#### EXPRESSIVE WRITING IN NEWLY DIAGNOSED BREAST CANCER PATIENTS

#### A DISSERTATION

# SUBMITTED IN PARTIAL FULFILLMENT OF THE REQUIREMENTS FOR THE DEGREE OF DOCTOR OF PHILOSOPHY IN THE GRADUATE SCHOOL OF THE TEXAS WOMAN'S UNIVERSITY

COLLEGE OF NURSING

BY

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To the Dean of the Graduate School:

I am submitting herewith a dissertation written by Melissa Craft entitled "Expressive Writing in Newly-Diagnosed Breast Cancer Patients." I have examined this dissertation for form and content and recommend that it be accepted in partial fulfillment of the requirements for the degree of Doctor of Philosophy with a major in Nursing.

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We have read this dissertation and recommend its acceptance:

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#### ABSTRACT

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## EXPRESSIVE WRITING IN NEWLY DIAGNOSED BREAST CANCER PATIENTS DECEMBER 2006

The purpose of this study was (a) to determine whether the positive benefits of expressive writing reported in other groups (i.e., improved psychological well-being and physical health related outcomes) are seen in newly diagnosed breast cancer patients and (b) to compare three specific writing assignments to determine which may provide the most benefit for reducing physical symptoms and psychological distress associated with breast cancer. Specifically it was proposed that women who do expressive writing about their diagnosis of breast cancer or about critical events in their lives will have less depression and anxiety and improved overall physical health as reflected by improved scores on the following measures: (a) Beck Depression Inventory (BDI-II) (b) State Trait Anxiety Inventory (STAI) and (c) Functional Assessment of Cancer Therapy-Breast cancer version (FACT-B).

This study was a longitudinal randomized controlled trial using a pretest-posttest control group design. Participants were randomized into one of four groups: three writing groups and one control group that did not write. Study instruments were administered at entry (T1), one month post intervention (T2), and six months post intervention (T3). One hundred seventeen newly diagnosed breast cancer women were recruited from multiple sites in central Oklahoma, and 68 of these completed the writing assignments and tests.

MANCOVA, ANOVA, and *t*-tests were used to evaluate differences among the groups. Writing about breast cancer as the traumatic event was statistically significant for improvement in functional quality of life as measured by the FACT-B and depression as measured by the BDI-II. Simply writing about exercise, diet, sleep, and medications related to the breast cancer experience (attentional control group) was also beneficial. The group that wrote about a self-selected worst traumatic event was only significant on

difference scores for anxiety. All three writing groups reported a decreased use of antidepressants that was significantly different than that of the control group.

Expressive writing was found to be a useful mechanism to deal with breast cancer and had an effect on physical functioning, depression and anxiety. Although barriers exist to its use, women find it helpful and can identify factors that would assist in its implementation.

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#### CHAPTER I

#### INTRODUCTION

The estimated number of new cases of invasive breast cancer diagnosed in the United States in 2006 is 212,920 and the estimated number of deaths caused by this disease is 41,430. In addition to invasive breast cancer, 58,400 cases of ductal carcinoma in situ are projected (Jemal et al., 2005). This means that approximately 271,320 women will deal with the diagnosis of breast cancer in 2006 alone. A diagnosis of breast cancer can lead to physical, cognitive and affective distress (McKenna, Zevon, & Corn, 1999; Zabalegui, 1999). Unrelieved distress may lead to impaired functional status that is unique and different from impaired status related to surgery and other breast cancer treatments (Cimprich, 1999). Several studies have been conducted about how people deal with cancer and, specifically, how women deal with breast cancer. While studies have examined various interventions (e.g., support groups, meditation and affirmation, religion, interventions to promote self-efficacy, positive thinking and structured group psychiatric interventions) to help women deal with their diagnosis, only moderate or limited effectiveness has been shown (Hosaka, Tokuda, Sugiyama, Hirai, & Okuyama, 2000; Lev & Owen, 2000; Stanton et al, 2002; Targ & Levine, 2002; Wilkinson & Kitzinger, 2000).

Emotional expression as a form of dealing with life-altering events has been explored in both the etiology of breast cancer and as an intervention to deal with the diagnosis of breast cancer (Servaes, Vingerhoets, Vreugdenhil, Keuning & Broekhuijsen, 1999; Spiegel, Fraemer, Bloom, & Gottheil, 1989). Recent research has focused on the relationship of expressive writing to coping with breast cancer and its use (Stanton et al., 2002; Walker, Nail, & Croyle, 1999). Although only one of these two studies demonstrated a positive effect from expressive writing, it is a popular suggestion given to patients. Several chemotherapy drug companies have even prepared elaborate journals to be given to all newly diagnosed breast cancer patients. While there is much well-meaning speculation about expressive writing as a strategy

to facilitate a woman's adjustment to breast cancer, little empirical evidence is available about this mechanism.

#### Problem and Purpose of Study

Newly-diagnosed breast cancer patients are faced with a life-altering experience. Dealing with their diagnosis may be difficult, and ineffective coping could exacerbate symptoms of the disease and/or cause emotional distress. Writing about significant events has been shown to be helpful in college students and patients with chronic or life-threatening illnesses in providing the following benefits: improved immune function, decreased doctor visits, reduction in physical symptoms and improved coping (Pennebaker & Beall, 1986; Smyth, Stone, Hurewitz, & Kaell, 1999; Stanton et al., 2000). If expressive writing is found to be useful in breast cancer patients, it could provide an efficient, low-cost and minimally burdensome coping strategy for this group. The purpose of this study was two-fold: (a) to determine whether the positive benefits of expressive writing that has been reported in other groups (i.e., improved psychological well-being and physical health-related outcomes) are seen in newly-diagnosed breast cancer patients and (b) to explore three specific writing assignments to determine which may provide the most benefit for reducing physical symptoms and psychological distress associated with breast cancer. Specifically, it is proposed that women who do expressive writing about their diagnosis of breast cancer or about critical events in their lives will have less depression and anxiety and improved overall physical health as reflected by improved scores on the following measures: Beck Depression Inventory (BDI-II); State-Trait Anxiety Inventory (STAI) and Functional Assessment of Cancer Therapy-Breast Cancer Version (FACT-B). Number and type of doctor visits will also be recorded with specific emphasis on cancer-related problems and self-reported physical symptoms.

#### Rationale for the Study

#### Background and Significance

Pennebaker's (1986) first study on college students and journaling indicated that writing about trauma produced short-term increased distress followed by long-term health benefits such as improvement in cardiovascular and immune functioning and increased insight about the traumatic experience. Since that

time, other studies have suggested that writing about both thoughts and feelings helps to translate the traumatic images and emotions into a more organized, coherent and simplified linguistic form (Greenberg & Stone, 1992; Murray & Segal, 1994; Paez, Velasco, & Gonzalez 1999; Pennebaker, Colder, & Sharp, 1990; Ullrich & Lutgendorf, 2002). In 1999, Smyth, Stone, Hurewitz, and Kaell reported a randomized controlled trial with patients suffering from asthma or rheumatoid arthritis. The patients were randomized to a control or experimental arm and asked to write about neutral topics or their worst trauma. At the study's conclusion, Smyth et al. found that the experimental group (i.e., writing about worst trauma) had significant reductions in pain and improved pulmonary function tests.

Few studies have been reported regarding the use of journaling with cancer. Rosenberg et al. (2002) reported a pilot study with 30 men who had been diagnosed with prostate cancer within the last four years. The study explored the feasibility and efficacy of a brief, well-defined intervention which they described as expressive disclosure. The participants were instructed to write about their experience with prostate cancer and its treatment. In addition to this they were given permission to write about other traumatic and upsetting experiences. The research demonstrated "limited support for the hypothesis that a written emotional disclosure task can positively impact health and quality of life outcomes in a cancer population" (Rosenberg et al., p. 48). Walker, Nail, and Croyle (1999) conducted the first study on breast cancer survivors and expressive writing. They assigned participants to a writing group on deepest thoughts and feelings regarding breast cancer or a control group that did not write. To be eligible women had to be just immediately past radiation therapy. They did not find a statistically significant difference between the groups on physical or psychological response to breast cancer. More recently, Stanton et al. (2002) reported a study in which 60 newly diagnosed breast cancer patients who were within 20 weeks since completion of medical treatments (surgery, radiation therapy, or chemotherapy) were randomly assigned to three different writing groups, including a group that wrote about the positive aspects of having breast cancer. They found that the group that wrote about their deepest thoughts and feelings related to breast cancer had reduced medical visits and improved results on psychological measures.

Neither the research on prostate cancer or on breast cancer examined the potential differences of writing about other traumatic events instead of the participant's cancer. Although Rosenberg et al. (2002) allowed participants to write about different, more distant traumatic events, it was not evaluated or controlled for in the analysis. Research has indicated that past trauma that has not been dealt with or that has been inhibited might make it more difficult for a person to deal with a new traumatic event (Greenberg & Stone, 1992). If that is true, writing about the individual's cancer may provide some benefit, but individuals may actually derive the same or more benefit from writing about a personally selected past traumatic event. This has not been evaluated in any published studies on cancer patients.

In summary, the research on expressive writing indicates that it may be beneficial in helping people sort through traumatic events in their lives, either that are recent or that occurred many years in the past. In general, it seems that the greatest benefit occurs when the trauma is relatively recent (Pennebaker, 2002), relatively intense (Lepore & Smyth, 2002) and is written about from a cognitive and affective perspective (Ullrich & Lutgendorf, 2000). Whereas support groups and other structured psychiatric interventions require planning and other participants, expressive writing is inexpensive, self-motivated and completely private. The research on expressive writing in breast cancer patients has not demonstrated a clear benefit and questions still remain regarding the effect size and the best design (e.g., deepest thoughts and feelings about breast cancer vs. positive thoughts vs. self-selected traumatic event).

#### Benefit of Study

Knowledge from this study will give nurses information needed so that they can critically evaluate the helpfulness of expressive writing and effectively facilitate their patients' ability to cope with their diagnosis of breast cancer. Additionally, knowledge from this study can be used to teach future nurses, as well as practicing nurses, about an intervention that may help not only their breast cancer patients but patients with other life-altering situations as well. Participants would also benefit from being part of such a study. Newly-diagnosed breast cancer patients do indeed suffer a life-altering experience. Most women have adequate resources to help them deal with this event; however, all women have times of uncertainty.

sadness, anxiety, fatigue and distress related to the changes breast cancer brings to their lives. In addition to these feelings, breast cancer survivors may feel lonely and isolated simply because their experience is unique and no one is going through it precisely as they are. Knowing that nurses are trying to find the best interventions to help them deal with their experience may help them feel less isolated. Many women also feel better when they are able to do something for others (Boswell, 2001). By participating in this study, breast cancer patients may feel as though they are contributing to the validation of helpful interventions and thereby gain a sense of belonging and 'sisterhood'. This belongingness may make them feel less isolated and may, in fact, facilitate their coping with being a breast cancer survivor (Spiegel et al., 1989).

In order to facilitate evidence-based practice and provide empiric evidence for meaningful recommendations regarding expressive writing as a therapeutic intervention for newly-diagnosed breast cancer patients, it is important to establish whether the positive effects of the technique evident in other groups are seen in this group as well. Issues, concerns, and benefits specific to the use of writing by breast cancer patients need to be explored.

#### Theoretical Framework

When a person who has a life-altering experience uses expressive writing, two concepts – reflection/reframing (Mezirow, 1978; Pennebaker, Mayne, & Francis, 1997) and caring consciousness (Watson, 2002) – are integrated, leading to transformative actions that can increase the quality of life and decrease the emotional and physical distress associated with a diagnosis of breast cancer.

The theoretical model guiding the development of this intervention is based on reflection/reframing which changes the way people view their experiences. The cognitive change that occurs with reframing allows people to bring difficult thoughts and feelings to the surface, and find meaning in an overwhelming situation. This meaning making is considered essential for positive resolution of critical situations (Frankl, 1959).

Cognitive change and inhibition are two theories proposed by Pennebaker and others regarding the beneficial effect of expressive writing (Pennebaker, Mayne, & Francis, 1997). Cognitive change is the

underlying principle related to cognitive therapy to treat clinical depression (DeRubeis & Feeley, 1990). The assumptions regarding cognitive change and cognitive therapy are that negative or maladaptive thinking promotes negative mood and changing the way one thinks about the world and about one's self can change one's mood (Oei & Free, 1995; Richardson & Richardson, 1999). Oei and Free (1995) published a comprehensive review of cognitive behavior therapy research studies that demonstrated a consistently positive relationship between a change in negative thinking and depression.

Pennebaker and Graybeal (2001) suggest that developing self-understanding is the 'hallmark' of most therapeutic approaches and the way people alter their self-perceptions or cognitions is through language. Cognitive change in expressive writing is related to helping people understand themselves better and see things in a new and different way by creating a coherent story of a traumatic event (Pennebaker, 1999). Donnelly and Murray (1991) reported on two studies where participants either wrote or talked about past traumatic events for four consecutive days. At the conclusion of the study, participants reported that the exercise forced them to think about the events differently and they had a better understanding of the problem and an awareness of alternative explanations for the event. Using language analysis of expressive writing, Pennebaker and others found improved results with increased use of cognitive words which he defined as "causal" and "insight words" (Pennebaker et al., 1997; Pennebaker & Graybeal, 2001; Petrie, Booth, & Pennebaker, 1998). Pennebaker hypothesizes that the more of these words people use, the greater the cognitive change expressive writing will cause. Pennebaker's analysis of the words people use when talking about critical events has also led him to propose that the simple transition from the use of 1<sup>st</sup> person singular in writing to 1st person plural indicates a change in feelings of isolationism that impacts mood and relationships with others (Pennebaker, 2002). Pennebaker states that the natural process of constructing a coherent story about a traumatic event facilitates organization of thoughts; provides a sense of structure and meaning and produces a more manageable emotional response to the experience. This self narrative helps people account for critical events in their lives and is considered an important step in helping people make sense of their lives (Gergen & Gergen, 1988). Pennebaker also asserts that "constructing stories facilitates a

sense of resolution, which results in less rumination and eventually allows disturbing experiences to subside gradually from conscious thought" (Pennebaker, 1999, p. 1243).

Clinicians have long asserted that inhibiting emotion is harmful to mental health (Rachman, 1980; Scheff, 1979) and that emotions related to past traumatic events that have not been expressed may interfere with a person's ability to deal with new critical incidents (Lepore, Wortman, Silver, & Wayment, 1996). Pennebaker and Susman (1988) noted that research participants who had not talked about their traumatic experience with others were more likely to have health problems compared to participants who had suffered similar traumas but had shared them with others. Researchers suggest that the energy of inhibiting negative thoughts is released when those thoughts are brought to the surface and formulated in "easier to store" packages (Kagan, Reznick, & Snidman, 1988). This inhibition energy is felt to produce a low level stressor which is measurable by examining skin conductance and cardiovascular indices and can cause or exacerbate psychosomatic processes (Gross & Levenson, 1993; Pennebaker, 1999). Esterling, Antoni, Fletcher, Margulies, and Schneiderman (1994) conducted a series of experiments on the association between emotional disclosure and repressive personality styles by looking at antibody titers to Epstein-Barr virus (EBV). Their research indicated that those persons who inhibited their feelings had impaired control of latent EBV. This research suggests that the inhibition of past trauma might interfere with current coping and that it might also be related to poorer immune system function. Esterling et al. reported that all groups (repressors and non-repressors) received benefit from expressive writing, supporting the use of expressive writing regardless of personality type. These researchers stress that expressive writing might prove particularly effective for repressors as the opportunity to ventilate negative feelings may improve immune system functioning. Petrie et al. (1998) demonstrated similar findings when they examined immune response to a Hepatitis B vaccination program in students who suppressed emotions. The researchers found that those participants who used an increasing rate of cognitive words and higher rates of positive emotions over the writing experiment had higher lymphocyte counts. In a recent study by Iwamitsu et al. (2003), women who expressed their negative emotions after being given the diagnosis of breast cancer had less

emotional distress as measured on the Profile of Mood States (POMS) than those who repressed their emotions.

The release and subsequent reformulation of thoughts and feelings in "easier to store" packages that occurs when persons are able to write about a traumatic event appears to provide benefit to people who might otherwise have inhibited these emotions Kagan et al. (1988). Petrie et al. (1998) propose that the immunological benefits from this release of inhibited emotions is a long-term process that impacts both short-term and long-term health as demonstrated by continued physical health differences between expressive writing groups months after the initial intervention.

Perspective transformation, a concept proposed by Mezirow (1978), is complementary to the theory of cognitive change and emotional inhibition. It encompasses the cognitive and affective changes that occur when a person experiences a life-altering experience, reflects on this experience, and finds new meanings in the event. This meaning reconstruction leads to changes in thinking and feeling. In Mezirow's (1996) work with adults learning English as a second language, he found that the students often not only learned English, but underwent a transformation in their view of the new culture. His careful analysis of this phenomenon led him to develop the transformation theory. According to this theory, when a person experiences a life-altering experience he/she may undergo a process of reflection which involves an examination of "the psychological or sociological assumptions that consciously or unconsciously are used to address life issues" (Mezirow, 1998, p.210). This reflective process helps the person reframe the situation and change attitudes and behaviors. The new way of thinking and acting that arises from the changed perspective leads to a foundational change in many cases (Mezirow, 1998). Consequences that result from this transformation include feelings of emancipation, empowerment, hope and an increase in self-esteem and a sense of mastery (Mezirow, 1978).

Mezirow's (1998) most recent publication about this theory emphasizes the use of critical self-reflection on the attitude and outlook one has on life. He proposes that a person can gain insight from a narrative related to a difficult or life-altering situation and impact thought and attitude toward the event. This theory is similar to Ullrich and Lutgendorf's (2002) discussion of cognitive processing. Building on

the concept of cognitive change discussed by Pennebaker, the researchers predicted that encouraging participants to focus on both their thoughts and feelings when writing about a traumatic experience would help them gain a greater understanding of the event and help them make sense of it. They proposed that this cognitive processing would, in turn, lead to a greater acceptance of the event. Ullrich and Lutgendorf (2002, p. 248) found that the groups that wrote about their traumatic experience with both thoughts and feelings had decreased physician visits and experienced "meaningful shifts in values, priorities, or perspectives in response to the event". Cognitive processing appears to be the mechanism through which perspective transformation occurs in the context of reflection through expressive writing. Simply stated, the cognitive change proposed by Pennebaker is associated with changes in thinking and feeling when participants create coherent stories of traumatic events. This narrative making facilitates the person's ability to incorporate events into their lives and gain a sense of mastery and control over the situation.

Cognitive processing and transformation theory seem intuitively logical when viewed with Frankl's theory of logotherapy which proposes that people can handle almost any suffering if they are able to find meaning in the suffering and a purpose for their lives (Frankl, 1959). Viktor Frankl wrote his landmark book, *Man's Search for Meaning*, shortly after being released from the last of three concentration camps to which he had been confined during World War II. He lost his entire family, including his wife, during the war. His book focuses on his observations of fellow inmates who died after they lost a feeling of meaning in their lives. He became convinced that, as he quotes Nietzsche "he who has a why to live for can bear almost any how". Frankl wrote that life can be meaningful in three ways: through what we give to life; by what we take from the world; and through the stand we take toward a fate we can no longer change. It is this last meaning that Frankl (1959, p.106) believes is existential and "not a matter of intellectual cognition". Although not a matter of intellectual cognition, Frankl did believe that "to live is to suffer, to survive is to find meaning in the suffering". Frankl proposed that meaning is not made, but detected; therefore, in order to discover the meaning in distressful situations, some degree of reflection has to occur. Researchers and breast cancer survivors have written about the importance of finding meaning in the intrusion of breast cancer into their lives (Fife, 1995; Fischer, 2001; Jones, 2001; Vickberg et al., 2000;

Webber, 1999). Fife's research with breast cancer survivors indicated that the ability to find meaning in the situation was predictive of personal control, body image and psychological adjustment. Vickberg et al. (2000, p. 157) also found that global meaning (the general sense that life is meaningful) was an "important moderating factor in the relation between intrusive thoughts and psychological distress". Their research indicated that breast cancer survivors who had higher scores on the Global Symptom Index of the Brief Symptom Inventory had less depression and anxiety as measured by the revised Symptom Checklist. They explained their findings by saying that having a sense of global meaning served as a buffer for distressful intrusive thoughts. They did not believe that women with a higher global meaning resisted having intrusive thoughts, but proposed that the impact of the thoughts was lessened by having a stronger sense of meaning about the event.

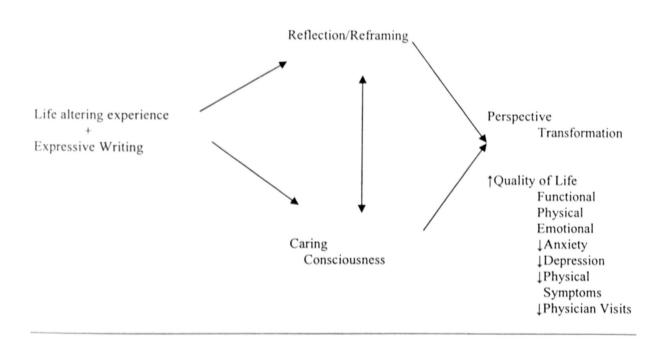
Lastly, the self-help nature of expressive writing is reciprocal in nature to Watson's Intentional Transpersonal Caring-Healing theory (Watson, 2002). Caring for oneself is the core of Watson's theory. Watson (2002) proposes that when persons intentionally direct their own positive thoughts and caring spirit toward being authentic and attentive in listening to themselves and becoming sensitive and mindful of what is most important about their lives, they can understand and transform their own suffering. Watson believes that the way persons cultivate the ability to engage in their own healing work is through a process of reflection and developing a caring relationship with themselves (Watson, personal communication, 2003). Expressive writing is an excellent example of an intervention to achieve the kind of self-healing that Watson talks about. Many persons do a tremendous job being caregivers for others, but do not spend much time listening or caring for themselves. Writing about traumatic events is a way for women to intentionally focus on themselves and thereby become part of their own meaning-making and their own healing.

By doing expressive writing the woman who has been diagnosed with breast cancer is able to reflect on her life-altering experience, reconstruct meaning and transform actions to assist with physical and psychological responses to breast cancer. This conceptualization of the effect of expressive writing is

consistent with holistic nursing and provides a more complete framework for studying the meaning of expressive writing (see Figure 1).

Figure 1.

Expressive writing conceptual framework.



#### Assumptions

Assumptions related to this topic are closely tied to three personal beliefs: (a) meaning plays a vital role in a person's life; (b) there is a strong relationship between thinking and feeling and (c) the mind and body are interrelated. The assumptions for this study are:

- 1. Breast cancer is a life-altering experience.
- 2. The diagnosis of breast cancer is a traumatic event that causes emotional suffering.
- 3. Finding meaning in suffering is an important element in dealing with situations.
- 4. Mind, body, and spirit are closely linked and interrelated.

 The number and types of visits made to the physician are reflective of the perception of physical effects related to the cancer diagnosis.

#### Hypotheses

Two major hypotheses were tested:

- 1. Women with newly-diagnosed breast cancer who use expressive writing (about breast cancer or self-selected worst trauma) will demonstrate significantly improved physical health-related outcomes (i.e., decreased medical appointments for cancer-related morbidity and fewer cancer-related issues) and psychological well-being (i.e., decreased depression and anxiety) than those women who write only about the facts of their breast cancer or who do not write at all.
- Women who write about a self-selected worst trauma will demonstrate outcomes that are not significantly different than those of women who are instructed to write about breast cancer.

Four additional specific aims were addressed:

- 1. Explore whether there is a difference in the observed benefits (i.e., depression, anxiety, and quality of life) of newly diagnosed breast cancer patients who write about breast cancer versus those who write about the facts of their breast cancer (e.g., diet, exercise, sleep, and medication), write about a different more distant trauma, or do not write at all.
- Determine if barriers exist that interfere with the use of expressive writing in this diagnostic group.
- Evaluate the perceived physical effect of expressive writing by comparing the number and type of physician visits made during the study period by participants in the four groups.
- 4. Explore the duration of benefits of writing following the expressive writing activity.

#### Definition of Terms

Expressive writing

Conceptual definition. Also referred to as reflective writing. Writing in such a manner to describe thoughts and feelings related to a specific event or trauma in a person's life (Pennebaker, Barger, & Tiebout, 1989).

Operational definition. Writing for at least 20 minutes for four consecutive days about deepest thoughts and feelings regarding a specific event.

Depression

Conceptual definition. An emotional symptom frequently manifested by increased reports of depressed mood, feelings of guilt and helplessness and hopelessness, psychomotor retardation, loss of appetite, and sleep disturbance (Radloff, 1977).

Operational definition. Scores obtained on the 21-item Beck Depression Inventory-II (BDI-II) (Beck, Ward, Mendelson, Mock, & Erbaugh, 1961). The higher the score, the greater the depressive symptoms.

Anxiety

Conceptual definition. Anxiety state: emotional state that exists at a given moment in time and at a particular intensity. Anxiety states are characterized by subjective feelings of tension, apprehension, nervousness, and worry, and by activation or arousal of the autonomic nervous system. Anxiety trait: "personality traits can be conceptualized as relatively enduring differences among people in specifiable tendencies to perceive the world in a certain way and in dispositions to react or behave in a specified manner with predictable regularity (Speilberger, Gorsuch, Lushene, Vagg, & Jacobs, 1983).

Operational definition. Scores obtained on the 40-item State Trait Anxiety Inventory (STAI) (Speilberger et al., 1983). The higher the score, the higher the anxiety.

Functional quality of life.

Conceptual definition. Functional quality of life is a multidimensional construct which includes factors such as pain, fear of recurrence, and fatigue. Specific quality of life issues related to breast cancer include altered sense of feminity, feelings of decreased attractiveness, and problems associated with treatment-related arm swelling.

Operational definition. Scores obtained on the Functional Assessment of Cancer Therapy-Breast (Brady, et al.,1997). Subscales for this instrument include physical well-being, emotional well-being, social/family well-being, functional well-being and the breast cancer subscale. A summed score of the four

subscales without the breast cancer subscale is reported as FACT-G and the total summed score is the FACT-B. Higher scores on each subscale and on the total scale reflect higher quality of life.

#### Delimitations and Limitations

The factors that limit the generalizability and/or conclusions of this study will be addressed in the following paragraphs. Threats to internal and external validity in this study include selection, history, testing, maturation, instrumentation, regression to the mean and experimenter bias. In addition to these, social threats to internal validity and issues of generalizability may exist. Methods of controlling each of the threats to internal and external validity will be covered.

#### Delimitations

Delimitations of the study were:

- 1. Conducting the study in one geographic area in the Midwest.
- 2. Selecting participants who had completed definitive therapy for breast cancer.

#### Limitations

Selection

Selection is a threat to internal validity when a control group is used and if assignment to the groups results in unequal distribution (Athabasca, 1998). Particular concerns regarding selection in this study are inclusion of patients with both invasive and noninvasive breast cancer; possible baseline differences in depression, anxiety and functional quality of life from breast cancer; and previous exposure to and use of journaling. Selection is a greater concern in multiple group studies because of an interaction between selection and other threats (e.g., maturation and mortality). A variance in attrition rate between groups poses a threat to internal validity. The use of the MANCOVA statistic is helpful in examining the impact that selection and randomization have on initial group differences as a co-variant related to pretest scores.

Threats to external validity represent ways that the selection of participants may interact with the journaling. A potential threat is the self-selection into this study (e.g., patients may have agreed to participate based on an already present difference in coping or a predisposition to journaling that differs

from that of patients who did not agree to participate). Additionally, this researcher found, when conducting a previous pilot study, that there was a definite bias toward not wanting to approach women who were in obvious distress related to their diagnosis or who appeared frail. To counteract this, all women who met entry criteria had an equal opportunity for selection into this study. Women were not eligible for study participation until they had completed their definitive treatment. Although these women may still have had some psychological and physical distress related to breast cancer, it was likely to be less than at the time of initial diagnosis.

History

History is defined by Pedhazur and Schmelkin (1991, p. 225) as "events that took place in the course of a study that might have affected its outcome". History could have been a threat to the internal validity of this study if a news report had come out about expressive writing that only one group was exposed to or if only one group received additional exposure to expressive writing information that was positive or negative. This effect was tempered by having multiple groups and the likelihood of one group receiving information that the others did not is unlikely.

Testing

A threat to internal validity related to testing involves "the effect that prior measurement of the dependent variable may affect the results obtained from subsequent measurements" (Athabasca, 1998). In this study the pretest and posttest are tools designed to measure depression, anxiety and functional quality of life. The questions do not necessarily provide information about these constructs and therefore were not likely to teach participants skills that would influence their responses on the survey. Another testing effect that may have been a factor in this study is the order in which the instruments were given to the participants. All instruments were presented in the same order for each participant at each data point including mailed instruments. In those cases instructions were given to complete the instruments in the order they were placed in the envelope.

#### Maturation

Maturation refers to the impact that time alone has on subjects and the concern that there will be a difference in subjects within the different treatment groups based on this. Maturation effects that posed threats to the internal validity of this study include changes due to differences in cancer treatment side effects (e.g., fatigue, nausea or pain). These were lessened by recruiting only those women who had completed their definitive breast cancer treatments, however this may have still been a factor in attrition as the data will demonstrate.

#### Instrumentation

Instrumentation is a threat based on the reliability of the instrument used to "gauge the dependent variable or manipulate the independent variable" (Athabasca, 1998). This study includes three self-administered instruments that were administered consistently with the same directions and procedure.

Instructions for expressive writing were written and, therefore, standardized across participants and groups.

Each of the tools has known psychometrics with other samples, and internal consistency was obtained with this study sample.

#### Regression to the mean

Portney and Watkins (2000) discuss the phenomenon of regression toward the mean as a movement of extreme scores on a pretest toward the group mean on subsequent retests. To correct for this potential issue, pretest scores were examined for outliers.

#### Experimenter bias

Some researchers refer to experimenter bias as a threat to internal validity. Experimenter bias is defined as the effect the experimenter's expectations have on the outcome of an experiment (Athabasca, 1998). In a limited pilot performed at the University of Oklahoma, this researcher noted that the presentation of the study to potential subjects varied from contact to contact and seemed to be based on the perception by the researcher of the patient's interest in journaling and the patient's current physical and emotional distress. Uniform notification of potential participants and consistent presentation of the study risks and benefits was implemented to reduce this potential threat.

Social threat to internal validity

Social threats to internal validity involve the interaction between researcher and subject and among subjects (Burns, 1997). Diffusion or imitation of treatment is probably the biggest social threat to internal validity in this study. If patients had already been journaling, it may have been difficult for them to be assigned to a control group or to be asked to write about something different and this may have influenced the results. Differences in group assignment could have caused participants to be resentful or to feel a rivalry with the other groups. The study participants had very little contact with each other, however, since their definitive treatment is over, and their contact with the researcher was limited as well. This helped to decrease the impact this threat had on internal validity.

Generalizability

Concerns regarding generalizabilty or threats to external validity have been addressed in the previous paragraphs on limitations and selection. The recruitment process that allowed for self-selection raises the question of generalizing the findings to those who did not agree to participate. In effect, those who agreed to be in the study might have had better coping skills or cope differently than those who chose not to be in the study. The results of this study cannot be generalized to patients dealing with different types of cancer.

#### Summary

This chapter has provided a discussion of the problem of dealing with breast cancer and an intervention proposed to be potentially helpful in facilitating coping with its diagnosis. Rationale for this intervention, along with possible benefits, to participants has been described. A theoretical model has been proposed to illustrate the connection between cognitive processes, affective state and physical and psychological outcomes of expressive writing. Assumptions, definitions and limitations have been identified

In summary, a diagnosis of breast cancer is life-altering and potentially distressful. Although expressive writing as a mechanism of adaptation and coping has been studied to a limited degree in breast cancer patients, several questions remain about the specific writing type that is most beneficial to this

group, the impact on physical and psychological symptoms, and barriers and concerns that may exist. Knowledge from this study will give nurses information needed to facilitate a patient's ability to cope with the diagnosis of breast cancer. The purpose of this research is: (a) to determine whether the positive benefits of expressive writing reported in other groups (i.e., improved psychological well-being and physical health related outcomes) are seen in newly diagnosed breast cancer patients and (b) to compare three specific writing assignments and a control group of "no writing" to determine which may provide the most benefit for reducing the occurrence of perceived physical symptoms and the psychological distress associated with breast cancer. The study is a randomized clinical trial using a pretest-posttest control group design. The effect of writing on physical and psychological distress will be determined by assessing the outcome variables of depression, anxiety, quality of life and number and type of physician visits. Findings from this study will provide information for evidenced-based practice about an intervention women might use to improve selected outcomes following a diagnosis of breast cancer.

#### CHAPTER II

#### REVIEW OF THE LITERATURE

The following review of the literature will give an overview of the research in expressive writing in both healthy college students and in specific patient populations. Studies involving cancer patients, and breast cancer in particular, will be discussed as well as issues related to coping with breast cancer.

#### The Diagnosis of Breast Cancer

The diagnosis of breast cancer is an undeniably stressful and life-changing event. The National Cancer Institute (1997) reports that breast cancer causes more distress than any other cancer diagnosis. Koopman et al. (2001) stated that the "average woman considers her diagnosis of breast cancer to be among the four most stressful life events she has ever experienced" (p. 28). Generalized distress in breast cancer patients has been reported to occur in 30-47% of patients (Zabalegui, 1999).

Multiple studies have documented the presence of high levels of depression and anxiety in breast cancer patients (McKenna, Zevon, & Corn, 1999; Monti, Mago, & Kunkel, 2005; Saleeba, Weitzner, & Meyers, 1996; Schneider, Prince-Paul, Allen, Silverman, & Talaba, 2004; Wong-Kim, & Bloom, 2005; Zhao, et al. 2001). The rate of depression in women with breast cancer has been reported to range from 1.5% to 50% with a mean of 24% across studies (Gallager, Parle, & Cairns, 2002; McDanial, Musselman, & Nemeroff, 1997). The occurrence of depressive symptoms is associated with poorer quality of life and potentially poorer treatment compliance (Dematteo, Lepper, & Croghan, 2000; Pascreta, 1997). "Depression ranks among the most frequent psychological side effects for women with breast cancer and poses a significant threat to functioning, health/well-being, and long-term survival" (Badger, Braden, & Mishel, 2001, p.568).

Rates of anxiety have also been reported as high in breast cancer patients with rates paralleling those of depression and ranging from 22% to 33% (Badger et al., 2001; Lehto & Cimprich, 1999).

Neuhaus, Zoh, Gohring, and Scharl (1994) found that women with breast cancer had rates of anxiety similar to psychiatric out-patients and higher than a control group without breast cancer. Depression and anxiety commonly occur together, and it has been reported that 17% of breast cancer patients have combined anxiety and depression using DSM-III criteria (Harrison & Maquire, 1995).

The elevation in depression and anxiety reported in breast cancer patients is not limited to a short term period immediately following diagnosis (Meyerowitz, 1983; Northouse, 1989; Spiegel, 1997).

Andrews, Hall, Teeson, and Henderson (1999) found the rate of psychological morbidity higher in breast cancer patients six months following diagnosis than in the general population. In a study by Hughes (1982), 20-30% of women treated for breast cancer had persistent distress for two years or more following surgery and Seleeba, Weitzner, and Meyers (1996) found mild emotional distress that persisted for five years or longer in breast cancer survivors. Newer studies have examined the incidence of post traumatic stress disorder (PTSD) in breast cancer survivors and indicate that it may be prevalent in women well after their treatment is complete (Levine, Eckhardt, & Targ, 2005). Fatigue and emotional distress were the most persistent symptoms experienced by women with breast cancer from diagnosis until one year later (Hoskins, 1997). Fallowfield, Hall, Maquire, Baum and A'Hern (1994) reported an "appreciable" minority of women demonstrated clinically significant anxiety and depression three years post diagnosis. Breast cancer not only impacts quality of life. Some researchers have reported an association between higher levels of mental distress and health care seeking behaviors, thus potentially increasing the cost of health care (Simpson, Carlson, & Trew, 2001).

Other studies have examined the impact of anxiety and depression on the long-term response to breast cancer including survival. Watson, Haviland, Greer, Davidson, and Bliss (1999) found a significantly increased risk of death in women who had high anxiety and depression. Recently Goodwin,

Zhang, and Ostir (2004) reported that a diagnosis of depression in breast cancer patients aged 67-90 was associated with worse survival unrelated to the type of treatment they received.

Emotional distress, particularly anxiety and depression, occurs commonly in women with breast cancer and impacts multiple aspects of their life. This distress may persist for an extended period of time. Interventions to facilitate adaptation to breast cancer and decrease emotional distress may have beneficial effects on treatment compliance, quality of life, symptom distress, and even survival.

#### Coping with Breast Cancer

In a seminal paper published in 1989, Spiegel, Kraemer, Bloom, and Gottheil reported the results of their research examining the impact of a weekly support group on survival in breast cancer patients. Eighty-six women were randomly assigned to a control arm or a weekly support group. At the study's conclusion, Spiegel et al. reported a significant difference in survival in the group that had received the support group intervention. Since Spiegel's work, additional researchers have further investigated the affect of support groups and other mechanisms such as meditation, affirmation, imagery and ritual on breast cancer patients with mixed results (Hosaka et al., 2000; Lev & Owen, 2000; Stanton et al., 2000; Targ & Levine, 2002). Meyer and Mark (1995) examined the overall treatment effect of psychosocial interventions for cancer patients. They found effect sizes ranging from .17 for medical measures to .26 for disease-related physical symptoms. They did not find a significant difference between any specific types of treatment (e.g., cognitive-behavioral, social support); however, they noted that emotional expression was common to several of the categories. In many of these studies a relationship between the type of coping women used and their adaptation to breast cancer was identified (Carver et al., 1993; Hilton, 1989; Wonghonghul et al., 2000).

Escape-avoidance coping has been found to be associated with increased distress, and positive reappraisal strategies have been shown to facilitate coping (Stanton & Snider, 1993). Spiegel (1995) postulated that the beneficial effect of psychotherapy for breast cancer is related to the opportunity for emotional expression whether in a group setting or on an individual basis. Denial in breast cancer

survivors has been associated with more distress (Carver et al., 1993), and providing women with the opportunity to develop active coping strategies such as emotional expression has been linked to improved coping (Rosberger, Edgar, Collet, & Fournier, 2002).

#### **Emotional Expression**

Spiegel (1995) and others have demonstrated the need for and the potential benefit of structured interventions to relieve physical, cognitive and affective distress following a diagnosis of breast cancer, particularly those interventions that facilitate the opportunity for emotional expression. Intrusive thoughts that lead to ruminative thinking is associated with increased distress (Baider & Denour, 1997; Carver et al., 1993). Labeling and expressing these thoughts and emotions has been found to reduce their intensity and facilitate coping (Keltner, Locke, & Andrain, 1993). Researchers who have offered women the opportunity to experience emotional expression via support group settings and/or individually have seen improvement in quality of life, depression, emotional adjustment, health care utilization and even increased survival from breast cancer (Fawzy et al., 1990; Kinney, Rodgers, Nash, & Bray, 2003; Meyer & Mark, 1999; Mumford, Schlesinger, & Glass, 1993; Reynolds et al., 2000; Simpson, Carlson, & Trew, 2001). Emotional expression via expressive writing has been a part of mankind since the inception of written language; however, research examining this intervention in healthy and medical populations is relatively new.

#### Expressive Writing in Students

Dr. James Pennebaker has written extensively about the beneficial effect of expressive writing and is the catalyst behind the modern paradigm used in most research on expressive writing. Begun in the early 1980's, Pennebaker's research involves having college students write about the most traumatic experience of their life. They are asked to write for 15-20 minutes on 3-5 consecutive days. Results have demonstrated that expressive writing can result in improved grades, fewer visits to the infirmary and better over all adjustment to college (Pennebaker, 1993). Multiple studies have since been performed with the writing paradigm developed by Pennebaker. Findings from these studies in college students have consistently demonstrated decreases in depression and anxiety; shifts from negative to positive feelings and

improvements in cognition, behavior and self-esteem; and improvements in physical health (Cameron & Nicholls, 1998; Donnelly & Murray, 1991; L'Abate, Boyce, Fraizer, & Russ, 1992; Pennebaker, Colder & Sharp, 1990). Paez et al. (1999) examined the relationship of expressive writing with avoidance and rumination. Their research indicted that brief writing (five minutes for one session only) was associated with increased negative affect. Longer, more intense periods of writing (20-30 minutes over 3-4 days) were associated with decreased emotional activation. They theorized that the intensive writing decreased rumination about the event and allowed participants to assimilate the event and "get past it". In all cases, the studies involved a control group that wrote about neutral events such as their plans for the evening and an experimental group that was asked to write about a traumatic event. All of the researchers concluded that writing about traumatic events is initially distressing but, in the majority of cases, leads to positive mental and physical health benefits. Following the first successful expressive writing study, Pennebaker and colleagues sought to understand the pathophysiological process behind the positive effect seen with expressive writing. Their second study focused on the impact of expressive writing on the immune system (Pennebaker et al., 1988). This study and others have provided evidence that expressive writing is "associated with some aspects of the host-virus interaction" (Esterling, Antoni, Fletcher, Margolies, & Schneiderman, 1994; Petrie, Booth & Pennebaker, 1995, p. 788). Other researchers have explored the amount of time spent writing, talking versus writing and perceived intensity of the traumatic event (Esterling et al., 1994; Greenberg & Stone, 1992; Murray & Segal, 1994; Paez et al., 1999). They have found that writing is just as effective as talking and is even better in improving immune function. Increased perceived intensity of the traumatic event is associated with increased benefit from writing. Ullrich and Lutgendorf (2002) randomly assigned students to four groups: (a) the traditional control group, (b) an experimental group that only wrote about feelings related to the traumatic event, (c) an experimental group that only wrote about what they thought about the event (e.g., a chronicle of the event and details), and (d) an experimental group that wrote about both thoughts and feelings regarding the traumatic event. The researchers found that only the group that wrote about both thoughts and feelings had increased positive growth. They proposed that writing about both thoughts and feelings helped to translate the traumatic

images and emotions into a more organized, coherent and simplified linguistic form. This organization is what Pennebaker and others claim is the key to the beneficial effect of journaling (Pennebaker, 1999; Wright & Chung, 2001).

Expanding on this, several researchers have looked at the effect of journaling in other healthy populations. Francis and Pennebaker (1991) studied the effect of journaling on healthy university employees. They concluded that writing about upsetting experiences can offer physical and mental benefits. In a similar study, Spera, Bohrfeind and Pennebaker (1994) examined the impact of expressive writing in 63 recently unemployed professionals. Those employees who were randomized to the study group and wrote about their deepest thoughts and feelings regarding their job loss were employed quicker and appeared to have better attitudes about their old job and finding new employment than the control group. A natural extension of the research on expressive writing in healthy populations is to explore its effects and potential benefits in medical populations.

#### Expressive Writing with Medical Populations

Smyth, Stone, Hurewitz and Kaell (1999) reported a randomized controlled trial with patients suffering from asthma or rheumatoid arthritis. The patients were randomized to a control or experimental arm. The control group was asked to write about neutral topics and the experimental group about their worst trauma. They were instructed to write for 20 minutes on three consecutive days. At the study's conclusion Smyth et al. found that the experimental group had significant reductions in pain and improved pulmonary function tests. In a related meta-analysis on written expression literature, Smyth (1998) examined 13 articles that included 800 participants. They concluded that short-term distress was increased by writing, but that the written emotional expression produced positive health benefits with an average of 23% (d = .46) difference in groups. This is well above the effect size of d = .17 to .26 found by Meyer and Mark (1999) for generalized psychosocial interventions. Smyth found that effect sizes were higher in those groups who were instructed to write about current traumas as well as past traumatic experiences. Expressive writing has also been explored as a mechanism to facilitate adjustment in parents to having an autistic child, as an intervention in psychiatric prison inmates, and as a tool for personal development and

healing (Campbell, 2003; Hunt & Sampson, 1998; Richards, Beal, Seagal, & Pennebaker, 2000). Because of the potential impact of expressive writing on the immune system and the traumatic nature of a cancer diagnosis, many recent studies of expressive writing and medical populations have focused on individuals dealing with a cancer diagnosis.

#### Expressive Writing in Cancer

Although most studies on medical populations and expressive writing have dealt with cancer, the number of studies is limited. Rosenberg and Rosenberg (2002) reported a pilot study which explored the feasibility and efficacy of a brief, well-defined intervention which they described as expressive disclosure. They studied the effect of writing for 20 minutes a day for four days about a traumatic event on behavioral, medical, immunological, and emotional outcomes in 30 men who were diagnosed with prostate cancer. The instructions were similar to those given by Pennebaker to the college students regarding their deepest thoughts and feelings regarding a trauma. The patients had been diagnosed with prostate cancer as long as 4 years prior to their participation in the study. The Rosenburgs' research demonstrated "limited support for the hypothesis that a written emotional disclosure task can positively impact health and quality of life outcomes in a cancer population" (Rosenburg, p. 48). Their data suggested benefits for physical symptoms and appeared promising in health care utilization. Health care utilization in the Rosenburgs' study was assessed with a questionnaire that examined multiple forms of health care utilization and personal behaviors including physician visits, current use of medication, and health-related behaviors such as smoking. In a similar study with patients diagnosed with metastatic renal cell carcinoma, de Moor et al. (2002) found no difference in emotional distress in an expressive writing group as compared to a control group; however, there was a statistically significant improvement in sleep disturbance in the experimental arm.

#### Expressive Writing in Breast Cancer

Although a few investigators have discussed the specific use of expressive writing, such as writing to the affected breast after mastectomy, and as an individual tool for women diagnosed with breast cancer (Day, 2001; Rancour & Brauer, 2003), only a handful of studies have been conducted with groups of breast

cancer patients. Studies have suggested that writing enhances self-reliance, self-mastery and insight and that it provides patients with a tool they can use in dealing with future life stressors. Day describes the insight one gains from expressive writing as a "soul-making" experience and believes that writing is a way to make contact with a deeper wisdom not usually accessed by logical, linear methods.

Walker, Nail, and Croyle (1999) published the first study on expressive writing with breast cancer patients. These researchers explored the effects of expressive writing on 44 breast cancer patients who had just completed radiation therapy. These women with Stage I or II breast cancer were randomized to a single dose (one 30-minute session of writing) versus a 3-dose (three 30-minute sessions of writing) and an attentional control group that did not write but who talked with the researcher on the final day of radiation therapy about events unrelated to cancer. The participants received follow-up phone calls at 1, 4-6, 16 and 28 weeks after radiation therapy. The researchers examined the effects on mood, intrusiveness of thoughts, trait negative affectivity, and side effects. Their findings did not show statistically significant differences between the three groups of approximately 12 subjects each. The researchers concluded that the intervention may simply not have been effective for these women or that the sample size was too small to detect a difference between groups. Physical health outcomes, which have been shown in previous studies to be more likely than psychological measures to show significant differences between groups, were not examined.

Stanton et al. (2002) have contributed most recently to the literature about breast cancer and expressive writing. They reported a study in which 60 Stage I or II breast cancer patients were randomly assigned to three different groups: a group that wrote about their deepest thoughts and feelings related to breast cancer, a group that wrote about their positive thoughts and feelings about their breast cancer experience and a group that wrote about the facts of their breast cancer experience. The researchers were interested in the effects of journaling on physical and psychological distress and wanted to test whether the outcomes varied as a function of the patient's cancer-related avoidance. They also wanted to explore the effect of benefit-finding on expressive writing outcomes. They found that the group that wrote about their deepest thoughts and feelings related to breast cancer had reduced medical visits and positive results on

psychological outcomes that were significantly better than those of the control group. The group that wrote about the benefit of breast cancer had improvements over the control group, but not as good as the group that wrote about their deepest thoughts and feelings about breast cancer. The benefit-finding group did not have as much immediate distress following writing; however, as in other expressive writing studies, this short-term distress yielded long-term improvement in psychological and physical distress in the expressive writing group. The researchers concluded that expressing the full thoughts and emotions surrounding a traumatic event may create more short-term distress but that it appears to provide the maximal benefit in the long-term. In a further analysis of this study using a computer linguistic program (the Linguistic Inquiry and Word Count developed by Pennebaker) Low, Stanton, and Danoff-Burg (2006) determined that postwriting mood, use of positive emotion, and cognitive mechanism words were not significant mediators of the changes seen between groups. Greater use of negative emotion, however, was related to the benefit seen from expressive writing. Two other studies have recently supported this finding and suggest that the expression of anger led to improvements in post-journaling depression and anxiety scores, whereas the expression of sadness and vulnerability did not (Lieberman & Goldstein, 2006; Smith, et al., 2005). Although these studies support the use of negative expression, they have limitations. Lieberman and Goldstein's study involved an uncontrolled on-line chat experience, and the study by Smith et al. involved only one group over a 12-week support group session.

# Summary

This chapter has reported the literature related to the impact of breast cancer on the individual and the psychosocial interventions for promoting adaptation and coping with a breast cancer diagnosis.

Emphasis was placed on describing the use of emotional expression as a mechanism of coping, particularly through a writing paradigm known as expressive writing. Research on expressive writing in healthy college students, healthy adults and medical populations was presented. Studies regarding expressive writing in cancer, and particularly breast cancer, were summarized, clearly demonstrating a need for research using experimental pretest-posttest designs with a control group.

In summary, the research on expressive writing indicates that it may be beneficial in helping people sort through traumatic life events that are either recent or may have occurred many years in the past. In general, it seems that the greatest benefit occurs when the trauma is relatively recent, relatively intense, and is written about from a cognitive and affective perspective. Written and verbal disclosures appear to be equally beneficial, although the written is easier to accomplish. Whereas support groups and other structured psychiatric interventions require planning with other participants, expressive writing is cheap, self-motivated and completely private. The research on expressive writing in breast cancer patients has not demonstrated a clear benefit and questions still remain regarding the effect size, the best design (e.g., focusing on deepest thoughts and feelings about breast cancer vs. positive thoughts vs. a self-selected traumatic event). Although research indicates better effect sizes when participants are allowed to write about either recent or past trauma, cancer studies have not reported the same degree of control. In the Rosenburgs' research (2002), participants were allowed to write about prostate cancer or another selfselected trauma. They could either write about the same trauma every day or a different trauma each day. This kind of inconsistency might impact the benefit seen with expressive writing. Theoretically, the benefit appears to be linked to forming a cohesive story related to the traumatic event. This requires sequentially deeper writing periods where the narrative is allowed to develop. In the prostate cancer study, there was no discussion of what the men chose to write about; therefore, it is unknown if people might benefit more if they are allowed to write about an event that they consider more traumatic than their current diagnosis of cancer. No study has been reported where writing about the current trauma of breast cancer is compared with writing about what the woman feels is her worst trauma. In fact, only four studies have been published about expressive writing in breast cancer and only one found a statistically significant improvement related to the intervention. Further research with breast cancer survivors is required to explore the effect of journaling, the optimal writing design, and the specific issues related to journaling in this population. Specific issues to address include the focus of the writing and the choice about what to write about (e.g., about the trauma of breast cancer itself or another significant life trauma) and the most beneficial timing of the intervention. The Rosenburgs' research included men up to four years following diagnosis. In the four

breast cancer studies, the women participated immediately post- treatment. Studies have demonstrated that the impact of breast cancer may last for several months to years and a larger group of women who have a relatively new diagnosis (within two years) may receive benefit from expressive writing.

This study addressed these issues revealed from the literature review by assigning women who were newly diagnosed with breast cancer (within two years since diagnosis) to a control group that did not write or to one of three treatment groups: (a) writing about treatment-related events (e.g. exercise and diet), writing about deepest thoughts and feelings regarding breast cancer, or (c) writing about a self-selected worst trauma. Symptoms related to breast cancer were evaluated, including physical, psychological, and affective responses.

# CHAPTER III

# PROCEDURE FOR COLLECTION AND TREATMENT OF DATA

#### Design

The research design for this study is a randomized clinical trial using a pretest-posttest control group design. Participants were randomized into one of three treatment groups or a control group: one that writes about breast cancer as the traumatic event; one that writes about a self-selected traumatic event; one that writes about the facts of their breast cancer (e.g., diet, exercise, sleep and medication); and one that does not write.

# Sample and Setting

The population from which the sample was drawn is newly-diagnosed breast cancer patients in central Oklahoma. Individuals who met the following criteria were eligible for study participation: (a) diagnosis of breast cancer, either invasive or non-invasive, (b) have completed definitive treatment (surgery, chemotherapy and/or radiation therapy) (c) be less than 2 years since diagnosis, (d) speak and write English, and (e) be physically able to write either by hand or with a word processor for 20-minute periods. Exclusion criteria included (a) recurrent or metastatic breast cancer (b) mental status precluding participation (e.g., mental confusion) (c) not currently or previously diagnosed and/or treated for clinical depression (must have been diagnosed by qualified mental health professional).

Participants were selected through nonrandom convenience sampling accomplished by consecutive sampling. Individuals were recruited from nine sites in the Oklahoma City and Tulsa metropolitan areas. (See Appendix A for a list of sites.) Within the designated geographical area, multiple settings were necessary due to the required sample size and the desired time of participant accrual. Flyers about the study with tear-off numbers for contacting the researcher were posted at the designated sites.

Within clinical agencies, liaisons (e.g., nurses and doctors in the agencies) were identified and briefed on the study so that they were able to initially present information about it to patients, provide the researcher's contact information, and provide interest forms which were completed by potential participants and returned to the researcher. Support groups also served as a point of contact for recruitment of participants where the researcher presented the study's purpose and information about it.

On entering the study, participants were randomly assigned to one of the four study groups. The total sample includes 117 participants with 30 in three groups and 27 in the fourth. In a meta-analysis of journaling/expressive writing studies, Smyth (1998) observed an overall effect size of .47. Using this number with an alpha of .05 and a power of .80 (Portney & Watkins, 2000), between 14 and 21 participants were indicated as desirable for each of the 4 groups. Thirty participants in each group were planned to account for an attrition of 30%.

# Protection of Human Subjects

Prior to initiation of the study, approval of Texas Woman's University's Institutional Review Board (IRB) was obtained (Appendix B). Prior to giving consent for study participation, individuals were given a thorough explanation of the study purpose and procedures, the rights of participants, and the possible risks and benefits of participation. After a verbal explanation and the opportunity to ask questions, the participants were given a written informed consent. This informed consent document conformed to the guidelines set by the National Institutes for Health for the protection of Human Rights in research studies and to specific requirements of the Health Insurance Portability and Accountability Act (HIPAA) regulations (Appendix C).

# Instruments

Three instruments were used to evaluate the physical and psychological effects of expressive writing in newly-diagnosed breast cancer patients: (a) Beck Depression Inventory (BDI-II), (b) State Trait Anxiety Inventory (STAI), (c) Functional Assessment of Cancer Therapy for Patients with Breast Cancer

(FACT-B). In addition to these, two other instruments prepared by the investigator for this study were used: a General Information Form (GIF) and the Follow-Up Questionnaire (FUQ) (Appendix D).

#### BDI-II

The BDI-II is a 21-item Likert-type scale based on the work of Beck, Ward, Mendelson, Mock, and Erbaugh (1961). The scale measures behavioral manifestations of depression and provides a summed score that can be used as a normative and criterion measure. Scores of 16 or above indicate potential clinical depression. Past studies have demonstrated reliability estimates ranging from 0.78 to 0.95 (Beck at al., 1961; Beck, Steer & Garbin, 1988; Kinney, Rogers, Nash, & Bray, 2003). Kinney et al. (2003) reported Cronbach alpha coefficients of .86 to .92 for the BDI-II when used with breast cancer patients. The BDI has been used in over 1000 research studies. In a review of 25 years of using the BDI, Beck states that most researchers do not distinguish between the two versions, but most use the BDI-II published in 1979. The original BDI was revised in an effort to eliminate response sets, alternate wordings of the same response, and double negatives (Beck, Steer, & Garbin, 1988).

Several types of validity have been reported for the BDI-II. Content validity was established by formulating items from Beck's personal experience with patients and then piloting in several different patient populations. In addition to this, four experts in the field reviewed the items and piloted them (Beck et al., 1961; Beck, Shaw, Rush, & Emery, 1979). Criterion validity was supported by administering the instrument to patients along with a clinical determination of depth of depression. Changes in the tool correlated highly with the clinical rating (Beck et al., 1961, Beck et al., 1988). Construct validity was established by a number of methods. Beck et al. (1988) reported results of a metaanalysis of 25 years of using the BDI-I or II in clinical practice. In this comprehensive review of the literature, they identified several types of construct validity. Known groups validity was demonstrated by consistently finding higher scores in groups expected to have more depression. The researchers also reported a metaanalysis of concurrent validity coefficients with respect to clinical ratings: coefficients of .72 and .73 were reported for psychiatric patients and .60 and .74 for nonpsychiatric patients. The last construct validity measure reported in the 1988 metaanalysis was factor analysis. The factor analysis demonstrated that the BDI

"reflects a general syndrome of depression composed of highly intercorrelated first-order symptom dimensions which include negative attitudes, performance difficulties and somatic complaints" (Beck et al., 1988, p.98).

Respondents to the BDI-II are asked to identify their level of agreement with statements regarding their feelings on a 4-point Likert scale from 0 to 3. A score is calculated for the tool as a whole by summing the 21 individual items. The higher the score, the greater the level of depression.

#### STAI

The 40-item STAI is a multidimensional self-report instrument that measures state and trait anxiety (Speilberger, Gorsuch, Lushene, Vagg, & Jacobs, 1983). It is a two-sided form with the 20 state items on one side and the 20 trait items on the other. State anxiety is conceptually defined as the "emotional state that exists at a given moment in time and at a particular intensity" and trait anxiety as "personality traits that can be conceptualized as relatively enduring differences among people in specifiable tendencies to perceive the world in a certain way and in dispositions to react or behave in a specified manner with "predictable regularity" (Speilberger et al., 1983). The STAI has demonstrated high internal reliability with Cronbach alphas ranging from .87 to .94 for state anxiety and .88 .92 for trait anxiety (Blanchard, Courneya, & Laing, 2001; Schreier & Williams, 2004; Speilberger et al., 1983). Validity of the tool has been documented in several studies, including studies of breast cancer patients examining the psychological effects of cancer (Blanchard, Courneya, & Laing, 2001; Schneider, Prince-Paul, Allen, Silverman, & Talaba, 2004; Schreier & Williams, 2004; Speilberger et al., 1983; Williams & Schreier, 2004). Content validity was established by expert review in multiple settings where each group of experts further reduced the number of items based on point-biserial coefficient. Concurrent validity coefficients were compared with two other instruments and the analysis was further refined by each new group of participants. At the conclusion, 20 items were retained for each section: state and trait (Speilberger et al., 1970). Speilberger et al. (1983) used concurrent validity and convergent/divergent validity measures and found the STAI correlated highly with other anxiety measures and consistently correlated negatively with tests measuring other dimensions. They also reported results from factor analysis which used principal axis method of

factor extraction and "provided strong empirical support for the conceptual distinction between state and trait anxiety" (Speilberger & Vagg, 1984 p. 96).

Respondents are asked to answer each statement with 0 (not at all) to 4 (very much so) in relation to the extent the statement reflects their feelings "right now" for the state of anxiety and how they "generally feel" for the trait of anxiety. Higher STAI scores indicate higher state/trait anxiety.

## FACT-B

The FACT scales have been under development since 1987 (Cella, 1997). The FACT-B contains 28 general items plus 10 breast cancer-specific items added in 1997 (Brady, et al., 1997). The instrument is a 38-item tool designed to measure multidimensional quality of life. Subscales include physical well-being, social/family well-being, emotional well-being, functional well-being and additional physical and psychological concerns related to breast cancer. The alpha coefficients reported for the FACT-B are high (.89 to.90) and subscale alpha coefficients have been reported to range from .63 to .89 (Brady et al., 1997). Validation of the instrument took place in four phases: item generation, item reduction, scale construction and psychometric evaluation and is well documented by Brady et al. (1997). Participants respond to a list of statements about their illness on a 5-point Likert scale from 0 (not at all) to 4 (very much). A total score is obtained in addition to a score for each subscale.

#### **GIF**

The GIF, used with all study participants, includes items related to age, race, and marital status. The GIF elicits individual cancer-related information (e.g., cancer stage and cancer treatment) and information related to journaling (e.g., prior and current use of journaling and a one-item rating scale to measure the person's perception of the value of journaling).

# FUQ

The FUQ focuses on open-ended questions designed to give participants an opportunity to provide feedback on the ease of journaling and their perception regarding this intervention. Additionally, information related to physician visits during the study were recorded on this form.

# Data Collection

The GIF, BDI-II, STAI, and FACT-B were administered to the participants at study entry and at 1-month and 6-month intervals. The FUQ was administered at 6 months (i.e., the study's conclusion). Table 1 outlines the procedure for data collection.

Table 1

Procedure for Data Collection

Data source	When	Who	Where
General Information	Study outset	PI	Rx Facility
Form			
Beck-II	Pre and 1 month	Self-administered	Participant home
STAI	& 6 months post		
FACT D			
FACT-B			
F/U Questionnaire	Study conclusion	Self-administered	Subject home

Participants were recruited from six breast cancer treatment facilities in a large metropolitan area. Recruitment methods included the following: flyers were posted in the treatment facilities with tear-off numbers; facility staff introduced the study to prospective participants and gave them a postcard with contact information. Information about the study was included in the monthly newsletter sent to support group participants at Breast Imaging of Oklahoma, and on-site at Breast Imaging of Oklahoma the researcher identified potential participants during follow-up appointments and asked if the study could be discussed in person. If the patient agreed to hearing about the study the researcher gave a brief description of the study and a postcard with contact information. After obtaining informed consent and a release for medical records, the GIF was completed by the participant. The records from the treatment facilities were requested on a random sub-sample of 30 participants in order to provide validity for the self-report of demographic data. This included collecting data from such documents as demographic face sheets,

pathology reports and physician notes regarding treatment. The number of physician visits and the reason for each visit during the study was also noted and analyzed.

The subsample was also used to provide concurrent validity for the self-report tool the participants turned in at the study's conclusion about physician visits. In a previous study by Stanton et al. (2002), a 92% rate of agreement between medical records and participant report was achieved. A similar rate of agreement was anticipated and achieved for this study.

The Principal Investigator (PI) attempted to meet in person with the participants either at the health care facility where they were recruited, at their house, or neutral areas such as coffee shops for the consent process. Approximately 10% of the participants received all the information over the phone and had study materials mailed to them. This was for the convenience of participants who found out about the study at a metropolitan treatment center, yet called from their home, miles from the area. Coming back to have a face-to-face meeting with the PI was deemed unrealistic and burdensome. Once consented, the participants were randomized into groups and given their blue books, their specific writing instructions, and their writing log. Participants who completed all their pretest instruments by mail did not get randomized to the study until they had mailed in their questionnaires. In order to control for test effect, the three instruments were given to all participants in the same manner each time. They were asked to complete the instruments in the order they came out of the mailed envelope. Instructions for the intervention and for the completion of the instruments were standardized and preprinted. These were read to the participants when they were first told of their group assignment. A letter of instructions was sent to the "mail" participants. All writing participants received a copy of the instructions as well as four blue books to write in with their study number pre-printed on the booklets. Participants were asked to record the date and time they began to write and the time they ended each writing session. They were asked not to put their name anywhere on the book for the purpose of maintaining confidentiality. When participants completed their four days of writing, they notified the PI and sent her the completed blue books. The PI examined the blue books to ensure completion of the assigned writing task. No other formal analysis of the contents of the blue books took place in this study; however, participant comments and informal themes are presented.

One month after completion of the writing, the first set of randomly-ordered post test instruments were mailed to the participants with pre-addressed and stamped return envelopes. Five months later the second post-test instruments were mailed along with the follow-up questionnaire. The final 12 participants received their second post-test instruments between 3-4 months to allow their data to be included in this analysis. Since the range in expressive writing research follow-up has extended from 3 months to 7 months, this adjustment was expected not to present a confounding factor (Kelley, Lumley & Liesen, 1997; Spera, et. al., 1994; Walker, Nail, & Croyle, 1999). A comparative analysis of the participants who completed their final follow-up questionnaires at or past 6 months with those who were truncated at 4-5 months is presented with the results.

If the participants did not mail their finished journaling assignment within four weeks of study entry, the PI contacted them and asked if they were having any problems or concerns. For participants who completed the assignment but failed to return their instruments at either post-test time, another set was sent. If this set was not returned, the PI sent a letter to determine continued interest in participating in the study. If the participant continued to express interest in participating, a third set of instruments was sent at that time.

# Preliminary Pilot Studies

Two preliminary studies were conducted by this investigator. Each is reported in the following paragraphs.

# Feasibility Study

This researcher conducted a feasibility study of the use of expressive writing with nine participants at the University of Oklahoma Breast Institute in 2002. Participants, recruited from the Breast Institute, included all newly diagnosed breast cancer patients who met eligibility requirements and consented to participate in the study. All participants were given a journal and asked to write for at least 10 minutes 3 times a week for 4 weeks. Each completed a Beck-II depression questionnaire and a STAI inventory regarding anxiety. The study assisted the investigator to determine the appropriate methodology for the

proposed study. Participants' anecdotal comments indicated that they felt like the writing experience was helpful. They did note, however, that writing for a whole month was difficult and if they had not been committed to the study they might not have continued.

# Pilot Study

A second study was conducted by this investigator in Spring/Summer 2004. After approval was obtained from Texas Woman's University Investigational Review Board (IRB), 30 newly-diagnosed breast cancer patients were enrolled in a study to explore the feasibility and content validity of three self-report instruments for possible use in the follow-up study (dissertation) dealing with expressive writing in newly diagnosed breast cancer patients. Specific aims were to:

- 1. Determine the feasibility of using three self-report instruments [(i.e., Ways of Coping-Cancer version (WOC-CA), Profile of Mood States (POMS) and the Functional Assessment of Breast Cancer (FACT-B)] to assess the effect of expressive writing in newly diagnosed breast cancer patients. Specific concerns to be evaluated included fatigue, discomfort or swelling in affected arm and ease of use.
- 2. Assess the content validity of these tools in this population.
- 3. Develop data organization and analysis techniques that will facilitate the structure of data analysis in the dissertation.
- 4. Explore survey results to determine any potential confounding variables (e.g., age and stage of diagnosis) that would aid in the design of the dissertation.

Twenty-two of the 30 (73%) enrolled participants returned all of their study materials and were included in the analysis. The majority of participants were between the ages of 50-70 (63.7%), Caucasian (86.4%), married (72.7%), with an annual income less than \$60,000 (54.5%), and fairly well educated. Education had a bimodal distribution; approximately half had a high school education (45.5%) and approximately half held a master's degree or above (45.5%). The majority had invasive breast cancer, either ductal, lobular or a rare subtype (63.6%). All of the participants had received either a mastectomy or lumpectomy and a majority (59%) had also received or was going to receive radiation therapy. Nearly half of the women were also receiving or planning to receive chemotherapy and hormonal therapy as well. A

large majority of the women (72.8%) with invasive breast cancer were in the early stages (Stage I or Stage II).

The participants were asked to complete the three self-report instruments in the order given in their packet. The order of the three different instruments was altered so that only 1/6 of the tools were in the same order. This was to control for the effect that order could possibly have on the participants' responses to the instruments.

The results of this pilot indicated that all three instruments had acceptable reliability and validity with this sample. Participants felt that all of the instruments were easy to use. Completion time for each tool took no longer than 30 minutes, with the average being 10-15 minutes per instrument. All three instruments, then, were completed easily by the participant within 45 minutes to one hour. Participants felt that the instruments appropriately asked how they were dealing with breast cancer, and they did not complain of any arm pain or swelling while they completed the tools. Construct validity for each tool was estimated by examining the correlation with each other instrument used in the study. Correlations were of the magnitude and direction predicted. Validity was estimated as moderate to high for each tool, particularly the FACT-B, which correlated highly with many of the subscales and the overall POMS. Correlations ranged from .44 to .73 with the lowest being the association of WOC-CA to the POMS and the highest being the overall POMS score with the FACT-G (i.e., FACT-B without the breast cancer items). All of the correlations were statistically significant. Overall, the pilot indicated an acceptance by newly-diagnosed breast cancer patients to complete three self-report instruments and provided acceptable reliability, validity and feasibility of the tools in this sample. Additionally, no confounding variables were identified through an examination of the group's age and cancer type.

The three instruments evaluated in this pilot study were found to be appropriate for use in a large scale interventional study of the effect of expressive writing in breast cancer patients. One consideration for the researcher is that the WOC-CA and the POMS do not give direct clinical information that a clinician may find useful in interpreting study results or determining the impact an intervention may have on his/her client. Other instruments, such as the BDI-II and the STAI, may be more useful to measure responses that

provide meaningful clinical assessments. These two instruments were used in the initial feasibility study reported by this investigator and have also been shown to have high reliability and validity estimates in prior studies. The consideration of which instrument to use to measure the effect of an intervention is critical for a research study. Although this pilot study demonstrated feasibility of use, as well as reliability and validity, of the WOC-CA, POMS and FACT-B in a sample of newly-diagnosed breast cancer patients, it does not mean they are necessarily the most appropriate tools to use to measure the effect of expressive writing. Concerns voiced by clinicians about the difficulty in applying the WOC-CA and the POMS to "real life" should be taken seriously (J. Pennebaker, personal communication, June 25, 2004). This consideration led to the selection of the BDI-II, STAI and FACT-B for use in this study of the effect of expressive writing in breast cancer patients

#### Treatment of Data

A brief review of the hypotheses and variables follows:

#### Hypotheses

- 1. Women with newly diagnosed breast cancer who use expressive writing (about breast cancer or self selected worst trauma) will demonstrate significantly improved physical health-related outcomes (i.e., decreased medical appointments for cancer-related morbidity and fewer cancer-related issues) and psychological well-being (i.e., decreased depression and anxiety) than those women who write only about the facts of their breast cancer or who do not write at all.
- Women who write about a self-selected worst trauma will demonstrate equal or enhanced outcomes relative to women who write about breast cancer.

MANCOVA was used to test the hypotheses with the pretest acting as the co-variance. Expressive writing is the independent variable. Table 2 lists the dependent variables and the level of data they are.

SPSS version 14 for graduate students was used to analyze the statistics for this study. The data were entered into SPSS by the PI. The levels of variables are described in the following table. The three self-report instruments are Likert-type scales yielding ordinal data. These were statistically treated as

interval data based on Knapp's (1990) persuasive argument for treating ordinal data as interval when a summed score is obtained.

Table 2

Level of variables

Variable	Level
Age	ratio
Race	nominal
Marital status	nominal
Cancer stage	ordinal
Cancer treatment	nominal
Prior use of journaling	ordinal
Current use of journaling	ordinal
Number of physician visits	ratio
Variable	Level
Type of physician visit	nominal
Depression	ordinal
State and trait anxiety	ordinal
Functional quality of life	ordinal

Exploratory data analysis to evaluate homogeneity of groups was performed using descriptive statistics, chi-square and ANOVA appropriate to the level of data. Missing data were coded as such for analysis and were not included in data analysis. As stated previously, the statistic used to test the hypothesis was MANCOVA. Using MANCOVA addresses the potential covariate of initial group differences based on the pretest (Portney & Watkins, 2000) and assisted in the assessment of the contribution of each dependent variable to significant differences in the independent variable (Mertler & Vannatta, 2002).

MANCOVA is thought to provide a "clearer picture of the true effects of the independent variable on the multiple dependent variables" (Mertler & Vannatta, 2002, p. 137) and is thought to be potentially more powerful than ANOVA. The MANCOVA also reduces the risk of a Type-I error by decreasing the number of separate analyses conducted on the variables. A preset alpha of .05 was used to determine whether the hypothesis was accepted or rejected.

# Summary

In summary, this chapter has presented the design for the study regarding expressive writing in breast cancer. Specific issues such as participant selection, setting, sample, protection of human subjects, instrument description including validity and reliability, data collection techniques and treatment of data have all been discussed. Rationale for each step has been provided and selected techniques for statistical analysis substantiated.

#### **CHAPTER IV**

#### ANALYSIS OF DATA

# Introduction to Study

The study findings presented in this chapter focuses on expressive writing in newly-diagnosed breast cancer patients. The research design for this study is a randomized clinical trial using a pretest-posttest control group design. Participants were randomized into one of three treatment groups or a control group: one that writes about breast cancer as the traumatic event, one that writes about a self-selected traumatic event, one that writes about the facts associated with their breast cancer (e.g., diet, exercise, sleep and medication), and one that does not write. Two major hypotheses were posed and four specific aims were delineated regarding expressive writing in breast cancer patients. They are as follows:

- 1. Women with newly-diagnosed breast cancer who use expressive writing (about breast cancer or self-selected worst trauma) will demonstrate significantly improved physical health-related outcomes (i.e., decreased medical appointments for cancer-related morbidity and fewer cancer-related issues) and psychological well-being (i.e., decreased depression and anxiety) than those women who write only about the facts of their breast cancer or who do not write at all.
- Women who write about a self-selected worst trauma will demonstrate equal or enhanced outcomes relative to women who write about breast cancer.

Four additional specific aims were addressed:

- 1. Explore whether there is a difference in the observed benefits (i.e., depression, anxiety, and quality of life) of newly-diagnosed breast cancer patients who write about breast cancer versus those who write about the facts of their breast cancer (e.g., diet, exercise, sleep, and medication), write about a different more distant trauma, or do not write at all.
- Determine if barriers exist that interfere with the use of expressive writing in this diagnostic group.

- Evaluate the perceived physical effect of expressive writing by comparing the number and type of
  physician visits made during the study period by participants in the four groups.
- Explore the duration of benefits of writing over six months following the expressive writing activity.

# Description of Sample

The population for this study was drawn from a group of newly-diagnosed breast cancer patients recruited from several metropolitan cancer centers, breast imaging centers, and breast cancer support groups. The majority was recruited from a breast imaging center in a suburb of Oklahoma City where the researcher works, and the rest came from two support groups, five radiation/oncology offices, another suburban breast imaging center, and referrals from friends who had heard about the study or who were already in the study. A convenience sample of 120 women was selected. To be included in the study, the participants had to (a) have a diagnosis of breast cancer, either invasive or noninvasive, (b) have completed definitive treatment (surgery, chemotherapy, or radiation therapy), (c) be less than 2 years since diagnosis, (d) speak and write English, and (e) be physically able to write either by hand or word processor for 20 minutes. Exclusion criteria included (a) recurrent or metastatic breast cancer, (b) mental status precluding participation (e.g., mental confusion, mental retardation, or senility), and (c) not currently or previously diagnosed and/or treated for clinical depression (must have been diagnosed by qualified mental health professional).

During a 12-month period from April 2005 through April 2006, 120 participants were recruited to participate in this study. The final sample of 117 participants completed at least the first set of instruments. Sample characteristics are displayed in Table 3.

As can be seen from Table 3, the participants ranged in age from 32-78 years with a mean of 55 (SD = 10.2). Seventy-three percent were married and the majority was Caucasian. The annual income was consistent with the affluent, suburban community setting of the center from which most were recruited; the majority of participants made over \$40,000 per year. The level of education was also consistent with that setting, with the majority of participants holding a bachelor's degree or higher. Seventy-five percent of

participants were employed in a professional setting which included education, health care, banking, real estate and consulting. Ten percent were homemakers, 10% retired, and only one participant was unemployed.

Consistent with the general presentation of breast cancer, the majority of participants had invasive ductal carcinoma which is the most common form of breast cancer. Twelve percent had noninvasive breast cancer and 12% had invasive lobular carcinoma, a rarer type of breast cancer. The stage at diagnosis was also consistent with national norms with 77% at stage I or II which is considered early stage invasive breast cancer. As stated earlier, 12% had noninvasive breast cancer, known as Ductal Carcinoma in Situ (DCIS), and only 4.2% or 5 patients had stage III breast cancer, or locally advanced breast cancer. The majority of participants had breast conserving surgery, commonly known as lumpectomy. Twenty percent had either a single mastectomy or bilateral mastectomy and 13% had some form of reconstruction. Three-fourths of the participants had radiation therapy and 59% had chemotherapy. Two-thirds of the participants were on hormonal therapy such as an aromatase inhibitor or Tamoxifen. This is again consistent with national statistics regarding Estrogen receptor (ER+) / Progesterone receptor (PR+) breast cancers and the use of hormonal therapy. The average time since diagnosis at study entry was 13 months with a range of 1-27 months. The eligibility criteria stated the cut-off was 24 months. The three participants who were at 25, 26, and 27 months were all accrued prior to that but failed to return their packets until after their 24 months had occurred. On a scale from 0-10, the majority of participants rated their perceived value of journaling prior to study randomization at an average of 7 (SD = 2.5). This was the mean for all groups except the control group who reported a mean of 6 (SD = 2.5).

Table 3
Sample Demographics and Clinical Characteristics

		Total	Con	trol Group	Attenti	onal Control	Breast CA Ti	rauma	Any tra	uma
	1	V = 117		n = 30		n = 27	n = 30		n =	30
Age	<i>M</i> =55 ran	ge: 32-78	M=57	7 range: 35-78	M=56	5 range: 43-76	M=52 range	: 39-66	<i>M</i> =55 rang	ge: 32-78
Marital Status										
Married	88	73.3%	20	66.7%	22	81.5%	23	76.7%	23	76.7%
Single	2	1.7%	0	0.0%	0	0.0%	1	3.3%	1	3.3%
Divorced	17	14.2%	5	16.7%	3	11.1%	5	16.7%	4	13.3%
Widowed	10	8.3%	5	16.7%	2	7.4%	1	3.3%	2	6.7%
Race/Ethnicity										
Caucasian	107	89.2%	28	93.3%	24	88.9%	28	93.3%	27	90.0%
Hispanic	3	2.5%	28	93.3%	3	11.1%	0	0.0%	0	0.0%
African America	n 3	2.5%	1	3.3%	0	0.0%	0	0.0%	2	6.7%
Native American	3	2.5%	0	0.0%	0	0.0%	2	6.7%	1	3.3%
Annual income										
<\$20,000	4	3.3%	3	10.0%	1	3.7%	0	0.0%	0	0.0%

		Total	Control	Group	Attentio	nal Control	Breast (	CA Trauma	Any tr	rauma
		N = 117	n=3	30	n =	= 27	n =	30	<i>n</i> =	30
Annual income (continu	ied)									
\$20,000-\$39,999	15	12.5%	5	16.7%	2	7.4%	3	10.0%	5	16.7%
\$40,000-\$59,999	26	21.7%	5	16.7%	2	7.4%	9	30.0%	10	33.3%
\$60,000-\$79,000	21	17.5%	6	20.0%	5	18.5%	4	13.3%	6	20.0%
\$80,000-\$100,000	24	20.0%	4	13.3%	9	33.3%	7	23.3%	4	13.3%
>\$100,000	25	20.8%	6	20.0%	7	25.9%	7	23.3%	5	16.7%
Highest level of educati	ion									
High School	32	26.7%	10	33.3%	4	14.8%	11	36.7%	7	23.3%
Associate degree	19	15.8%	4	13.3%	7	25.9%	2	6.7%	6	20.0%
Bachelor's degree	33	27.5%	11	36.7%	5	18.5%	6	20.0%	11	36.7%
Master's degree	24	20.0%	3	10.0%	7	25.9%	10	33.3%	4	13.3%
MD/Doctorate	9	7.5%	2	6.7%	4	14.8%	1	.3%	2	6.7%

	Total		Cont	Control Group Attentional Control		Breast (	CA Trauma	Any t	rauma	
	N = 1	17	n	= 30	n	n = 27		n = 30		= 30
Occupation										
Professional	86	75.0%	20	65.5%	21	81.0%	25	83.0%	19	63.3%
Skilled laborer	4	3.3%	2	6.6%	0	0.0%	1	3.3%	1	3.3%
Homemaker	12	10.0%	1	3.3%	3	11.1%	4	13.3%	4	13.3%
Retired	12	10.0%	6	20.0%	1	3.7%	0	0.0%	5	16.7%
Unemployed	1	1.0%	0	0.0%	1	3.7%	0	0.0%	0	0.0%
Cancer type	=116									
DCIS	15	12.5%	4	13.3%	7	25.9%	1	3.3%	3	10.0%
Invasive ductal (IDC)	78	65.0 %	19	63.3%	17	63.0%	20	66.7%	22	73.3%
Invasive lobular (ILC	14	11.7%	5	16.7%	1	3.7%	6	20.0%	2	6.7%
Bilateral ca, mixed	3	2.5%	0	0.0%	0	0.0%	1	3.3%	2	6.7%
Other	6	5.0%	2	6.7%	2	7.4%	2	6.7%	0	0.0%

Total Control Group Attentional Control Breast CA Trauma Any trauma N = 117n = 27n = 30n = 30n = 30Radiation therapy 74.2% 22 73.3% 19 70.4% 22 73.3% 26 86.7% Yes 23.3% 8 26.7% 8 29.6% 8 26.7% 4 13.3% No 28 Chemotherapy 59.3% 66.7% 17 56.7% Yes 59.3% 18 60.0% 16 20 38.3% 40.0% 11 40.7% 10 33.3% 13 43.3% No 12 Hormonal therapy 70.4% 73.3% 19 63.3% 79 65.8% 63.3% 19 22 Yes 29.6% 26.7% No 37 30.8% 10 33.3% 8 8 11 36.7% M = 14 SD = 5.8M = 13 SD = 6.0M = 13 SD = 5.7M = 14 SD = 5.8Months since diagnosis M = 13 SD = 5.8Range = 1-27range = 1-26range = 4-27range = 5-25range = 5-24Perceived value of M = 7M = 6M = 7M = 7M = 7Journaling SD = 2.5SD = 2.5SD = 2.4SD = 2.7SD = 2.6

ANOVA was used to evaluate the four study groups for differences on the demographic variables.

No statistically significant differences were found among them. These data are displayed in Table 4.

Table 4

ANOVA Results for Group Differences

Demographic variable	F	p	
Age	1.234	.301	
Marital status	.934	.427	
Race	.493	.688	
Annual household income	1.872	.138	
Highest level of education	.976	.407	
Occupation	.640	.436	
Cancer type	.104	.751	
Type of surgery	.212	.651	
Radiation therapy	.190	.668	
Chemotherapy	1.000	.332	
Hormonal therapy	.190	.668	
Perceived value of journaling	.075	.788	

# Statistical Comparison of Group Differences

As can be seen from this table, the randomization process produced four groups with no statistically significant differences. The majority of each group completed all of the follow-up forms; however, differences between those who completed all of the study instruments versus those who did not presents a potential rival hypothesis. Subsamples of completers versus noncompleters were examined for variances. Table 5 displays a comparison of the four study groups with a focus on those who completed all of the study versus those who did not complete all follow-up questionnaires. ANOVA was used to examine

the groups for differences. Three variables were statistically significantly different among those who completed the study versus those who did not.

#### Income Level

Income level was statistically significant (p = .003) for the breast cancer trauma group. Women who completed the study reported income in the range of \$60,000-79,999 versus those who dropped out who reported an average income of \$40,000-59,999.

# Breast Cancer Stage

Those who completed the study in the breast cancer trauma group were in earlier stages of breast cancer than those who did not complete the study (p = .038). Although this is statistically significant, it does not appear to be clinically significant as both participant groups reported stage I breast cancer as the predominant stage.

# Chemotherapy

Two groups demonstrated significant results in regards to chemotherapy. Both the breast cancer trauma group and the attentional control group had significant differences (p=.022) for whether they had received chemotherapy or not. Those in the attentional control group who dropped out reported chemotherapy as part of their treatment 83% of the time, whereas those who completed the study had chemotherapy 40% of the time. In the breast cancer trauma group, the finding was similar with 100% of the group who did not complete the study reporting chemotherapy as part of their treatment compared to 50% of the completers (p=.010). Notably the other two groups (i.e., control group and any trauma group) were much closer to each other regarding the percent reporting chemotherapy. It is also important to note that the participants were not eligible to participate in the study until all treatment, including chemotherapy, was over.

Table 5

Comparison of Completers and Noncompleters

Demographic Variable	Completers	Noncompleters	Group	F	р
Age	n = 76	n = 41	Total	1.778	.185
	n = 25	n = 5	Control	.761	.390
	n = 12	n = 15	Attentional control	.267	.610
	n = 21	<i>n</i> = 9	Breast CA trauma	.313	.580
	<i>n</i> = 15	n = 15	Any trauma	.587	.450
Marital status			Total	.530	.468
			Control	.521	.476
			Attentional control	.267	.610
			Breast CA trauma	1.568	.221
			Any trauma	3.048	.092
Race			Total	.767	.483
			Control	.319	.577
			Attentional control	.641	.431
			Breast CA trauma	.386	.539
			Any trauma	3.330	.079

Table 5 (Continued)

# Completers versus Noncompleters

	Demographic variable	Group	F	p
	Annual household income	Total	2.501	.117
		Control	.002	.964
		Attentional control	.459	.504
		Breast CA trauma	10.791	.003
	*	Any trauma	.071	.792
54	Highest level of education	Total	.297	.587
		Control	1.569	.221
		Attentional control	1.376	.252
		Breast CA trauma	1.814	.189
		Any trauma	.840	.367
	Occupation	Total	.831	.364
		Control	.101	.753
		Attentional control	2.874	.102
		Breast CA trauma	1.359	.254
		Any trauma	.289	.595

Table 5 (Continued)

Completers versus Noncompleters

	Demographic variable	Group	F	p
	Cancer type	Total	.231	.632
		Control	.085	.773
		Attentional control	.968	.335
		Breast CA trauma	.124	.728
		Any trauma	.240	.628
55	Cancer stage	Total	6.039	.015
		Control	.839	.368
		Attentional control	1.101	.304
		Breast CA trauma	4.756	.038
		Any trauma	1.651	.209
	Type of surgery	Total	.250	.658
		Control	.504	.484
		Attentional control	.623	.437
		Breast CA trauma	1.336	.257
		Any trauma	.197	.661

Table 5 (Continued)

Completers versus Noncompleters

	Demographic variable	Group	F	p
	Radiation therapy	Total	.007	.933
		Control	.519	.477
		Attentional control	.207	.653
		Breast CA trauma	.275	.604
		Any trauma	.000	1.000
56	Chemotherapy	Total	8.415	.004
		Control	.966	.334
		Attentional control	5.942	.022
		Breast CA trauma	7.636	.010
		Any trauma	.127	.724
	Hormonal therapy	Total	.479	.470
		Control	1.378	.250
		Attentional control	.207	.653
		Breast CA trauma	2.084	.160
		Any trauma	.135	.716

Table 5 (Continued)

Completers versus Noncompleters

Demographic variable	Group	F	p
Months since diagnosis	Total	1.219	.272
	Control	.152	.699
	Attentional control	.762	.391
	Breast CA trauma	.473	.497
Descrived value of investing	Any trauma	.464	.501
Perceived value of journaling	Total	.520	.472
	Control	1.769	.194
	Attentional control	.063	.803
	Breast CA trauma	.790	.382
	Any trauma	.496	.487

# Reported Values, Normative Data and Reliability of Instruments

Results of the instruments including average scores and reliabilities obtained from the sample will be reported in this section. Each instrument is a Likert scale or Likert-type scale with summative scoring.

Two have subscales. Where it is available, normative data from breast cancer patients are used to compare results; when it is not available, norms from adult populations or generic cancer patients are used.

## BDI-II

As was stated previously, the Beck Depression Inventory II (BDI-II) is a 21-item Likert-type scale based on the work of Beck, Ward, Mendelson, Mock, and Erbaugh (1961). The scale measures behavioral manifestations of depression and provides a summed score that can be used as a normative or criterion measure. Scores of 16 or above indicate potential clinical depression. Past studies have demonstrated reliability (i.e., internal consistency) between 0.78 to 0.95 for the tool in general (Beck at al., 1961; Beck, Steer & Garbin, 1988; Kinney, Rogers, Nash, & Bray, 2003). Kinney et al. (2003) reported reliabilities of .86 to .92 for the BDI-II when used with breast cancer patients. The reliabilities for the BDI-II in this study are displayed in Table 6.

BDI-II reliabilities obtained for this study are within the range reported for other studies, both with cancer and non-cancer patients. Note that all alphas except one improved from Pretest (T1) to the one-month posttest (T2) (see Table 6). There were fewer participants for the posttests. This drop was due to study mortality and incomplete responses; three participants failed to turn the two-sided instrument over and complete the second side at the six-month testing. Once this error was noted, the researcher started highlighting the need to complete the flip side, and no other incomplete instruments were returned. This illustrates a problem with the BDI-II instrument; since the instrument is purchased in bulk with copyright protection it would be difficult to overcome this barrier. Inter-item correlations ranged from .055 to .737 on T1, .006 to .705 on T2 and .014 to .747 on the six-month posttest (T3). Item-total correlations ranged from .098 to .658 with the group average of .485 on T1, .256 to .748 and group average of .566 for T2 and .165 to .869 with average of .613 for T3. Overall, item-total average was .554.

The average scores for each of the three time points were: T1 = 7.89 (SD = 6.48), T2 = 7.38 (SD = 6.68), and T3 = 7.5 (SD = 7.35). This compares to an average of 8.61 reported for nine other reported applications of the instrument in breast cancer populations (Özalp et al., 2003; Simpson, Carlson, & Trew, 2001). The norm in college students is 12.56 and in a sample of outpatient psychiatric patients, 22.45 (Beck, Steer, & Brown, 1996).

#### STAI

The 40-item STAI is a multidimensional self-report instrument that measures state and trait anxiety (Speilberger, Gorsuch, Lushene, Vagg, & Jacobs, 1983). It is a two-sided form with the 20 state items on one side and the 20 trait items on the other. The STAI has demonstrated high internal reliability with Cronbach alphas ranging from .87 to .94 for state anxiety and .88 to .92 for trait anxiety (Speilberger et al.). The pretest used both state and trait anxiety while the two post-tests examined only the state anxiety. Inter-item correlations ranged from .003 to .728 for T1 total STAI with an item-total range of .254 to .724 and average of .523. For the trait the inter-item correlations ranged from .025 to .666 and item-total; .348 to .726, average .532. The state portion of the STAI inter-item correlations ranged from .262 to .758 for T1, .095 to .739 for T2 and .076 to .800 for T3. The state portion item-total correlations ranged from .262 to .758, group average .565 for T1, .438 to .801 with group average of .665 for T2 and .413 to .820 with group average .820 for T3. Overall average item-total correlation was .680. Test means and reliability scores are reported in Table 7.

Reliabilites obtained for the state and trait portions of the STAI instrument were high, ranging from .90 to .94 for trait anxiety and .90 to .96 for state anxiety. This is well within the values obtained from other studies (Schreier & Williams, 2004; Spielberger et al., 1983). The average score obtained on the anxiety questionnaires was also very similar to the norm reported in other breast cancer studies and in normal adult populations (McKenna et al., 1999; Williams & Schreier, 2004). Averages on trait anxiety ranged from 32.6-33.3 which compares to 34.25 for other breast cancer patients, and 30.5-34 for the state anxiety. This compares to 33.15 observed in other breast cancer studies.

Table 6

BDI-II Reliabilities

Group	Pretest			1 month			6 months		
	(n)	$M \pm SD$	Alpha	(n)	$M \pm SD$ Alpha	(n)	$M \pm SD$	Alpha	
Total	(117)	$7.89 \pm 6.48$	88.14	(83)	$7.38 \pm 6.68 90.13$	(80)	$7.5 \pm 7.35$	92.70	
Control	(30)	$8.80 \pm 7.45$	89.55	(29)	$9.00 \pm 7.71$ 91.91	(28)	$8.7 \pm 9.91$	95.70	
Att. control	(27)	$6.29 \pm 4.65$	78.44	(17)	$6.23 \pm 6.90  90.92$	(17)	$5.5 \pm 4.81$	88.40	
BR CA trauma	(30)	$7.63 \pm 4.85$	79.49	(21)	$6.04 \pm 4.45  80.39$	(19)	$7.3 \pm 4.88$	79.30	
Any trauma	(30)	$8.70 \pm 8.09$	93.22	(16)	$7.43 \pm 6.85$ 89.68	(16)	$7.8 \pm 6.89$	91.60	

#### FACT-B

As stated previously, the FACT-B is a 38-item tool designed to measure multidimensional quality of life. Subscales include physical well-being, social/family well-being, emotional well-being, functional well-being and additional physical and psychological concerns related to breast cancer. The alpha coefficient for the FACT-B is high (.89 to.90) and subscale alpha coefficients have been reported to range from .63 to .89 (Brady et al., 1997). Inter-item reliabilities and item-scale reliabilities are reported in Table 8 while test means and scale reliabilities obtained on these measures are presented in Table 9.

As Table 9 shows, the overall group means and the subgroup means were all reasonably close to the means that have been reported in other breast cancer samples (Brady et al., 1997; Wrońska, Stępien, & Kulik, 2003). For the most part, the participants in this study had higher scores on the subscales and summative scales than previously reported. (The higher the score, the greater the perceived quality of life). Reliabilities were also similar to those reported by Brady et al. (1997), but findings demonstrate some reliability concerns for a few of the subscales when the intervention groups are evaluated separately. Particularly noticeable are reliabilities under .30 for the attentional control group with the social and family well-being subscale and for the any trauma group with the emotional well-being subscale. Other reliabilities for subscales and summative scores ranged from 43 to .96. Inter-item reliabilities and item-total reliabilities were all acceptable.

The social and family well-being subscale includes questions regarding feeling close to my partner or person who is my main support (Item GS6) and being satisfied with my sex life (Item GS7). These questions were left unanswered more than any other questions of all three instruments. Some participants wrote in beside question GS6 that they did not have a significant other or main support person. The emotional well being subscale contains questions regarding worries about dying and about whether the condition will get worse. Some of these questions, particularly "worry that the condition will get worse", were not answered by a few participants. Overall, however, the FACT-B scales have good reliability for the summative scales, particularly the 36-item total score which represents the sum of all items. Reliabilities for this total ranged from .84 to .93 and remained consistently high across all three time intervals.

Table 7

STAI Reliabilities

Group		Pretest			Pretest		1 month				6 month			
0.	oup													
	Trait Score			State Score		State Score			State Score					
		( <i>N</i> )	Mean $\pm SD$	Alpha	Mean $\pm SD$	Alpha	( <i>N</i> )	Mean $\pm SD$	Alpha	(N)	Mean $\pm SD$	Alpha		
T	`otal	(117)	$32.9 \pm 8.4$	92.3	$31.2 \pm 9.6$	90.4	(87)	$33.4 \pm 11.4$	94.6	(78)	$33.0 \pm 11.3$	94.3		
C	Control	(30)	$32.6 \pm 9.4$	94.0	31.3 ±10.13	90.6	(29)	$33.2 \pm 12.3$	96.5	(28)	$35.5 \pm 12.1$	93.5		
A	Att. control	(27)	$32.8 \pm 8.3$	90.4	$30.5 \pm 8.92$	91.1	(18)	$32.9 \pm 12.0$	92.7	(16)	$30.6 \pm 8.0$	90.3		
	BR CA rauma	(30)	$32.8 \pm 8.1$	93.1	$30.9 \pm 9.75$	90.6	(21)	$33.9 \pm 10.8$	95.8	(18)	$32.9 \pm 13.2$	96.7		
A	Any trauma	(30)	$33.3 \pm 8.3$	91.7	$31.1 \pm 9.16$	90.1	(19)	$34.0 \pm 9.9$	92.6	(16)	$31.3 \pm 10.7$	94.7		
A B tr	Att. control BR CA rauma	(27)	$32.8 \pm 8.3$ $32.8 \pm 8.1$	90.4 93.1	$30.5 \pm 8.92$ $30.9 \pm 9.75$	91.1 90.6	(18)	$32.9 \pm 12.0$ $33.9 \pm 10.8$	92.7 95.8	(16) (18)	$30.6 \pm 3$ $32.9 \pm 1$	8.0 3.2		

Table 8

Inter-item and Item to Scale Reliabilities for FACT-B

Subscale	Inter-item reliabilities (range)	Item-to-scale Range	M
Physical Well-	being	3	
Т1	.309 to .692	.544 to .741	.639
T2	.211 to .650	.529 to .730	.623
Т3	.387 to .818	.613 to .810	.701
Overall group	M		.654
Emotional We	II-being		
Т1	.034 to .631	.140 to .564	.383
T2	.031 to .599	.024 to .607	.385
Т3	.010 to .570	.089 to .697	.409
Overall group	M		.392
Breast Ca subs	scale		
Т1	.005 to .416	.171 to .355	.231
T2	.004 to .671	.183 to .589	.383
Т3	.003 to .654	.183 to .567	.362
Overall group	M		.325
Social and Fan Well-Being	nily		
T1	.291 to .788	.482 to .723	.604
T2	.011 to .825	.179 to .597	.441
Т3	.016 to .837	.002 to .788	.623
Overall group	M		.556

Table 8 (Continued)

Inter-item and Item to Scale Reliabilities for FACT-B

Subscale	Inter-item reliabilities (range)	Item-to-scale	17
Functional We	ll-being	Range	M
Т1	.242 to .816	.462 to .854	.681
T2	.285 to .713	.573 to .785	.672
Т3	.418 to .829	.564 to .863	.747
Overall group	M		.700

Table 9

FACT-B Reliabilities

	Scale	Group	(N)	Pretest Score		(N)	One Month Post Te	est	(N)	Six month post-t	est
				Mean ± SD Alpha			Mean ± SD	Alpha		Mean $\pm SD$	Alpha
	Physical	Total	(116)	24.84 ±4.82	81.3	(88)	$23.33 \pm 4.25$	80.2	(79)	$21.14 \pm 3.30$	84.5
	Well-Being	Control	(30)	$22.32 \pm 5.06$	82.4	(29)	$21.68 \pm 4.72$	73.3	(28)	$20.36 \pm 3.87$	84.2
	(PWB)	Att. Control	(27)	$23.63 \pm 4.24$	86.2	(18)	$25.00 \pm 2.68$	62.7	(16)	$22.50 \pm 3.12$	68.4
		Br CA trauma	(30)	$23.13 \pm 4.17$	80.3	(22)	$24.41 \pm 3.71$	80.1	(19)	$21.68 \pm 2.65$	66.7
		Any trauma	(29)	$22.38 \pm 5.77$	89.7	(19)	$23.32 \pm 4.68$	89.9	(16)	$20.49 \pm 3.93$	92.0
65	Social/Family	Total	(116)	$23.67 \pm 4.30$	82.3	(88)	$23.21 \pm 6.28$	50.4	(76)	$22.34 \pm 3.94$	85.9
	Well-Being	Control	(30)	$23.86 \pm 4.44$	88.3	(29)	$22.51 \pm 4.29$	54.5	(26)	$22.50 \pm 2.35$	62.3
	(SFWB)	Att. Control	(27)	$24.05 \pm 4.10$	81.3	(18)	$24.72 \pm 2.45$	29.4	(15)	$22.67 \pm 3.31$	86.4
		Br CA trauma	(30)	$33.26 \pm 3.66$	71.2	(22)	$23.29 \pm 3.39$	51.0	(19)	$22.63 \pm 3.82$	80.4
		Any trauma	(29)	$29.07 \pm 5.07$	86.8	(19)	$22.73 \pm 3.77$	58.4	(16)	$21.81 \pm 6.35$	96.5
	Emotional	Total	(115)	$19.45 \pm 3.12$	69.0	(88)	$19.74 \pm 3.86$	79.3	(74)	$17.03 \pm 3.19$	69.8
	Well-Being	Control	(29)	$20.16 \pm 2.88$	59.0	(29)	$18.41 \pm 5.10$	86.7	(27)	$15.89 \pm 4.47$	77.3
	(EWB)	Att. control	(27)	$19.11 \pm 3.40$	75.4	(18)	$20.61 \pm 3.53$	77.9	(14)	$18.12 \pm 2.00$	43.4

Table 9 (Continued)

FACT-B Reliabilities

Scale	Group	(N)	Pretest Score		(N)	One Month Po	st Test	(N)	Six month post-	-test
EWB (cont)			Mean $\pm SD$	Alpha		Mean $\pm SD$	Alpha		Mean ± SD	Alpha
	Breast ca trauma	(30)	$19.70 \pm 2.90$	67.1	(22)	$21.27 \pm 2.31$	75.9	(14)	$17.89 \pm 1.94$	70.7
	Any trauma	(29)	$18.83 \pm 3.27$	51.9	(19)	$19.16 \pm 2.59$	29.2	(15)	$17.00 \pm 1.77$	24.5
Functional	Total	(115)	$22.04 \pm 5.19$	87.9	(88)	$21.69 \pm 5.91$	85.1	(79)	$21.66 \pm 6.75$	89.3
Well-Being	Control	(29)	$22.36 \pm 4.76$	87.5	(29)	$19.08 \pm 7.82$	80.2	(28)	$18.89\pm8.68$	87.2
(FWB)	Att. Control	(27)	$22.67 \pm 5.06$	88.3	(18)	$23.67 \pm 3.82$	87.6	(16)	$24.19 \pm 2.88$	78.2
66	Breast CA traum	a (30)	$22.23 \pm 3.47$	64.3	(22)	$22.82 \pm 3.86$	81.9	(19)	$23.58 \pm 4.03$	83.0
	Any trauma	(29)	$20.97 \pm 7.00$	93.9	(19)	$22.48 \pm 5.03$	92.6	(16)	$21.69 \pm 6.92$	96.0
Breast CA	Total	(116)	$24.92 \pm 5.01$	52.1	(88)	$22.86 \pm 4.73$	72.9	(79)	$25.14 \pm 7.41$	69.0
Subscale	Control	(30)	$22.23 \pm 8.45$	45.6	(29)	$21.76 \pm 5.11$	76.9	(28)	$22.39 \pm 10.16$	76.6
	Att. Control	(27)	$25.48 \pm 5.42$	65.9	(18)	$25.72 \pm 4.31$	86.6	(16)	$28.79 \pm 4.95$	76.3
	Breast CA trauma	(30)	$24.18 \pm 4.99$	48.7	(22)	$21.95 \pm 4.34$	49.5	(19)	$25.56 \pm 4.28$	27.1
	Any trauma	(29)	$24.58 \pm 4.97$	46.2	(19)	$22.86 \pm 4.11$	44.7	(16)	$25.84 \pm 4.91$	66.1
FACT-G	Total	(109)	87.49 ± 13.50	90.0	(88)	87.96 ± 14.44	88.2	(72)	81.91 ± 13.06	87.8
	Control	(29)	$88.97 \pm 13.91$	90.3	(29)	81.70 ± 18.06	87.0	(26)	77.11 ± 16.32	88.9

Table 9 (Continued)

FACT-B Reliabilities

Scale	Group	(N)	Pretest Score		(N)	One Month Post Test	:	(N)	Six month pos	t-test
FACT-G (cont.)			Mean $\pm SD$	Alpha		Mean ± SD	Alpha		Mean ± SD	Alpha
	Att. Control	(24)	$88.26 \pm 14.04$	91.9	(18)	$94.00 \pm 10.61$	87.0	(13)	$87.51 \pm 5.98$	79.2
	Breast CA trauma	(28)	87.57 ± 10.22	85.0	(22)	$91.52 \pm 10.43$	88.0	(18)	$85.56 \pm 8.76$	86.2
	Any trauma	(28)	$85.25 \pm 16.74$	93.0	(19)	87.68 ± 12.35	88.1	(15)	$81.00 \pm 13.26$	88.9
FACT-B	Total	(113)	$114.97 \pm 16.52$	90.0	(88)	$110.81 \pm 17.86$	87.9	(72)	$107.25 \pm 19.00$	89.1
67 Total	Control	(29)	$112.97 \pm 13.91$	90.3	(29)	$103.25 \pm 22.28$	89.2	(26)	$99.34 \pm 26.40$	92.1
	Att. Control	(24)	$114.93 \pm 17.56$	92.0	(18)	$119.72 \pm 14.36$	91.3	(13)	$117.32 \pm 8.23$	86.7
	Breast CA trauma	(28)	$112.97 \pm 13.87$	85.8	(22)	$113.47 \pm 12.14$	81.8	(18)	$111.48 \pm 10.77$	84.3
	Any trauma	(28)	$110.39 \pm 20.30$	93.3	(19)	$110.54 \pm 15.07$	81.0	(15)	$107.45 \pm 13.08$	84.6
Trial Outcome	Total	(115)	$69.87 \pm 12.44$	88.0	(88)	$67.87 \pm 12.51$	84.0	(79)	$67.94 \pm 15.03$	88.7
Index	Control	(29)	$65.93 \pm 11.88$	85.8	(29)	$62.53 \pm 15.23$	85.8	(28)	$61.64 \pm 21.13$	92.0
	Att. Control	(27)	$67.04 \pm 11.00$	84.1	(18)	$74.39 \pm 9.77$	84.6	(16)	75.47 ± 7.89	85.6
	Breast CA trauma	(30)	$65.20 \pm 7.46$	81.6	(22)	$68.91 \pm 8.80$	81.6	(19)	$70.82 \pm 7.93$	76.4
	Any trauma	(29)	$63.59 \pm 13.16$	84.8	(19)	68.65 ± 11.14	84.8	(16)	68.02 ± 9.40	82.6

#### **Findings**

Two major hypotheses were tested in this study regarding the use of expressive writing in women with breast cancer:

- 1. Women with newly-diagnosed breast cancer who use expressive writing (about breast cancer or self-selected worst trauma) will demonstrate significantly improved physical health-related outcomes (i.e., decreased medical appointments for cancer-related morbidity and fewer cancer-related issues) and psychological well-being (i.e., decreased depression and anxiety) than those women who write only about the facts of their breast cancer or who do not write at all.
- Women who write about a self-selected worst trauma will demonstrate outcomes that are not significantly different than those of women who are instructed to write about breast cancer.

Four additional specific aims were addressed, the first of which is:

1. Explore whether there is a difference in the observed benefits (i.e., depression, anxiety, and quality of life) of newly diagnosed breast cancer patients who write about breast cancer versus those who write about the facts of their breast cancer (e.g., diet, exercise, sleep, and medication), write about a different more distant trauma, or do not write at all.

The two major hypotheses and the first of the four specific aims are discussed together in this section as they are similar in their breadth and scope. Prior to statistical evaluation for the hypothesized differences between groups of writing levels, the data were screened for missing data, outliers and assumptions of normality, linearity, and homoscedasticity. The statistical analyses used were multivariate of covariance (MANCOVA) analysis of variance (ANOVA) and paired *t*-tests on difference scores or gain scores.

## Examination of Data

Missing data

As was previously mentioned in the discussion about the FACT-B instrument, a question on sexuality on the social and well-being subscale of the FACT-B was left blank more often than any other question on the instruments. The only other questions missed with more frequency than one per group,

were the missed questions on the back side of the BDI-II inventory. Five participants in total failed to complete the reverse side of the instrument. Since the missed items on the FACT-B and BDI-II were minimal except for the question on sexuality and the back page, respectively, it was decided to replace missing items with group means in order to allow those participants to be included in the analysis. The majority of items missed on the STAI was apparently random and based on individual decisions not to answer or were simply overlooked. Less than 5% of all items were missed. As with the FACT-B and the BDI-II, the missing items on the STAI state anxiety portion were also replaced with group means to allow inclusion of these participants.

#### **Outliers**

Evaluation of the data for outliers was comprehensive, and their examination included the use of univariate and multivariate techniques. Demographic data indicated the participants were not normally distributed on some areas. In particular, as a group they were skewed toward being married, being in a middle income group, being more highly educated and being Caucasian. This has a bearing on the external validity of this study but ANOVA results comparing the groups indicated no significant differences on these variables within the study. The instruments were evaluated for univariate outliers by visual examination of q-q plots, box plots and review of the Kolmogorov-Smirnov statistic. Significant results of the Kolmogorov-Smirnov tests are displayed in Table 10 with significance at p < .01 and p < .001, respectively.

Table 10
Outliers

Instrument	Group	Kolmogorov-Smirnov		Corrected
		( <i>p</i> <.01)	( <i>p</i> <.001)	(p value)
T2 FACT-G	Att. Control	p = .006		p = .006
T2 FACT-TOTAL	Att. Control	p = .002		p = .002
T2 TOI	Att. Control	p = .002		p = .017

Table 10 (Continued)

# Outliers

Instrument	Group	Kolmogorov-Sn	nirnov	Corrected	
		( <i>p</i> <.01)	( <i>p</i> <.001)	(p value)	
	Breast CA trauma			p = .002	
T1 BDI-II	Any trauma	p = .007		p = .007	
T2 BDI-II	Control	p = .007		p = .120	
	Att. Control	p = .004		p = .004	
T3 BDI-II	Control		p = .000	p = .000	
T1 FACT-G	All		p = .000	p = .000	
T1 FACT-TOTAL	All		p = .001	p = .002	
T1 FACT-TOI	All	p = .002		p = .007	
T2 FACT-G	All		p = .000	p = .000	
T2 FACT-TOTAL	All		p = .001	p = .001	
T2 FACT-TOI	All		p = .000	p = .002	
T3 FACT-G	All		p = .000	p = .000	
T3 FACT-TOTAL	All		p = .000	p = .000	
T3 FACT-TOI	All		p = .000	p = .000	
T1 BDI-II	All		p = .000	p = .000	
T2 BDI-II	All		p = .000	p = .000	
T3 BDI-II	All		p = .000	p = .000	
T1 STAI	All		p = .000	p = .001	
T2 STAI	All		p = .000	p = .000	
T3 STAI	All		p = .000	<i>p</i> = .000	

Mertler and Vannatta (2005) propose a significance value of .01 or .001 for small to moderate sample sizes when evaluating significance tests for skewness and kurtosis. The attentional control group had more instances of univariate outliers than any other group. If the p value of .001 is used to accept or reject the null hypothesis of normal distribution, then all but one group on one instrument meets the assumption of normality in regards to outliers. If the more conservative value of .01 is used then this hypothesis is rejected seven times; however, this occurred only one time in more than one group. Upon examining the boxplots for outliers for each instrument by group; three participants consistently occurred as outliers across each instrument and across time. When these three participants were omitted and the Kolmogorov-Smirnov re-run, the overall significance was still statistically significant (p < .01) and several cases remained significant (p < .001). In fact, while correcting one outlier the exclusion of these cases created "new" outliers. Data transformations were also attempted for these three outliers by replacing the critical value with the highest value within the "normal range". Evaluation of the Kolmogorov-Smirnov significance tests indicated improvement in the p values overall, but other values again emerged in the new dataset as new "outliers". Transforming this data set for normality purposes and dealing with outliers is complicated in that the outliers most likely do represent differences in individuals. This would indicate that normaliy is affected by skewness, not by outliers. These differences are important for the analysis of the data. The three participants who consistently appeared as outliers on all three instruments across time obviously experienced higher levels of anxiety and depression than did the other participants. Leaving their scores in the analysis seemed appropriate to the evaluation of the intervention. For interest, the test statistic was run with the three outliers out and with them in with no significant difference in results. Transforming outliers is also complicated in that each group has its own "outlier" window. Additionally, although the Kolmogorov-Smirnov statistic was generally significant, values for skewness and Kurtosis were rarely less than -1 or above 1 (see Table 11). Therefore, univariate outliers were not excluded from the analysis; however, multivariate outliers were evaluated to determine further the impact this might have on evaluation of the data.

Table 11

Skewness and Kurtosis

Instrument	Skewness	Kurtosis	
T3 FACT-G	-1.219	1.024	
T3 FACT-TOTAL	-1.377	1.633	
T3 FACT-TOI	-1.613	2.534	
T1 BDI-II	1.641	3.008	
T2 BDI-II	1.740	3.204	
T3 BDI-II	2.443	7.179	

Mahalanobis distance was evaluated for the presence of multivariate outliers. For these data, the critical value of  $\chi 2$  at p < .001 and df = 15 is 37.70. One outlier was identified which exceeded this critical value. For the reasons cited previously, this outlier was not excluded from the analysis. When the test statistic was performed with and without this outlier, the outcome was not affected.

## Normality

The assumption of normality was evaluated further using both univariate and multivariate methods. Graphical and statistical methods were used. As was discussed previously, the data appears to be skewed due to individual differences and not errors in data collection or analysis. Each participant's data were important for the evaluation of the intervention and were kept in the sample. The resultant sample sizes for all three time intervals had only minor violations of normality (see Table 12).

Table 12

Sample Size

Group	( <i>N</i> )
Total	68
Control group	25
Attentional control group	12
Breast CA trauma	17
Any trauma	14
•	

Multivariate normality was further examined using bivariate scatterplots (see Figure 2).

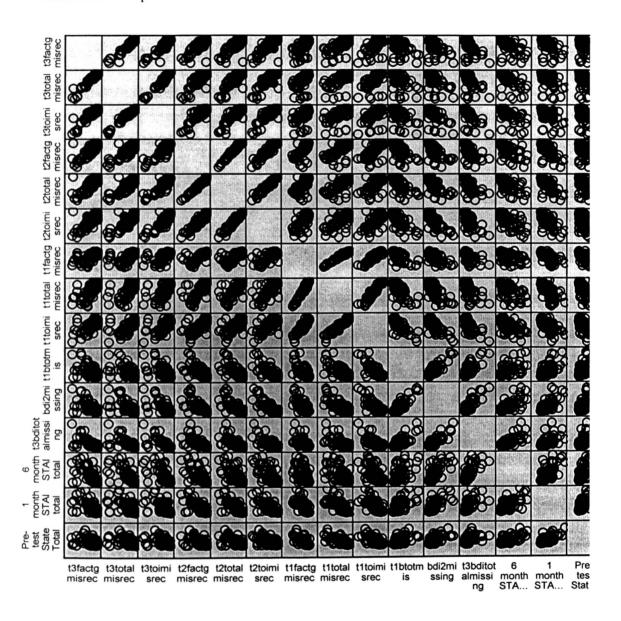
Figure 2 demonstrates that the pairwise combinations of variables are approximately elliptical.

This provides graphical evidence for the assumption of normality and linearity for this study population.

Results of this test and the results discussed in pervious paragraphs led the investigator to determine that this sample did not substantially deviate from the assumption of normality and also met the assumption of linearity.

Figure 2.

Multivariate scatterplots.



# Homoscedasticity

The sample population was evaluated for the assumption of homoscedasticity by both univariate and multivariate measures. Results of Levene's test are displayed in Table 13. Using the MANCOVA model of all of the summed scores of the FACT-B and the Emotional well-being subscale, BDI-II, and

STAI at T2 and T3, Levene's test indicates the assumption of homogeneity of variances at a univariate level is met. (Note: A legend for the variables in this table and in tables to follow is provided in Table 15 on page 78).

Table 13

Levene's Test of Equality Variances

Variable	F	df1	df2	Sig.
T2factgmisrec	.341	4	64	.796
T2totalmisrec	.887	3	64	.453
T2toimisrec	.326	3	64	.806
T3 factgmisrec	.639	3	64	.593
T3totalmisrec	.525	3	64	.666
T3toimisrec	.760	3	64	.521
T2ewbmisrec	.587	3	64	.625
T3ewbmisrec	.369	3	64	.776
Bdi2missing	.592	3	64	.623
T3bditotalmissing	1.886	3	64	.141
T2staimis	.780	3	64	.510
6 months STAI total	1.798	3	64	.157

Box's Test was also performed as part of the MANCOVA statistic. The results (Table 14) indicate that homogeneity of variance-covariance is questionable. However, Mertler and Vannatta (2005, p. 125) state that Box's test is "highly sensitive to the violation of normality, and should be interpreted with caution". They indicate that typically, if Box's test is significant at p < .001 with extremely unequal group sizes, then robustness cannot be assumed due to unequal variances. They recommend using Pillai's Trace statistic in that situation when interpreting the MANCOVA results. In this study, although the Box's test is

significant, the group sizes are not extremely unequal and robustness is more assured. As has been discussed previously, the sample sizes, while small, are large enough (12 in the smallest cell) to provide more robustness for the assumption of unequal variances. Pillai's Trace was used in interpreting the MANCOVA results to provide more protection since the question of unequal variances existed.

Table 14

Tests of Homogeneity of Variance: Box's Test

Box's Te	st of Equality of Covariance Ma	trices
Box's M	454.522	
F	1.846	
df1	156	
df2	5103.099	
Sig.	.000	
J.B.	.000	

Tests the null hypothesis that the observed covariance matrices of the dependent variables are equal across groups.

- a. Design: Intercept+group \* t1factgmisrec \* t1totalmisrec
  - \* tltoimisrec \* tlewbrecmis \* tlbtotmis \* tlstaimis

### Test Statistic: MANCOVA

MANCOVA was the statistic used to test the first hypothesis: Women with newly-diagnosed breast cancer who use expressive writing (about breast cancer or self-selected worst trauma) will demonstrate significantly improved physical health-related outcomes (i.e., decreased medical appointments for cancer-related morbidity and fewer cancer-related issues) and psychological well-being (i.e., decreased depression and anxiety) than those women who write only about the facts of their breast cancer or who do not write at all.

MANCOVA is commonly used when a pretest is used prior to the manipulation of an independent variable followed by identical posttests (Mertler & Vannatta, 2005). In this study three instruments (i.e., FACT-B, BDI-II and STAI) were given as pretests (T1) prior to two posttest intervals (T2 and T3). The pretests for all three instruments are included in the MANCOVA model, including three summed scores

representing the FACT-B subscales. Each summed score provides a different perspective on the physical and psychosocial aspects of breast cancer and does not contribute negatively to covariate interaction. The emotional well-being subscale was also included in the MANCOVA as its inclusion facilitated the model in meeting assumptions of normality and did not contribute to covariate interaction. The other subscales did not contribute in this way and were not included separately in the model.

Testing Homogeneity of Regression

The MANCOVA statistic is performed by first conducting a preliminary or custom MANCOVA which examines homogeneity of variance (Box's Test) and homogeneity of regression slopes. Results of the Box's Test were discussed previously. Homogeneity of regression slopes were interpreted by examining the F ratio and p value for the interaction. This was found to be significant at p < .01 (Pillai's Trace = 1.143, F (48, 220) = 1.834, p = .002. Therefore, factor-covariate interaction was significant. A decision was made to run the full MANCOVA based on the statement of Tabachnick and Fidell (2001) who state, "when dependent variables are unreliable, use another method for assessing the importance of dependent variables, and report known or suspected unreliability of covariates in results section" (p. 331).

They propose a significance of .01 to evaluate homogeneity of regression but indicate this is based on robustness of sample. As was stated previously the robustness of this sample is expected. This decision is further supported by the interpretation that a violation of homogeneity of regression in this group could increase the risk of a Type II error therefore making it less likely to find statistical significance for the intervention (M. Hamner, personal communication, October 20, 2006; Myers, 1972). As suggested by Mertler and Vannatta (2005), if there is such a violation of this assumption), ANOVA was also preformed. An additional statistical evaluation, *t*-tests on difference scores, was also done to provide a check of the MANCOVA results.

The MANCOVA Analysis

The full one-way MANCOVA analysis was conducted to determine the effect of expressive writing on anxiety, depression and physical quality of life while controlling for the initial pretest of each instrument. Missing data were replaced for each instrument using group means. The full MANCOVA

yields data regarding the main effect of expressive writing and the effects of the covariates. The main effect will be discussed first, followed by a discussion of the covariates. Univariate ANOVA was conducted on each dependent variable as a follow-up test to MANCOVA. A comparison of adjusted means is then performed to indicate which groups differ on each dependent variable.

The main effect of expressive writing indicates a significant effect on the combined dependent variable (Pillai's Trace = .834, F (36,147) = 1.573, p = .032, partial  $\eta^2$  = .278). Overall, the covariates significantly affected the combined dependent variable. FACT-G: Pillai's Trace = .353, F(12,47) = 2.134, p = .032; FACT-TOTAL: Pillai's Trace = .386, F(12,47) = 2.463, p = .014; FACT-TOI: Pillai's Trace = .589, F(12,47) = 5.608, p < .001; STAI: Pillai's Trace = .505, F(12,47) = 4.001, p < .001; BDI-II: Pillai's Trace = .610, F(12,47) = 6.136, p < .001 (Table 16). Table 15 provides a list of the variable names and their representative names as used in the SPSS analysis.

Table 15

SPSS Variables

SPSS Notation	Variable Name
Tlfactgmisrec	T1 FACT-G missing data included and recoded
	(FACT-G = All FACT subscales except Breast CA)
Tltotalmisrec	T1 FACT-B missing data included and recoded
	(FACT total = all subscales including Breast CA)
Tltoimisrec	T1 FACT-TOI missing data included and recoded
	(TOI is trial outcome index = physical well-being
	subscale + functional well-being subscale + breast
	cancer subscale)
Tlewbmisrec	T1 emotional well-being subscale missing data included and recoded
T1btotmis	T1 BDI-II summed scale with missing data included
T1staimis	T1 STAI state summed scale with missing data.

Table 16

MANCOVA Summary Table With Missing Data Included

Effect		Value	F	Hypothesis(df)	Error(df)	Sig.	Partial Eta Squared
Intercept	Pillai's Trace	.657	7.491	12.000	47.000	.000	.657
	Wilk's Lambda	.343	7.491	12.000	47.000	.000	.657
	Hotellings Trace	1.913	7.491	12.000	47.000	.000	.657
	Roy's Largest Root	1.913	7.491	12.000	47.000	.000	.657
T1factgmisrec	Pillai's Trace	.353	2.134	12.000	47.000	.032	.353
	Wilk's Lambda	.647	2.134	12.000	47.000	.032	.353
	Hotellings Trace	.545	2.134	12.000	47.000	.032	.353
	Roy's Largest Root	.545	2.134	12.000	47.000	.032	.353
T1totalmisrec	Pillai's Trace	.386	2.463	12.000	47.000	.014	.386
	Wilk's Lambda	.614	2.463	12.000	47.000	.014	.386
	Hotellings Trace	.629	2.463	12.000	47.000	.014	.386
	Roy's Largest Root	.629	2.463	12.000	47.000	.014	.386
T1toimisrec	Pillai's Trace	.589	5.608	12.000	47.000	.000	.589
	Wilk's Lambda	.411	5.608	12.000	47.000	.000	.589

Table 16 (Continued)

MANCOVA Summary Table With Missing Data Included

Effect		Value	F	Hypothesis(df)	Error(df)	Sig.	Partial eta squared
Tltoimisrec	Hotellings Trace	1.432	5.608	12.000	47.000	.000	.589
	Roy's Largest Root	1.432	5.608	12.000	47.000	.000	.589
Tlewbmisrec	Pillai's Trace	.274	1.475	12.000	47.000	.168	.274
	Wilk's Lambda	.726	1.475	12.000	47.000	.168	.274
	Hotellings Trace	.377	1.475	12.000	47.000	.168	.274
!	Roy's Largest Root	.377	1.475	12.000	47.000	.168	.274
T1btotmis	Pillai's Trace	.610	6.136	12.000	47.000	.000	.610
	Wilk's Lambda	.390	6.136	12.000	47.000	.000	.610
	Hotellings Trace	1.567	6.136	12.000	47.000	.000	.610
	Roy's Largest Root	1.567	6.136	12.000	47.000	.000	.610
T1staimis	Pillai's Trace	.505	4.001	12.000	47.000	.000	.505
	Wilk's Lambda	.495	4.001	12.000	47.000	.000	.505
	Hotellings Trace	1.022	4.001	12.000	47.000	.000	.505
	Roy's Largest Root	1.022	4.001	12.000	47.000	.000	.505

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Table 16 (Continued)

MANCOVA Summary Table With Missing Data Included

Effect		Value	F	Hypothesis(df)	Error(df)	Sig.	Partial Eta Squared
Group	Pillai's Trace	.834	1.573	36.000	147.000	.032	.278
	Wilk's Lambda	.370	1.550	36.000	136.594	.038	.282
	Hotellings Trace	1.200	1.522	36.000	137.000	.045	.286
	Roy's Largest Root	.553	2.257	12.000	49.000	.023	.356

#### Univariate ANOVA Results

Univariate ANOVA results (Table 17) indicate that the dependent variable of physical effects as measured by FACT-G was significantly affected by the expressive writing intervention at T2 FACT-Total: F(3,58) = 3.787, p = .015. The dependent variable of depression was also significantly affected by the expressive writing intervention F(3,58) = 4.010, p = .012. Table 18 presents the adjusted and unadjusted group means for the dependent variables.

Adjusted and Unadjusted Group Means for FACT-B

A comparison of the adjusted and unadjusted group means revealed that the attentional control and breast cancer writing groups differed by 4 and 2.5 points, respectively, from the control and any trauma groups for the T2 FACT-G. These were also the two groups who differed the most on the T2 FACT-TOTAL, by 14 and 7 respectively. On the T2 FACT-TOI the same trend continued. However, the breast cancer trauma group only differed from the control by .75 points, whereas the attentional control group differed by 5.5 points. The trend stays the same but the difference is less at T3. The breast cancer trauma group actually differs more than the attentional control group at this time interval except for the T2 FACT-TOI scale.

Adjusted and Unadjusted Group Means for BDI-II

Depression scores (BDI-II) were much lower in the breast cancer trauma group at T2 than in the attentional control group. This means the breast cancer trauma group reported lower depression scores than the attentional control group at the first month after writing. By six months this had reversed and the attentional control group once again was the one showing more improvement in scores.

Adjusted and Unadjusted Group Means for STAI

Anxiety scores improved minimally in both the breast cancer and any trauma groups. They both differed .05 from the control group at one month post writing. By six months, the control group actually recorded lower anxiety scores than any of the writing groups.

# MANCOVA on Data Set Without Missing Data Replaced

When the preliminary MANCOVA statistic was run on the data set that does not have the missing data replaced (Figure 3), Box's Test was not significant (p = .006), therefore Wilks' Lambda was used to interpret the homogeneity of regression. As with the previous data set, this assumption was violated (p = .007). Thus, the results presented in the previous paragraphs for the data set that included missing data are used in the discussion section of this paper for the acceptance or rejection of hypotheses as well as the ANOVA statistics and the *t*-tests on difference scores.

Table 17

MANCOVA Univariate Test Results

Tests of Between-S	ubjects Effects						
Source	Dependent Variable	Type III Sum of Squares	df	Mean Square	F	Sig	Partial
Corrected Model	t2factgmisrec	8477.256	9	941.917	22.121	.000	.774
	t2totalmisrec	14342.735	9	1593.637	10.780	.000	.626
	t2toimisrec	7391.602	9	821.289	19.804	.000	.754
	t3factgmisrec	5455.343	9	606.149	11.960	.000	.650
∞	t3totalmisrec	9849.616	9	1094.402	14.278	.000	.689
<b>%</b>	t3toimisrec	6363.055	9	707.006	16.896	.000	.724
	t2ewbmisrec	356.872	9	39.652	7.204	.000	.528
	t3ewbmisrec	140.643	9	15.627	3.033	.005	.320
	bdi2missing	3234.166	9	359.352	35.099	.000	.845
	t3bditotalmissing	2593.805	9	288.201	12.549	.000	.661
	t2staimis	5114.021	9	568.225	11.138	.000	.633
	6 month STAI total	5474.782	9	608.309	7.881	.000	.550

Table 17 (continued)

MANCOVA Univariate Test Results

Tests of Between	n-Subjects Effects						
Source	Dependent Variable	Type III Sum of Squares	df	Mean Square	F	Sig	Partial
Intercept	t2factgmisrec	1023.399	1	1023.399	24.034	.000	.293
	t2totalmisrec	2986.012	1	2986.012	20.198	.000	.258
	t2toimisrec	1173.119	1	1173.119	28.288	.000	.328
	t3factgmisrec	263.164	1	263.164	5.193	.026	.082
85	t3totalmisrec	1108.424	1	1108.424	14.461	.000	.200
	t3toimisrec	906.851	1	906.851	21.672	.000	.272
	t2ewbmisrec	34.852	1	34.852	6.332	.015	.098
	t3ewbmisrec	39.314	1	39.314	7.630	.008	.116
	bdi2missing	3.815	1	3.815	.373	.544	.006
	t3bditotalmissing	4.017	1	4.017	.175	.677	.003
	t2staimis	124.894	1	124.894	2.448	.123	.040
	6 month STAI total	15.388	1	15.388	.199	.657	.003

Table 17 (continued)

MANCOVA Univariate Test Results

Tests of Between	n-Subjects Effects						
Source	Dependent Variable	Type III Sum of Squares	df	Mean Square	F	Sig	Partial
t1 factgmisrec	t2factgmisrec	2.400	1	2.400	.056	.813	.001
	t2totalmisrec	87.749	1 ,	87.749	.594	.444	.010
	t2toimisre	33.512	1	33.512	.808	.372	.014
	t3factgmisrec	32.338	1	32.338	.638	.428	.011
86	t3totalmisrec	3.760	1	3.760	.049	.826	.001
	t2ewbmisrec	14.790	1	14.790	2.687	.107	.044
	t3ewbmisrec	11.368	1	11.368	2.206	.143	.037
	bdi2missing	6.626	1	6.626	.647	.424	.011
	t3bditotalmissing	.734	1	.734	.032	.859	.001
	t2staimis	22.208	1	22.208	.435	.512	.007
	6 month STAI total	262.215	1	262.215	3.397	.070	.055
t1totalmisrec	t2factgmisrec	28.311	1	28.311	.665	.418	.011
	t2totalmisrec	133.694	1	133.694	.904	.346	.015

Table 17 (continued)

MANCOVA Univariate Test Results

Tests of Betwee	en-Subjects Effects						
Source	Dependent Variable	Type III Sum of Squares	df	Mean Square	F	Sig	Partial
Tltotal	t2toimisrec	1.612	1	1.612	.039	.844	.001
Misrec (cont)	t3 factgmisrec	39.225	1	39.225	.774	.383	.013
	t3totalmisrec	4.606	1	4.606	.060	.807	.001
	t3toimisrec	93.384	1	93.384	2.232	.141	.037
87	t2ewbmisrec	11.619	1	11.619	2.111	.152	.035
37	t3ewbmisrec	6.485	1	6.485	1.259	.267	.021
	bdi2missing	.106	1	.106	.010	.919	.000
	t3bditotalmissing	15.776	1	15.776	.687	.411	.012
	t2staimis	46.127	1	46.127	.904	.346	.015
	6 month STAI total	103.748	1	103.748	1.344	.251	.023
tltoimisrec	t2factgmisrec	3.657	1	3.657	.086	.771	.001
	t2totalmisrec	14.196	1	14.196	.096	.758	.002
	t2toimisrec	228.484	1	228.484	5.510	.022	.087

Table 17 (Continued)

MANCOVA Univariate Test Results

T	ests of Between-Subject	s Effects						
S	ource	Dependent Variable	Type III Sum of Squares	df	Mean Square	F	Sig	Partial
t	Itoimisrec (cont)	t3factgmisrec	396.287	1	396.287	7.819	.007	.119
		t3totalmisrec	474.957	1	474.957	6.196	.016	.097
		t3toimisrec	632.091	1	632.091	15.106	.000	.207
	t2ewbmisrec	.503	1	.503	.091	.763	.002	
88		t3ewbmisrec	.522	1	.522	.101	.751	.002
		bdi2missing	32.305	1	32.305	3.155	.081	.052
		t3bditotalmissing	100.195	1	100.195	4.363	.041	.070
		t2staimis	33.489	1	33.489	.656	.421	.011
		6 month STAI total	.292	1	.292	.004	.951	.000
1	lewbrecmis	t2factgmisrec	8.643	1	8.643	.203	.654	.003
		t2totalmisrec	32.723	1	32.723	.221	.640	.004
		t3totalmisrec	30.524	1	30.524	.398	.530	.007
		t3toimisrec	72.020	1	72.020	1.721	.195	.029

Table 17 (Continued)

MANCOVA Univariate Test Results

	Tests of Between	n-Subjects Effects						
	Source	Source Dependent Variable		es df	Mean Square	F	Sig	Partial
	tlewbrecmis (co	nt) t2ewbmisrec	35.099	1	35.099	6.377	.014	.099
		t3ewbmisrec	2.697	1	2.697	.523	.472	.009
		bdi2missing t3bditotalmissin	.480	1	.480	.047	.829	.001
			g 3.402	1	3.402	.148	.702	.003
0	8	t2staimis	7.315	1	7.315	.143	.706	.002
4	5	6 month STAI t	otal .606	1	.606	.008	.930	.000
	tlbtotmis	t2factgmisrec	642.544	1	642.544	15.090	.000	.206
		t2totalmisrec	712.629	1	712.629	4.820	.032	.077
		t2toimisrec	489.403	1	489.403	11.801	.001	.169
		t3factgmisrec	2.321	1	2.321	.046	.831	.001
		t3totalmisrec	81.134	1	81.134	1.058	.308	.018
		t3toimisrec	173.870	1 -	173.870	4.155	.046	.067
		t2ewbmisrec	8.887	1	8.887	1.615	.209	.027

Table 17 (Continued)

MANCOVA Univariate Test Results

Tests of Between-S	ubjects Effects						
Source	Dependent Variable	Type III Sum of Squares	df	Mean Square	F	Sig	Partial
t1btotmis (cont.)	t3ewbmisrec	1.149	1	1.149	.223	.639	.004
	bdi2missing	658.286	1	658.286	64.298	.000	.526
	t3bditotalmissing	508.875	1	508.875	22.158	.000	.276
	t2staimis	360.078	1	360.078	7.058	.010	.108
<b>10</b>	6 month STAI total	288.903	1	288.903	3.743	.058	.061
8 t1staimis	t2factgmisrec	241.352	1	241.352	5.668	.021	.089
	t2totalmisrec	1549.340	1	1549.340	10.480	.002	.153
	t2toimisrec	363.312	1	363.312	8.761	.004	.131
	t3 factgmisrec	1.854	1	1.854	.037	.849	.001
	t3totalmisrec	121.381	1	121.381	1.584	.213	.027
	t3toimisrec	217.606	1	217.606	5.200	.026	.082
	t2ewbmisrec	14.751	1	14.751	2.680	.107	.044
	t3ewbmisrec	7.428	1	7.428	1.442	.235	.024

Table 17 (Continued)

MANCOVA Univariate Test Results

Tests of Between-Subjects Effects										
Source	Dependent Variable	Type III Sum of Squares	df	Mean Square	F	Sig	Partial			
t1staimis (cont.)	bdi2missing	45.425	1	45.425	4.437	.040	.071			
	t3bditotalmissing	8.005	1	8.005	.349	.557	.006			
	t2staimis	1144.600	1	1144.600	22.436	.000	.279			
	6 month STAI total	1526.139	1	1526.139	19.773	.000	.254			
group	t2factgmisrec	189.933	3	63.311	1.487	.228	.071			
=	t2totalmisrec	1679.446	3	559.815	3.787	.015	.164			
	t2toimisrec	315.839	3	105.280	2.539	.065	.116			
	t3factgmisrec	97.364	3	32.455	.640	.592	.032			
	t3totalmisrec	244.425	3	81.475	1.063	.372	.052			
	t3toimisrec	232.543	3	77.514	1.852	.148	.087			
	t2ewbmisrec	27.955	3	9.318	1.693	.179	.081			
	t3ewbmisrec	3.528	3	1.176	.228	.876	.012			
	bdi2missing	123.166	3	41.055	4.010	.012	.172			

Table 17 (Continued)

MANCOVA Univariate Test Results

Tests of Between-Subje	cts Effects						
Source	Dependent Variable	Type III Sum of Squares	df	Mean Square	F	Sig	Partial
Group (cont.)	t3bditotalmissing	60.200	3	20.067	.874	.460	.043
	t2staimis	55.892	3	18.631	.365	.778	.019
	6 month STAI total	29.784	3	9.928	.129	.943	.007
Error	t2factgmisrec	2469.685	58	42.581			
92	t2totalmisrec	8574.592	58	147.838			
2	t2toimisrec	2405.310	58	41.471			
	t3 factgmisrec	2939.496	58	50.681			
	t3totalmisrec	4445.782	58	76.651			
	t3toimisrec	2426.979	58	41.844			
	t2ewbmisrec	319.246	58	5.504			
	t3ewbmisrec	298.852	58	5.153			
	bdi2missing	593.809	58	10.238			
	t3bditotalmissing	1332.043	58	22.966			

Table 17 (Continued)

# MANCOVA Univariate Test Results

Tests of Between-Subjects Effects									
Source	Dependent Variable	Type III Sum of Squares	df	Mean Square	F	Sig	Partial		
Total	t2staimis	2958.943	58	51.016					
	6 month STAI total	4476.689	58	77.184					
	t2factgmisrec	551941.209	68						
	t2totalmisrec	847423.170	68						
93	t2toimisrec	327952.515	68						
ŭ	t3factgmisrec	479108.423	68						
	t3totalmisrec	834920.508	68						
	t3toimisrec	344718.508	68						
	t2ewbmisrec	28682.000	68						
	t3ewbmisrec	20524.231	68						
	bdi2missing	8015.851	68						
	t3bditotalmissing	7608.312	68						
	t2staimis	85293.532	68						
	6 month STAI total	84400.000	68						

Table 17 (Continued)

MANCOVA Univariate Test Results

Tests of	Between-Sub	ects Effects
1 6363 01	DCLWCCII-3u0	ccis Lilecis

Source Partial	Dependent Variable	Type III Sum of Squares	df	Mean Square	F	Sig
Corrected Total	t2factgmisrec	10946.941	67			
	t2totalmisrec	22917.327	67			
	t2toimisrec	9796.912	67			
	t3factgmisrec	8394.839	67			
94	t3totalmisrec	14295.398	67			
	t3toimisrec	8790.034	67			
	t2ewbmisrec	676.118	67			
	t3ewbmisrec	439.495	67			
	bdi2missing	3827.975	67			
	t3bditotalmissing	3925.849	67			

Table 18

Adjusted and Unadjusted Group Means for Dependent Variables

	Contro	ol group		Att. Co.	ntrol		Breast CA			Any Trauma	
	Unadjusted M	Adjusted M	SE	Unadjusted M	Adjusted I	M SE	Unadjusted M	Adjusted A	M SE	Unadjusted M	Adjusted M
T2 FACT-G	87.00 ± 13.85	87.99	1.34	95.18 ± 11.44	92.02	1.93	90.78 ± 11.44	90.46	1.60	$86.06 \pm 12.63$	87.39 1.82
T2 FACT TOTAL	$103.84 \pm 22.32$	104.86	2.50	121.64 ± 15.12	119.18	3.60	112.84 ± 13.10	112.59	2.98	$108.13 \pm 15.00$	108.72 3.38
T2 FACT-TOI	$66.32 \pm 14.28$	67.43	1.32	$75.42 \pm 10.41$	73.06	1.91	$68.59 \pm 9.40$	68.18	1.58	$65.89 \pm 10.76$	66.43 1.79
T3 FACT-G	82.88 ± 12.41	83.22	1.46	$86.05 \pm 7.53$	83.14	2.11	$85.00 \pm 9.65$	84.87	1.75	79.14 ± 13.00	81.19 1.98
T3 FACT TOTAL	$109.68 \pm 18.02$	110.32	1.80	114.76 ± 12.46	111.47	2.59	111.33 ±11.72	111.17	2.15	104.17 ± 11.80	106.05 2.43
T3 FACT-TOI	$69.56 \pm 14.88$	70.32	1.33	75.21 ± 9.81	73.00	1.92	$71.57 \pm 8.06$	71.06	1.59	$65.81 \pm 7.67$	7 66.90 1.80
T2 BDI-II	$9.04 \pm 8.46$	7.96	.69	$5.67 \pm 7.61$	7.56	.95	$5.67 \pm 4.26$	6.01	.78	$10.36 \pm 8.38$	3 10.13 .89
T3 BDI-II	$8.80 \pm 10.49$	7.83	.98	$3.83 \pm 3.51$	5.56	1.42	$6.52 \pm 4.40$	7.00	1.78	$8.83 \pm 6.74$	8.50 1.33
T2 STAI	$33.96 \pm 11.31$	33.17	1.47	$32.25 \pm 11.90$	33.47	2.10	32.85 ±11.83	33.12	1.75	$35.50 \pm 10.24$	33.12 1.99
T3 STAI	$33.12 \pm 12.7$	2 32.28	1.80	32.42 ± 9.90	33.14	2.60	$33.88 \pm 14.72$	33.98	2.16	$32.64 \pm 10.75$	33.41 2.44
	T2 FACT TOTAL  T2 FACT-TOI  T3 FACT-G  T3 FACT TOTAL  T3 FACT-TOI  T2 BDI-II  T3 BDI-II  T2 STAI	Unadjusted $M$ T2 FACT-G 87.00 $\pm$ 13.85 T2 FACT 103.84 $\pm$ 22.32 TOTAL  T2 FACT-TOI 66.32 $\pm$ 14.28 T3 FACT-G 82.88 $\pm$ 12.41 T3 FACT 109.68 $\pm$ 18.02 TOTAL  T3 FACT-TOI 69.56 $\pm$ 14.88 T2 BDI-II 9.04 $\pm$ 8.46 T3 BDI-II 8.80 $\pm$ 10.49 T2 STAI 33.96 $\pm$ 11.31	T2 FACT-G $87.00 \pm 13.85$ $87.99$ T2 FACT $103.84 \pm 22.32$ $104.86$ T0TAL  T2 FACT-TOI $66.32 \pm 14.28$ $67.43$ T3 FACT-G $82.88 \pm 12.41$ $83.22$ T3 FACT $109.68 \pm 18.02$ $110.32$ T0TAL  T3 FACT-TOI $69.56 \pm 14.88$ $70.32$ T2 BDI-II $9.04 \pm 8.46$ $7.96$ T3 BDI-II $8.80 \pm 10.49$ $7.83$ T2 STAI $33.96 \pm 11.31$ $33.17$	Unadjusted $M$ Adjusted $M$ SE  T2 FACT-G $87.00 \pm 13.85$ $87.99$ $1.34$ T2 FACT $103.84 \pm 22.32$ $104.86$ $2.50$ T0TAL  T2 FACT-TOI $66.32 \pm 14.28$ $67.43$ $1.32$ T3 FACT-G $82.88 \pm 12.41$ $83.22$ $1.46$ T3 FACT $109.68 \pm 18.02$ $110.32$ $1.80$ T0TAL  T3 FACT-TOI $69.56 \pm 14.88$ $70.32$ $1.33$ T2 BDI-II $9.04 \pm 8.46$ $7.96$ $.69$ T3 BDI-II $8.80 \pm 10.49$ $7.83$ $.98$ T2 STAI $33.96 \pm 11.31$ $33.17$ $1.47$	Unadjusted $M$ Adjusted $M$ SE Unadjusted $M$ T2 FACT-G $87.00 \pm 13.85$ $87.99$ $1.34$ $95.18 \pm 11.44$ T2 FACT $103.84 \pm 22.32$ $104.86$ $2.50$ $121.64 \pm 15.12$ TOTAL T2 FACT-TOI $66.32 \pm 14.28$ $67.43$ $1.32$ $75.42 \pm 10.41$ T3 FACT-G $82.88 \pm 12.41$ $83.22$ $1.46$ $86.05 \pm 7.53$ T3 FACT $109.68 \pm 18.02$ $110.32$ $1.80$ $114.76 \pm 12.46$ TOTAL T3 FACT-TOI $69.56 \pm 14.88$ $70.32$ $1.33$ $75.21 \pm 9.81$ T2 BDI-II $9.04 \pm 8.46$ $7.96$ $.69$ $5.67 \pm 7.61$ T3 BDI-II $8.80 \pm 10.49$ $7.83$ $.98$ $3.83 \pm 3.51$ T2 STAI $33.96 \pm 11.31$ $33.17$ $1.47$ $32.25 \pm 11.90$	Unadjusted $M$ Adjusted $M$ SE Unadjusted $M$ Adjusted $M$ Adjusted $M$ T2 FACT-G 87.00 $\pm$ 13.85 87.99 1.34 95.18 $\pm$ 11.44 92.02 T2 FACT 103.84 $\pm$ 22.32 104.86 2.50 121.64 $\pm$ 15.12 119.18 TOTAL T2 FACT-TOI 66.32 $\pm$ 14.28 67.43 1.32 75.42 $\pm$ 10.41 73.06 T3 FACT-G 82.88 $\pm$ 12.41 83.22 1.46 86.05 $\pm$ 7.53 83.14 T3 FACT 109.68 $\pm$ 18.02 110.32 1.80 114.76 $\pm$ 12.46 111.47 TOTAL T3 FACT-TOI 69.56 $\pm$ 14.88 70.32 1.33 75.21 $\pm$ 9.81 73.00 T2 BDI-II 9.04 $\pm$ 8.46 7.96 .69 5.67 $\pm$ 7.61 7.56 T3 BDI-II 8.80 $\pm$ 10.49 7.83 .98 3.83 $\pm$ 3.51 5.56 T2 STAI 33.96 $\pm$ 11.31 33.17 1.47 32.25 $\pm$ 11.90 33.47	Unadjusted $M$ Adjusted $M$ SE	Unadjusted $M$ Adjusted $M$ SE Unadjusted $M$ Adjusted $M$ SE Unadjusted $M$ T2 FACT-G 87.00 $\pm$ 13.85 87.99 1.34 95.18 $\pm$ 11.44 92.02 1.93 90.78 $\pm$ 11.44 T2 FACT 103.84 $\pm$ 22.32 104.86 2.50 121.64 $\pm$ 15.12 119.18 3.60 112.84 $\pm$ 13.10 TOTAL T2 FACT-TOI 66.32 $\pm$ 14.28 67.43 1.32 75.42 $\pm$ 10.41 73.06 1.91 68.59 $\pm$ 9.40 T3 FACT-G 82.88 $\pm$ 12.41 83.22 1.46 86.05 $\pm$ 7.53 83.14 2.11 85.00 $\pm$ 9.65 T3 FACT 109.68 $\pm$ 18.02 110.32 1.80 114.76 $\pm$ 12.46 111.47 2.59 111.33 $\pm$ 11.72 TOTAL T3 FACT-TOI 69.56 $\pm$ 14.88 70.32 1.33 75.21 $\pm$ 9.81 73.00 1.92 71.57 $\pm$ 8.06 T2 BDI-II 9.04 $\pm$ 8.46 7.96 .69 5.67 $\pm$ 7.61 7.56 .95 5.67 $\pm$ 4.26 T3 BDI-II 8.80 $\pm$ 10.49 7.83 .98 3.83 $\pm$ 3.51 5.56 1.42 6.52 $\pm$ 4.40 T2 STAI 33.96 $\pm$ 11.31 33.17 1.47 32.25 $\pm$ 11.90 33.47 2.10 32.85 $\pm$ 11.83	Unadjusted $M$ Adjusted $M$ SE Unadjusted $M$ Adjusted $M$ SE Unadjusted $M$ Adjusted $M$ Adjus	Unadjusted $M$ Adjusted $M$ SE T2 FACT-G 87.00 $\pm$ 13.85 87.99 1.34 95.18 $\pm$ 11.44 92.02 1.93 90.78 $\pm$ 11.44 90.46 1.60 T2 FACT TOTAL 103.84 $\pm$ 22.32 104.86 2.50 121.64 $\pm$ 15.12 119.18 3.60 112.84 $\pm$ 13.10 112.59 2.98 TOTAL TOTAL 75.42 $\pm$ 10.41 73.06 1.91 68.59 $\pm$ 9.40 68.18 1.58 T3 FACT-G 82.88 $\pm$ 12.41 83.22 1.46 86.05 $\pm$ 7.53 83.14 2.11 85.00 $\pm$ 9.65 84.87 1.75 T3 FACT 109.68 $\pm$ 18.02 110.32 1.80 114.76 $\pm$ 12.46 111.47 2.59 111.33 $\pm$ 11.72 111.17 2.15 TOTAL T3 FACT-TOI 69.56 $\pm$ 14.88 70.32 1.33 75.21 $\pm$ 9.81 73.00 1.92 71.57 $\pm$ 8.06 71.06 1.59 T2 BDI-II 9.04 $\pm$ 8.46 7.96 6.69 5.67 $\pm$ 7.61 7.56 9.95 5.67 $\pm$ 4.26 6.01 7.8 T3 BDI-II 8.80 $\pm$ 10.49 7.83 9.8 3.83 $\pm$ 3.51 5.56 1.42 6.52 $\pm$ 4.40 7.00 1.78 T2 STAI 33.96 $\pm$ 11.31 33.17 1.47 32.25 $\pm$ 11.90 33.47 2.10 32.85 $\pm$ 11.83 33.12 1.75	Unadjusted M Adjusted M SE Unadjusted M SE Unadjusted M SE Unadjusted M Adjusted M SE Unadjusted M SE Unadjus

Figure 3.

MANCOVA with data set without missing variables replaced

				Multivariate Tests					
Box'	s Test of Eq	uality of Covariance	Effect		Value	F	Hypothesis df	Error df	Sig.
	Mati	rices	Intercept	Pillai's Trace	.997	1454.955	10.000	48.000	.000
			Wilks' Lambda	.003	1454.955	10.000	48.000	.000	
	Box's M	44.177		II . III . T	303.116	1454.955	10.000	48.000	.000
	F	1.405		Hotelling's Trace					
		165		Roy's Largest Root	303.116	1454.955	10.000	48.000	.000
	dfl	100	group * t1btotal *	D'11- 11- T	1.452	2.905	40.000	204.000	.000
	df2	6863.884	tltotal * tlstotal	Pillai's Trace					
96	uj 2	001		Wilks' Lambda	.086	4.177	40.000	183.866	.000
	Sig.	.001		Hotelling's Trace	5.419	6.299	40.000	186.000	.000
				Hoteling's Hace					
				Roy's Largest Root	4.548	23.194	10.000	51.000	.000

### Hypothesis # 1 Analysis

When reviewing the results of the MANCOVA in respect to the major hypothesis tested, it is only partially accepted. While women in the group who wrote about breast cancer as their trauma did demonstrate significantly improved outcomes as measured by the FACT-B and the BDI-II, the women who were in the self-selected worst trauma group did not. The hypothesis was that they would both receive benefit and the control group and the group that wrote only about the facts of their breast cancer would not receive benefit. In fact, the data shows the women who wrote about a self-selected worst trauma demonstrated outcomes that were not as good as those of the attentional control group. In addition to this finding, the women in the attentional control group, those who wrote only about the facts of their breast cancer, scored better on most measures than the women who wrote about their deepest thoughts and feelings regarding breast cancer. This is an unexpected finding and in an effort to explore this further, one-way ANOVAs were performed for each instrument using different combinations of the independent variable (i.e., all groups as with MANCOVA, all writing groups together as one intervention group, and a collapsed group of just the two trauma groups minus the attentional control group) ( see Tables 19-25).

The separate ANOVAs along with post-hoc tests, using Bonferroni, indicated that the attentional control group was statistically significant (p = .026) for T2 FACT-TOTAL (Table 22). The tables indicate that there is movement toward significance (p = .086) for T2 FACT-TOTAL when the groups are collapsed into only a control group and intervention groups excluding the attentional control. When this is further explored by comparing three groups - the control group and the two trauma groups separately - the results not only remain insignificant but move further away from significance (p = .205). As a final analysis, the groups were evaluated by comparing the control group and the three writing groups together as one intervention group. At this point, significance re-emerged for the T2 FACT-TOTAL (p = .014). Table 26 summarizes these results.

Table 19

Analysis of BDI-II with ANOVA

		Sum of Squares	df	Mean Square	F	Sig
T1botmis	Between groups	95.818	3	31.939	.745	.528
	Within groups	4802.362	112	42.878		
	Total	4898.179	115			
Bdi2totmissing	Between groups	215.104	3	71.701	1.418	.243
	Within groups	4146.568	82	50.568		
	Total	4361.672	85			
3bdittotalmis	Between groups	107.692	3	35.897	.655	.582
	Within groups	4165.171	76	54.805		
	Total	4272.863				

Table 20

Analysis of STAI with ANOVA

		Sum of Squares	df	Mean Square	F	Sig.
t1staimis	Between Groups	90.646	3	30.215	.322	.810
	Within Groups	10421.861	111	93.891		
	Total	10512.507	114			
t2staimis	Between Groups	92.172	3	30.724	.259	.855
	Within Groups	8318.751	70	118.839		
	Total	8410.923	73			
6 month STAI total	Between Groups	91.175	3	30.392	.218	.884
	Within Groups	10609.025	76	139.592		
	Total	10700.200	79			

Table 21 ANOVA of FACT-B With All Groups

			Sum of Squares	df	Mean Square	F	Sig
	Tlfactgmisrec	Between groups	326.283	3	108.761	.692	.559
		Within groups	17279.492	110	157.086		
		Total	17605.775	113			
	T1totalmisrec	Between groups	437.786	3	145.929	.674	.569
		Within groups	23799.841	110	216.362		
		Total	24327.627	113			
100	Tltoimisrec	Between groups	176.998	3	58.999	.483	.695
		Within groups	13561.750	111	122.178		
		Total	13738.748	114			
	T2factbmisrec	Between groups	157.366	3	52.455	2.398	.074
		Within groups	1837.662	84	21.877		
		Total	1995.027	87			
	T2factgmisrec	Between groups	636.134	3	212.045	1.483	.225
		Within groups	12011.864	84	142.998		
		Total	12647.998	87			

Table 21 (Continued)

ANOVA of FACT-B With All Groups

			Sum of Squares	df	Mean Square	F	Sig
	T2totalmisrec	Between groups	2561.197	3	853.732	3.032	.034
		Within groups	23654.058	84	281.596		
		Total	26215.255	87			
	T3factgmisrec	Between groups	211.066	3	70.355	.601	.616
		Within groups	8539.942	73	116.986		
_		Total	8751.008	76			
101	T3totalmisrec	Between groups	271.171	3	90.390	.442	.724
		Within groups	14923.830	73	204.436		
		Total	15195.001	76			
	T3toimisrec	Between groups	340.600	3	115.533	.900	.445
		Within groups	9584.146	76	126.107		
		Total	9924.756	79			

			Mean			95% Confidence Int	
Dependent Variable	(I) intervention group	(J) intervention group	Difference (I-J)	Std. Error	Sig.	Lower Bound	Upper Bound
t2totalmisrec	0=control group	1=attentional control group	14.78728(*)	5.03532	.026	-28.3936	-1.1810
		2=breast cancer trauma	-8.53950	4.74447	.453	-21.3599	4.2809
		3=any trauma	-5.81788	4.95288	1.000	-19.2014	7.5657
	1=attentional control	0=control group	14.78728(*)	5.03532	.026	1.1810	28.3936
	group	2=breast cancer trauma	6.24778	5.33329	1.000	-8.1637	20.6593
		3=any trauma	8.96940	5.51952	.647	-5.9453	23.8841
	2=breast cancer trauma	0=control group	8.53950	4.74447	.453	-4.2809	21.3599
		1=attentional control group	-6.24778	5.33329	1.000	-20.6593	8.1637
		3=any trauma	2.72162	5.25554	1.000	-11.4798	16.9230
	3=any trauma	0=control group	5.81788	4.95288	1.000	-7.5657	19.2014
		1=attentional control group	-8.96940	5.51952	.647	-23.8841	5.9453
		2=breast cancer trauma	-2.72162	5.25554	1.000	-16.9230	11.4798

		Sum of squares	df	Mean Square	F	Sig.
tlfactgmisrec	Between Groups	102.594	1	102.594	.663	.418
	Within Groups	13162.901	85	154.858		
	Total	13265.495	86			
tltotalmisrec	Between Groups	215.932	1	215.932	1.014	.317
	Within Groups	18105.921	85	213.011		
	Total	18321.853	86			
tltoimisrec	Between Groups	45.060	1	45.060	.371	.544
	Within Groups	10452.776	86	121.544		
	Total	10497.836	87			
t2factbmisrec	Between Groups	2.093	1	2.093	.093	.761
	Within Groups	1530.369	68	22.505		
	Total	1532.462	69			
t2factgmisrec	Between Groups	111.529	1	111.529	.742	.392
	Within Groups	10222.586	68	150.332		
	Total	10334.115	69			

Table 23 (Continued)

ANOVA With Combined Groups

		Sum of squares	df	Mean Square	F	Sig.
t2factgmisrec	Between Groups	111.529	1	111.529	.742	.392
	Within Groups	10222.586	68	150.332		
	Total	10334.115	69			
t2totalmisrec	Between Groups	899.785	1	899.785	3.026	.086
	Within Groups	20221.603	68	297.377		
	Total	21121.389	69			
t3factgmisrec	Between Groups	5.744	1	5.744	.043	.837
	Within Groups	7964.508	59	134.992		
	Total	7970.252	60			
t3totalmisrec	Between Groups	2.689	1	2.689	.012	.912

Table 24

ANOVA of Control Group and Both Trauma Groups

		Sum of Squares	df	Mean Square	F	Sig.
t l factgmisrec	Between Groups	267.683	2	133.842	.865	.425
	Within Groups	12997.812	84	154.736		
	Total	13265.495	86			
tltotalmisrec	Between Groups	348.218	2	174.109	.814	.447
	Within Groups	17973.635	84	213.972		
	Total	18321.853	86			
t1toimisrec	Between Groups	83.049	2	41.525	.339	.714
	Within Groups	10414.787	85	122.527		
	Total	10497.836	87			
t2factbmisrec	Between Groups	10.411	2	5.206	.229	.796
	Within Groups	1522.051	67	22.717		
	Total	1532.462	69			
t2factgmisrec	Between Groups	245.871	2	122.935	.816	.446
	Within Groups	10088.244	67	150.571		
	Total	10334.115	69			

Table 24

ANOVA of Control Group and Both Trauma Groups

		Sum of Squares	df	Mean Square	F	Sig.
T2totalmisrec	Between groups	975.303	2	487.651	1.622	.205
	Within groups	20146.086	67	300.688		
	Total	21121.389	69			
T3factgmisrec	Between groups	163.837	2	81.919	.609	.548
	Within groups	7806.415	58	134.593		
	Total	7970.252	60			
T3totalmisrec	Between groups	140.938	2	70.469	.322	.726
	Within groups	12702.491	58	219.008		
	Total	12843.429	60			

Table 25

ANOVA of FACT-B Control Group and all Writing Groups

		Sum of Squares	df	Mean Square	F	Sig
Tlfactgmisrec	Between groups	50.222	1	50.222	.320	.572
	Within groups	17555.553	112	156.746		
	Total	17605.775	113			
Tltotalmisrec	Between groups	116.972	1	116.972	.543	.463
	Within groups	24120.655	112	215.263		
	Total	24237.627	113			
T1toimisrec	Between groups	10.486	1	10.486	.086	.769
	Within groups	13728.621	113	121.489		
	Total	13738.748	114			
T2factbmisrec	Between groups	8.748	1	8.748	.379	.540
	Within groups	1986.279	86	23.096		
	Total	1995.027	87			
T2factgmisrec	Between groups	285.409	1	285.409	1.985	.162
	Within groups	12362.589	86	143.751		
	Total	12647.998	87			

Table 25 (Continued)

ANOVA of FACT-B Control Group and all Writing Groups

		Sum of Squares	df	Mean Square	F	Sig
T2totalmisrec	Between groups	17870.385	1	178.385	6.266	.014
	Within groups	24434.871	86	284.126		
	Total	26215.255	87			
T3factgmisrec	Between groups	22.503	1	22.503	.193	.661
	Within groups	8728.505	75	116.380		
	Total	8751.008	76			
T3totalmisrec	Between groups	7.006	1	7.006	.035	.853
	Within groups	15187.994	75	202.507		
	Total	15195.001	76			

Table 26
Summary Results for T2 FACT-B TOTAL ANOVAS

Analysis model	F	Sig.		
All groups separate	3.032	.034		
Collapsed groups				
Control and	3.026	.086		
Two trauma groups				
Three groups separate	1.622	.205		
Control and				
Two trauma groups				
Collapsed groups	6.266	.014		
Control and				
Three writing groups				

## Analysis of Difference Scores

As a final measure to explore the data in relation to the three major variables (i.e., anxiety, depression and physical quality of life with FACT-B), difference scores were created by subtracting values obtained at T2 and T3 from T1 and T3 from T2 within each group for each instrument. Paired t-tests were run on these difference scores. The results are presented in Table 27.

The analysis of difference scores indicates that, like the previous results have shown, there is a statistically significant difference between T1 and T2 on the FACT-B TOTAL scores. The difference scores also indicate a statistically significant difference in the T1 to T3 scores. Similar to the other results, there was no significance on the scores regarding anxiety from T1 to T2 or from T2 to T3. However, there was a statistically significant difference noted from T1 to T3. Anxiety did not significantly improve from the 1<sup>st</sup> to 2<sup>nd</sup> time interval or from 2<sup>nd</sup> to 3<sup>rd</sup>, but it did from beginning to end (T1 to T3). Each group's difference scores are presented in Tables 28-31.

The data in these tables show no significant difference in the difference scores on any of the instruments for the control group. Significant differences were found for the FACT-B scales (p = .007 and p = .001) for the attentional control group and for the FACT-B scales (p = .039 and p = .004) for the breast cancer trauma group, and for the any trauma group on the anxiety scales (p = .021).

Table 28

Paired Samples T-test on Difference scores for Control group

Paired Differences				95% Confidence Interval of the difference					
		Mean	Std. Deviation	Std. Error	lower	upper	t	df	Sig.(two-tailed)
Pair 1	facttoi2to1diff - facttoi3to1	42013	8.85131	1.73588	3.99525	3.15499	242	25	.811
Pair 2	facttoi2to1diff - facttoi3to2	2.67583	11.05948	2.16894	-7.14285	1.79119	-1.234	25	.229
Pair 3	facttoi1to3diff - facttoi3to2	-2.25570	11.87115	2.32812	-7.05056	2.53916	969	25	.342
Pair 4	bdi2to1diff - bdi3to1diff	.15283	4.00998	.78642	-1.46684	1.77249	.194	25	.847
Pair 5	bdi2to1diff - bdi3to2diff	15486	4.78017	.93747	-2.08562	1.77589	165	25	.870
Pair 6	bdi3to1diff - bdi3to2diff	30769	3.31987	.65108	-1.64862	1.03323	473	25	.641
Pair 7	stai2to1diff - stai3to1diff	14815	7.76929	1.49520	-3.22158	2.92528	099	26	.922
Pair 8	stai2to1diff - stai3to2diff	1.88889	12.26419	2.36024	-2.96266	6.74044	.800	26	.431
Pair 9	stai3to1diff - stai3to2diff	2.03704	8.16409	1.57118	-1.19257	5.26664	1.297	26	.206

Table 29

Paired Sample T-tests on Difference scores for Attentional Control Group

Paired D	Differences				Inte	onfidence rval lifference			
		Mean	Std. Deviation	Std. Error	lower	upper	t	df	Sig.(two-tailed)
Pair 1	facttoi2to1diff - facttoi3to1	.03333	4.88608	1.26158	-2.67249	2.73916	.026	14	.979
Pair 2	facttoi2to1diff - facttoi3to2	6.03333	7.39321	1.90892	1.93911	10.12756	3.161	14	.007
Pair 3	facttoi1to3diff - facttoi3to2	6.00000	5.22357	1.34872	3.10728	8.89272	4.449	14	.001
Pair 4	bdi2to1diff - bdi3to1diff	1.00350	4.80664	1.28463	-1.71177	3.77878	.781	13	.449
Pair 5	bdi2to1diff - bdi3to2diff	1.21779	6.96009	1.86016	-2.80084	5.23643	.655	13	.524
Pair 6	bdi3to1diff - bdi3to2diff	.21429	2.77845	.74257	-1.38994	1.81851	.289	12	.777
Pair 7	stai2to1diff - stai3to1diff	1.33333	10.27248	2.65234	-4.35538	7.02204	.503	14	.623
Pair 8	stai2to1diff - stai3to2diff	2.73333	17.77425	4.58929	-7.10972	12.57638	.596	14	.561
Pair 9	stai3to1diff - stai3to2diff	1.40000	8.87855	2.29243	-3.51677	6.31677	.611	12	.551

Table 30

Paired Sample T-tests on Difference Scores for Breast Cancer Trauma Group

Paired I	Differences				95% Confidence Interval of the difference			
		Mean Std	l. Deviation	Std. Error	lower upper	t	df	Sig.(two-tailed)
Pair 1	facttoi2to1diff - facttoi3to1	-2.97917	5.66404	1.33503	-5.7958316251	-2.232	17	.039
Pair 2	facttoi2to1diff - facttoi3to2	09124	7.95884	1.87592	-4.04908 3.86659	049	17	.962
Pair 3	facttoi1to3diff - facttoi3to2	2.88792	3.70967	.87438	1.04315 4.73270	3.303	17	.004
Pair 4	bdi2to1diff - bdi3to1diff	95148	4.08407	.99053	-3.05131 1.14836	961	16	.351
Pair 5	bdi2to1diff - bdi3to2diff	-2.51836	6.02242	1.46065	-5.61480 .57808	-1.724	16	.104
Pair 6	bdi3to1diff - bdi3to2diff	-1.56688	3.74722	.90883	-3.49493 .35976	-1.724	16	.104
Pair 7	stai2to1diff - stai3to1diff	22222	14.09445	3.32209	-7.23123 6.78678	067	17	.947
Pair 8	stai2to1diff - stai3to2diff	1.1.6667	23.26130	5.48274	-10.40091 12.73424	.213	17	.834
Pair 9	stai3to1diff - stai3to2diff	1.38889	10.97665	2.58722	-4.06967 6.84745	.537	17	.598

Table 31

Paired T-tests for Difference Scores on Any Trauma Group

Paired I	Differences				Inte	onfidence erval lifference			
		Mean Sto	d. Deviation	Std. Error	lower	upper	t	df	Sig.(two-tailed)
Pair 1	facttoi2to1diff - facttoi3to1	.12341	9.75500	2.43875	-5.07467	5.23148	.051	15	.960
Pair 2	facttoi2to1diff - facttoi3to2	2.95350	19.07044	4.76761	-7.20842	13.11542	.619	15	.545
Pair 3	facttoi1to3diff - facttoi3to2	2.83009	11.61755	2.90439	-3.36046	9.02065	.974	15	.345
Pair 4	bdi2to1diff - bdi3to1diff	1.33681	3.53084	.88271	54465	3.21826	1.514	15	.151
Pair 5	bdi2to1diff - bdi3to2diff	3.02431	6.32589	1.58147	34652	6.39513	1.912	15	.075
Pair 6	bdi3to1diff - bdi3to2diff	1.68750	4.46794	1.11699	69330	4.06830	1.511	15	.152
Pair 7	stai2to1diff - stai3to1diff	2.18750	5.49204	1.37301	73900	5.11400	1.593	15	.132
Pair 8	stai2to1diff - stai3to2diff	5.62500	8.70919	2.17730	.98420	10.26580	2.583	15	.021
Pair 9	stai3to1diff - stai3to2dif	3.43750	5.34127	1.33532	.59134	6.28366	2.547	15	.021

## Hypothesis # 1

The first hypothesis was only partially accepted based on results from all three statistical analyses (i.e., MANCOVA, ANOVA and *t*-tests on difference scores). There was statistically significant improvement in physical health and psychological well-being for the trauma writing groups. This was seen in the Functional Assessment of Cancer Therapy-Breast Cancer results and in depression and anxiety scores across time and across groups. This was not seen, however, in physician visits for cancer-related morbidity. Physician visits were not statistically different for cancer-related issues or for any other medical issues across the groups. These data are presented on pages 117-120. The attentional control group, though, also demonstrated statistically significant improvement in these areas. This group's results were more consistent with what might be expected of an experimental group.

## Hypothesis # 2

For Hypothesis 2 (Women who write about a self-selected worst trauma will demonstrate outcomes that are not significantly different than those of women who are instructed to write about breast cancer), the data analysis supports rejection of this hypothesis. There were statistically significant differences between the two trauma groups in relation to anxiety, depression, and physical functioning. The breast cancer trauma group demonstrated significant results for physical functioning and depression related to breast cancer. The any trauma group was found to be statistically significant only for an improvement in anxiety. Since the majority of women in this group chose to write about breast cancer as their trauma this presents an interesting question: Why would the any trauma group not behave similarly to the breast cancer trauma group if the majority of them wrote about breast cancer? This question is discussed in depth in Chapter V.

# Specific Aim 1

The results of the first of the four specific aims are also provided in this section:

Explore whether there is a difference in the observed benefits (i.e., depression, anxiety, and quality of life) of newly-diagnosed breast cancer patients who write about breast cancer versus those who write about the

facts of their breast cancer (e.g., diet, exercise, sleep, and medication), write about a different more distant trauma, or do not write at all. Evaluation of the data indicates that there is a difference in the observed benefits. Participants who wrote about their breast cancer trauma showed significant improvement on health-related factors as measured by the FACT-B. They also demonstrated an improvement in depression. Women who wrote about a self-selected trauma only demonstrated an improvement in anxiety. Women who wrote about the facts of their breast cancer demonstrated significant improvement in physical functioning and in depression, similar to the women who wrote about the trauma of breast cancer. A lengthy discussion regarding these results is presented in Chapter V.

#### Specific Aim 2

The second specific aim for this study (Evaluate the perceived physical effect of expressive writing by comparing the number and type of physician visits made during the study period by participants in the four groups) was evaluated using self-report data regarding physician visits (see Table 32). There were no significant differences in the number or type of any of the physician visits in the groups.

Additionally, as can be seen, physician visits for cancer symptom control was not statistically significant (*p* = .193). The average number of visits for each group is displayed in Table 33. A random sampling of 30 participants was drawn at the study's conclusion to obtain medical records and provide correlation between self-report and medical records. An agreement of 92% has been obtained in previous research (Stanton, 2002). A 92.5% agreement between participant self-report and medical records was obtained for the current study group.

Table 32

Physician Visits for Cancer Related Morbidity

		Sum of Squares	df	Mean Square	F	Sig
Number of doctor visits	Between groups	141.097	3	47.032	.481	.697
	Within groups	6945.889	71	97.829		
	Total	7086.987	74			
Normal cancer follow-up	Between groups	3.226	3	1.075	.226	.878
	Within groups	338.054	71	4.761		
≂ Routine annual health visit	Total	341.280	74			
	Between groups	3.014	3	1.005	.350	.789
	Within groups	203.733	71	2.869		
	Total	206.747	74			
Cancer symptom control visit	Between groups	192.994	3	64.331	1.616	.193
	Within groups	2825.673	71	39.798		
	Total	3018.667	74			
Sick, not cancer visit	Between groups	110.515	3	36.838	.808	.494
	Within groups	3238.472	71	45.612		
	Total	3348.987	74			

Table 32 (Continued)

Physician Visits for Cancer Related Morbidity

		Sum of Squares	df	Mean Square	F	Sig
Lymphedema	Between groups	15.182	3	5.061	.994	.401
	Within groups	361.405	71	5.090		
	Total	376.587	74			
Psych visit/counseling	Between groups	1.841	3	.614	.903	.444
	Within groups	48.239	71	.679		
	Total	50.080	74			
CAM visit	Between groups	5.617	3	1.872	1.392	.252
	Within groups	95.529	71	1.345		
	Total	101.147	74			
Cancer scare	Between groups	.007	3	.002	.043	.988
	Within groups	3.780	71	.053		
	Total	3.787	74			
Reconstruction	Between groups	19.925	3	6.642	.630	.598
	Within groups	748.075	71	10.536		
	Total	768.000	74			

Table 33

Physician Visits All Reasons

		Γotal 7 = 75	Control $n = 1$		Attentiona $n = 1$		Breast CA $n = $		•	trauma = 16
Type of visits	M	SD	M	SD	M	SD	M	SD	M	SD
Normal CA F/U	3.36	2.15	3.36	2.16	3.12	2.03	3.71	2.31	3.25	2.24
Routine annual health	1.83	1.67	1.76	2.05	1.50	1.00	2.00	1.37	2.06	1.95
CA symptom control	1.27	6.39	.40	1.04	.82	2.90	.12	.33	4.31	13.33
Sick, not CA visit	4.01	6.73	3.48	7.05	6.24	10.07	3.47	3.84	3.06	3.51
Lymphedema	.45	2.26	.12	.60	0.00	0.00	1.12	3.87	.75	2.74
Psych visit/counseling	.16	.82	.04	.20	0.00	0.00	.29	1.21	.38	1.26
CAM visit	.23	1.17	.20	1.00	0.00	0.00	.71	2.11	0.00	0.00
Cancer scare	.05	.23	.04	.20	.06	.24	.06	.24	.06	.25
Reconstruction	1.00	3.22	1.24	3.81	.53	1.70	1.71	4.47	.38	1.50
Total # of visits	12.34	9.79	10.72	7.63	12.06	10.82	13.18	7.73	14.31	13.46

#### Specific Aim 3

The third specific aim was to determine if barriers exist that interfere with the use of expressive writing in this diagnostic group. To explore this Aim, a follow-up questionnaire (FUQ) was given to participants at the conclusion of the study. The questionnaire sought to determine the ease, acceptance, and use of expressive writing in the study population. Likert-type scale items were used to assess the participants' perspectives regarding the intervention. Also included were questions about other coping mechanisms used and previous use of expressive writing, as well as open-ended questions asking participants for feedback regarding the use of expressive writing.

The majority of participants in all groups completed the writing exercise. The control group was exempt from completing this portion of the follow-up questionnaire, but a few participants must have still felt compelled to do so. The majority agreed that they enjoyed the writing exercise, thought it was helpful, and would recommend it to anyone newly diagnosed with breast cancer. All of the groups agreed that the instructions given were sufficient and that they usually felt better after writing. Some did seem to be a little unsure about whether the writing made them feel worse. While all three groups were close to "4" (disagree), many participants answered this question by selecting "no opinion." They answered in a similar fashion to the question regarding sharing their results with a group, representing some possible ambivalence about this. The majority of the participants felt they would rather write with paper and pen/pencil rather than with a computer. Participants were also asked to check off various measures they used to deal with their breast cancer. Results are shown in Figure 4.

Figure 4.

Measures used to deal with breast cancer.

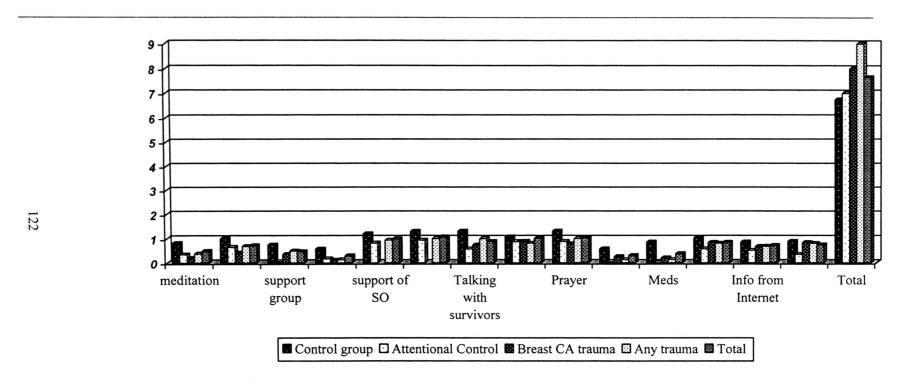


Figure 5 graphically displays the methods used to deal with breast cancer in descending order. Overall, talking with family/friends, prayer, having a positive attitude and support from significant others and other survivors were reported the most. There were some differences in the groups in their use of measures to deal with breast cancer. Notably, the number of measures used (M = 9, SD = 2.41) by the any trauma group was statistically more significant (p = .03) than the number used by the control group (M = 6.7, SD = 3.08). Other significant differences are displayed in Table 34.

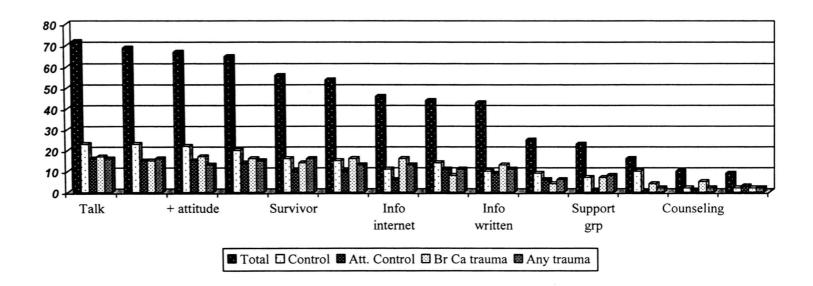
Table 34.

Significant Differences in Measures Used to Deal With Breast Cancer

Measure	Groups with difference	p value
Meditation	Breast CA trauma & Control group	p = .046
Support group	Att. Control grp. & Control group	p = .021
Prayer/spirituality	Breast CA trauma and control group	p = .011
Medicine	Breast CA trauma versus control	p = .015
	Any trauma versus control group	p = .007
	Att. Control versus control group	p = .001

A finding of interest was that medications, such as antianxiety drugs and antidepressants, were used significantly more often to deal with breast cancer by the control group than by the three writing groups. Since the FUQ was completed at the conclusion of the study, it is unknown whether these participants were taking the drugs at the beginning of the study or if they were prescribed for them at some point during the study.

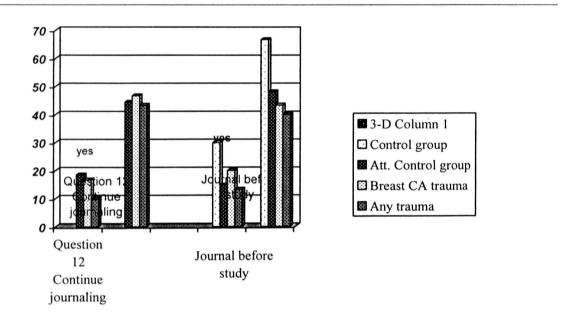
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Participants were also queried about their past and current use of expressive writing. These results can be viewed in Figure 6.

Figure 6.

Past and current use of expressive writing.



This Figure demonstrates that the majority of participants in the writing groups did not continue expressive writing after the study's conclusion, though the participants in the attentional control group were somewhat more likely to continue than the other groups. The control group had journaled more before the study, though this was not a statistically significant finding (p = .21). Fewer than 30% in all groups had done expressive writing prior to participating in the study and an even smaller percent said they had continued to do so after the study. Participants who reported continued use of expressive writing reported writing about their moods or emotions and thoughts. Other subjects listed were reflections on their life, reflections on their thoughts and how they felt physically.

#### Barriers to Expressive Writing

In order to identify barriers that might interfere with the use of expressive writing in breast cancer patients, the study participants were asked to provide open-ended answers to specific prompts regarding their participation in the writing exercise. In addition to asking what the participants liked the least about the writing exercise, they were also asked to discuss what they liked the most and what they would recommend to other breast cancer patients who might use this intervention. By asking all three questions the researcher felt that barriers as well as methods to address identified barriers might be uncovered. The results of these questions were reviewed for general categories of responses and are summarized in the next paragraphs.

Question #1: What have you liked the most about this expressive writing exercise?

Participants were very willing to share their thoughts and feelings related to this question and many of their responses are poignant and powerful. Generally their answers seemed to fall into the following categories:

- Having a written record to remember their experience, to see how far they have come, and to use
   when helping other women who have been diagnosed with breast cancer.
- Reflection which leads to clarification of issues and identification of solutions, likened to a
  process of cleansing by one participant.
- Reframing or perspective transformation. Many participants discussed how writing had helped them see things in a different, mostly positive, light and find a new perspective about their situation that they had not had before the writing exercise.
- Most participants wrote about how they were "forced" to take the time and "listen" to themselves; in so doing they discovered how they really perceived their breast cancer experience. Many women talked about the realization of their anger about their diagnosis which they had never let themselves verbalize to any family or friends. Many others discussed how looking back on what they had gone through made them feel very grateful and lucky for where they were now.
- The opportunity to benefit other women through the study was important to the participants.

- The calming effect of writing was acknowledged by several women.
- Knowing that someone cared about their story and recognizing that they had a story to tell was mentioned as a positive aspect.
- Not having to write every day or for very long at one time was positively noted.

Question #2: What have you liked the least about this expressive writing exercise?

The participants were also very willing to share their thoughts related to this question and, like the previous question, their responses have been grouped into broad categories for summary.

- Having to relive a painful and sometimes terrifying experience.
- Finding the time to do the writing, taking the time to do it, and having to do it four days in a row
  was difficult for some women.
- No resolution to questions asked/feelings explored, focused too much on negative.
- Not writing long enough, not continuing the writing after the exercise was over.
- Forced to dwell on something negative, prefer to think about positive things.
- Being in the attentional control group and not being in the trauma groups was identified as what they liked least by five participants.
- Writing something they might not want to go back and read.
- Don't like writing, don't like how their handwriting looks.
- Did not like having a project with a deadline.
- Wondering who would read their writing.
- Feel like they are being silly when expressing feelings.

Question # 3: What recommendations would you give other breast cancer patients who may want to use expressive writing following diagnosis?

As the women have already noted, the desire to help other women with breast cancer is frequently mentioned as a motivation for breast cancer survivors. Most of the participants had suggestions for other women based on this question. Key categories are listed below:

- Begin writing sooner, the first day of diagnosis; do it from the beginning even if it is just a word or two every day about what is going on.
- Just do it.
- Write every day until treatment finished.
- Do it at a regular time.
- Try working from preprinted list of topics if you can't think about what to write about.
- Attend group writing sessions to share entries and discuss them or participate in "pen pal" writing sessions where two women who both have breast cancer could write to each other.
- Write everything they feel. "Spill it all out". Write innermost thoughts. Write feelings and be honest.
- Do it long term so you can see the changes; don't give up on the process.
- Write because it makes the world stop and gives you time just to "BE".
- May need to provide structure, like a time limit or using prompt such as Oprah's "grateful five
  things for the day", write something positive every day, write one-liners—don't have to have
  complete thoughts.

From the open-ended answers on the FUQ it can be seen that women with breast cancer felt that the writing exercise was generally very helpful and would recommend it to other women. Several barriers to expressive writing were identified and some potential solutions for those barriers were alluded to. These will be discussed in chapter five.

## Specific Aim 4

The fourth and last specific aim of this study was to explore the duration of benefits of writing following the expressive writing activity.

Although the writing revealed significant findings related to physical and psychosocial measures, it does appear as though the benefit diminished somewhat over the six-month period of the study. Figures 7 through 9 display the study groups' physical well-being, depression, and anxiety benefits over time.

Depression Scores Over Time per Groups

Figure 7 demonstrates that the benefit obtained from expressive writing related to depression was sustained in both the attentional control group and the breast cancer trauma group. As Figure 7 shows, depression actually increased at T2 for the any trauma and control groups returning to T1 levels by the end of the study.

Anxiety Scores Over Time per Groups

Anxiety was similar across all groups and times with little variation noted on the figure except the jump in anxiety at T2 for the any trauma group returning to near the T1 level at T3. This decrease from T2 to T3 is statistically significant (p = .021).

FACT-B Scores Over Time per Groups

The summed scale of the total FACT-B indicates that the benefit obtained from the expressive writing intervention was sustained in the breast cancer trauma group and in the attentional control group. In the any trauma group, the FACT-B scores appeared to be on a downward trend after improving at T2, with the control group actually demonstrating better scores at T3 than the any trauma group.

Figure 7.

BDI-II Scores per group over time.

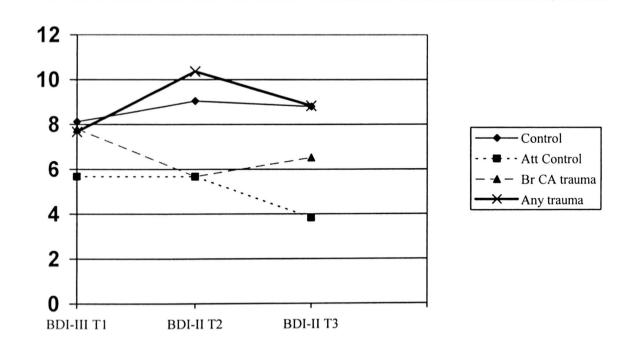
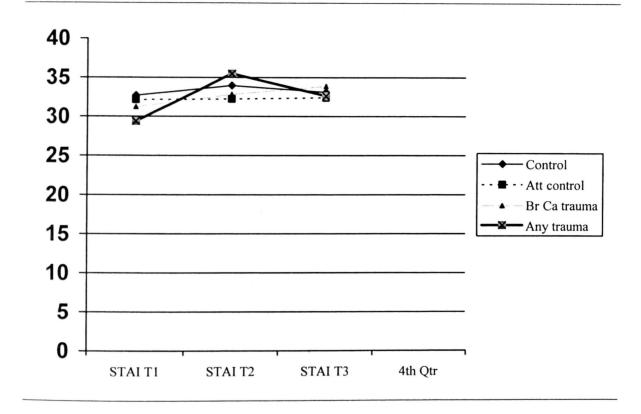
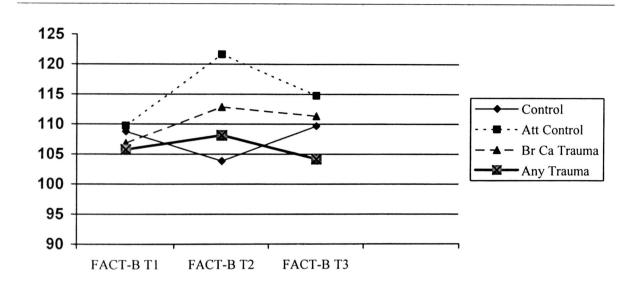


Figure 8.
STAI scores per group over time.



FACT-B scores per group over time.



## Summary

This chapter has presented the results of a randomized clinical trial using a pretest-posttest control group design. Participants were randomized into one of three writing groups or a control group: one that wrote about breast cancer as the traumatic event, one that wrote about a self-selected traumatic event, one that wrote about the facts of their breast cancer (e.g., diet, exercise, sleep and medication), and one that did not write. The results per MANCOVA indicate a statistically significant difference in physical functioning and depression. Specifically it was found that participation in either the attentional control group or the breast cancer trauma group had a significant effect on physical functioning as measured by the FACT-B. The breast cancer trauma group also showed an effect on depression as measured by the BDI-II. Paired t-tests were performed on difference scores to further characterize the effect of expressive writing in this sample. Findings supported those from the MANCOVA, but also indicated a significant difference in anxiety in the any trauma group. The attentional control group behaved much more like a treatment group and appeared to be a confounding variable.

Barriers for using expressive writing in breast cancer patients was explored by open-ended answers to a follow-up questionnaire completed by participants at the conclusion of the study. Results of this questionnaire demonstrate several barriers to the implementation of expressive writing including the time it takes to do it and a reluctance to relive negative experiences. Many suggestions for implementing expressive writing with breast cancer patients were also offered by the participants and provide potential solutions to the barriers. An interesting finding in the follow-up questionnaire pertained to the use of anti-depressants in the participants. An ANOVA performed on this question indicated a statistically significant difference between the use of antidepressants as recorded at the conclusion of the study in all of the writing groups versus the control group.

The final study question explored by this research was the duration of the benefits with expressive writing. A visual review of this data by line graphs indicates persistence, albeit lessening, of the effect through the study period.

In summary, expressive writing was found to be a useful mechanism to deal with breast cancer, it had an effect on physical functioning, depression and anxiety. Although barriers exist to its use, women find it helpful and can identify factors that would assist in its implementation. Long term effects are unknown but benefits appear to persist over a six-month period.

#### CHAPTER V

#### DISCUSSION

#### Summary of the Study

The study presented in this paper is a longitudinal randomized controlled trial evaluating the effect of a structured expressive writing intervention in newly-diagnosed breast cancer patients. Women were randomized to one of four groups: (a) wrote about their experience of breast cancer, (b) wrote about a self-selected traumatic event in their life, (c) wrote about a neutral topic such as their exercise and diet, or (d) did not write at all. The first two groups represented expressive writing groups, and the latter two represented an attentional control group and a control group, respectively. Participants were enrolled within 24 months of diagnosis, but after they had completed all of their therapy including surgery, chemotherapy and radiation therapy.

Expressive writing has demonstrated efficacy in student populations and in adult populations both healthy and ill. Limited research has been conducted with cancer patients; only a few studies have been reported. Additional research on this subject was needed to clearly indicate the effect of expressive writing with the belief that this intervention would prove beneficial to patients dealing with traumatic, life-changing diagnoses of cancer. The specific best writing assignment (i.e., writing about breast cancer or about a self-selected traumatic event) is not clear, thus steps to clarify this with breast cancer patients was needed. Expressive writing is thought to produce benefits by impacting the way a person thinks and feels about a life-changing situation and finding meaning in it. This found meaning assists in developing a new way of looking at the situation and is thought to provide physical and psychological benefits.

The effects of expressive writing were evaluated using three different self-report instruments: the Beck Depression Inventory II (BDI-II), the State-Trait Anxiety Inventory (STAI), and the Functional Assessment of Cancer Therapy-Breast Cancer (FACT-B). These measures were given to the participants at

study entry (T1) and at one month (T2) and six months (T3) after the writing intervention. Physician visits were also evaluated as well as barriers to writing and duration of effects seen with expressive writing.

Interpretation of Statistical Outcomes Related to Sample and Instruments

#### Sample Characteristics

The data presented in Chapter IV demonstrated that the four groups of breast cancer patients did not differ in any statistically significant ways at study entry. A difference was noted, however, in the groups that completed the study versus those who did not complete the study. Women in the breast cancer trauma group were more likely to complete the study if they had a higher income, had a lower stage of breast cancer, and had not received chemotherapy. These differences were statistically significant (p = .003, p = .038, and p = .010, respectively). The women in the attentional control group, or who wrote about a neutral topic, who completed the study were also significantly different based on the use of chemotherapy (p = .022).

Interestingly, though, the breast cancer trauma group, who wrote about their breast cancer, had the highest number of completers than any of the writing groups; whereas the attentional control group had the lowest number of completers. In both cases, the completers reported receiving chemotherapy 50% less than the noncompleters. This finding cannot be due to acute treatment side effects, since participants had to be finished with treatment to be eligible for the study. It is possible that the noncompleters were having more late effects of treatment, such as fatigue, than the completers; but that is not known.

Overall, the completion rate was 58% of the sample completing all time intervals. Several participants completed T3 but had not completed T2. Although these participants are considered "completers", they were not included in the test analysis since they lacked T2 data. The group of participants who filled out the T3 instruments and the Follow-Up Questionnaire (FUQ) comprised 65% of the initial sample.

# Review of Instruments

Reliabilities obtained on all three instruments were well within acceptable ranges. Subscales on the FACT-B did not do as well when evaluated by the individual groups; but, overall, performed within

ranges reported in other studies. The question on satisfaction with one's sex life on the FACT-B was left blank more than any other question on the instruments. The women who did choose to answer this question, however, reported dissatisfaction with their sex life 25-50% of the time. This was not significant between groups. Complementing this question was question #21 on the BDI-II which asked participants to rate their loss of interest in sex. Fifty percent of participants reported less interest in sex. Normative data are not known regarding healthy women's satisfaction with their sex lives and interest in sex. Although beyond the scope of this paper, this finding does suggest a need for further research in this area.

Another question noticed by the researcher that consistently received negative answers by participants was a question on the BDI-II pertaining to sleep. Seventy to 80% of the participants reported some change in their sleeping pattern within the two weeks prior to completing the questionnaire. The researcher noticed this because many women would mark only one negative answer on the BDI-II, and this was the item on sleep. Sleep has been studied as part of many symptom clusters existing for breast cancer survivors and was identified frequently as an issue for this group of breast cancer survivors as well.

#### Missing Data

The issue of missing data for this study was discussed at some length in Chapter IV. Overall, the amount of missing data was low and appeared random. Efforts to replace missing data were done solely to allow inclusion of all eligible participants. This researcher does feel compelled to comment on both the FACT-B and the BDI-II in regards to missing data. Because the BDI-II is a two-sided proprietary instrument, it is important to either fill the BDI-II out with the participant to ensure completion of the back side or apply additional highlighting on the form so participants do not miss turning it over.

The FACT-B has been used in many breast cancer studies and performs well with good reliability. It is somewhat cumbersome, though, when dealing with missing data due to the many reversals within subscales. The potential for error with so many computations goes up and must be balanced with the value of the instrument. A computer disc is available for coding the instrument and future researchers might consider that a worthwhile resource tool if using the FACT-B.

Interpretation of Statistical Outcomes Related to Study Hypotheses and Aims

The statistical analyses were guided by two hypotheses and four aims. A discussion of the interpretation of findings related to the two hypotheses and first study aim is presented together due to the similar focus of each of these. For clarity of reading, these are restated along with the discussion.

#### Hypotheses 1 and 2 and Specific Aim 1

Hypothesis 1

Women with newly-diagnosed breast cancer who use expressive writing (about breast cancer or self-selected worst trauma) will demonstrate significantly improved physical health-related outcomes (i.e., decreased medical appointments for cancer-related morbidity and fewer cancer-related issues) and psychological well-being (i.e., decreased depression and anxiety) than those women who write only about the facts of their breast cancer or who do not write at all.

#### Hypothesis 2

Women who write about a self-selected worst trauma will demonstrate outcomes that are not significantly different than those of women who are instructed to write about breast cancer.

Specific Aim 1

Explore whether there is a difference in the observed benefits (i.e., depression, anxiety, and quality of life) of newly diagnosed breast cancer patients who write about breast cancer versus those who write about the facts of their breast cancer (e.g., diet, exercise, sleep, and medication), write about a different more distant trauma, or do not write at all.

Discussion of Results

The statistical analysis revealed those women who wrote about their breast cancer benefited from writing, whether it was about the trauma cancer presents or simply about their diet, exercise, sleep and medications. The majority of the women in the any trauma group (i.e., those who were allowed to choose their traumatic experience) wrote about their breast cancer. Only 4 out of 18 women in this group wrote about something besides their breast cancer. Interestingly, some of those women considered dropping out of the study because they did not want to write about what they thought was really most traumatic for them.

One woman who made that statement did not finish the study even after completing the writing and the T2 instruments. She wrote a very poignant account of her brother's death. Another woman who expressed dismay at being assigned to this group also wrote of her brother's early death in an automobile accident and the resultant family dynamics. Even though these women did not initially want to do this writing, they did comply and turn it in. The participant who wrote about her young brother's death said in her evaluation that it was good for her to get that out but that she would have liked to have written about her breast cancer. It is interesting that this group did demonstrate benefits on the psychological measures of anxiety and depression, but not for physical functioning as the other two writing groups did.

When the first few participants were completing the study and sending back their Follow-Up Questionnaires (FUQs), the researcher began to suspect that the attentional control group was really behaving as an experimental rather than control group. This was based on the statements the participants were making on their open-ended questions on the FUQ. As was discussed in Chapter IV, these questions asked the participants to discuss what they liked and did not like about the study. Some of the statements made are listed below to give the reader a sense of what the participants were saying.

- "It helped me to see some things in a different manner. It was like talking to someone who totally agreed with me"
- "I'm a very non-verbal person and I wrote things I would not have discussed with any one. I
  thought I could never fill that much space but found it easy. I could write things I would not
  discuss with anyone. It was easier than I imagined."
- "I uncovered how I truly felt about being diagnosed. I put up a brave front for my kids-I'm single-but I discovered I was really angry about it. It seemed unfair in light of what I consider to be a healthy lifestyle."
- "I really would have liked to have been in the group that did more writing. I only responded to the
  questionnaires when they came. My answers might appear I'm more sad since having breast
  cancer, but I'm not, just dealing with teenager issues."
- "I have reread them several times. It is interesting to review my feelings at times"

- "This was a chance to write specifically about a particular topic that relates to a positive outcome after my breast cancer diagnosis."
- "Reflecting on what happened to me and analyzing my actions and decisions"
- "I enjoyed the experience and was glad to be able to contribute to research. It made me realize that
   I have been truly blessed."

These comments seem unlikely coming from women who were asked only to write about their diet, exercise, sleep and medications related to their breast cancer; however, they did write as they were assigned.

Another intriguing question arising from the results is "if the majority of the women in the any trauma group chose to write about breast cancer, why were there not the same beneficial results seen for this group as seen in the group assigned to write about breast cancer?" In fact, the any trauma group seems to have only statistically benefited on the anxiety measure. In the analysis from T1 to T2, anxiety was found to be significant (p = .02) for the any trauma group. By T3, their anxiety had once again exceeded that of the control group. It was still lower than the breast cancer trauma group which might indicate some small advantage to choosing one's trauma over being instructed what to write about in regards to anxiety related to breast cancer.

The following comments were made by both the women from the breast cancer trauma group and the any trauma group and reflect the advantage of being forced to write about any aspect of one's experiences.

- "It forced me to compile a written record of my cancer journey. Something I had started to do but never did."
- "I was able to stop my activities and focus on what I had and was going through. When I journaled
  I had been through the hardest time of my diagnosis and treatment. It was good to reflect on how I
  had felt and how far I had come."
- "It forced me to write which did calm me and help express my feelings"

- "It was good for me in that I was forced to sit down and write. I enjoy writing, especially letters
  and notes to friends and family. I recognized through this exercise the benefits of the 'release' one
  feels through writing about personal thoughts."
- "It made me have to sit down and take time for just myself."

As was stated, these comments were written by women in both the breast cancer trauma group and the any trauma group. Some women in the any trauma group did feel forced to write. One has to wonder if being given a choice about what to write about somehow invalidated the personal breast cancer experience and created less benefit for the intervention. Balancing these comments with those made by the women in the attentional control group, a possible explanation is that writing about the facts of one's illness at a very basic level lends validation to the experience. One of the attentional control participants wrote:

I was limited to the diet, exercise, etc group. It was interesting, though; regardless of the topic given, the real topic was breast cancer. There is no escaping the fact that it dominates one's thinking. It still does. I am doing well but it still is in my mind frequently.

This comment coupled with one from the breast cancer trauma group,

It tapped into feelings I did not know were there until I started writing, my thoughts continued to flow when I was not writing. After I finished with the assignment I did feel a great sense of relief. It felt like a purge of negative energy. I also did some drawing along with the writing which was very cleansing! I highly recommend this for healing the soul and spirit,

emphasizes the continued cognitive work that occurs long after the writing has ended. This cognitive work may very well be initiated by either a simple task of writing about one's diet or as complex as delving into one's deep thoughts and feelings. The study indicates that writing about cancer-related issues such as diet may be less threatening and provide even more benefits.

There still remains the mystery of why the any trauma group that primarily chose breast cancer as their trauma of choice would not show physical functioning benefit at the same level as the other trauma writing group, yet showed more benefit on the psychological measure of anxiety. Comments from participants in the any trauma group indicate that they felt like the exercise had indeed been beneficial:

- "I was able to stop my activities and focus on what I had and was going through. When I journaled
  I had been through the hardest time of my diagnosis and treatment. It was good to reflect on how I
  had felt and how far I had come."
- "Expressing my feelings helps me work through issues and find solutions"
- "I am not by nature or habit an introspective person. Therefore it was good discipline to require
  myself to think about where breast cancer fits into my life in relation to all the experiences of
  almost 60 years of living."
- "Cleared my thoughts that I tried to put aside"
- "Bringing to reality what was in my mind. Taking time to reflect on my situation and realizing how blessed I was not to have to have any follow-up treatments!"
- "I didn't like that it was not lengthy or every day."
- "Releasing feelings of fear, anger, and depression on paper. Finding and embracing hope during darkness, allowing creative juices to flow. Exploring meaning and purpose as to why I got this disease."
- "It seemed to release a lot of emotional feelings that I didn't even know I was feeling. It was
  almost a relief to identify those feelings and actually put my thoughts down on paper, many of
  which I had not shared with anyone and as a consequence I was able to share with others."
- "Helped me to be in touch with my feelings"

The comments indicate that these participants did feel that writing was beneficial even though analysis did not reveal the same overall benefits for them as for the other writing groups. It is noted on the ANOVA evaluation of the combined depression scores of the breast cancer trauma group and the any trauma group that at T2 they only approach statistical significance; however significance was found for depression on the MANCOVA. Examining difference in means scores is how the direction of effect of the MANCOVA is determined. The difference in means obtained on the BDI-II scores from T1 to T2 and T2 to T3 indicate a more sustained improvement in depression in the any trauma group than in the breast cancer trauma group. It may be that the group that chose their trauma was more emotionally traumatized by the

event. As one participant said "when I reviewed how breast cancer stood in contrast to the other events that had occurred in my life", it was the one chosen as most traumatic. Choosing it may indicate that, for these women, it is more troublesome; therefore, the women may benefit more at a psychological level than women who do not get to weigh the impact of breast cancer on their life as a traumatic event.

To summarize all of these findings in regards to the two major hypotheses and the first study aim, it can be said that:

- Writing about breast cancer, whether it is only the facts prescribed by specific questions
  regarding one's diet, exercise, sleep and medications or one's deepest thoughts and feelings
  about it, provides statistically significant benefits for physical functioning, depression and
  anxiety.
- The prompt a breast cancer survivor uses to write (i.e., choosing to write about the facts of one's illness when prompted to write about worst trauma as opposed to being instructed to write about one's breast cancer) does make a difference in the type of benefit she might expect. Choosing one's trauma may not improve physical functioning, but may improve the reduction of depression and anxiety. Writing about breast cancer, as instructed, may lead to benefits related to physical and emotional functioning.

#### Specific Aim 2

Specific Aim

Evaluate the perceived physical effect of expressive writing by comparing the number and type of physician visits made during the study period by participants in the four groups.

Results of Specific Aim 2

Participants were given a log to record all physician visits over the 6-month interval of the study. They were instructed to include all visits including eye exams, dental exams and annual healthy woman check-ups. They were asked to do that so there would be no question of what to record; they simply would record everything. In previous research on expressive writing, Dr. Stanton and her research team (2002) conducted a random analysis of a small percentage of participants' medical records to demonstrate validity

for the self-report tool. They achieved a 92% rate of agreement between participants' self-reports and medical records regarding physician visits. A similar process was employed with this study. A random sample of 30 participants was drawn and medical records obtained. Self-report was validated not only for medical visits, but also for demographic data such as pathology of breast cancer and stage of breast cancer. This was done because in the pilot study performed by the researcher, it was noted that some women were unsure of their pathology and stage of cancer. Medical records for 21 of the 30 selected participants were complete and could be evaluated. The results of the analysis indicated a 92.5% agreement between participants' self-report and medical records. The agreement of 97.6% related to physician visits was very strong. The agreement of 87.4% between pathology and stage was slightly less. Similar to the pilot, six participants reported incorrect pathology or stage of their breast cancer. No significant changes were identified in physician visits for cancer related problems. On the whole, women were quite healthy with little cancer related morbidity. There were no significant differences on any other types of medical visits either, including CAM (complementary and alternative medicine) and psychotherapy.

#### Specific Aim 3

Specific Aim

Determine if barriers exist that interfere with the use of expressive writing in this diagnostic group.

Results of Specific Aim 3

As was discussed in Chapter IV, participants were given a follow-up questionnaire (FUQ) at the end of the study and asked to provide feedback about things they liked and didn't like about the expressive writing exercise. They were also asked to list suggestions for using expressive writing with other breast cancer survivors. The number one barrier participants listed as interfering with their ability to do expressive writing was simply taking and/or having the time to do it. Many women stated that the thing they liked least about the writing study is that they didn't keep writing. Other barriers listed or things women didn't like were:

reliving negative experiences

- not being given prompts that encouraged deep thoughts and feelings (several women from the attentional control group stated this)
- not perceiving themselves to be writers either by what they wrote or how they wrote, i.e. two
   women expressed dismay at how their handwriting looked
- Not liking to write
- having to sit still to do the writing
- Not liking to dwell on the cancer; a participant wrote "I'm a very private person who finds it difficult to share my thoughts with strangers. Although I'm totally accepting the fact I have had cancer, stopping each day to dwell on it was a step backwards for me. I much prefer a positive attitude with the realization that things may be changing as I write. Mom often quoted a verse she'd learned in school "Don't trouble till trouble troubles you" (This participant was in the attentional control group)
- Too much focus on self and problems and no way to resolve issues identified.

(Major themes and excerpts from the journals will be discussed in a later section of this chapter and the reader will see that indeed some of the participants wrote some very bleak thoughts and feelings about where they were in their breast cancer journey.)

- · Regretting what one writes; not wanting to see it later
- Fear of who might read one's writing
- A participant in the any trauma group wrote, "Perhaps the answer is that it was a little painful to
  try to think about unpleasant things in the past in order to compare to the experience of having
  cancer." (For a woman like that, choosing her trauma might not be best.)

For the majority of respondents the biggest barriers to writing were finding the time to do it and being willing to face negative emotions. As one participant summarized: "The hardest part was to actually find time for the writing. The discipline was difficult especially knowing I was again going to face all the fears and all the emotions I felt during that time." Paradoxically, many participants also wrote that what they liked best about the writing exercise was essentially being forced to do it. And then, when they were

finished, wrote that they were unhappy that they had not continued to write. It seems that women are so busy doing other things that it is hard to find time to do something for themselves. Once that time is taken and the benefits seen, they become unhappy with themselves when they don't continue to make time for it. This supports the concept of validation. It could be argued that women in general do not validate their unique experiences and give sufficient recognition to their own needs. One benefit from this exercise appears to be the inherent validation of the traumatic event and the forced 'decompression' of that traumatic event. Similar to Critical Incident Stress Debriefing (CISD) that is mandatory for emergency personnel after a critical event; these women at first do not necessarily recognize their breast cancer as traumatic and don't recognize the need to express feelings about that event. When they are forced to recognize the trauma and write about it, the majority express a sense of relief and "purging of emotion". This seems to occur even if they do not write about their feelings, but simply write about themselves in relation to how they eat, sleep, exercise, and take medications.

Possible solutions for these barriers include shortening the amount of time a woman does the expressive writing. For some women 10 minutes might be sufficient and might make her more likely to do the writing. A study looking at the "dose" required for benefit would be helpful. Reliving negative emotions might actually be the route to benefit for some women; but, if it keeps them from writing, they may simply want to use the daily prompts employed by the attentional control group. This may not work for all women, however; because, as the comment quoted in a previous paragraph showed, some women in the attentional control group did not like being forced to think about their breast cancer even if it was only their diet.

Other barriers include physically not being able to write or being unhappy with one's penmanship.

This could be dealt with by encouraging those women to use a computer to write. For women who do not see themselves as writers or who do not like to write, one woman had a suggestion for them. She said, "Write one liners. How you feel, and so forth, throughout the day. I found it difficult to sit down and write. I felt like I was in school and had an assignment. For me, it's easier to write single thoughts during the day or evening, whenever I'm having the thought or feeling."

A concern for some participants was that writing presented them with feelings that were not resolvable. Women who are encouraged to do expressive writing about their breast cancer should be encouraged to seek help if they find themselves feeling considerably worse after writing or if they have raised issues that are not resolved. It may be that these women would benefit from counseling, and the expressive writing exercise is a tool to identify that need.

If clinicians recommend their clients do expressive writing, it would be appropriate to evaluate the intervention just as any intervention is evaluated. If women report that it has generated feelings of sadness that are not resolved, then an appropriate referral can be made. The last barrier identified by the women in this study was one of regretting what was written and fear of who might read what one writes. Gillie Bolton (1999) talks about the cathartic effect of writing something and then destroying it. Women who are concerned about later reading what they write or about someone else reading it could simply destroy it.

Overall, although several barriers to expressive writing were identified by respondents, they overwhelmingly supported using it for other newly diagnosed breast cancer patients. Table 35 displays pairs of comments made by respondents. Each pair is the same woman responding first to what she did not like about the expressive writing exercise and, secondly, what she would suggest for other women considering the use of expressive writing after being diagnosed with breast cancer. This display graphically demonstrates that, although there are barriers, expressive writing is seen as a very useful tool for breast cancer survivors.

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## Things they did not like

It brought back all terror and fear of being diagnosed with breast cancer

It made me relive what I had initially felt and thought I had put

behind me.

I experienced some guilt that I did not journal through this whole experience to have something to look back on. Yet at the time I would have considered it somewhat of a burden. I learned so much about myself and my world that I don't want to forget those lessons.

There was no resolution to questions. In a way it seemed that writing Focused too much on self and negative feelings.

Taking the time to do it.

# Suggestions for others

I suggest to people to use a journal to help relieve stress and to express their innermost worries/feelings.

I give this advice but I do not follow it.

Don't let it be a burden but recognize its merits. I kept in touch with family and friends with very personal emails that I have saved. I intend to make a book out of them so I will never forget the support I was given by so many. I think it will help me to support others through their trials.

Do it on a long term so you can see change and how you

To overcome issues. Don't give up on the process.

Write your innermost thoughts. Trust yourself and God.

Table 35 (Continued)

# Participants' Paired Comments Regarding Use of Expressive Writing

	Things they did not like	Suggestions for others		
	I do not like to write and I never have.	I would encourage writing because it helps a person		
		release ideas and thoughts they may be pondering.		
148	Just having to sit down, take time and think about the experience.	Do it immediately. My expressive writing was too long after my treatments and it was almost like reliving it. It would have been better while I was going through it, although I might not have felt like doing it.		
	It made me deal with emotions that were painful.	If it is a positive experience and helps them deal with their		
	I did not find it therapeutic.	pain, experiences and current conditions, then by all means.		

Specific Aim

Explore the duration of benefits of writing following the expressive writing activity.

Results of Specific Aim 4

The results across T1 to T2 to T3 indicated that the improvements in physical and psychosocial interventions seen in this population of breast cancer patients do appear to be sustained, albeit not strongly sustained, over the six-month period of time. Most participants had worsening in their scores from T1 to T2 and gradual improvement by T3. This may be a maturation effect as participants are getting further past the acute treatment and dealing better with physical and psychological sequelae of breast cancer. Some women in this sample actually completed the study at four months rather than six months to allow them to be part of the data analysis. This was supported by expressive writing designs that have reported the final evaluation time anywhere from 3 months to 6 months past initial study entry. A comparison of these women's final scores indicated no difference from those who had completed in 6 months or longer. In summary, the beneficial effects of expressive writing are sustained over time; but the effects are only minimal

## Discussion of Clinical Significance of Outcomes

The results of this study indicate that women who are diagnosed with breast cancer may benefit physically and emotionally from doing some form of expressive writing. A finding that was unexpected also indicated that there was a reduction in the use of antidepressants in all groups who did some form of writing. This finding has limitations in that the number of women who identified the use of antidepressants was small (see Table 36). In addition, the use of antidepressants at the beginning of the study was unknown. Nevertheless; this finding has clinical significance due to the problem of depression in breast cancer survivors. Depression is reported to occur in up to 30% of breast cancer survivors and persist beyond initial diagnosis. In a study by Hughes (1982), 20-30% of women treated for breast cancer had persistent distress for two years or more following surgery. Seleeba, Weitzner, and Meyers (1996) found mild emotional distress that persisted for five years or longer in breast cancer survivors.

Table 36

Use of Antidepressants in Study Population

Number. who used Antidepressants
3
0
1
1

It is also apparent that using expressive writing was beneficial for women's physical functioning and related quality of life. Although this was not reflected in the number of physician visits, it is clinically important for women to have a higher level of physical functioning. This has an impact on their ability to perform household tasks, job functions and in general feel "well" or as one participant put it "feel like myself again". The individual subscales on the FACT-B were evaluated to determine specific items that contributed to the significant findings on this instrument. Three items were found to either be statistically significant or approaching significance (Table 37).

Table 37

FACT-B Items of Clinical Significance

Item	Group	M	SD	p value
T2 Breast CA Subscale Item #4: "I feel sexually attractive"	Attentional Control	2.56	1.09	.053
	Breast CA trauma	1.59	1.01	
T2 Breast CA Subscale Item #2:				
"I am self-conscious about	Control Group	2.93	1.25	.119
the way I dress"	Attentional Control	3.72	.57	
T2 Physical Well-Being Subscale	Control Group	2.76	1.12	.021
Item #5: "I am bothered by side	Attentional Control	3.61	.61	
effects of treatment"	Breast CA group	3.32	.95	.228

The results displayed in Table 37 demonstrate that women in the attentional control group felt better about their sexual attractiveness as compared to the breast cancer trauma group. This echoes the previous discussion on sexuality concerns. Self-consciousness regarding dress approached significance (p = .119) with the attentional control group showing improvement in this over the control group. The third item dealt with physical well-being, specifically being bothered by side effects of treatment. The attentional control group was doing significantly better in this area than the control group, with the breast cancer trauma group approaching significance.

These results support the previous discussion regarding satisfaction with sexuality and the loss of interest in sex that was identified by up to 50% of the participants. It is unknown whether including a "day" of writing about sex along with diet, exercise, etc would be beneficial for women; acknowledging that the women who were in the group that wrote about such topics were the ones who had improvement in the area of feeling sexually attractive.

Anxiety was not found to be a significant issue for this sample except for the any trauma group. Except for this group, none had levels of anxiety higher than the norms obtained for other breast cancer groups or for working adults, and the norms were much lower than those reported for college students or outpatient mental health patients. Overall, it seems that anxiety was not a significant issue for this sample. The literature does suggest though, that like depression, anxiety can be a long-term problem for breast cancer survivors.

The writing the participants did provides additional information regarding significant clinical findings. Although this study is not qualitative, the writing shared by the women in their journals is powerful and illuminating; therefore excluding this from the clinical discussion of findings would be neglectful. The journals were carefully read by the researcher and very broad themes/categories or general issues were identified. These will be presented along with select excerpts to allow the women participants to instruct the reader about some other very important clinical findings.

The first general category that women wrote about can be termed "the body". This includes issues similar to those identified for the women in the attentional control group (i.e., diet, exercise, sleep, and

medications). Other issues frequently addressed were joint pain, breast-related concerns and a final category of getting back to "feeling normal" is included because it really seemed to focus on feeling physically like one's old self.

#### Diet:

- There is pride about taking care of oneself in what they eat
- Women learn they are worth the effort to eat right
- Women see caring for their body in losing weight as a sign of moving on and past their breast cancer experience

#### Exercise:

 Working out, exercise, and walking are emphasized as important and signs of taking care of themselves

# Sleep:

 Sleep disturbance is almost uniform and some women struggle with not wanting to take meds to help them sleep. They desire nonpharmaceutical interventions but are frustrated with the lack of information given to them about that.

#### Breasts:

- "Why does having decent looking breasts have to be so difficult?" "It is really bothersome to me
  to look at my chest and have uneven breasts"".
- "I remember looking down at my chest and thinking how strange 'no breasts after almost a life
  time of having them' and I remember my husband holding my hand and kissing my forehead and
  saying 'they got it all' and in my drugged mind, I was thinking 'they certainly did, there is nothing
  left'

#### Joint pain:

Joint pain with aromatase inhibitors is mentioned frequently as an issue

Many women do not like taking medications and express a desire to limit the amount of
medications they are on. It seems to be linked with a feeling of control. As one participant wrote,
"I'd rather control things with diet and exercise than take more pills!"

#### Getting back to "normal":

- Women also seemed to have a goal of "feeling like myself again". They seem to mark time by when they feel like themselves. "It's not as easy as my surgeon and oncologist have suggested to 'just go live your life', This is a part of my life now'."
- "I sometimes wonder if I'll feel normal or like myself ever again. I guess after this I shouldn't think about normal and ought to just be grateful I'm still here to be thinking about it". "I started a journal while traveling and it has helped me considerably. I find that if I'm thinking about something that's really bothering me, if I write it down along with my feelings surrounding it, I stop carrying it around with me. The thoughts aren't as muddled and my communication is more clear."

A second category identified by the researcher is simply termed "emotional". Issues included in this category include anger, guilt, uncertainty, control/fear and family.

#### Anger:

Anger does not seem to surface until after treatment is over. Women regain energy following
treatment which seems to allow them to deal with negative feelings that had not occurred to them
before.

#### Guilt:

- Women struggle with guilt in two ways; one is looking and feeling better than other women with breast cancer. They also talk about guilt over causing their breast cancer through unhealthy habits such as not eating right and not exercising.
- "There, I tried to eat the right foods, exercise, meditate and yet I still could not control the mass that grew so rapidly in my breast taking my right breast. Yes, I hate to admit this, but here I am still believing that my misery and anxiety manifested itself in my body. My life was malignant,

full of stress and despair; I was convinced at one level that it was all my fault. This cancer was my consequence for my inadequacies. But I know today that it has been my gift to share with others. The journey is just beginning and I must be reminded and my scars offer that reminder sometimes gently and at times quite loudly".

#### Uncertainty:

- Women talk about a struggle between what is immediately recommended versus one's personal responsibility to research available choices. They wonder if the decision they made was wellinformed and second guess themselves.
- The participants expressed uncertainty related to their role in long-term care and prevention.

### Control/fear:

- Women write about fear of recurrence, fear of death and fear of family responses. They talk about
  not wanting to talk to their family about these fears because they don't want to upset them. They
  say that leads to loneliness even within a loving structure because they cannot verbalize what
  scares them the most.
- They talk about worrying about stress because stress is not supposed to be good. (Stressing about stress.) "I have so many pills I have to take now also. I'm sick of that too." "I've read where stress isn't good for you so I really am trying to stay positive."
- Through writing they talk about unearthing thoughts that cause existential distress i.e. thoughts
  that cannot be resolved, as one participant said, they can only be acknowledged and lived through.
- Maintaining a positive attitude is recognized as a burden, but again women are hesitant to talk to
  their family about their concerns so as not to upset them. "Not all of us can win the Tour de
  France. What about us normal survivors?"
- A way that some of the women deal with this is to remind themselves of how much worse it can be.

#### Family

Family secrets

- Loneliness within loving relationships "Everyone, including myself wants it to be gone. Lets talk about something else, you will be fine".
- "I find that I've learned to hide my fears and worries from everyone else".
- Family support is vital. Participants mention the importance of having family at appointments
   The third major category identified is termed "health providers". This incorporates journal entries that dealt with the health care system, information/teaching that was provided (or not provided), and care received.
   Subcategories include communication, education, and compassion.

#### Communication:

- Many women talked about not remembering much of what was said after the diagnosis was made.
- Even though women talk about not remembering a lot of what is said, they are impacted by things
  that sound frightening. Even when communication is not meant to be frightening or upsetting, it
  may still be because the woman does not understand the terms the clinician is using.
  - One patient talked about how scared she was when the doctor talked about having an MRI and checking her lymph nodes. Although this is routine, the patient thought it meant she was dying.
  - Another patient talked about how a radiologist told her right before surgery that she would be disfigured.
  - "I'm sure the nurse was trying to be helpful but telling me to get right with God wasn't comforting".
  - Trust is vital. Some women talked about seeking a second opinion because they did not feel the surgeon generated a feeling of trust.
  - "His nurse was not personable. One time I called to talk about the side effects I was reading about on the internet and I asked my questions and she said 'when you come in to start the chemo we will go over all the side effects with you.' I said why do you wait until then and she said 'because if we do it earlier, the patients do not come back.' "I was so upset with her, I thought when I get all through with this chemo I will go back to school

and become an oncology nurse and take her job. I was sure I could be a better nurse than she was."

#### Education:

- Many women wrote about their hormones "showing up" in their tumors. They believe this means that the exogenous hormones they were taking as hormone replacement therapy caused their breast cancer. This causes a great deal of guilt. They do not appear to have been educated in the correct understanding of what ER+/PR+ tumors really mean. "Its kind of ironic that now I have to take Arimedex which causes hot flashes which was why I was taking the hormones which caused the cancer".
- Many women in the attentional control group wrote extensively about diet, expressing concern
  about what they read on the internet about milk, beef, chickens in cages and fruits and vegetables
  not grown naturally. Although changing their diet may represent a source of control, the
  information may be incorrect or at a minimum unproven and has the potential to cause guilt and
  fear.
- Several women talked about being frightened by information viewed on the internet. They often
  discuss feeling overwhelmed and scared by what they read.

#### Compassion:

- Women identified that being left in the room after being told they were to have a biopsy is frightening.
- Even though antinausea drugs provide reduction in nausea 80% of the time, several women talked about uncontrolled nausea and vomiting. What was even more distressing was the comments made about poor care received in hospitals and feelings of despair related to the inability to get the help or compassion they needed from their health care provider. One participant wrote about her horrible experience in the hospital. "Had to wait for hours in ER waiting room full of sick children. No response when told nurses IV was out. Was given IM injection for nausea!"

Along with the issue of compassion is that of respect. Women questioned whether they really were
allowed to participate in some decisions such as when they went back to work or what type of
birth control they should use when they have to come off birth control pills.

The final category of journal entries is entitled "Meaning Making". Within this overall category are subcategories of inward versus outward meaning and Post Traumatic Stress Disorder (PTSD) versus peace.

## Inward versus outward meaning making

- Several respondents wrote about the desire to help other women, faith that God will use their
  experience to help others and a search for how it has made a difference in their family such as
  helping their children learn how to handle things
- Inward meaning making centered on making changes in diet, exercise, etc. to reduce the chance of
  having a recurrence or even a different kind of cancer. Using the breast cancer experience as a
  platform to improve their overall health seemed to validate the experience.

# PTSD versus peace:

- The writing indicates that breast cancer is a hugely traumatic experience especially if the woman
  has a negative experience with chemotherapy.
- Peace is possible after confronting the terror and coming through
- "I'm beginning to see that writing my feelings and thoughts seems somehow therapeutic. It helps me put the "cancer trash" that's in my head somewhere else—on paper—out of my life". I think
  I'll have to take up journal writing as my own personal therapy."

Clinically significant findings include the impact of breast cancer on basic physical issues such as diet, exercise, sleep, pain, body image and sexuality. Expressive writing was demonstrated to provide potential benefit to how women feel about these issues. Clinicians may benefit from knowing that women wrote about feeling anger, guilt, uncertainty and fear. It is important to note that participants discussed the importance of family but also identified the paradoxical isolation that occurs when

communication with families is censored to protect the family. This makes one wonder if simply determining the presence of family support is sufficient.

Support may be available, but not accessed for deep thoughts and feelings. Communication by health care providers was frequently discussed by participants as a source of dissatisfaction. Health care workers can read these comments and recognize the need to choose words carefully when discussing treatment with patients and considering how "stories" or recommendations (such as getting right with God) may be interpreted by individual patients. The overwhelming importance too, of completing the feedback loop of communication and ensuring the understanding of what was said is highlighted. Finding meaning and reducing the traumatic aspect of the breast cancer experience are fundamental outcomes of the expressive writing intervention and will be discussed in depth in a later section.

#### Case Studies

As a final presentation of the journal entries, the following five entries are presented as individual case studies. Table 38 lists the scores obtained for each of these participants. The entries are chosen to illustrate the trauma that may be experienced by breast cancer survivors and the apparent personal benefit obtained for these women through expressive writing.

Participant 1: "Writing makes me think about my deep dark hidden feelings. It makes me search out the corners of my heart". "Is it okay to have days when I don't stop and think or stop and worry?" "I hate the word cancer, I hate seeing doctors". People who stop and say something about the breast cancer.... I struggle for an answer to them: 'Well, I had put it out of my mind until you reminded me!' "Where is my mother when I need her?" Am I trying to 'suffer in silence'?" "Has this writing assignment brought feelings to the surface I have chosen to ignore? Am I depressed? Scared? "How does my husband feel about my breast cancer? Is he afraid for me?" Has it made me a better or bitter person? "The bottom line: I feel responsible for causing the breast cancer... Was this brought on by me? Am I to blame? Do I need help? Some one tell me."

Evaluation comments made by this participant:

- Liked about the exercise: "Expressing my feelings helps me work through issues and find solutions"
- Did not like about the exercise: "Sometimes I write things that I later don't like what I see".
- Recommendations for other breast cancer survivors: "Do it!"

The difference between BDI-II scores for this woman was a worsening in depression scores from T1 to T2 and a stabilization of the score from T2 to T3. None of the scores are considered clinically significant. FACT-B scores all went down between T1 to T2 but had started recovering from T2 to T3. STAI for the State component showed a gradual decrease in anxiety scores from T1 to T3 with an 8 point overall difference from beginning to end. Her first two scores were higher than other breast populations reported in the literature of 33.15 (Williams, 2004) but dropped to 31 by the end of the study. The FACT-B scores for this participant were all within norms set by other breast cancer populations. Similar to her other scores, she dropped from T1 to T2 and began recovery by T3.

Participant 2: "I have decided to write about my breast cancer experience partly because I have felt the need to express myself since the diagnosis which occurred almost a year ago and partly because I am feeling very alone with the disease". "There seems to be a lot of wondering when you have had cancer, not the least of which is wondering if I have received the best treatment". "The holidays are almost here and I will be at big family gatherings where relatives will ask me how I feel: I will respond, fine, just fine." "When I am gone I hope my children don't think of what disease I died of but rather how very much I loved and cared for them."

Table 38

Case Studies

	Group	BDI-II	FACT-G	FACT-Total	FACT-TOI	STAI
	1: Any trauma group	T1=4 T2=7 T3=7	T1=99 T2=87 T3=90	T1=125 T2=109 T3=113	T1=78 T2=68 T3=69	T1=40 T2=37 T3=31
	2: Any trauma group	T1=9 T2=20 T3=14	T1=73 T2=64 T3=71	T1=94 T2=85 T3=92	T1=60 T2=61 T3=57	T1=44 T2=53 T3=54
	3: Any trauma group	T1=22 T2=19 T3=10	T1=62 T2=68 T3=78	T1=83 T2=90 T3=108	T1=51 T2=55 T3=73	T1=30 T2=38 T3=26
	4: Any trauma group	T1=5 T2=12 T3=11	T1=86 T2=86 T3=78	T1=112 T2=109 T3=102	T1=71 T2=69 T3=62	T1=37 T2=44 T3=52
	5: Breast CA group	T1=10 T2=n/a T3=11	T1=86 T2=n/a T3=84	T1=98 T2=n/a T3=103	T1=57 T2=n/a T3=63	T1=28 T2=n/a T3=40

Evaluation comments made by participant 2:

- Things I liked about this exercise: "I discovered many feelings about the diagnosis, treatments,
   and responses of others that I had not allowed myself to think about prior to writing the journal".
- Things I did not like about this exercise: "There was really nothing that I disliked. It was very beneficial".
- Recommendations to other breast cancer survivors: I would really encourage the use of writing as
  it is clearly a tool to assist with dealing with all the jumble of feelings brought on by this
  experience.

As Table 38 shows, this participant had an 11-point rise in her BDI-II score from T1 to T2, but then a 6-

point drop from T2 to T3. She, like Patient 1, also dropped on all T2 FACT scores but had recovered almost to baseline before the end of the study. Her anxiety scores, however, started high and got higher. The rate of increase was much lower from T2 to T3 however. These values are higher than reported norms in breast cancer and may indicate a true increased level of depression and anxiety for this participant. Her BD1-II score dropped below clinical significance at T3 but her anxiety score was still high.

Participant 3: "I will never ever forget what the radiologist said to me nor her tone of voice. I knew it was bad news because her upbeat voice didn't sound so upbeat today. She told me that I did have a cancer in that breast. Immediately my life was in slow motion. Fun times flashed before my eyes and I could barely hold the phone or hold it together". "From there she told me to come in for an MRI to see if it had spread to the lymph nodes. Lymph nodes? I didn't know much about them, but I thought that's how people die. If it spreads to their lymph nodes. Oh shit! I thought. All I could think about was that movie Terms of Endearment and that I was going to be like the daughter in that movie, and my mom and family would be so sad if I died."

Evaluation comments from this participant:

Things I liked: Releasing feelings of fear, anger, depression on paper. Finding and embracing hope
during darkness, allowing creative juices to flow. Exploring meaning and purpose as to why I got
this disease.

- Things I didn't like: Really nothing, except keeping track of doctor's appointments was stressful at times.
- Recommendations to other breast cancer survivors: I would tell a newly diagnosed person they may be having feelings of fear related to mortality, anger, questioning everything, depression and those are all normal. I would encourage them to talk to someone they trust about these feelings as opposed to "bottling them up". If they don't like journaling, they have got to find a healing avenue to release their feelings, so I would explore these avenues with them. I would also talk to this person and say "drat it, it is ok to honor any and all feelings and they don't have to be positive all the time. What does a cancer diagnosis mean to them? Are they afraid of dying (most family members are not going to bring this up with them) because they are scared too. Finally, I would listen, listen, listen, listen.

This participant's scores demonstrated an "across the board" improvement on all measures from T1 to T2 and even higher at T3. Her scores were clinically significant for depression at T1 and T2 but had improved to not being clinically significant at T3.

Participant 4: "Even though I had support from family and friends I had never felt so alone in all my life". It was difficult to pray, I felt abandoned by God and I absolutely could not turn this over to him. It was something that was an integral part of my life that clung to me even though I wanted just to fling it away". "There were many days I couldn't even think of a reason why I was alive".

Evaluation comments from this participant:

- Things I liked: It seemed to release a lot of emotional feelings that I didn't even know I was feeling. It was almost a relief to identify those feelings and actually put my thoughts down on paper, many of which I had not shared with anyone and as a consequence I was able to share with others.
- Things I didn't like: The hardest part was to actually find time for the writing. The discipline was
  difficult especially knowing I was again going to face all the fears and all the emotions I felt
  during that time.

• Recommendations for others: I think it is a very worthwhile thing to do. I really wish I had done it from the time I was diagnosed, even to jot down a few lines. Chemo was so difficult I don't know if I would have had the energy or the courage to face those emotions at that time but the reflection back to that time after treatment was like a huge burden being lifted.

This participant's scores indicate that, like other women, her depression score went up from T1 to T2 but not to a clinically significant level. It did drop slightly at T3. Her scores, however, on FACT-B and on STAI worsened over the course of the study with anxiety being seven points higher from T1 to T2 and eight points higher from T2 to T3.

Participant 5: Even now, after treatment, I struggle with what this has done to me both physically and emotionally"." I know that every life experience changes us, but I'm not yet happy with the person the cancer has made me." "Probably the thing that has changed the most in my life because of cancer has been the relationship with my husband. During treatment, I could not have had more emotional and/or physical support from him. But our physical relationship has and is suffering. We do not have the bond there that we had before and I am afraid things will never be the same. There are of course, other ways to express our love, but I miss the physical relationship that we had before this happened. I feel as if I've grown old before my time". To examine my deepest thoughts about cancer means to face death." But somehow along the way, I think you have to figure out how to live with cancer, also." "I don't want pity, I just need someone to talk to who doesn't think they have to cheer me up or solve my problem". "That's why I try to keep writing in a journal. It lets me vent and then sometimes I see what I have written and I can better understand myself, how I really feel".

No evaluation comments were available from this participant and she failed to return her T2 instruments, therefore only T1 and T3 are available for comparison. Her scores indicate no real differences between her BDI-II scores and her FACT-B scores from T1 to T2. Her STAI however is elevated from 28 at T1 to 40 at T3.

These women's stories portray the traumatic experience of breast cancer. Existential, physical, emotional and spiritual crises are all discussed in frank honesty. All of these women rated the writing

experience helpful, enlightening, and cathartic. The positive benefits mentioned by these women in their evaluation comments are not always reflected in their scores on quantitative measures. This is important to recognize when the 'importance' of this study is addressed.

In summary, the improvement in feelings of sexual attractiveness, feeling good about one's overall appearance, reduction in side effects and depression including the reduction in antidepressants are seen as clinically significant results from this study. Women in the attentional control group benefited the most from the writing exercise in these areas; however, all writing prompts demonstrated clinically important improvement in physical and psychological functioning.

### Study Implications

This work is important because a diagnosis of breast cancer can lead to physical, cognitive and affective distress (McKenna, Zevon, & Corn, 1999; Zabalegui, 1999). Unrelieved distress may lead to impaired functional status that is unique and different from impaired status related to surgery and other breast cancer treatments (Cimprich, 1999). If expressive writing is found to be useful in breast cancer patients, it could provide an efficient, low-cost, and minimally burdensome coping strategy for this group. The research on expressive writing indicates that it may be beneficial in helping people sort through traumatic events in their lives, either when events are recent or occurred many years in the past (Greenberg & Stone, 1992; Lepore & Smyth, 2002; Pennebaker, Colder, & Sharp, 1990; Rosenberg et al., 2002; Stanton et al., 2002; Walker, Nail, and Croyle, 1999).

The research presented in this paper has provided further evidence for the practice of expressive writing in breast cancer survivors. Quality of life effects related to physical functioning included such elements as positive thoughts about sexuality and body image and dealing with side effects from chemotherapy. Other important findings support the use of expressive writing as a mechanism to reduce the incidence of anxiety, depression, and possibly even the use of antidepressants.

This work also contributes to understanding the writing prompts that might be most beneficial for women who are using expressive writing to deal with the trauma of being diagnosed with breast cancer.

Previous research on cancer in general and breast cancer specifically has not delineated differences in

prompts for trauma. Rosenberg et al. (2002) allowed participants to write about prostate cancer or about a self-selected trauma but they did not separate the groups or report on results separately. Stanton's work (2002) on breast cancer survivors randomized participants to groups who wrote about the trauma of breast cancer or about the positive benefits of breast cancer in their life. None of the studies listed involved allowing participants to choose their own trauma and the evaluation of that choice. Another difference between this study and the others previously mentioned is that the attentional control group used in this study demonstrated statistically significant results. This actually leads to additional information regarding the writing prompt that might be useful for women with breast cancer. The results obtained in this study indicate that women may receive as much, if not more benefit, by simply writing about apparently "safe" topics such as diet, exercise, sleep, and medications.

This study also differed from others in the use of open-ended questionnaires for feedback from participants to provide information regarding barriers to writing and possible solutions for those barriers.

The comments received from participants proved a valuable source of information regarding the effectiveness of the writing intervention beyond the data provided by quantitative analysis.

In summary, this study differed from previous studies on expressive writing with cancer patients by presenting a different design using self-selected trauma and reporting significant results of the attentional control group along with evaluation comments to provide clarification and illumination of these results. This study also differed from others by providing an in-depth exploration of the barriers, perceived benefits, and recommendations for the use of expressive writing in breast cancer survivors.

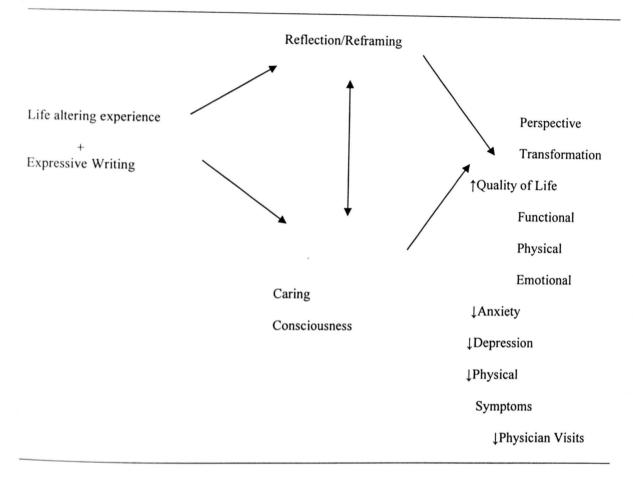
# Results and Theory

The theoretical framework for this work was summarized in Chapter I in the following manner:

By doing expressive writing the woman who has been diagnosed with breast cancer is able to reflect on her life-altering experience, reconstruct meaning, and transform actions to assist with physical and psychological responses to breast cancer (see Figure 10).

Figure 10.

Expressive writing conceptual framework.



Components of this framework involve the perspective transformation (Mezirow, 1978) that occurs when people reflect and subsequently reframe life-altering occurrences; this reframing allows for cognitive change in how the individual thinks and feels about the experience in context with their life. Inhibition of traumatic thoughts is a facet of this process whereby persons may expend energy suppressing unpleasant thoughts. When the unpleasant thoughts are expressed and reframed, the energy is released for improvement in health, whether physical or mental. Changes in mood and decreased isolationism are reported as components of this cognitive change (Pennebaker, 2002). Pennebaker also asserts that "constructing stories facilitates a sense of resolution, which results in less rumination and eventually allows disturbing experiences to subside gradually from conscious thought" (Pennebaker, 1999, p. 1243). In

addition to the cognitive change and perspective transformation that occurs when a person reflects on traumatic events, a meaning for, and of, the event emerges that provides an essential element to dealing with life's trauma. Although not a matter of intellectual cognition, Frankl (1959) believed that "to live is to suffer, to survive is to find meaning in the suffering". Frankl, a holocaust survivor, became convinced that, as he quotes Nietzsche "he who has a why to live for can bear almost any how". He proposed that meaning is not made, but detected; therefore, in order to discover the meaning in distressful situations, some degree of reflection has to occur. Fife's (1995) research with breast cancer survivors indicated that the ability to find meaning in their situation was predictive of personal control, body image and psychological adjustment. Lastly, Watson (2002) proposes that when persons intentionally direct their own positive thoughts and caring spirit toward being authentic and attentive in listening to themselves and becoming sensitive and mindful of what is most important about their lives, they can understand and transform their own suffering.

The results of this study support this theoretical framework. The women used many of the same words used by the above mentioned sources to describe the impact of expressive writing on their lives.

Women reported that writing helped them see things in a new and different way; helped them release emotions they did not even know they had, thus giving them a sense of relief; helped them feel better about themselves regarding body image and side effects of chemotherapy; and provided internal and external meaning for the experience of having breast cancer. Several participants talked about how nice it was to discover things about themselves they were not even aware of, how writing was like talking to someone who completely agreed with them, and how writing allowed them to share previously undisclosed thoughts and feelings with others. All of this substantiates the theoretical framework of perspective transformation through the action of caring consciousness, active reflection, reframing, and cognitive change. The importance of finding meaning in the trauma of breast cancer was reflected in the belief that good could come from the experience and reflecting on how the experience fit in their lifetime of other experiences.

Many of the participants talked about their happiness in being able to help others through their participation in the study while focusing on helping themselves.

#### Critique of the Study Limitations and Strengths

#### Limitations

Limitations to this study include several confounding factors that may interfere with the relationship between the independent and dependent variables. Several of these were previously discussed in Chapter I. Overall; the limitations involved the increased attrition rate seen (a) in women who had received chemotherapy and (b) in women who were in the attentional control group. It is possible that late effects of chemotherapy such as fatigue may have contributed to this, possibly altering the outcome. More interesting, was the relatively higher rate of attrition for the women in the attentional control group than in the other groups. Some of these women remarked about not feeling they had received an in-depth assignment and wishing they had been in the intervention group. It may be this feeling of less value may have contributed to the attrition rate in this group. It may also be true that these women were less bothered by their breast cancer as reflected by their scores on the instruments and thereby did not feel the need to stay on the study. In essence, it is not possible to know whether these women dropped out because of feeling unimportant or feeling too healthy to continue with the study; or some other unknown reasons. Therefore, sample size is a limitation in this study as the sample of attentional control women who met all the criteria for inclusion in the final analysis was only 12, the lowest of the four groups. Another limitation of the study includes the inability to generalize findings beyond breast cancer survivors, women who would actively agree to participate in expressive writing and women who come from different demographic backgrounds. A final limitation includes the use of the MANCOVA statistic when the data set violated the assumption of homogeneity of regression. This limitation was offset by further evaluation of the data ANOVA and paired t-tests on difference scores but remains a statistical limitation of the study. Strengths of the Study

Strengths of this study include the experimental design which included a randomized, control group design. Statistical analysis of the groups indicated the randomization process worked to produce groups with no significant differences at the onset of the study. The overall sample size is adequate with 68

participants being included in the test statistic. Except for the attentional control group, group sizes were good with 25 in the largest group.

The study included both quantitative data and open-ended answers to evaluation questions which provided the ability to explore and illuminate the results of the quantitative analysis. The experimental design included different aspects of expressive writing that have not been explored in other research studies, providing structure for specific writing prompts for breast cancer survivors.

Another strength of this study is the ability to provide not only aggregate data analysis, but also individual case study analysis. By presenting the words of the women and their evaluation of things they liked and did not like about the exercise along with their quantitative scores, a more holistic picture is created. This holistic view of the deeply personal and traumatic experience of breast cancer seems inherently fitting. Both the quantitative and qualitative data aspects of this study provide evidence for the benefit of expressive writing in women experiencing breast cancer.

### Suggestions for Further Study

This study has contributed to the evidence base for the use of expressive writing in breast cancer survivors. It has also generated several questions for future research. Specific suggestions for future research are listed below followed by a brief discussion of each.

- 1. Using the attentional control group as a true experimental group
- Offer expressive writing much sooner after diagnosis.
- Use surrogate markers for emotional measures (e.g. antidepressants).
- Explore expressive writing impact on sexuality and breast cancer
- 5. Delete any trauma group and structure writing groups to include only breast cancer focus

Attentional Control Group as Experimental Group and Impact on Sexuality

The attentional control group could be structured as an experimental group and possibly expanded to include a day of writing on sexuality. The attentional control group, although experiencing the most attrition, was comparable enough in size to the other writing groups to believe the results are truly significant. The knowledge that women may not need to write about deep thoughts and feelings as the

prompt to gain access to these thoughts and feelings opens up a potentially new way of using expressive writing for some women. This obviously needs to be studied further but may provide an excellent option for women to gain the benefits of expressive writing without the discomfort some women feel when they think they have to write something so intense.

#### Earlier Intervention

Another suggestion for future research is to offer expressive writing much sooner after diagnosis. Many of the participants in this study wrote that they wished they had started writing when they were first diagnosed. They recognized that they may not have had the energy to do it but felt that it would have been valuable. If women can benefit from writing about such topics as exercise, then it is possible that they may benefit from writing short periods of time about specific prompts such as first chemotherapy, appetite, hair loss and so on. This early writing might be more beneficial if it is structured like the attentional control group rather than open ended like the trauma groups. This is obviously a question that can only be answered well in a similar structured experimental design study.

### Surrogate Markers for Emotional Distress

The finding regarding antidepressant medication was intriguing but limited by the very small number of participants in each group that responded yes to using antidepressants. It was statistically significant and with three in the control group and only two in the other three groups combined reporting use of antidepressants, raises the question about whether expressive writing affects the use of antidepressants. It would be an excellent dependent variable to include in a future study of expressive writing. It also raised the question about alternative markers for measuring psychological measures. Significant findings on psychological markers have usually been harder to achieve in studies on expressive writing than physical findings, as was the case in this study. A possible solution is to use a more physical measure of a psychological concept such as antidepressants, antianxiety drugs, quality of sleep, or as this study seemed to indicate, satisfaction with sexuality.

#### Delete Any Trauma Group from Design

Very few women in the any trauma group wrote about other topics besides their breast cancer and when they did they seemed to do so almost grudgingly. The mere fact of selecting one's trauma seemed to alter the effect of expressive writing in this group. This raises the question that it might be best to not allow a choice about writing and instruct women to write about their breast cancer. The concept of validation as a theoretical framework for the effectiveness of this approach would be interesting to explore. Women seem to underestimate the traumatic effect breast cancer has in their lives, and in so doing, may actually be practicing inhibition. Choosing it as their traumatic experience may somehow impact the benefit of writing about it as seen with the quantitative instruments. The case studies, however, were mostly women in the any trauma group whose writings resounded with trauma and whose evaluations wholeheartedly lauded the effect the writing exercise had on them. Therefore, before abandoning the prompt of using one's own trauma it would be very interesting to see the results of a replication of this design.

#### Summary

This study has produced some intriguing findings regarding the use of expressive writing in breast cancer. The questions it has answered have led to a bevy of new questions. What does seem clear is that the individual woman, when asked to write about her breast cancer, does so with frank honesty and brutal openness. After only a short "dose" of expressive writing, quantitative instruments and evaluation comments alike indicate that, for the aggregate and for the individual, expressive writing is a valuable tool for women diagnosed with breast cancer.

#### REFERENCES

- Andrews, G., Hall, W., Teeson, M., & Henderson, S. (1999). *The mental health of Australians*. Canberra: Mental Health Branch, Commonwealth Department of Health and Aged Care.
- American Cancer Society. (2004). Breast cancer facts and figures. Atlanta: Author.
- Athabasca University. Internal validity Tutorial. (1998). Retrieved March 17, 2003, from <a href="http://www.psych.athabascau.ca/html/Validity/testing.shtml">http://www.psych.athabascau.ca/html/Validity/testing.shtml</a>
- Badger, T.A., Braden, C.J., & Mishel, M.H. (2001). Depression burden, self-help interventions, and side effect experience in women receiving treatment for breast cancer. *Oncology Nursing Forum*, 28 (3), 567-574.
- Baider, L., & Denour, A.K. (1997). Psychological distress and intrusive thoughts in cancer patients. *Journal of Nervous and Mental Disorders*, 185, 346-348.
- Beck, A., Steer, R., & Brown, G. (1996). BDI-II Manual. (2<sup>nd</sup> Ed.) San Antonio: Harcourt Brace & Company.
- Beck, A., Steer, R., & Garbin, M. (1988). Psychometric properties of the Beck Depression Inventory:

  Twenty-five years of evaluation. *Clinical Psychology Review, 8,* 77-100.
- Beck, A.T., Rush, A.J., Shaw, B.F., & Emery, G. (1979). Cognitive therapy of depression. New York: Guilford Press.
- Beck, A., Ward, C., Mendelson, M., Mock, J., & Erbaugh, J. (1961). An inventory for measuring depression. *Archives of General Psychiatry*, 4, 561-571.
- Bolton, Gillie. (1999). The therapeutic potential of creative writing. London: Jessica Kingsley Publishers.
- Boswell, L. (2001). Mysterious ways: Margie Jones answers the call. MAMM. 36-37.

- Brady, M.J., Cella, D.F., Mo, F., Bonomi, A.E., Tulsky, D.S., Lloyd, S.R., Deasy, S. et al. (1997).
  Reliability and validity of the Functional Assessment of Cancer Therapy-Breast Quality-of-Life instrument. *Journal of Clinical Oncology*, 15(3), 974-986.
- Burns, P.A. (1997). Securing internal validity: How to avoid the threats. Retrieved March 17, 2003 from http://www.trochim.human.cornell.edu/tutorial/burns.int.html.
- Cameron, L.D., & Nicholls, G. (1998). Expression of stressful thoughts through writing; effects of a self-regulation manipulation for pessimists and optimists. *Health Psychology*, 17 (1), 84-92.
- Campbell, N.B. (2003). Emotional disclosure through writing: an intervention to facilitate adjustment to having a child with autism. *Dissertation Abstracts International; Section B: The Sciences and Engineering, 64* (5-B), 2380.
- Carver, C.S., Pozo, C., Harris, S.D., Noriega, V., Scheier, M.F., Robinson, D.S., Ketchan, A.S., Moffat, F.L., & Clark, K.C. (1993). How coping mediates the effect of optimism on distress: A study of women with early stage breast cancer. *Journal of Personality and Social Psychology*, 65 (2), 375-390.
- Cella, D.F. (1997). F.A.C.T. manual: Manual for the functional assessment of cancer therapy (FACT) scales and the functional assessment of breast cancer scale. Chicago, IL, Rush-Presbyterian-St.Luke's Medical Center.
- Cimprich, B. (1999). Pre-treatment symptom distress in women newly diagnosed with breast cancer.

  Cancer Nursing, 22(3), 185-194.
- Day, A.L. (2001). The journal as a guide for the healing journey. *Nursing Clinics of North America*, 36, 131-142.
- DeMatteo, M.R., Lepper, H.S., & Croghan, T.W. (2000). Depression is a risk factor for noncompliance with medical treatment: meta-analysis of the effects of anxiety and depression on patient adherence. *Archives of Internal Medicine*, 160, 2101-2107.

- de Moor, C., Sterner, J., Warneke, C., Gilani, Z., Hall, M., & Amato, R. (2002). A pilot study of the effects of expressive writing on psychological and behavioral adjustment in patients enrolled in a phase II trial of vaccine therapy for metastatic renal cell carcinoma. *Health Psychology*, 21 (6), 615-619.
- DeRubeis, R.J., & Feeley, M. (1990). Determinants of change in cognitive therapy for depression.

  Cognitive Therapy and Research, 14, 469-482.
- Donnelly, D.A., & Murray, E.J. (1991). Cognitive and emotional changes in written essays and therapy interviews. *Journal of Social and Clinical Psychology*, 10, 334-350.
- Dunkel-Schetter, C., Feinstein, L., Taylor, S., & Falke, R. (1992). Patterns of Coping with cancer. *Health Psychology*, 11(2), 79-87.
- Esterling, B.A., Antoni, M.H., Fletcher, M.A., Margulies, S. & Schneiderman, N. (1994). Emotional disclosure through writing or speaking modulates latent Epstein-Barr virus antibody titers. *Journal of consulting and clinical Psychology*, 62(1), 130-140.
- Fallowfield, L.J., Hall, A., Maquire, P., Baum, M., & A'Hern, R.P. (1994). Psychological effects of being offered choice of surgery for breast cancer. *British Medical Journal*, 309, 448.
- Fawzy, I.F., Kemeny, M.E., Fawzy, N.W., Elashoff, R., Morton, D., Cousins, N., Fakey, J.L. (1990). A structured psychiatric intervention for cancer patients. *Archives of General Psychiatry*, 47, 729-735.
- Fife, B.L. (1995). The measurement of meaning in illness. Social Science Medicine, 40(8), 1021-1028.
- Fischer, P.C. (2001). Putting theory into practice: A psychologist's story. Women and Therapy, 23(1), 101-110.
- Francis, M.E. & Pennebaker, J.W. (1991). Putting stress into words: the impact of writing on physiological, absentee, and self-reported emotional well-being measures. *American Journal of Health Promotion*, 6(4), 280-287.
- Frankl, V. (1984). Man's search for meaning: An introduction to logotherapy. (3<sup>rd</sup> ed.). New York: Simon & Schuster. (Original work published 1959).

- Gallagher, J., Parle, M., & Cairns, D. (2002). Appraisal and psychological distress six months after diagnosis of breast cancer. *British Journal of Health Psychology*, 7, 365-376.
- Ganz, K., & Lerman, C. (1992). Psychosocial impact of breast cancer: A critical review. *Annals of Behavioral Medicine*, 14, 204-212.
- Gergen, K.J., & Gergen, M.M. (1988). Narrative and the self as relationship. In L. Berkowitz (Ed.), Advances in experimental social psychology, 21, (pp. 17-56). New York: Academic.
- Goodwin, J.S., Zhang, D.D., & Ostir, G.V. (2004). Effect of depression on diagnosis, treatment, and survival of older women with breast cancer. *Journal of the American Geriatric Society*, 52 (1), 111-117.
- Greenberg, M.A., & Stone, A.A. (1992). Emotional disclosure about traumas and its relation to health:

  Effects of previous disclosure and trauma severity. *Journal of Personality and Social Psychology*,
  63, 75-84.
- Gross, J., & Levenson, R.W. (1993). Emotional suppression: Physiology, self-report, and expressive behavior. University of California: Berkeley.
- Harrison, J., & Maquire, P. (1995). Influence of age on psychological adjustment to cancer. *Psycho-Oncology*, 4, 33-38.
- Hilton, A. (1989). The relationship of uncertainty, control, commitment, and threat of recurrence to coping strategies used by women diagnosed with breast cancer. *Journal of Behavioral Medicine*, 12 (1), 39-54.
- Hosaka, T., Tokuda, Y., Sugiyama, Y., Hirai, K. & Okuyama, T. (2000). Effects of a structured psychiatric on immune function of cancer patients. *Tokai Journal of Experimental Clinical Medicine*, 25 (4-6), 183-8.
- Hoskins, C.N. (1997). Breast cancer treatment-related patterns in side effects, psychological distress, and perceived health status. *Oncology Nursing Forum, 24,* 1575-1583.
- Hughes, J. (1982). Emotional reactions to the diagnosis and treatment of early breast cancer. *Journal of Psychosomatic Research*, 26 (2), 277-283.

- Hunt, C., & Sampson, F. (Eds.), (1998). The self on the page; theory and practice of creative writing in personal development. London: Jessica Kingsley.
- Iwamitsu, Y., Shimoda, K., Abe, H., Tani, T., Kodama, M., & Okawa, M. (2003). Differences in emotional distress between breast tumor patients with emotional inhibition and those with emotional expression. *Psychiatry & Clinical Neurosciences*, 57(3), 289-295.
- Jemal, A., Murray, T., Ward, E. et al. (2005). Cancer statistics, 2005. CA A Cancer Journal for Clinicians, 55(1), 10-30.
- Kagan, J., Reznick, J.S. & Snidman, N. (1988). Biological bases of childhood shyness. *Science*, 240, 167-171.
- Kelley, J.E., Lumley, M.A., & Liesen, J.C. (1997). Health effects of emotional disclosure in rheumatoid arthritis patients. *Health Psychology*, 16, 331-340.
- Keltner, D., Locke, K.D., and Andrain, P.C. (1993). The influence of attributions on the reliance of negative feelings to personal satisfaction. *Personality and SocialPsychology*, 19, 21-29.
- Kinney, C.K., Rodgers, D.M., Nash, K.A., & Bray, C.O. (2003). Holistic healing for women with breast cancer through a mind, body, and spirit self-improvement program. *Journal of Holistic Healing*, 21 (3), 260-279.
- Klein, Kl, & Boals, A. (2001). Expressive writing can increase working memory capacity. *Journal of Experimental Psychology: General*, 130, 520-533.
- Knapp, T.R. (1990). Treating ordinal scales as interval scales: An attempt to resolve the controversy.

  Nursing Research, 39 (2), 121-123.
- Koopman, C., Angell, K., Turner-Cobb, J., Kreshka, M., Donnelly, P., McCoy, et al.(2001). Distress, coping, and social support among rural women recently diagnosed with primary breast cancer. *The Breast Journal*, 7(1), 25-33.
- L'Abate, L., Boyce, M., Fraizer, J., & Russ, D. (1992). Programmed writing: research in progress.

  Comprehensive Mental Health Care, 2, 45-62.
- Lazarus, R.S., & Folkman, S. (1984). Stress, appraisal and coping. New York: Springer-Verlag.

- Lehto, R.H., & Cimprich, B. (1999). Anxiety and directed attention in women awaiting breast cancer surgery. *Oncology Nursing Forum*, 26 (4), 767-772.
- Lepore, S.J. & Smyth, J.M. (2002). The writing cure: An overview. In S.J. Lepore & J.M. Smyth (Eds.),

  The writing cure: How expressive writing promotes health and emotional well-being. Washington,

  DC: American Psychological Association.
- Lepore, S.J., Wortman, C.B., Silver, R.C., & Wayment, H.A. (1996). Social constraints, intrusive thoughts, and depressive symptoms among bereaved mothers. *Journal of Personality and Social Psychology*, 70, 271-282.
- Lev. E.L. & Owen, S.V. (2000). Counseling women with breast cancer using principles developed by Albert Bandura, *Perspectives in Psychiatric Care*, 36 (4), 131-8.
- Levine, E.G., Eckhardt, J., & Targ, E. (2005). Change in post-traumatic stress symptoms following psychosocial treatment for breast cancer. *Psycho-Oncology*, 14, 618-635.
- Lieberman, M.A., & Goldstein, B.A. (2006). Not all negative emotions are equal: The role of emotional expression in on-line support groups for women with breast cancer. *Psycho-Oncology*, 15, 160-168.
- Low, C.A., Stanton, A. L, & Danoff-Burg, S. (2006). Expressive disclosure and benefit finding among breast cancer patients: Mechanisms for positive health effects. *Health Psychology*, 25 (2) 181-189).
- McDaniel, J.S., Musselman, D.L., & Nemeroff, C.B. (1997). Cancer and depression: theory and treatment.

  \*Psychiatric Annals, 27, 360-364.
- McKenna, M.C., Zevon, M.A., & Corn, B. (1999). Psychosocial factors and the development of breast cancer; a meta-analysis. *Health Psychology*, 18 (5), 520-531.
- McNair, D.M., Lorr, M., & Droppleman, L.F. (1992). EdITS manual for the Profile of Mood States, San Diego: EdITS/Educational and Industrial Testing Service
- Mertler, C.A., & Vannatta, R.A. (2005). Advanced and multivariate statistical methods: Practical application and interpretation (3<sup>rd</sup> ed.) Glendale: Pyrczak Publishing.

- Meyer, T.J., Mark, M.M. (1999). Effects of psychosocial interventions with adult cancer patients: A metaanalysis of randomized experiments. *Health Psychology*, 14 (2), 101-108.
- Meyerowitz, B.E. (1983). Postmastectomy coping strategies and quality of life. *Health Psychology*, 2 (2), 117-132.
- Mezirow, J. (1978). Perspective Transformation. Adult Education, 28 (2), 100-110.
- Mezirow, J. (1996). Toward a learning theory of adult literacy. [electronic version]. *Adult Basic Education*, 6(3), 1-8.
- Mezirow, J. (1998). On critical reflection. Adult Education Quarterly, 48(3), 208-216).
- Monti, D.A, Mago, R., & Kunkel, E. J. (2005). Depression, cognition and anxiety among postmenopausal women with breast cancer. *Practical Geriatrics*, 56, 1353-1355.
- Moore, D.S., & McCabe, G.P. (1998). Introduction to the Practice of Statistics. New York: W.H. Freeman & Co.
- Mumford, E., Schlesinger, H.J., & Glass, G.V. (1983). Reducing medical costs through mental health treatment: Research problems and recommendations. In A. Broskowski, E. Markos, & S.K. Budman (Eds.), *Linking health and mental health*. Beverly Hills: Sage.
- Murray, E.J. & Segal, D.L.(1994) Emotional processing in vocal and written expression of feelings about traumatic experiences. *Journal of Traumatic Stress*, 7(3), 391-405.
- Myers, J.L. (1972). Fundamentals of experimental design (2<sup>nd</sup> ed.). Boston: Allyn and Bacon, Inc.
- National Cancer Institute (1997). Cancer facts: 1996. Washington D.C.: Author.
- Neuhaus, W., Zoh, G., Gohring, U.J., & Scharl, A. (1994). A prospective study concerning psychological characteristics of patients with breast cancer. *Archives of Gynecology Obstetrics*, 225, 201-209.
- Northouse, L. (1989). A longitudinal study of adjustment of patients and husbands to breast cancer.

  Oncology Nursing Forum, 16, 511-516.
- Nunnally, J.C. (1978). Psychometric theory. New York: McGraw-Hill.
- Oei, T.P.S., & Free, M. Do cognitive behavior therapies validate cognitive models of mood disorders? A review of the empirical evidence. *International Journal of Psychology*, 30 (2), 145-179.

- Özalp, G., Sarioglu, R., Tuncel, G., Aslan, K., & Kadiogullari, N. (2003). Preoperative emotional states in patients with breast cancer and postoperative pain. *Acta Anaesthesiologica Scandinavica*, 47, 26-29.
- Paez, D., Velasco, C. & Gonzalez, J. (1990). Expressive writing and the role of alexythimia as a dispositional deficit in self-disclosure and psychological health. *Journal of Personality and Social Psychology*, 77(3), 630-741.
- Pascreta, J. (1997). Depressive phenomena, physical symptom distress, and functional status among women with breast cancer. *Nursing Research*, *4*, 214-220.
- Pedhazer, E.F. & Schmelkin, L.P. (1991). Measurement design and analysis: An integrated approach.

  Washington D.C.: Author.
- Pennebaker, J.W. (1993). Putting stress into words: health, linguistic and therapeutic implications. Behavioral Research Therapeutics, 31(6), 539-548.
- Pennebaker, J.W. (1999). The effects of traumatic disclosure on physical and mental health: the values of writing and talking about upsetting events. *International Journal of Emergency Mental Health, 1*, 9-18.
- Pennebaker, J.W. (2002). What our words can say about us: toward a broader language psychology.

  \*Psychological Science Agenda, 8-9.
- Pennebaker, J.W. (2002). Writing about emotional events: From past to future. In Lepore, S.J., & Smyth, J.M. (Eds.), *The writing cure: How expressive writing promotes health and emotional well-being*. (pp. 281-291). Washington, D.C.: American
- Pennebaker, J.W., Barger, S.D., & Tiebout, J. (1989) Disclosure of traumas and health among Holocaust survivors. *Psychosomatic Medicine*, 51, 577-589.
- Pennebaker, J.W. & Beall, S. (1986). Confronting a traumatic event: toward an understanding of inhibition and disease. *Journal of Abnormal Psychology*, 95(3), 274-281.
- Pennebaker, J.W. Colder, Ml, & Sharp, L.K. (1990). Accelerating the coping process.

  \*\*Journal of Personality and Social Psychology, 72, 863-871.

- Pennebaker, J.W., & Graybeal, A. (2001). Patterns of natural language use: disclosure, personality, and social integration. *Current Directions in Psychological Science*, 10(3), 90-93. Psychological Association.
- Pennebaker, J.W., Kiecolt-Glaser, J.K., & Glaser, R. (1988). The immunological effects of thought suppression. *Journal of Consulting and Clinical Psychology*, 56, 239-245.
- Pennebaker, J.W. Mayne, T.J., & Francis, M.E. (1997). Linguistic predictors of adaptive bereavement. *Journal of Personality and Social Psychology*, 72, 863-871.
- Petrie, K.J., Booth, R.J., & Pennebaker, J.W. (1998). The immunological effects of thought suppression. *Journal of Personality and Social Psychology*, 75, 1264-1272.
- Portney, L. & Watkins, M. (2000). Foundations of clinical research. New York: Appleton & Lange.
- Rachman, S.J. (1980). Emotional processing. Behavior research and therapy, 18, 51-60.
- Rancour, P., & Brauer, K. (2003). Use of letter writing as a means of integrating an altered body image: a case study. *Oncology Nursing Forum*, 30 (5), 841-846.
- Reynolds, P., Hurley, S., Torres, M., Jackson, J., Boyd, P., & Chen, V.W. (2000). Use of coping strategies and breast cancer survival: Results from the Black/White cancer survival study. *American Journal of Epidemiology, 152* (10), 940-949.
- Richards, J.M., Beal, W.E., Seagal, J.D., & Pennebaker, J.W. Effects of disclosure of trauma events on illness behavior among psychiatric prison inmates. *Journal of Abnormal Psychology*, 109 (1), 156-160.
- Ritz, L. J., Nissen, M. J., Swenson, K. K., Farrell, J. B., Sperduto, P. W., Sladek, M. L., et al. (2000).
  Effects of advanced nursing care on quality of life and cost outcomes of women diagnosed with breast cancer. Oncology Nursing Forum, 27, 923–932.
- Rosberger, Z., Edgar, L., Collet, J.P., & Fournier, M.A. (2002). Patterns of coping in women completing treatment for breast cancer: A randomized controlled trial of Nucan: A brief psychoeducational workshop. *Journal of Psychosocial Oncology*, 20 (3), 19-35.

- Rosenberg, H.J, Rosenberg, S.D., Ernstoff, M.S., Wolford, G.L., Amdur, R.J., Elshamy, M.R., Bauer-Wu, S.M., Ahles, T.A., & Pennebaker, J.W. (2002). Expressive disclosure and health outcomes in a prostate cancer population. *International Journal of Psychiatry in Medicine*, 32(1), 37-53.
- Saleeba, A.K., Weitzner, M.A., & Meyers, C.A. (1996). Subclinical psychological distress in long-term survivors of breast cancer: A preliminary communication. *Journal of Psychosocial Oncology*, 14 (1), 83-93.
- Scheff, T.J. (1979). Catharsis in healing, ritual, and drama. Berkeley: University of California Press.
- Schneider, S., Prince-Paul, M., Allen, M., Silverman, P., & Talaba, D. (2004). Virtual reality as a distraction intervention for women receiving chemotherapy. *Oncology Nursing Forum, 31* (1), 81-88.
- Schreier, A.M., & Williams, S.A. (2004). Anxiety and quality of life for women who receive radiation or chemotherapy for breast cancer. *Oncology Nursing Forum*, 31, 127-130.
- Servaes, P., Vingerhoets, A. J., Vreugdenhil, G., Keuning, J.J., Broekhuijsen, A.M. (1999). Inhibition of emotional expression in breast cancer patients. *Behavioral Medicine*, 25(1), 23-28.
- Simpson, J.S., Carlson, L.E., & Trew, M.E. (2001). Effect of group therapy for breast cancer on healthcare utilization. *Cancer Practice*, 9 (1), 19-26.
- Smith, S., Anderson-Hanley, C., Langrock, A., & Compas, B. (2005). The effects of journaling for women with newly diagnosed breast cancer. *Psycho-Oncology*, *14*, 1075-1082.,
- Smyth, J.M. (1998). Written emotional expression: Effect sizes, outcome types, and moderating variables.

  \*\*Journal of Consulting & Clinical Psychology, 66, 174-184.
- Smyth, J.M., Stone, A., Hurewitz, A. & Kaell, A. (1999). Effects of writing about stressful experiences on symptom reduction in patients with asthma or rheumatoid arthritis: a randomized trial. *Journal of the American Medical Association*, 28(14), 1304-1309.
- Speilberger, C.D., Gorsuch, R.L., Lushene, R., Vagg, P.R., & Jacobs, G.A. (1983). State-Trait Anxiety Inventory for Adults Form Y Manual. Redwood City: Mind Garden.

- Speilberger, C.D., & Vagg, P.R. (1984). Psychometric properties of the STAI: A reply to Ramanaiah, Franzen, and Schill. *Journal of Personality Assessment*, 48 (1), 95-97.
- Spera, S.P., Bohrfeind, E.D., & Pennebaker, J.W. (1994). Expressive writing and coping with job loss.

  Academy of Management Journal, 37 (3), 722-733.
- Spiegel, D. (1995). Essentials of psychotherapeutic interventions for cancer patients. Supportive Care in Cancer, 3 (4), 252-256.
- Spiegel, D. (1997). Psychosocial aspects of breast cancer treatment. *Seminars in Oncology*, 24, (Suppl. 1), S1-36- S1-47.
- Spiegel, D., Bloom, J. R., & Yalom, I. (1981). Group support for patients with metastatic cancer: A randomized prospective outcome study. *Archives of General Psychiatry*, 38, 527–533
- Spiegel, D., Kraemer, H.C., Bloom, J.R. & Gottheil, E. (1989). Effect of psychosocial treatment on survival of patients with metastatic breast cancer. *The Lancet*, October 14, 1989, 888-891.
- Stanton, A.L., Danoff-Burg, S., Cameron, C.L., Bishop, M., Collins, C.A. et al. (2000). Emotionally expressive coping predicts psychological and physical adjustment to breast cancer. *Journal of Consultative Clinical Psychology*, 68 (5), 875-82.
- Stanton, A.L., Danoff-Burg, S., Sworowski, L.A., Collins, C.A., Branstetter, A.D., Rodriquez-Hanley, A. et al. (2002). Randomized, controlled trial of written emotional expression and benefit finding in breast cancer patients. *Journal of Clinical Oncology*, 20(20), 4160-4168.
- Stanton, A.L., & Snider, P.M. (1993). Coping with a breast cancer diagnosis: A prospective study. *Health Psychology*, 12 (1), 16-23.
- Tabachnick, B.G., & Fidell, L.S. (2001). Using multivariate statistics. Boston: Allyn and Bacon.
- Targ, E.F., Levine, E.G.(2002). The efficacy of a mind-body-spirit group for women with breast cancer: a randomized controlled trial. *General Hospital Psychiatry*, 24(4), 238-48.
- Trask, P. C., Paterson, A. G., Wang, C., Hayasaka, S., Milliron, K. J., Blumberg, L. R., et al. (2001).

  Cancer-specific worry interference in women attending a breast and ovarian cancer risk evaluation program: Impact on emotional distress and health functioning. *Psychooncology*, 10,349–360.

- Ullrich, P. M. & Lutgendorf, S.K. (2000). Journaling about stressful events: effects of cognitive processing and emotional expression. *The Society of Behavior Medicine*, 24(3), 244-250.
- Vickberg, S.M.J., Bovbjerg, D.H., DuHamel, K.N., Currie, V., & Redd, W.H. (2000). Intrusive thoughts and psychological distress among breast cancer survivors: Global meaning as a possible protective factor. *Behavioral Medicine*, 25(4), 152-161.
- Walker, B.L., Nail, L., & Croyle, R.T. (1999). Does emotional expression make a difference in reactions to breast cancer? *Oncology Nursing Forum, 26*, 1025-1032.
- Watson, J. (2002). Intentionality and caring-healing consciousness: a practice of transpersonal nursing.

  Holistic Nursing Practice, 16 (4), 12-19.
- Watson, M., Haviland, J.S., Greer, S., Davidson, J., & Bliss, J.M. (1999). Influence of psychological response in survival in breast cancer: A population-based cohort study. *Lancet*, 354 (9187), 1331-1336.
- Webber, S. (1999). Living with the experience: making meaning since having had breast cancer.

  Unpublished dissertation. *Dissertations Abstracts International*,
- Wilkinson, S. & Kitzinger, C. (2000). Thinking differently about thinking positive; a discursive approach to cancer patients' talk. *Social Science Medicine*, 50, 797-811.
- Williams, S.A., & Schreier, A.M. (2004). The effect of education in managing side effects in women receiving chemotherapy for treatment of breast cancer. *Oncology Nursing Forum, 31* (1), E16-E23.
- Wonghonghul, T., Moore, S. M., Musil, C., Schneider, S., Dermiling, G. (2000). The influence of uncertainty on illness, stress appraisal, and hope on coping in survivors of breast cancer. *Cancer Nursing*, 23 (6), 422-429.
- Wong-Kim, E.C., & Bloom, J.R. (2005). Depression experienced by young women newly diagnosed with breast cancer. *Psycho-Oncology*, 14, 564-673.
- Wright, J. & Chung, M. (2001). Mastery or mystery? Therapeutic writing: a review of the literature. British Journal of Guidance & Counseling, 29(3), 277-291.

- Wrońska, I., Stępień, R., & Kulik, T.B. (2003). The quality of women's life after mastectomy in Poland.

  Health Care for Women International, 24, 900-909.
- Zabalegui, A. (1999). Coping strategies and psychological distress in patients with advanced cancer. *Oncology Nursing Forum*, 26(9), 1511-1518
- Zhao, W., Wu, Z., He, J., Zhen, M., Fan, S., Zon, Q., Si, S., & Lian, H. (2001). Depression, anxiety, and coping styles in patients with breast cancer. *Chinese C*Journal of Clinical Psychology, 9 (4), 286-289.

APPENDIX A

List of Sites

### List of participating sites

Breast Imaging of Oklahoma

Norman Hospital Women's Center

Mercy Breast Center

**Baptist Hospital** 

OU Health Sciences Center

Oklahoma Breast Care Center

The offices of Dr. Beverly Talbert and Dr. Brian Boggs

Cancer Care Associates with affiliates in Oklahoma City and Norman and led by Dr. Vickie Canfield

Breast cancer support groups in Oklahoma City, Norman, and Edmond.

APPENDIX B

IRB Approvals



#### Institutional Review Board

Office of Research and Sponsored Programs P.O. Box 425619, Denton, TX 76204-5619 940-898-3378 Fax 940-898-3416 e-mail: IRB@twu.edu

March 31, 2005

Ms. Melissa Craft 3500 Smoky Hollow Road Edmond, OK 73013

Dear Ms. Craft:

Re: Expressive Writing in Newly Diagnosed Breast Cancer Patients

The above referenced study has been reviewed by the TWU Institutional Review Board (IRB) and appears to meet our requirements for the protection of individuals' rights.

If applicable, agency approval letters must be submitted to the IRB upon receipt PRIOR to any data collection at that agency. A copy of the approved consent form with the IRB approval stamp and a copy of the annual/final report are enclosed. Please use the consent form with the most recent approval date stamp when obtaining consent from your participants. The signed consent forms and final report must be filed with the Institutional Review Board at the completion of the study.

This approval is valid one year from February 4, 2005. According to regulations from the Department of Health and Human Services, another review by the IRB is required if your project changes in any way, and the IRB must be notified immediately regarding any adverse events. If you have any questions, feel free to call the TWU Institutional Review Board.

Sincerely.

Dr. David Nichols, Chair

Institutional Review Board - Denton

enc.

cc. Dr. Marcia Hern, College of Nursing Dr. Gail Davis, College of Nursing Graduate School



Institutional Review Board

Office of Research and Sponsored Programs P.O. Box 425619, Denton, TX 76204-5619 940-898-3378 Fax 940-898-3416

e-mail: IRB@twu.edu

January 20, 2006

Ms. Melissa Craft 3500 Smoky Hollow Road Edmond, OK 73013

Dear Ms. Craft:

Re: Expressive Writing in Newly Diagnosed Breast Cancer Patients

The request for an extension of your IRB approval for the above referenced study has been reviewed by the TWU Institutional Review Board (IRB) and appears to meet our requirements for the protection of individuals' rights.

If applicable, agency approval letters must be submitted to the IRB upon receipt PRIOR to any data collection at that agency. A copy of all signed consent forms and an annual/final report must be filed with the Institutional Review Board at the completion of the study. A copy of the approved consent form with the IRB approval stamp is enclosed. Please use a copy of this stamped consent form when obtaining consent from your participants.

This extension is valid one year from February 4, 2006. According to regulations from the Department of Health and Human Services, another review by the IRB is required if your project changes in any way. If you have any questions, feel free to call the TWU Institutional Review Board.

Sincerely,

Dr. David Nichols, Chair

Institutional Review Board - Denton

cc. Dr. Marcia Hern, College of Nursing Dr. Gail Davis, College of Nursing Graduate School

# INTEGRIS

Baptist MEDICAL CENTER 3300 Northwest Expressway Street Oklahoma City, OK 73112-4481 405.949.3011 www.integris-health.com

12/19/2005

Melissa Craft, RN, MS, AOCN 2601 Kelley Pointe Pkwy, #101 Edmond, OK 73013

Dear Ms. Craft:

The Institutional Review Board of INTEGRIS Baptist Medical Center, Inc. met on 12/19/2005 and reviewed the following request for continuing review:

Expressive Writing in Newly Diagnosed Breast Cancer Patients (Sponsor: None; Consent Dated: 12/10/2004) (C-0412-213)

The Board approves this continuing review for the term of twelve months (12/18/2006) and requires an annual report in one year, or a final report in the event the study is closed prior to that time. Please ensure that you consent all patients with the most current stamped IRB approved consent form. Proposed changes in the approved protocol or consent form must be submitted to the I.R.B. for review and approval. Unanticipated problems involving risks to subjects or others must be promptly reported to the I.R.B.

This IRB is in compliance with the regulations of the FDA as described in 21 CFR parts 50 and 56, as well as the ICH and GCP Guidelines for IRB's.

Sincerely,

R.C. Brown, M.D., Chairman
IBMC Institutional Review Board

rcb/sm

# Norman Regional Hospital

901 North Porter, Box 1308 Norman, Oklahoma 73070-1308 Phone: 405.307.1000 www.normanregional.com

February 11, 2005

Melissa Craft, RN 2601 Kelley Pointe Parkway, Suite 101 Edmond, OK 73013

RE:

IRB # 04-006 study entitled "Expressive Writing in Newly Diagnosed Breast Cancer Patients"

Dear Ms. Craft:

Thank you for your response to requests from the November 16, 2004 IRB review of your application for the new study listed above. This type of response qualified for expedited review under FDA and DHHS (OHRP) regulations.

This is to confirm that your application is now fully approved. The protocol is approved through Abstract – Dissertation. The consent form dated December 9, 2004 is also approved. You must obtain signed written consent from all subjects.

You are granted permission to conduct your study as most recently described effective immediately. The study is subject to continuing review on or before February 9, 2006, unless closed before that date.

Please note that any changes to the study as approved must be promptly reported and approved. Some changes may be approved by expedited review; others require full board review. Contact Doris Gonzalez [(405) 307-1051; fax (405) 307-1073; email: <a href="mailto:dgonzalez@nrh-ok.com">dgonzalez@nrh-ok.com</a>] if you have any questions or require further information.

Sincerely,

Thomas Kuhls, MD

Norman Regional Hospital IRB Chairman

Jon Kulls, MD

PS Please send a revised protocol for our files.



#### MERCY HEALTH SYSTEM OF OKLAHOMA

Meeting Date: 10-21-05 Approval Date: 10-21-05

November 19, 2004

Melissa Craft, RN MS AOCN 3500 Smokey Hollow Road Edmond, OK 73013

RE: Continuing Review
"Expressive Writing in Newly Diagnosed Breast Cancer Patients

Dear Ms. Craft;

This letter is to inform you that the Mercy Health System Oklahoma Institutional Review Board approved the request for continuing review for the above project at its regularly scheduled meeting. The project and current consent form were reapproved as submitted.

As principal investigator of this protocol, it is your responsibility to insure that this study is conducted as approved by the Board. Any modifications to the protocol or consent form, initiated by you or by the sponsor, will require prior approval, which you may request in an amendment, letter or memorandum to the IRB office. All study records including copies of signed consent forms, must be retained for three (3) years after termination of the study.

It is a condition of this re-approval that you report promptly to the Board any serious, unanticipated adverse effects experienced by subjects in the course of this research, whether or not they are directly related to the study protocol. These adverse effects include, but may not be limited to, any experience that is fatal or immediately life-threatening, is permanently disabling, requires (or prolongs) inpatient hospitalization, or is a congenital anomaly, cancer or overdose. For multi-site protocols, the Board must be informed of serious adverse effects at all sites.

The re-approval granted here is effective for one year. The approval will expire on or before October 20, 2006. Should you wish to maintain this protocol in an active status beyond that date, you will need to provide the Board with a progress report summarizing the study results to date. The appropriate forms will be distributed to you prior to the approval date by the IRB office.



# The University of Oklahoma

### Health Sciences Center

INSTITUTIONAL REVIEW BOARD

IRB Number: 11953

Approval Date: December 10, 2005

December 14, 2005

Rhonda Johnson, M.D. Dept of Obstetrics and Gynecology 920 Stanton L. Young Blvd, WP 2410 Oklahoma City, OK 73104-5020

RE: Expressive Writing in Newly Diagnosed Breast Cancer Patients

Dear Dr. Johnson:

Thank you for completing and returning the IRB Application for Continuing Review (Progress Report) for the above-referenced study. You have indicated that the study is still active. At the meeting held November 21, 2005 the Institutional Review Board (IRB) reviewed and approved the Progress Report and determined that this study was appropriate for continuation.

This letter documents approval to conduct the research as described in:

Cont Review Form Dated: October 17, 2005

Protocol Dated: October 17, 2005

Priv - Research Auth 1 Dated: January 06, 2005

Consent form - Subject Version: 4.0 Dated: December 06, 2005

Please remember that any change in the protocol, consent document or other recruitment materials (adverstisements, etc.) must be approved by the IRB prior to its incorporation into the study procedures. Submit a completed Protocol Modification form to the IRB office. Any serious, unanticipated adverse events involving participants enrolled in this study at OUHSC must be reported within four working days on the IRB Adverse Event Report form. Any event which involves the death of a participant must be reported no later than the next working day. All other adverse events (from outside sites) must be forwarded to the IRB office within 14 working days of receipt.

Approximately three months prior to the expiration date of this approval, you will be contacted by the IRB staff about procedures necessary to maintain this approval in an active status. Although every attempt will be made to notify you when a study is due for review, it is the responsibility of the investigator to assure that their studies receive review prior to expiration.

The approval of this study expires on October 31, 2006 and must be reviewed by the convened IRB prior to this time if you wish to remain in an active status. Federal regulations do not allow for extensions to be given on the expiration date.

If we can be of further assistance, please call the IRB office at (405) 271-2045 or send an email to irb@ouhsc.edu.

Sincerely yours

Karen J. Beckman, M.D.

Chair, Institutional Review Board

POCY3/0625



# The University of Oklahoma

DEC 0 5 2005

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## Health Sciences Center

INSTITUTIONAL REVIEW BOARD

IRB Number: 11953

Meeting Date: November 21, 2005

November 29, 2005

Rhonda Johnson, M.D. Dept of Obstetrics and Gynecology 920 Stanton L. Young Blvd, WP 2410 Oklahoma City, OK 73104-5020

RE: IRB No. 11953: Expressive Writing in Newly Diagnosed Breast Cancer Patients

Dear Dr. Johnson:

The Institutional Review Board (IRB) reviewed your IRB Application for Continuing Review (Progress Report) dated October 17, 2005 for the above-referenced study at the meeting on November 21, 2005 and determined that it was approvable with the specified changes:

#### **CONSENT FORM**

#### What is Involved in the Study?

1) On page 1, reword the first sentence to read "... four consecutive days, the fourth group will be a control group..."

2) Delete the second sentence ("Some groups will be asked to write about something very traumatic.").

#### Are There Benefits to Taking Part in The Study?

On page 3, delete the first paragraph ("Direct benefits will also include a \$5 pink ribbon breast cancer bracelet..."), since this information is provided elsewhere in the consent form.

Please make the necessary corrections and return one corrected copy, WITH REVISIONS HIGHLIGHTED, to the IRB.

As soon as I, on behalf of the Institutional Review Board, have reviewed and approved your revisions, written authorization will be sent to you authorizing the continuation of this research. Please note that your response must be received by December 09, 2005. If revisions have not been approved within that time period, this protocol will be administratively suspended. Suspension of research means that you no longer have approval to enroll new participants or continue with participants already enrolled (unless it is in the patient's best interest).

If you have any questions about the revisions requested in this letter or the procedures described here for completion of the approval process, please do not hesitate to call the IRB office at (405) 271-2045 or send an email to irb@ouhsc.edu.

Sincerely yours

Karen V. Beckman, M.D. Chair, Institutional Review Board APPENDIX C

Consent

# TEXAS WOMAN'S UNIVERSITY CONSENT TO PARTICIPATE IN RESEARCH

Title: "Expressive Writing in Newly Diagnosed Breast Cancer Patients"

Investigator: Principal Investigator: Melissa Craft, RN, MS, AOCN

College of Nursing, Texas Woman's University.

Phone: (405) 705-2705

Advisor: Gail Davis, EdD, RN Phone number: 940-898-2409

#### Purpose of the Study

You are being asked to participate in a dissertation study exploring how women deal with breast cancer. The purpose of this study is to evaluate the benefits of writing for women who have recently had a diagnosis of breast cancer.

### Description of the Study Procedure

The study procedure will require the completion of several questionnaires and, for some participants, writing in a journal. If you agree to participate in this study, you will be randomly assigned to a group that may or may not involve the journal writing.

If you are assigned to a writing group, you will be asked to write in your journal for 20 minutes on 4 consecutive days. The writing groups will be randomly assigned to write about either: their deepest thoughts and feelings regarding their experience with breast cancer **OR** their deepest thoughts and feelings regarding a self-selected traumatic life event **OR** specific topics regarding their breast cancer treatment such as diet, exercise, sleep and medication.

You will also be asked to complete three different instruments related to your cancer experience. These are related to feelings of anxiety and depression and how you feel about your treatment. You will be asked to complete these same three instruments 1 month after you finish writing for 4 consecutive days and again in 5 more months. You will be asked to complete an additional questionnaire evaluating the writing exercise; this will be added to the last set of tests. If you are not asked to write, your participation will involve taking the tests initially and again in 1 month and 6 months. You will also be asked to sign a release to allow the researcher to obtain information from your medical records and in some cases a copy of records such as pathology reports and office visit notes.

The study is designed to last for 6 months from the time you take the first tests until you take the last ones. The maximum total time estimated for your active participation in the study is approximately 2 ¾ hours. This includes 90 minutes for each of the testing periods and 80 minutes for the writing.

#### Potential Risks

 Loss of confidentiality is a possible risk to you as a result of your participation in this study. Confidentiality will be protected to the extent that is allowed by law. Participants will be assigned an identification number to be used instead of your name. A master list

Approved by the Texas Woman's University Institutional Review Board February 4, 2006 Participant initials Page 1 of 3 with names and identification numbers will be separated from the rest of the data and kept in a locked file in the researcher's office. The only way to link data with participants is with this list. The researcher is the only one with access to this locked file. Medical records information will be recorded on data sheets using your identification number and then those records containing your identifying information will be destroyed. The researcher is the only individual who will have access to your identifying data. All computer data that is potentially identifiable will be erased following completion of the study.

- There is also a possibility that completing the study may fatigue you and/or cause some
  tenderness or discomfort in the affected arm of a breast cancer patient who has recently had
  a lymph node dissection. You may choose not to continue in the study if you experience
  any fatigue, tenderness, or discomfort related to the writing activity and you are
  encouraged to contact your physician if the symptoms persist.
- There is a possibility that filling out these forms might cause you emotional discomfort due to the self-recognition of depression with breast cancer, feelings of anxiety or functional issues with adaptation to breast cancer. If you feel this way and would like help in dealing with these feelings, you may contact your physician and you may want to contact a counselor. Two counselors in the Oklahoma City metropolitan area frequently used by women dealing with breast cancer include Rhonda Johnson, PhD who can be reached at 405-271-8663, ext. 48263 and Ann Benjamin, LPC at 405-340-4321. You are reminded that you may withdraw from the study at any time.
- You may feel coerced to participate in the research. Please be assured that your decision regarding participation is completely voluntary and you may withdraw from the study at any time and your breast cancer treatment will not be affected.

The researchers will try to prevent any problem that could happen because of this research. You should let the researchers know at once if there is a problem and they will help you. However, TWU does not provide medical services or financial assistance for injuries that might happen because you are taking part in this research.

## Participation and Benefits

Your participation in this study is completely voluntary, and you may withdraw from the study at any time without penalty. Please feel free to ask any questions you may have at any time during the study. We hope that the information learned from this study will benefit other patients in the future. Benefits for you may also include the following:

Direct benefits will include a \$5 pink ribbon breast cancer bracelet that will be presented to
you at the conclusion of this study and an attractive journal published by the Oncology
Nursing Society. The proceeds from the sale of the bracelets are donated to the local
Oklahoma City Komen Foundation for research in breast cancer and to provide care for
underinsured and uninsured women in Oklahoma with breast cancer.

Questions Regarding the Study

You will be given a copy of this signed and dated consent form to keep. If you have questions about the study you may ask the researcher and/or advisor whose names and phone numbers are at the top of this form. If you have questions about your rights as a participant in this research or the way this study has been conducted, you may contact the Office of Research and Sponsored Programs at 940-898-3375 or by e-mail at IRB@twu.edu.

Participant initials

Approved by the Texas Woman's University Institutional Review Board February 4, 2006

Page 2 of 3

described. You have not given up any of your leg from liability for negligence. You have been give given a copy of this consent document.	gal rights or released any individual or institution
I agree to participate in this study:	
Signature of Participant	Date
So that you may be contacted, if needed, about the number at which you may be contacted.	e study arrangements please provide a phone
Phone:	
If you would like to receive a summary of the resu which this summary should be sent:	ılts of this study, please provide an address to

By signing this form, you are agreeing to participate in this research study under the conditions

Signature:

APPENDIX D

Instruments

# General Information Form Expressive Writing in Newly Diagnosed Breast Cancer Patients

## Item 1. Participant number\_\_\_\_\_

Item 2. Age		Item 6. Highest Level of Education				
a. 18-29 b. 30-39 c. 40-49 d. 50-59 e. 60-69 f. 70-79 g. 80-89 h. 90-100		a. 8 <sup>th</sup> grade b. High school c. Associate degree d. Bachelor's degree e. Master's degree f. Doctorate/MD				
Item 3. Marital Status		Item 7. Occupation				
a. Married b. Single c. Divorced d. Widowed  Item 4. Race		a Item 8. Cancer Type				
a. Caucasian b. Hispanic c. African American d. Native American e. Asian f. Other, please list		<ul> <li>a. DCIS</li> <li>b. Invasive ductal ca (IDC)</li> <li>c. Invasive lobular ca (ILC)</li> <li>d. Bilateral ca, both IDC</li> <li>e. Bilateral ca, both ILC</li> <li>f. Bilateral ca, mixed</li> <li>g. Other</li> </ul>				
Item 5. Annual Household Incom	ne	Item 9. Cancer Stage				
a. <\$20,000 b. \$20,000-\$39,999 c. \$40,000-\$59,999 d. \$60,000-\$79,999 e. \$80,000-\$100,000 f. >\$100,000		<ul> <li>a. Stage 0, DCIS</li> <li>b. Stage I, &lt; 2cm, -LN</li> <li>c. Stage II, &gt; 2cm, and/or LN+</li> <li>d. Stage III, locally advanced</li> </ul>				

Item 10. Surgery	Item 14. Hormonal therapy
a. no	a. yes b. no
Item 11. Type of surgery	Item 15. Date of diagnosis
a. Lumpectomy b. Mastectomy c. Mastectomy w/recon d. Bilateral mastectomy e. Bilateral mastectomy With reconstruction f. Mastectomy with delayed recon.	
Item 12. Radiation therapy	Item 16. Months since diagnosis
a. yes D	
Item 13. Chemotherapy	Item 17. Perceived value of journaling
a. yes	0-10 scale. 0 being no value, 10 being the most valuable

## Item 18. Intervention Group

- a. Control
- b. Attentional Control
- c. Breast cancer trauma
- d. Self-selected worse trauma

## FACT-B (Version 4)

Below is a list of statements that other people with your illness have said are important. By circling one (1) number per line, please indicate how true each statement has been for you during the past 7 days.

	PHYSICAL WELL-BEING	Not at all	A little bit	Some- what	Quite a bit	Very much
GP1	I have a lack of energy	. 0	1	2	3	4
GP2	I have nausea	0	1	2	3	4
GP3	Because of my physical condition, I have trouble meeting the needs of my family	0	1	2	3	4
GP4	I have pain	0	1	2	3	4
GP5	I am bothered by side effects of treatment	0	1	2	3	4
GP6	I feel ill	0	1	. 2	3	4 ·
GP7	I am forced to spend time in bed	0	1	2	3	4
	SOCIAL/FAMILY WELL-BEING	Not at all	A little bit	Some- what	Quite a bit	Very much
GS1	I feel close to my friends	0	1	2	3	4
GS2	I get emotional support from my family	0	1	2	3	4
GS3	I get support from my friends	0	1	2	3	4
GS4	My family has accepted my illness	0	1	2	3	4
GSS	I am satisfied with family communication about my illness	0	1	2	3	4
GS6	I feel close to my partner (or the person who is my main support)	0	1	2	3	4
QI	Regardless of your current level of sexual activity, please answer the following question. If you prefer not to answer it, please check this box and go to the next section.					
GS7	I am satisfied with my sex life	0	1	2	3	4

## FACT-B (Version 4)

By circling one (1) number per line, please indicate how true each statement has been for you during the past 7 days.

		EMOTIONAL WELL-BEING	Not at all	A little bit	Some- what	Quite a bit	Very much
	GEI	I feel sad	0	1	2	3	.4
	GE2	I am satisfied with how I am coping with my illness	0	1	2	3	4
	GE3	I am losing hope in the fight against my illness	0	1	2	3	4
	GE4	I feel nervous	0	1	2	3	4
	GE5	I worry about dying	0	1	2	3	4
	GE6	I worry that my condition will get worse	0	1	2	3	4
Ĺ							

		FUNCTIONAL WELL-BEING	Not at all	A little bit	Some- what	Quite a bit	Very much
	G₽1	I am able to work (include work at home)	0	1	. 2	. 3	4
	GF2	My work (include work at home) is fulfilling	0	1	2 2	3	4
	GF3	I am able to enjoy life	0	1	2	3	4
	GF4	I have accepted my illness	0	1	2	3	4
	GF5	I am sleeping well	0	1	2	. 3	4
	GF6	I am enjoying the things I usually do for fun	0	1	2	3	4
	GF7	I am content with the quality of my life right now	0	1	2	3	4
١	93						

## FACT-B (Version 4)

By circling one (1) number per line, please indicate how true each statement has been for you during the past 7 days.

	ADDITIONAL CONCERNS	Not at all	A little bit	Some- what	Quite a bit	Very much
BI	I have been short of breath	0	1	2	3	4
B2	I am self-conscious about the way I dress	0	1	2	3	4
B3	One or both of my arms are swollen or tender	0	1	2	3	4
B4	I feel sexually attractive	0	1	2	3	4
B5	I am bothered by hair loss	0	1	2	3	4
B6	I worry that other members of my family might someday get the same illness I have	0	1	2	3	4
В7	I worry about the effect of stress on my illness	0 .	1	2	, 3	4
В8	I am bothered by a change in weight	0	1	2	3 .	4
В9	I am able to feel like a woman	0	1	2	3	4
P2	I have certain parts of my body where I experience significant pain	0	* 1	2	3	4

Hello Melissa Craft:

Thank you for your interest in the Functional Assessment of Chronic Illness Therapy (FACIT) Measurement System, more specifically the FACT-B. I have attached a copy of the most current version of the questionnaire (Version 4) for your review and possible use. The questionnaire is available to users free of charge (English version only) and permission for use granted given your agreement to a few simple requests. Our user's agreement can be found on our website at <a href="www.facit.org">www.facit.org</a> (See registration & requests: user's agreement). Should you actually decide to include the questionnaire in your research, we would also request that you take the time to complete a Collaborator's Project Information Form on line to submit for our files. We are in the process of updating our website, so, many areas of the site are under construction. We appreciate your patience as we continue to create an efficient and user friendly site. Hereafter, by becoming a registered user you will be able to download the English scales directly to your system. I have attached the scoring and administration guidelines as well as the raw scoring template for the FACT-P. The raw scoring templates will eventually be available on our new website; however, a fee will be associated with this downloadable form. During this transition, we will not be charging a fee.

I would be happy to assist with your FACIT requests. However, I should tell you that we are currently in the process of revamping the FACIT manual and our website, <a href="www.FACIT.org">www.FACIT.org</a>. It might be in your best interest to consider waiting until the manual is available in the latest format, keeping in mind the version will still be Version 4. The Manual should be available in 8 weeks and prices are subject to change (manual \$100, scoring diskette \$30). That being said, the manual is still available and there is unfortunately a one week wait time with that as well. The following is the standard response to general inquires on the manual.

Our comprehensive users manual contains general information about the development of the scales, information on our multilingual translations, administration and scoring guidelines with raw score scoring templates for all currently available scales, copies of all scales with reliability and validity reports and effect size tables where applicable, and a 20+ page reference section. The manual is available for a fee of \$75.00 which is used to cover our communication, production and shipping costs. We also offer a scoring diskette with programs written for use with SAS or SPSS Statistical Software packages for all available FACIT scales. The diskette, available for a \$20.00 fee, will be of little use if your system can not support these statistical programs.

We will send out the materials with an enclosed invoice, which will have all of the appropriate remittance information and can then be submitted to the most appropriate payee. Unfortunately, credit card payment is not accepted. Our shipping method within the US is via US Mail, unless otherwise requested.

If you would like to order any of these products, simply respond to this email indicating your acceptance of the cost and your complete shipping address or let me know if you would prefer to be added to the list to contact when the new manual is completed.

Keeping that in mind, the documents I have attached should be enough for your study, without having to purchase the entire manual (anything to save a buck!  $\Box$ )

I hope you will find this information useful. If you have additional questions, please do not hesitate to contact me again.

Thank you,

Helen Albrecht Morrow, MA Research Assistant www.facit.org Tel: 847.570.7303

Fax: 847.570.8033 Halbrecht@enh.org information@facit.org

Sent: Thursday, September 25, 2003 12:49 PM

To: Melissa Craft

Subject: your facit.org registration

RN MS AOCN Melissa Craft, Thank you for registering with facit.org. When visiting the site in the future, please take the time to log in so that you will have access to restricted information and features of our site.

Your password at facit.org is: "stories".

Thank you, The staff at facit.org

## SELF-EVALUATION QUESTIONNAIRE

STAI Form Y-1

Name				Date	 ;	S		
Age	Gender (Circle)	M	F			T		
	DIRECTIONS:				40,	5	<b>S</b> .	
A number of statements which pure Read each statement and then control to indicate how you feel right now answers. Do not spend too muck seems to describe your present for the seems the seems to describe your present for the seems the seems to describe your present for the seems the seems to describe your present for the seems to describe your present for the seems to describe your present for the seems the se	circle the appropriate number to w, that is, at this moment. Ther h time on any one statement but feelings best.	the rine are ut give	ight on right the state of the	f the statement ght or wrong answer which		ENANTE 2	ALANCH 3	- A
2. I feel secure						2	3	4
3. I am tense						2	3	4
4. I feel strained						2	3	4
5. I feel at ease					 . 1	2	3	4
6. I feel upset					 . 1	2	3	4
7. I am presently worrying						2	3	4
8. I feel satisfied						2	3	4
9. I feel frightened						2	3	4
10. I feel comfortable				••••••	 1	2	3	4
11. I feel self-confident						2	3	4
12. I feel nervous					 1	2	3	4
13. I am jittery					 1	2	3	4
14. I feel indecisive					 1	2	3	4
15. I am relaxed						2	3	4
16. I feel content					1	2	3	4
17. I am worried					 1	2	3	4
18. I feel confused						2	3	4
19. I feel steady						2	3	4
20. I feel pleasant					 1	2	3	4

## SELF-EVALUATION QUESTIONNAIRE

## STAI Form Y-2

nameDate				
DIRECTIONS  A number of statements which people have used to describe themselves are given below. Read each statement and then circle the appropriate number to the right of the statement to indicate how you <i>generally</i> feel. There are no right or wrong answers. Do not spend too much time on any one statement but give the answer which seems to describe how you generally feel.	SO, TENEY	ARTINES	NANOS! OFTEN	N. T. K. Y.
generally feel.  21. I feel pleasant				3 4
22. I feel nervous and restless				3 4
23. I feel satisfied with myself				3 4
24. I wish I could be as happy as others seem to be				
25. I feel like a failure				
26. I feel rested				
27. I am "caim, cool, and collected"				
			_	
28. I feel that difficulties are piling up so that I cannot overcome them				
29. I worry too much over something that really doesn't matter			3	4
30. I am happy			3	4
31. I have disturbing thoughts	. 1	2	3	4
32. I lack self-confidence	. 1	2	3	4
33. I feel secure	. 1	2	3	4
34. I make decisions easily	. 1	2	3	4
35. I feel inadequate			3	4
36. I am content			3	4
37. Some unimportant thought runs through my mind and bothers me	1	2	3	4
38. I take disappointments so keenly that I can't put them out of my mind	1	2	3	4
39. I am a steady person	1	2	3	4
40. I get in a state of tension or turmoil as I think over my recent concerns			3	4

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STAID-AD Test Form Y www.mindgarden.com

## State-Trait Anxiety Inventory for Adults

Self-Evaluation Questionnaire STAI Form Y-1 and Form Y-2

Permission to reproduce up to 150 copies for one year starting from date of purchase

<u>April 1, 2005</u>

Developed by Charles D. Spielberger in collaboration with R.L. Gorsuch, R. Lushene, P.R. Vagg, and G.A. Jacobs

Published by Mind Garden, Inc.

1690 Woodside Road Suite 202, Redwood City California 94061 USA

Phone: (650) 261-3500 Fax: (650) 261-3505

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www.mindgarden.com

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STAID-AD Test Form Y www.mindgarden.com

Name:		Marital Status:	 Age:	 Sex:	
Occupati	on:	Education:		 	

Instructions: This questionnaire consists of 21 groups of statements. Please read each group of statements carefully, and then pick out the one statement in each group that best describes the way you have been feeling during the past two weeks, including today. Circle the number beside the statement you have picked. If several statements in the group seem to apply equally well, circle the highest number for that group. Be sure that you do not choose more than one statement for any group, including Item 16 (Changes in Sleeping Pattern) or Item 18 (Changes in Appetite).

#### 1. Sadness

- 0 I do not feel sad.
- 1 I feel sad much of the time.
- 2 I am sad all the time.
- 3 I am so sad or unhappy that I can't stand it.

#### 2. Pessimism

- 0 I am not discouraged about my future.
- I feel more discouraged about my future than I used to be.
- I do not expect things to work out for me.
- 3 I feel my future is hopeless and will only get worse.

#### 3. Past Failure

- 0 I do not feel like a failure.
- 1 I have failed more than I should have.
- 2 As I look back, I see a lot of failures.
- 3 I feel I am a total failure as a person.

#### 4. Loss of Pleasure

- 0 I get as much pleasure as I ever did from the things I enjoy.
- I don't enjoy things as much as I used to.
- I get very little pleasure from the things I used to enjoy.
- 3 I can't get any pleasure from the things I used to enjoy.

#### 5. Guilty Feelings

- 0 I don't feel particularly guilty.
- I feel guilty over many things I have done or should have done.
- 2 I feel quite guilty most of the time.
- 3 I feel guilty all of the time.

#### 6. Punishment Feelings

- 0 I don't feel I am being punished.
- 1 I feel I may be punished.
- 2 I expect to be punished.
- 3 I feel I am being punished.

#### 7. Self-Dislike

- 0 I feel the same about myself as ever.
- I have lost confidence in myself.
- 2 I am disappointed in myself.
- 3 I dislike myself.

#### 8. Self-Criticalness

- 0 I don't criticize or blame myself more than usual.
- 1 I am more critical of myself than I used to be.
- 2 I criticize myself for all of my faults.
- 3 I blame myself for everything bad that happens.

#### 9. Suicidal Thoughts or Wishes

- 0 I don't have any thoughts of killing myself.
- 1 I have thoughts of killing myself, but I would not carry them out.
- 2 I would like to kill myself.
- 3 I would kill myself if I had the chance.

## 10. Crying

- 0 I don't cry anymore than I used to.
- 1 I cry more than I used to.
- 2 I cry over every little thing.
- 3 I feel like crying, but I can't.

#### 11. Agitation

- 0 'I am no more restless or wound up than usual.
- I feel more restless or wound up than usual.
- I am so restless or agitated that it's hard to stay still.
- 3 I am so restless or agitated that I have to keep moving or doing something.

#### 12. Loss of Interest

- 0 I have not lost interest in other people or activities.
- 1 I am less interested in other people or things than before.
- I have lost most of my interest in other people or things.
- 3 It's hard to get interested in anything.

#### 13. Indecisiveness

- 0 I make decisions about as well as ever.
- I find it more difficult to make decisions than usual.
- I have much greater difficulty in making decisions than I used to.
- 3 I have trouble making any decisions.

#### 14. Worthlessness

- 0 I do not feel I am worthless.
- 1 I don't consider myself as worthwhile and useful as I used to.
- 2 I feel more worthless as compared to other people.
- 3 I feel utterly worthless.

#### 15. Loss of Energy

- 0 I have as much energy as ever.
- I have less energy than I used to have.
- 2 I don't have enough energy to do very much.
- I don't have enough energy to do anything.

## 16. Changes in Sleeping Pattern

- I have not experienced any change in my sleeping pattern.
- 1a I sleep somewhat more than usual.
- 1b I sleep somewhat less than usual.
- 2a I sleep a lot more than usual.
- 2b I sleep a lot less than usual.
- 3a I sleep most of the day.
- 3b I wake up 1-2 hours early and can't get back to sleep.

## 17. Irritability

- . 0 I am no more irritable than usual.
- 1 I am more irritable than usual.
- 2 I am much more irritable than usual.
- 3 I am irritable all the time.

#### 18. Changes in Appetite

- I have not experienced any change in my appetite.
- a My appetite is somewhat less than usual.
- 1b My appetite is somewhat greater than usual.
- 2a My appetite is much less than before.
- 2b My appetite is much greater than usual.
- 3a I have no appetite at all.
- 3b I crave food all the time.

#### 19. Concentration Difficulty

- 0 I can concentrate as well as ever.
- 1 I can't concentrate as well as usual.
- 2 It's hard to keep my mind on anything for very long.
- 3 I find I can't concentrate on anything.

## 20. Tiredness or Fatigue

- 0 I am no more tired or fatigued than usual.
- I get more tired or fatigued more easily than usual.
- 2 I am too tired or fatigued to do a lot of the things I used to do.
- 3 I am too tired or fatigued to do most of the things I used to do.

## 21. Loss of Interest in Sex

- 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.
- 3 I have lost interest in sex completely.

## Writing instructions and log

You have agreed to participate in a study looking at how women deal with breast cancer. You have been asked to write about your **deepest thoughts and feelings regarding breast cancer** for 20 minutes on four consecutive days. Thoughts include when something happened, what is going on as far as treatment etc. Feelings are how you feel about these events i.e. sadness, anger, fear, etc. Please try to incorporate both of these in your writing. There is no structure to how you write or what time of day. Please feel free to be as creative as you like and to incorporate this into your schedule. You do not have to write at the same time every day. If you run out of things to write please just repeat what you have already said until the time is up for that day.

		Journaing Record
Number		_
Date of study entry_		-
Date	Time	Place
		,
	1	

## Writing instructions and log

You have agreed to participate in a study looking at how women deal with breast cancer. You have been asked to write about your deepest thoughts and feelings regarding a self-selected worse trauma for 20 minutes on four consecutive days. Thoughts include when something happened, what the events were that led to the incident and specific details about what occurred. Feelings are how you feel about these events i.e. sadness, anger, fear, etc. Please try to incorporate both of these in your writing. There is no structure to how you write or what time of day. Please feel free to be as creative as you like and to incorporate this into your schedule. You do not have to write at the same time every day. If you run out of things to write about please repeat yourself until the full 20 minutes is elapsed.

		Journaling Record
Number		
Date of study entry_		-
Date	Time	Place

## Writing instructions and log

You have agreed to participate in a study looking at dealing with breast cancer. You have been asked to write about the facts of your treatment only. On day one please write about your diet, day two: your exercise regimen, day three: your sleep pattern and day four: your medications. There is no structure to how you write or what time of day. Please feel free to be as creative as you like and to incorporate this into your schedule. You do not have to write at the same time every day however please write for 20 minutes on each topic.

		Journaing Record
Number		
Date of study entry_		-
Date	Time	Place

# Expressive Writing in Newly Diagnosed Breast Cancer Patients Follow-Up Questionnaire

Participant number:	-				
Date:					
1. Please answer the following following scale of 1-5: 1=strongly a				expressive w	riting on the
Item	1	2	3	4	5
	Strongl y agree	Agree	No opinion	Disagree	Strongly Disagree
I completed the expressive writing exercise every day it was assigned.					
I enjoyed the writing exercise.					
I thought the writing exercise was helpful.	,				
I would recommend the use of expressive writing to anyone newly diagnosed with breast cancer.					
The instructions given about expressive writing were sufficient to get me started.	,				
I usually felt better after writing.				,	*
I usually felt worse after writing.					
I would have liked to have shared my writing with a group.					
I liked writing with paper and pen/pencil				×	
I would rather write on the					

computer than with paper and

pen/pencil.

	Please check any of the following that you used to deal with the diagnosis of breast neer.
	meditation
	exercise
	support group
	imagery
	support of spouse, partner, or other close to me
	talking with friends/family
	talking with individuals who have experienced breast cancer
	keeping a positive attitude
	prayer/religion/spirituality
	individual counseling medications such as antidepressants
	gathering information from health care professionals
	gathering information from written resources
	gathering information from the Internet
_	other, please list
3.	After you completed the writing assignment did you continue to journal?yesno
4.	If you answered yes to number 3, please answer the following questions, if you answered no please skip to question # 5:  a. Please circle the <b>one</b> response below that shows how often you wrote in you journal:  More than once daily
	Daily
	More than once a week
	Once a week
	More than once a month
	Monthly
	b. What did you journal about? If any of the following apply, please check as many as do. Under "other", please list other things that you wrote about? My mood or emotionsHow I felt physicallyThoughts I was havingQuestions I hadReflections on my thoughtsReflections on my life Other

5.	Prior to being involved in this study did you journal?
	yes no
6. of	If you answered yes to number 5, please circle the <b>one</b> answer below that shows how ten you wrote in your journal.
	More than once daily
	Daily
	More than once/week
	Once/week
	More than once/month
	Monthly
	answer the following open-ended questions. Use as much space as you need and additional pages if necessary.
6.	What have you liked the most about this expressive writing exercise?
7.	What have you liked the least about this expressive writing exercise?
7.	what have you liked the least about this expressive writing exercise:
8.	What recommendations would you give other breast cancer patients who may want to use expressive writing following diagnosis?
9.	Any other comments or suggestions:

## Physician/medical visits

Please use the following table to record the information about medical visits you have had during the study. Please include all appointments including vision and dental appointments, the reason for the visit, (i.e. routine exam, pain, cough, etc.) and the outcome of the visit (i.e. prescription for pain medicine, no action needed, etc.).

Type of visit	Date of visit	Purpose of visit	Outcome of visit
	*		
		-	