week (Go to question 7a)
- 5 or more days per week (Go to question 7a)

7a. How long do you usually exercise like this at one time?

Less than 20 minutes 20-39 minutes 40-59 minutes 1 hour or more

# Open-ended Items

We are interested in how your life, in general, has been since your diagnosis.

1. What major challenges have you faced since your diagnosis?

2. What positive experiences have you had? (For example, things you learned about yourself, how you interact with your family, etc.)

### APPENDIX C: QUALITATIVE CODEBOOK

### Codes for Question 1 (14 themes):

"What major challenges have you faced since your diagnosis?"

#### 1. Side effects/treatment issue

Side effects of chemotherapy, radiation, surgery such as: hot flashes, fatigue, decrease in sexual desire, weight gain, pain, difficulty sleeping, change in personality, infertility; anxiety/fear of procedures and test results

\*Statements related to how a person *coped* with side effects should be coded under "coping"

#### 2. Concern for future

Fear of cancer recurrence (e.g., worry that headache = cancer); worries about ability to have children

#### 3. Employment issues/changes

Trying to find employment; conflict at work due to missing for appointments; difficulty going to work due to side effects; leaving/changing jobs

\*Return to work is included in "adjustment to life after cancer" category

### 4. Appearance/Self-esteem issues

Feeling less attractive; disliking the look of reconstructive surgery; dislike of appearance post-mastectomy/reconstruction

### 5. General life event/stressor not explicitly related to cancer

Moving; getting married/planning wedding; completing dissertation; events that were planned prior to diagnosis; Illness of other family members/friends; loss of family, friends

## 6. Adaptive Coping Efforts

Acceptance that life has changed; adjusting to changes; learning to deal with medical illness

### 7. Difficulty coping/Emotional difficulties

Ruminative thoughts; missing life prior to cancer; feeling sad, depressed, anxious, lack of interest in things; betrayal of body; wondering what the point of life is; general confusion

### 8. Relationship/Interpersonal issues

Feeling as though healthy people don't understand/aren't comfortable; trying to stay away from negative people; trying to remain energetic around loved ones; dealing with in-laws; intimate relations; difficulty relating to others

# 9. Parenting/Caregiver Stress

Parenting while going through treatment/dealing with side effects; behavioral problems of children (e.g., sneaking out of the house, defiance); single parenthood

# 10. Adjustment to Life after Cancer

Transitioning back to work; return to dating; getting back to regular schedule

#### 11. Financial difficulties

Ex. Medical bills

# 12. Educating the self about cancer/treatment options

Learning information specifically about the disease (e.g., how cancer functions within the body) and treatment options (e.g., mastectomy, radiation, chemotherapy, etc.)

#### 13. Positive statements/changes

Living a more youthful life; recovery/return to previous self; being finished with treatment; focus on making life better

# 14. Other

Statements that do not fit neatly within other categories; not enough information to fully understand meaning of statement

### Codes for Question 2 (10 themes):

"What positive experiences have you had? (For example, things you learned about yourself, how you interact with your family, etc.)"

### 1. Relating to others – positive change:

This code is meant to reflect growth in the way a person relates to others. Examples include clarity in relationships (who friends are, how strong family members are, how supportive family members are); feeling closer to family/friends; spending more time with loved ones; greater compassion for others; positive experience with medical staff \*Acquiring new friends/support groups due to cancer experience is coded under new possibilities.

### 2. Greater Appreciation of Life:

Changed priorities (enjoyment of more things, not "sweating the small stuff"); new outlook on life; "life goes on" mentality; recognition of how fragile life is

#### 3. New Possibilities:

Meeting new people/friends otherwise would not have met; accomplishing new things; different hair style/texture

\*Must be clear that changes/new activities are due to cancer experience

#### 4. Personal strength:

Stronger than previously thought; Greater self-confidence; Greater self-worth

\*This code reflects a change in the way the person viewed themselves. "Staying
strong" would be coded under the coping category as it does not necessarily reflect
growth.

#### 5. Spiritual growth:

Stronger faith; feelings of peace; interest in creating meaning in life/doing more meaningful things

### 6. Coping:

Relying on others for emotional support and asking for help; sense of humor; positive attitude; religious coping (e.g., prayer)

#### 7. Self-care:

Eating better; resting; seeking mental health treatment when needed

8. Negative statement/difficulties related to cancer experience:

Any statement that describes hardships brought on by cancer; negative experiences in relationships for the cancer survivor (e.g., feeling as though family/friends were not supportive; difficulty with social interactions due to cancer; negative experiences with medical team)

9. No positive change attributed to cancer:

Any statement indicating that all of the good in a person's life existed prior to cancer.

#### 10. Other:

Does not fit into other categories; Statements are too vague to understand without further details

Unclear whether change is related to cancer or not: \*Example: "God is always here for me" is a general statement about faith in God that does not reflect change and/or is unclear whether faith has changed due to cancer experience

TABLE 1. Timeline of Administration of Measures

Measure	Baseline	3	6	12	18
Demographic Variables	X			X	X
Medical Chart Review (Completed by staff)	Within 12 months of enrollment			Х	
PTGI	X		X	X	X
Brief COPE	X		X	X	X
BDI	X	X	X	X	X
SF-36	X		X	X	X
FACT-B	X	X	X	X .	X
Health Behavior Items (Drinking, Smoking, Exercise)	X		X	X	X
MOS Social Support Survey	X		X	Х	X
Open-ended items	\$			X	
QLACS				X	X

TABLE 2. Demographic Statistics

# A. Descriptives of Participants at 12-month follow up survey

Variable	Frequency	Percentage
Ethnicity		
Asian/Pacific Islander	1	1.15%
Black	5	5.75%
Hispanic	0	0%
White	81	93.10%
Marital Status		
Never Married	16	18.39%
Presently Married	61	70.11%
Living in marriage-like relationship	6	6.90%
Divorced	1	1.15%
Separated	1	1.15%
Widowed	2	2.30%
Education Level		
High school diploma/GED	3	3.45%
Business or vocational school	5	5.75%
Some college	6	6.90%
Associates Degree	3	3.45%
Undergraduate degree	28	32.18%
Some graduate school	13	14.94%
Master's degree	20	22.99%
Doctoral degree	9	10.34%
Total Family Income		
Less than 10,000	2	2.2007
\$10,000 - \$19,999	2 3	2.30%
\$20,000 - \$19,999	5 6	3.45%
\$35,000 - \$34,999	6	6.90%
\$50,000 - \$74,999	8	6.90%
\$75,000 - \$74,999 \$75,000 - \$100,000	o 16	9.20%
More than \$100,000	45	18.39% 51.72%
Employment	,-	a m.c.
Unemployed	5	5.75%
Retired	0	0%
Homemaker	24	27.69%
Employed Full time	27	31.03%
Employed Part time	13	14.94%
Disabled, unable to work	6	6.90%
Student	0	0%

Other	12	13.79%
Type of Employment		
Professional, Technical	29	33.33%
(teachers, nurses, lawyers, physicians)		
Manager, Administrator	8	9.20%
(sales managers, real estate agents) Clerical	4	4.60%
(secretaries, clerks)	·	1.0070
Sales	1	1.15%
(sales persons, agents, brokers)	1	1 1 "0 /
Service Occupations (police, cooks, hairdressers)	1	1.15%
Military Members	***	1.15%
Other	8	9.20%
Radiation		
Yes	60	68.97%
No	27	31.03%
Chemotherapy		
Yes	75	86.21%
No	12	13.79%
Both Radiation and Chemotherapy	53	60.92%

Note. N = 87 with the exception of income (N = 86).

TABLE 3. T-test Results Comparing PTG Total score by Medical Variables

0	Ye	s	N	<u>o</u>		
	M	SD	M	SD	t-test	p-value
Chemotherapy <sup>a</sup>	64.78	19.19	53.00	14.59	-2.03	.05
Radiation <sup>b</sup>	62.64	19.53	64.22	18.05	.36	.72
Lymph Node Invasion <sup>c</sup>	64.24	19.03	62.69	19.03	34	.73
Estrogen Receptor Positive <sup>d</sup>	63.26	19.31	63.03	18.85	05	.96
Progesterone Receptor Positive <sup>e</sup>	62.92	20.08	63.27	18.08	.08	.93
Mastectomy <sup>f</sup>	65.86	19.55	60.28	18.17	-1.37	.18
Reconstructiong	66.25	19.68	61.30	18.50	-1.17	.24
Note. ${}^{a}N = 74$ (Yes), 12 (	No); <sup>b</sup> N =	= 59 (Yes)	, 27 (No);	$^{c}N = 25$ (	Yes), 61 (1	$\sqrt{(o)}; \sqrt[d]{N} = 27$

(Yes), 56 (No);  ${}^{e}N = 38$  (Yes), 45 (No);  ${}^{f}N = 44$  (Yes), 42 (No);  ${}^{g}N = 32$  (Yes), 54 (No)

TABLE 4. Psychosocial characteristics of the study sample by survey time point

	Т	<u> </u>		1		1			·T				1
hs	CS	19.46		6.80	6.18	4.62	3.63	3.26	5.83	6.62	.91	.92	.81
18 Months	Mean	64.91		23.86	11.68	13.86	4.31	11.20	7.49	17.95	2.54	2.38	4.24
	N	81		81	81	81	<u>8</u>	- S	08	81	08	08	83
S	SD	18.99		6.38	5.6	4.87	5.58	3.25	6.11	6.50	.92	.79	08.
12 Months	Mean	63.14		24.05	11:11	13.34	3.95	10.69	7.59	17.8	2.48	2.46	4.19
	N	98		98	98	98	98	98	87	87	87	87	87
S	SD	20.95		7.13	6.50	4.96	3.48	3.36	6.29		98.	.85	.83
6 Months	Mean	62.40		23.25	11.38	13.07	3.92	10.79	8.75		2.73	2.75	4.15
	N	85		85	85	85	84	85	85		85	85	84
6)	as	20.12		7.08	6.24	5.16	3.49	3.74	7.36		88.	.74	.74
Baseline	Mean	60.09		23.32	10.40	12.13	3.83	10.43	11.09	***************************************	2.79	3.07	4.28
	N	87		87	87	87	87	87	87		87	87	87
		PTGI – Total	PTGI Domains	Relating to Others	New Possibilities	Personal Strength	Spiritual Change	Appreciation of Life	BDI	QLACS benefits*	Brief COPE positive reappraisal	Brief COPE active coping	MOS total social support

					-	***************************************						
MOS emotional support	87	87 4.29 .81 84 4.17	.83	84	4.17	.90 87 4.20	87	4.20	.90 83 4.26	83	4.26	68.
FACT-B	87	94.83	22.95	84	104.82	19.12	87	87 94.83 22.95 84 104.82 19.12 87 107.51 18.50 83 109.90 17.86	18.50	83	109.90	17.86
SF-36 MCS	87	45.29	11.47	85	87     45.29     11.47     85     47.33     11.68     87     49.71	11.68	87		10.55 82 48.63	82		9.65
SF-36 PCS	87	44.89	8.56	85	48.72	10.15	87	87   44.89   8.56   85   48.72   10.15   87   51.40   8.73   82   53.28   8.32	8.73	82	53.28	8 32

\*Note. QLACS not administered at Baseline or 6 Months.

TABLE 5. Frequencies of Themes: Major Challenges Experience

Themes	Number of Participants endorsing theme*	Frequency of theme**
Side effects/treatment issues	38 (45.78%)	73 (26.16%)
Concern for the future	e 18 (21.69%)	26 (9.32%)
Relationship/interpersissues	sonal 17 (20.48%)	26 (9.32%)
Difficulty coping	16 (19.28%)	21 (7.53%)
General life event or s not explicitly related t		24 (8.60%)
Positive statements	11 (13.25%)	20 (7.17%)
Appearance/self-estee issues	m 11 (13.25%)	14 (5.02%)
Parenting/caregiver st	ress 10 (12.05%)	11 (3.94%)
Employment issues	9 (10.84%)	18 (6.45%)
Adjustment to life after treatment	er 9 (10.84%)	12 (4.30%)
Other	9 (10.84%)	10 (3.58%)
Adaptive coping effor	ts 8 (9.64%)	13 (4.66%)
Financial Difficulties	6 (7.23%)	7 (2.51%)
Educating the self abo cancer/treatment optio	` ,	3 (1.08%)

Note. \*N = 83 participants. \*\*N = 279 units.

TABLE 6. Frequencies of Themes: Positive Experiences

Themes	Number of Participants endorsing theme*	Frequency of theme**
Relating to others	54 (62.07%)	85 (30.91%)
Personal strength	34 (39.08%)	35 (16.36%)
Greater appreciation of life	28 (32.18%)	40 (14.55%)
New possibilities	19 (22.84%)	25 (9.09%)
Coping	18 (20.69%)	22 (8.00%)
Other	16 (18.39%)	23 (8.36%)
Self-care	13 (14.94%)	13 (4.73%)
Difficulties related to cancer experience	8 (9.20%)	13 (4.73%)
Spiritual growth	5 (5.75%)	5 (1.82%)
No positive change attributed to cancer	2 (2.30%)	4 (1.45%)

Note. \*N = 87 participants. \*\*N = 275 units.

TABLE 7. 12-month QLACS and LIWC Positive/Negative Emotions Zero-order correlations

	M	QS	-	7	m	4	5	9	7
1. LIWC Positive Emotions	6.54	5.24			*				
2. LIWC Negative Emotions	2.40	2.09	25*						
3. QLACS Cognitive Problems	9.89 s	5.39	.28**	.27*					
4. QLACS Pain	7.95	4.34	21	,24 *	.48**				
5. QLACS Negative Feelings	10.20	4.63	29**	.25*	**29.	.38**			
6. QLACS Positive Feelings	21.03	4.81	.22*	*.24*	56**	37**	61**		
7. QLACS Social Avoidance	7.26	4.41	24*	60.	.50**	.45**	.61**	58**	
8. QLACS 70.7 Generic Summary Score	70.71 Score	25.73	.28**	.28**	.78**	**59.	.82**	79**	.71**

Note. N = 87. \*indicates  $p \le .05$ .\*\* indicates  $p \le .01$ .

<u>TABLE 8. Hierarchical Regression Analysis for Variables Predicting Posttraumatic Growth</u>

$R^2$	$\Delta R^2$
.11**	
.11*	.004
_	.11**

Note. N = 86. \*indicates  $p \le .05$ . \*\*indicates  $p \le .01$ . B = regression coefficient;  $\beta =$  standardized beta weight. TNES = Total Negative Experiences Score, TPES = Total Positive Experiences Score, TNESxTPES = interaction term.

TABLE 9. 12-month PTGI and Additional Study Variables Zero-order correlations

	M	QS		2	E.	4	5	9	7
1. PTGI Total	63.14	18.99		***************************************	***************************************			į į	
2. TNES		2.97	1.97	04					
3. TPES	3.00	1.92	.29**	.38* **					
4. BDI	7.59	6.11	16	.28**	90.				
5. MOS Total	4.19	.80	.28**	60	03	47**			
6. SF-36 PCS	51.40	8.73	90.	29**	13	57**	.28**		
7. SF-36 MCS	49.71	10.55	.20	60	.13	*.47**	.38**	03	
8. FACT-B	107.51	18.50	.15	22**	.04	78**	.52**	.47**	***9.
9. Brief COPE Positive Reappraisal	2.48 iisal	.92	.31**	90.	,5 ** **	.03	.02	12	07

Note. N = 87 except PTGI (N = 86). \*indicates  $p \le .05$ .\* indicates  $p \le .01$