The Power of the Written Word

by

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Abstract

A diagnosis of cancer can catapult a person into a time period dominated by uncertainty and a perceived decrease in quality of life. Literature supports that writing honestly about emotions associated with traumas may address and reverse negative emotions and increase people's positive functioning. The purpose of this study was to investigate if expressive writing made a difference in uncertainty and quality of life for newly-diagnosed cancer patients. Fourteen patients just beginning their treatment phases were recruited and randomized into writing and non-writing groups. The writing group was given Pennebaker's writing prompt. Mishel's Uncertainty in Illness scale and Ferrans and Powers Quality of Life Index were administered at entry into the study and after three months. Findings were not statistically significant, however the small sample size and having multiple cancer diagnoses may have contributed to this. Findings reinforced uniqueness of illness experience and quality of life for each individual.

Acknowledgments

This thesis represents my personal "K2," a mountain I declared I would never "climb." But now, standing on the summit, I can honestly say I'm glad I did. However, I could not have done it without several invaluable "sherpas" guiding me along this journey. Therefore I would like to extend my deepest gratitude and appreciation to…

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I love you more.

Table of Contents

List of Tables

List of Figures

List of Abbreviations

M or m = mean

S.D. or sd = standard deviation

N = group sample

n = subgroup sample

ANOVA = analysis of variance

MCC = Montgomery Cancer Center

EAMC = East Alabama Medical Center

IRB = Institutional Review Board

MUIS = Mishel Uncertainty in Illness Scale

MUIS-C = Mishel Uncertainty in Illness Scale – Community form

QLI = Quality of Life Index

QLI-C = Quality of Life Index – Cancer Version III

QOL – CS = City of Hope Quality of Life – Cancer Patient version

USS = Uncertainty Stress Scale

IOM = Institute of Medicine

QL-Index = Spitzer Quality of Life Index

CHAPTER I

INTRODUCTION

Personal injury or illness is consistently listed as one of life's top stressors, along with death of a spouse and divorce. According to the American Cancer Society (2009), over 1.4 million people will be diagnosed with cancer this year. For these recently-diagnosed cancer patients, life turns upside down. Their physical body is under attack, their future uncertain, and emotionally, psychologically and cognitively they are reeling (Ferrell et al., 2005; Morgan, Graves, Poggi, & Cheson, 2008).

A diagnosis of cancer generates overwhelming uncertainty. "Will I die? Is this really happening? What if they mixed up the test results and these are not even mine? How will cancer affect my life? I have plans! When will life get back to normal? Will I live to see my children grown up and married? Will my husband or wife leave me? Does this doctor know what he or she is doing? Will I have much pain?" These questions and the uncertainty inherent in them can lead to a variety of emotional reactions. Those newly diagnosed with cancer may feel fear, sadness, hopelessness, helplessness (Ferrell & Coyle, 2008), shock (Morgan et al., 2008), anxiety, anger, grief, (Hochwald, 2008), betrayal by their bodies, a loss of control over their lives (both for the present and the fore-seeable future) (Boehmke & Dickerson, 2006), denial, and many other human emotions (Pennebaker & Chung, 2007; Penrod & Morse, 1997).

The experience of cancer can affect all aspects of life: multiple roles and relationships, the ability to work, the luxury of relaxing and having some control over a

daily schedule, one's spirituality, and the personal vision of a future. All of these factors influence one's perception of uncertainty and quality of life (Ferrell et al., 2005).

Quality of life is characterized as a multidimensional concept (Andersen, Kiecolt-Glaser, & Glaser, 1994; Ferrell, Wisdom, & Wenzl, 1989; Osaba, 1994). Literature described it as having several components: physical or health, general functioning, psychological, spiritual, social, economic, and family or significant others (Ferrans & Powers, 1992; Ferrell, Grant, Padilla, Vemuri, & Rhiner, 1991). Introducing cancer into a life has a negative impact on quality of life, at least temporarily (Stanton et al., 2002).

An individual's response to this diagnosis depends on their personality and normal coping behaviors. Some people cope through expressing themselves by crying, talking, writing (journaling) or more recently, by blogging (Lyubomirsky, Sousa, & Dickerhoff, 2006). Others internalize their emotions and maintain a staid exterior, and there are those who stay in denial, avoiding and ignoring their emotions altogether (Pennebaker & Beall, 1986). While each is a normal reaction, literature has revealed that not expressing emotions can negatively affect one's health, physically as well as psychologically (Lyubomirsky et al., 2006; Pennebaker & Beall, 1986).

Expressive writing is a patient-focused intervention which has gained increasing attention in clinical settings in the last two decades. Research has suggested that expressing thoughts on paper has health benefits to those who participate (Frattoroli, 2006; Pennebaker & Beall, 1986). There are differing opinions as to why writing makes a difference in the writers' health, but writing out one's feelings regarding a traumatic event, whether in the past or present, can result in both physiological and psychological benefits. Some of the benefits identified have included less intentional isolation and more

honest social interactions (Niederhoffer & Pennebaker, 2002), decreased anger, distress, depression and anxiety (Frattoroli, 2006), improved positive overall functioning and outlook (Frattoroli, 2006; Smyth, Stone, Hurewitz, & Kaell, 1999), improvements in liver and immune functioning (Frattoroli, 2006), and fewer doctor visits (Pennebaker & Beall, 1986).

In order to give holistic care, nurses need to address not only the physical symptoms of cancer, but also assess for and identify other areas of the individual's life that might also have been affected by the cancer, including psychological, social/family/significant others, spirituality (Ferrans & Powers, 1985; Ferrell et al., 2005) and socioeconomic (Ferrans & Powers, 1985). Chemotherapy, radiation and medications treat the physical body, but therapies are needed for addressing other areas "wounded" by the uncertainty and perceived threats to the individual's quality of life (Ferrell et al., 2005).

Current Research

Review of the literature revealed research that has recently been conducted on expressive writing with cancer patients (Frattaroli, 2006; Kállay & Băban, 2008; Laccetti, 2007; Morgan et al., 2008), and uncertainty and quality of life in patients (Eastwood, Doering, Roper, & Hays, 2008; Sammarco, 2001; Wallace, 2003: Wonghongkul, Dechaprom, Phumivichuvate, & Losawatkul, 2006). However, there have been very few studies (Laccetti, 2007; Rosenberg et al., 2002; Stanton et al., 2002) which looked at the effect of expressive writing on perceived quality of life in cancer patients, and none which additionally measured specifically for uncertainty. This lack of literature suggested a need to conduct research in this area.

Purpose

The purpose of this research was to investigate whether expressive writing makes a positive difference in the lives of those newly diagnosed with cancer with regard to their feelings of uncertainty and perceived quality of life. Information obtained from this research will add to the growing amount of literature which reports the link between expressive writing and positive outcomes.

This research can contribute to the literature on the effects of expressive writing in a general cancer population. Prior studies were composed mainly of breast cancer or prostate cancer patients, with only a few studies involving the general cancer population. This research will add to the combined measurement of quality of life and uncertainty in the general cancer population.

Study questions

Research measuring uncertainty and quality of life in patients was found in the literature (Eastwood et al., 2008; Sammarco, 2001; Wallace, 2003), as well as research on expressive writing in various population groups (Frattaroli, 2006; Kállay & Băban, 2008; Laccetti, 2007; Morgan et al., 2008; Smyth et al., 1999) however, no studies were located which looked specifically at writing's effects on uncertainty and quality of life in the lives of newly-diagnosed cancer patients. A non-experimental, causal-comparative study design was chosen to guide this research; therefore study questions were appropriate instead of a hypothesis (Gall et al., 2007). The following study questions guided the research:

1. Does expressive writing cause a difference in cancer patients' perceived level of uncertainty after writing for three months?

2. Does expressive writing cause a difference in cancer patients' perception of their quality of life after writing for three months?
3. Does expressive writing affect the relationship between quality of life and uncertainty in the intervention group as compared to the control group?

Theoretical and Operational Definitions

Before a study can commence, important terms must be defined. Theoretical definitions describe the abstract meaning of a concept, while operational definitions delineate how the concept is used and measured in a study (Polit & Beck, 2008).

Uncertainty

Life is full of events which cause uncertainty. From the mundane and immediate, such as wondering which cereal will taste better, to the life-altering and lingering questions where life may literally hang in the balance, people can face varying degrees of uncertainty every day.

Theoretical definition.

Uncertainty has been defined as "the quality or state of being uncertain, or in doubt; something that is uncertain" (Merriam-Webster Online Dictionary, 2008). It is a "dynamic, discomforting, non-normative state", one which is unique and based on each individual's perception of their situation (Penrod, 2007, p. 663). Uncertainty causes a person to become stuck in the present; unsure of how to proceed and move forward to his or her future goals. In essence, "hope was paralyzed" (Penrod, 2001, p. 243).

Operational definition.

Uncertainty has been measured through Mishel's Uncertainty in Illness scale (1989). Since this study looked beyond uncertainty to the more specific application of

uncertainty in illness, this scale was chosen instead of other scales which looked at uncertainty in a more general way.

Uncertainty in Illness

Uncertainty is a very real part of any illness, but especially in the cancer experience. It is highest at time of diagnosis, and gradually decreases as the causes of the uncertainty are taken care of, or over time as the individual learns how to cope and adapt (Hjörleifsdóttir, Hallberg, Gunnarsdóttir, & Bolmsjö, 2008; Stanton et al., 2002). Uncertainty never goes away completely however, but remains to some degree with the individual for the rest of his or her life (Ferrell, Grant, Funk, Otis-Green, &Garcia, 1998; Hjörleifsdóttir et al., 2008).

Theoretical definition.

Mishel (1988) described uncertainty in illness as "the inability to determine the meaning of illness-related events" (p. 225). These uncertainty-causing events have the characteristics of being "vague, ambiguous, unpredictable, unfamiliar, inconsistent, or lacking information" (Mishel, 1984, p.163). Based on these characteristics, three attributes of uncertainty were identified: "probability, temporality and perception" (McCormick, 2002, p.129).

Operational definition.

Mishel's Uncertainty in Illness scale – Community form was used to define the concept in this study (Mishel, 1989). Four key characteristics are addressed in this scale. These characteristics include "inconsistency, unpredictability, ambiguity, and complexity" (Mishel, 1997b, p. 6). The Uncertainty in Illness scale – Community form is composed of 23 questions covering these four uncertainty characteristics. A 5-point

Likert-type scale is used to answer each question. The scale consists of numbers 1-5, where 1 = strongly disagree and 5 = strongly agree. The higher the score, the greater the feelings of uncertainty. The domains of this scale include:

- ***Inconsistency.*** This domain includes questions regarding the inconsistency of the information being given the patient by various health care providers;
- ***Unpredictability.*** This domain includes a question regarding the inconsistencies between treatments given and anticipated and actual outcomes;
- ***Ambiguity.*** This domain includes questions regarding the ambiguity of the state or stage of the disease;
- ***Complexity.*** This domain includes questions regarding the treatments and care given to the patient (Mishel, 1997b, p. 8).

Quality of Life

Each individual has a unique perspective on his own quality of life. It cannot be assessed for him nor assumed, for no one fully knows another person's deepest satisfactions or highest priorities except for that individual.

Theoretical definition.

Quality. (noun) a peculiar and essential character, an inherent feature, a distinguishing attribute; (adjective) being of high quality (Merriam-Webster Online Dictionary, 2008).

Life. (noun) a way or manner of living (Merriam-Webster Online Dictionary, 2008).

Quality of life. (noun) your personal satisfaction (or dissatisfaction) with the cultural or intellectual conditions under which you live (as distinct from material comfort) (WordNet 1..7.1, 2001). Quality of life is a multidimensional concept (Andersen et al., 1994; Ferrell et al., 1989; Osaba, 1994). Ferrans and Powers (1992) defined quality of life as "a person's sense of well-being that stems from satisfaction or dissatisfaction with the areas of life that are important to him/her" (p. 29). This definition highlights the uniqueness of each individual's perception of his experiences and how these perceptions impact his quality of life. According to Ferrans and Powers (1992) quality of life comprises four domains: health and functioning, psychological/spiritual, social and economic, and family**.**

Operational definition.

Ferrans and Powers Quality of Life Index - Cancer Version III was used in this study to measure and define quality of life (Ferrans & Powers, 1998a). This index, a self-report survey, is composed of 66 questions covering the four domains of "health and functioning, psychological/spiritual, socioeconomic and family": 33 questions on how satisfied the individual is with an item in their life, and 33 questions on how important that item is to them. A 6-point Likert-type scale is used in this survey, with 1 = very dissatisfied or very unimportant, and 6 = very satisfied or very important. The domains of this scale include:

- ***Health and functioning*****.** This domain includes questions about the usefulness to others, physical independence, ability to meet family responsibilities, own health, pain, energy (fatigue), stress or worries,

control over own life, leisure-time activities, potential for a long life/retirement, ability to travel on vacations, sex life, health care;

- ***Psychological and spiritual*.** This domain includes questions about satisfaction with life and self, happiness in general, achievement of personal goals, peace of mind, personal appearance and personal faith in God;
- ***Social and economic*.** This domain includes questions about standard of living, financial independence, home (house or apartment), neighborhood, job/unemployment, friends, emotional support from others, education, and influence in government;
- ***Family*.** This domain includes questions on family happiness and health, children, relationship with spouse or significant other, and emotional support from family (Ferrans & Powers, 1992, p. 295).

Expressive Writing

Expressive writing, reflective journaling, experimental or emotional disclosure: all are names describing the act of writing down one's private thoughts. It is the baring of one's soul on paper, sometimes to be kept private, and other times to be read or shared with others. Research has suggested that expressive writing is associated with positive physical and psychological effects for clinical populations (Frisina, Borod, & Lepore, 2004).

Theoretical definition.

***Expressive*.** (adjective) 1. of or relating to expression, 2. serving to express, utter or represent, 3. effectively conveying meaning or feeling (Merriam Webster Online Dictionary, 2008).

***Writing*.** (noun) 1. the act or process of one who writes as: a) the act or art of forming visible letters or characters; b) the act or practice of literary or musical composition 2. something written as: a) letters or characters that serve as visible signs of ideas, words or symbols; b) a letter, note or notice used to communicate or record; c) a written composition (Merriam-Webster Online Dictionary, 2008).

***Expressive writing*.** Writing with the intent to divulge honest thoughts and emotions.

Operational definition.

Countless studies found in the literature used Pennebaker's original writing prompt or a variation of it for their research study (e.g. Kovac & Range, 2002; Morgan et al., 2008; Rosenberg et al, 2002; Smyth et al., 1999). Following their example, the current study participants were asked to write about "their very deepest thoughts and feelings" about past or present traumas, conflicts or stressors. However, they were also given the option to write about anything else, negative or positive, provided they included honest thoughts, feelings or emotions. Participants were asked to write at a minimum of twice a week, with no specific amount of time set per episode.

Study Assumptions

Assumptions are defined as "principles which are accepted as being true based on logic or reason, without proof" (Polit & Beck, 2008, p. 748). Assumptions for this study were:

1. Participants would actually do some type of writing on a regular basis - regular being at least twice a week - throughout the three months of being in the study.
2. Participants would answer survey items honestly and correctly.
3. Participants would return surveys in the time and manner requested.
4. Data collected would contribute to the knowledge base about beneficial interventions for cancer patients.

Study Limitations

Limitations are those things over which the researcher has no control, but which can affect the accuracy or purity of the study findings and which must be taken into account during the interpretations of the findings. Limitations for this study included, but were not limited to:

1. Participants' responses may have been influenced by their diagnosis and prognosis.
2. Participants' responses may have been influenced by the progression of their disease, or by metastasis of disease.
3. Participants' responses may have been influenced by their treatment regime and the intensity or lack of side effects.
4. Participants' responses may have been influenced by their degree of spirituality, which was not assessed in this study.

5. Participants' responses may have been influenced by the presence or lack of a support system, which was not assessed in this study.
6. Participants' responses may have been influenced by their age.
7. Participants' responses may have been influenced by previous and ongoing uncertainties and quality of life.
8. Participants' responses may have had limitations imposed by self-identification and self-report of uncertainties and perceived quality of life.
9. Participants' responses may have been influenced by the Hawthorne effect. Gall, Gall and Borg (2007) defined the Hawthorne effect as any situation which causes participants to respond in a different way (than they would have) due to the fact that they know they are in a study, they know the goals of the study, or they are receiving special attention for being in the study.
10. This researcher mailed surveys to participants, therefore the time, place and setting in which the surveys were completed could not be controlled beyond requesting that the outlined procedures be followed.

Summary

A diagnosis of cancer will always bring with it accompanying emotions such as uncertainty, anxiety and distress. Keeping these emotions to oneself has been found to negatively impact one's health, both physiologically as well as psychologically. In contrast, allowing these emotions to be recognized and processed through writing has shown positive health benefits. For cancer patients, writing could be an inexpensive intervention; a way for nurses or others to give more holistic care.

CHAPTER II

LITERATURE REVIEW

Improvements in cancer outcomes continue as new technology and treatment options are discovered and become available. Whereas a few decades ago a cancer diagnosis would have been a death sentence, thankfully now the prognosis for some cancers can be less grim. That said, a diagnosis of cancer, and the uncertainty which accompanies it, still evokes a myriad of intense emotions (Boehmke & Dickerson, 2006; Hjörleifsdóttir et al., 2008). These emotions in turn often have a negative effect on an individual's perceived quality of life (Wallace, 2003). Quality of life is important as it is what gives life meaning. Treatments can wear a person down physically, and the uncertainty and reduced perceived quality of life can be psychologically draining. Overwhelmed by it all, patients can experience helplessness and a feeling of powerlessness (Rancour & Brauer, 2003). Research has reported that writing expressively about one's emotions can help reduce negative emotions such as anxiety, distress and depression (Frattaroli, 2006). As these emotions decrease, there is a corresponding increase in the perceived quality of life (Stanton et al, 2002). To empower, by definition, is to "enable" and/or "promote the self-actualization of" someone or something (Merriam-Webster's Online Dictionary, 2009). Therefore, the act of writing empowers individuals to be a part of their own treatment plan. While medical treatments fight cancer on a physiological level, writing can fight the effects of cancer on a psychological

level. This review of literature will describe the evolution of the various components and their current state.

Review of the Literature

An extensive literature review was conducted prior to initiating this research project. A careful review of literature must be done in order to guarantee the proposed research project will contribute to an expanding body of knowledge (Gall et al., 2007). Literature review focused on four main topics: individuals with cancer, the concept of uncertainty, the concept of quality of life, and expressive writing/reflective journaling. This search was conducted not only in nursing literature, but also that of psychology, sociology and medicine. This review of literature found very few studies which examined the effect of expressive writing in a general cancer population. Most studies were conducted with specific cancer populations. There were also few studies which explored individuals' feelings of uncertainty and quality of life. Most studies looked at one or the other, rarely both.

Individuals with Cancer

It is estimated that in 2009 there will be nearly 1.5 million adults in America diagnosed with some type of cancer (excluding squamous and basal cell skin cancer and all in-situ carcinomas except urinary bladder) (American Cancer Society, 2009). The state of Alabama is projected to have a little over 24,000 newly diagnosed cases (American Cancer Society, 2009). The main cancer sites are breast cancer (for women) and prostate cancer (for men), followed by cancer of the lung or bronchus, and colon or rectal cancer. According to the American Cancer Society (2009), over the course of a

lifetime and with the chances increasing with age, women have about a 33% chance of getting cancer, whereas men are closer to a 50% chance that they will get cancer.

No matter when it comes, the diagnosis of cancer brings with it an incredible variety of intense emotions. Studies found that even before the actual diagnosis was made, individuals experienced feelings of uncertainty (Morgan et al., 2008), anxiety, and fear of the unknown (Hochwald, 2008). Once the diagnosis was official, emotions often intensified with the shock of this new reality (Morgan et al., 2008). Whereas the uncertainty of "what is wrong with me" had been settled, suddenly a whole new set of fears and uncertainties plagued an individual: "Will treatments work? Will I be horribly disfigured? Will I die? Will treatments and their side effects be too painful for me to stand? What will happen to my family? Can I continue working? Who will stay and support me, and who will abandon me when they hear of the diagnosis?" Individuals felt overwhelmed with their new reality and all of the decisions which must be made (Beatty, Oxlad, Koczwara, & Wade, 2008; Boehmke & Dickerson, 2006; Penrod & Morse, 1997). Some individuals experienced denial (Boehmke & Dickerson, 2006; Doell, 2008; Pennebaker & Chung, 2007; Penrod & Morse,1997; Carver et al., 1993), others behavioral disengagement (Pennebaker & Chung, 2007; Carver et al., 1993), grief, and/or anger (Hochwald, 2008) fear, anguish, self blame and/or shock (Beatty et al., 2008) and feelings of being betrayed by their bodies (Boehmke & Dickerson, 2006).

Individuals often cope through the expression of these emotions, either verbally or through writing. Family members, friends, and medical healthcare professionals can all listen and help an individual work through their emotions, but individuals do not always feel comfortable expressing emotions to those closest to them. Individuals may feel they

need to be strong (Smith, Anderson-Hanley, Langrock, & Compas, 2005) or stay positive (Beatty et al., 2008). Others may feel embarrassed by the diagnosis or afraid of being treated differently. Some individuals get tired of saying the same thing over and over – and perhaps think that others get tired of listening to the same thing – and yet are still dealing with whatever the issue or emotion is and thus need to continue to process what is happening.

Support groups were an outlet mentioned in the literature which allowed and encouraged verbalization of emotions. Here individuals found others who were going through the same or very similar situation. Often individuals experienced new strength from knowing that they were not the only one going through this crisis or feeling a certain side effect or emotion. They felt freer to verbalize what they were thinking or feeling, knowing they would be understood. Support groups can offer suggestions for ways to cope with various therapies or the uncomfortable side effects, as well as general encouragement. These support groups can meet in a physical location, or be held online in chat rooms. The American Cancer Society local chapter in Lee county, Alabama, offers a variety of support groups including the "I Can Cope" group which meets in Opelika, two "Look Good, Feel Better" support groups - one which meets in Montgomery and the other in Opelika, a "Reach to Recovery" support group which meets in Montgomery, and two general support groups, one which meets in Opelika and one in Alexander City. There are two support groups specifically for those with breast cancer: one in Opelika sponsored by the American Cancer Society, and the other in Montgomery called "Women of Hope" sponsored by Frazer Memorial United Methodist Church.

For those individuals who chose not to bare their soul verbally to loved ones around them, some found release through writing. Writing can be very private through the use of a journal, or more open through an online journal or blog. Through writing privately in a journal, individuals are free to express any and all emotions as intensely as they are being experienced. No words need to be checked, no tongue bit. Raw emotions can pour forth from the pen, coming from the depths of the soul (Rancour & Brauer, 2003).

If individuals desire to share their emotions and experiences with others, then an online journal or web log (blog) can be created. A patient can set up his or her own blog, or utilize websites which have been created specifically for patients going through a health crisis where the patient or family members can keep friends and family updated on the patient's condition. The Caring Bridge website is an example of a website of blogs created specifically for those going through illnesses. Blogs allow patients to diary about daily happenings, how they are feeling both physically and psychologically, and anything else they want to share, and they can also post pictures. Most blogs are set up to allow readers to post responses and encouragement, thus creating a virtual circle of support around the patient, unrestricted by distance (Ko & Kuo, 2009).

There are individuals however who choose not to express any emotion. Their coping mechanism is to either stay on the island of denial, or to keep everything bottled up inside, maintaining a stoic or positive front, and never acknowledging the depth and breadth of their emotions. This style of coping may be adequate during normal life happenings, but may not give effective support during major life changes such as a diagnosis of cancer (Iwamitsu et al., 2003). Additionally, research has suggested that

talking or writing about traumatic events could improve ones' physical and mental health (Pennebaker, 1999), a finding which should be relevant to anyone facing a cancer diagnosis.

Uncertainty

The definition of uncertainty varies depending on the subject matter. WordNet (2006), a dictionary website sponsored by Princeton University, defines uncertainty as "being unsettled or in doubt or dependent on chance; the state of being unsure of something". The APA Dictionary of Psychology (2007) defines uncertainty as: "1. the state or condition in which something (e.g. the probability of a particular outcome) is not accurately or precisely known. 2. lack of confidence or clarity in one's ideas, decisions or intentions" (p. 966). A definition of uncertainty used in cancer research is "the lack of sureness or confidence in results of measurements or predictions of quantities owing to stochastic variation or to a lack of knowledge founded on an incomplete characterization, understanding or measurement of a system" (Genetic Consequences of Cancer Treatment, 2008, p. 1). Dictionary.com Unabridged (n.d.) added another dimension to the definition with its' third definition: "unpredictability; indeterminacy; indefiniteness".

In this literature search, the articles fell into one of three groups: uncertainty as a concept, intolerance of uncertainty, and uncertainty in illness. Interestingly, each of these groups has at least one established scale or tool with which to measure or study its particular focus of uncertainty.

Uncertainty concept.

While exploring the relationship between the concepts of enduring, suffering and hope, Morse and Penrod (1999) discovered uncertainty was a related concept.

Uncertainty was described as a middle ground where the ultimate goal was known, but the best route to that goal was not known. The individual was stuck in the present with an uncertain future, somewhere between the states of suffering and hope. A lack of knowledge and information about the various options which could lead to reaching the goal contributed to the uncertainty. In this description, hope was "paralyzed" (Morse & Penrod, 1999, p.148). Penrod studied the general concept of uncertainty further, and defined uncertainty's attributes as a "dynamic" and "pervasive but non-normative state," having a "discomforting, uneasy sensation," and as one which was impacted by an individual's perceptions of their degree of control and confidence (Penrod, 2001, 2007, p. 663). While not using the term "dynamic," Hilton (1994) described the flexible nature of uncertainty as one which could wax and wane and believed that uncertainty was always accompanied by both positive and negative emotions (p. 18).

McCormick, however, identified three different defining attributes: "temporality, probability and perception" (McCormick, 2002, p. 129). Temporality was described as not knowing how long the source of uncertainty would last. The end was not in sight; the future was unknown. Probability spoke to the likelihood of something happening, and in uncertainty that probability could not be pinned down. Perception was how one saw the uncertainty at that point in time; it was unique and individualized. If an individual tried to classify the perception of uncertainty, they could not. Was the situation causing the uncertainty seen as a threat or an opportunity (Mishel, 1988)? Would it produce a positive outcome or a negative one? Penrod (2007) identified these same three attributes but categorized them as strategies to help manage uncertainty.

Uncertainty could have a positive outcome as an individual perceived greater control and confidence, and experienced growth towards a "new normal" (Penrod, 2007, p. 663). Individuals saw life in a new way (Mishel, 1988; Penrod, 2007) and experienced hope (Hilton, 1994; Mishel, 1988). Uncertainty could also be seen as a negative outcome where the perception was of a decline of control and confidence which resulted in the individual feeling immobilized (Penrod, 2007), both with hope (Morse & Penrod, 1999) and in their coping mechanisms (Hilton, 1994). Anxiety, depression (Hilton, 1994; Leite & Kuiper, 2008), frustration, fear, helplessness (Hilton 1994) and distress (Berenbaurm, Bredemeier, & Thompson, 2008) were all identified as negative outcomes.

Intolerance of uncertainty.

"Intolerance of uncertainty" has been explored in the halls of psychology (Berenbaum et al., 2008; Bredemeier & Berenbaum, 2008; Leite & Kuiper, 2008). Intolerance of uncertainty can be linked to one's perception of self and the ability to tolerate change and uncertainty, both in life and inside one's self. Those more intolerant of uncertainty experience greater discomfort and anxiety as a result of the uncertainty (Leite & Kuiper, 2008), as well as worry, depression, distress and a feeling of being "paralyzed" (Berenbaum et al., 2008). Bredemeier and Berenbaum (2008) found that those with a higher intolerance for uncertainty tended to concentrate more on the potential negative outcomes of options instead of the positive ones, ignoring the probabilities attached to the options.

Uncertainty in illness.

Mishel (1981) studied uncertainty in illness and identified contributing factors such as ambiguity of symptom patterns, unpredictability of the disease prognosis and

progression, insufficient information regarding the diagnosis, and the lack of clarity regarding the treatment plans (p. 259). Further research revealed additional contributing factors to this uncertainty came from events which were "vague, unfamiliar and inconsistent" (Mishel, 1984, p. 163). While Mishel (1997a) thought that uncertainty was a "neutral cognitive state" (p. 66), Hilton (1994) disagreed and believed that both positive and negative emotions accompanied uncertainty.

Uncertainty in illness is a unique and individualized experience and the issues or questions causing it may differ depending on if one is asking a health care provider or an individual (Kasper, Geiger, Freiberger, & Schmidt, 2008; Penrod, 2007). Seven categories of patient uncertainty identified by Kasper et al. and Donovan-Kicken and Bute (2008) included uncertainty regarding "social integration, diagnosis and prognosis, deciphering information, mastering of requirement, causal attribution, own preferred degree of involvement, physician's trustability, and treatment" (Kasper et al., 2008, p. 46). An individual's reaction to uncertainty often depends on the potential diagnosis, for instance, if the individual thinks it is a minor illness or cancer. Cancer survivorship is a new interest in research and one of its identified attributes is uncertainty (Doyle, 2008). Interestingly, while some patients focus on hope and move towards the goal of ending the uncertainty (Morse & Penrod, 1999), others with chronic illnesses switched from a goal of reducing uncertainty to just trying to manage it (Donovan-Kicken & Bute, 2008).

Individual patients face many sources of uncertainty. Some of it comes from hours of waiting, not only in waiting rooms, but also in the time lapses between discovery, confirmation and treatments (Fogarty & Cronin, 2008). During these periods of waiting, the perceived threat to their health and life is unknown, their symptoms might

be unpredictable and distressing, and the timetable of when a diagnosis will be known or symptoms gone is not known (Fogarty & Cronin, 2008). Individuals experience feelings of uncertainty and powerlessness (Fogarty & Cronin, 2008).

Measurement of uncertainty.

In the review of literature, there were no expressive writing studies found which looked specifically at uncertainty. The majority of the expressive writing studies were conducted with cancer survivors and measured the survivors' general mood; only two looked at patients during their active treatment phase. The most common tool utilized was the Profile of Mood States (McNair, Lorr, & Droppleman, 1971). This tool is composed of 65 adjectives which describe the following domains: tension/anxiety, depression/dejection, anger/hostility, vigor/activity, fatigue/inertia and confusion/bewilderment. Using the above tool, female cancer patients reported being depressed and furious (Kállay & Băban, 2008) and prostate patients reported little mood change over the course of the study (Rosenberg et al., 2002).

This research study wanted to specifically look at uncertainty, therefore a search was made for such a tool. There were four tools or scales found in the literature which had been developed and used to measure the concept of uncertainty. Two focused specifically at uncertainty and illness, and the other two looked at uncertainty and life in general.

Uncertainty Stress Scale.

The Uncertainty Stress Scale (USS) was designed to measure uncertainty in illness-related situations and to specifically look at the stress, threat, and positive feelings which are created by the situation (Hilton, 1994). Hilton believed that uncertainty had an

emotional component and thus included questions probing for positive feeling along with perceptions of threat that accompanied the state of uncertainty. As of 1994, the USS has undergone three revisions. Since then it has been translated into several languages, and used in a variety of clinical populations with adapted versions of the USS. A sampling of groups which have used this tool includes Portugese individuals with type 2 diabetes (Apóstolo, Viveiros, Nunes, & Domingues, 2007), high-risk pregnant women (Clauson, 1996), and adult survivors of cancer (Hilton & Skrutkowski, 2002).

The USS is composed of three parts (Hilton & Skrutkowski, 2002). Part A consists of 54 items. Statements about the patient's health condition and coping are presented and participants are asked to rate their level of uncertainty regarding these items. Each item is answered on a 5-point Likert scale. The choices range from 0 = no uncertainty, to 4 = a great deal of uncertainty. Participants are also given "not applicable" as an answer option. Part B looks at the same 54 items, but now the participant is asked to rate the items based on how much stress is being generated by the uncertainty. Each item is answered on a 3-point Likert scale. The choices are 0 = no stress, to 2 = very high stress. Part C consists of four 10-cm long visual analog scales. These measure "global uncertainty, global stress, global threat and positive feelings" (Hilton & Skrutkowski, 2002, p. 4). The USS has questions pertaining to the following uncertainty factors: "uncertainty/clarity/reliability/dependability, symptom uncertainty, doubt regarding present and future state of the condition, and doubts about coping and understanding" (Hilton, 1994, p. 23).

Reliability and validity.

Scoring of the USS consists of summing Part A for an overall look at uncertainty, or summing each of the individual subscales. Part B can also be scored in that same way. Part C is scored by measuring where the individual marked on the 10 cm line. Reliability of the USS is supported by a Cronbach alpha of 0.96 (Hilton, 1994).

Hilton (1994) demonstrated construct validity of this scale by testing it on a variety of patient populations and situations. Through factor analysis the original scale with eight factors was reduced to four, and testing with a new group of sample patients validated the two major theoretical themes. Multidimensional scaling confirmed both the factors and reflected similar themes. Convergent validity for the uncertainty component was tested through correlating the USS with Mishel's Uncertainty in Illness scale (r = .69, p = .00). Convergent validity for the stress component was tested through correlating the USS with the Spielberger State Trait Anxiety Inventory. Results were r = .43 (p = .01) for total stress, and r = .63 (p = .00) for the stress visual analogue items. Hypothesis testing was conducted in several different people groups and results confirmed that there was a positive correlation between uncertainty and stress (r = .50, p = .00). The data also revealed a positive correlation between uncertainty and stress (r = .54, p = .00) and uncertainty and threat (r = .55, p = .00). Multiple regression analysis revealed that cancer recurrence, shorter time interval since treatment, lower education level and poorer state of health were all associated with greater uncertainty. Finally, the use of contrasted-groups also supported the scale.

Content validity was demonstrated by having the USS reviewed for "appropriateness and clarity" by known experts in the field including physicians, nurses,

cancer patients, individuals with medical disorders, psychometricians, and researchers on uncertainty (Hilton, 1994). Revisions were made per the reviewers' recommendations.

Mishel Uncertainty in Illness Scale.

The Mishel Uncertainty in Illness Scale (MUIS) was originally developed in 1980 to assess for uncertainty in ill, hospitalized patients (Mishel, 1981). In the last twenty years the scale has been translated into over 10 languages, used in many clinical populations, and spawned four versions. One of the versions is the Mishel Uncertainty in Illness Scale – Community form (MUIS-C). While the MUIS was created for hospitalized patients, the MUIS-C was created to assess for the pervasiveness of uncertainty caused by illness as perceived by a non-hospitalized patient (Mishel, 1997b). The MUIS-C was developed in 1986, and revised in 1989 to its current form. A small sampling of population groups which have utilized this tool includes breast cancer survivors (Sammarco, 2001; Wonghongkul et al., 2006), patients with prostate cancer (Wallace, 2003), patients who had coronary angiography (Eastwood et al., 2008), patients undergoing coronary artery bypass surgery (Staples & Jeffrey, 1997), and patients who survived life-threatening arrhythmias (Carroll, Hamilton, & McGovern, 1999). Permission was obtained from Mishel (personal communication, January 15, 2009) to use the scale as part of this current research study.

The MUIS-C consists of 23 items. Each item is answered on a 5-point Likert scale. The choices are 1 = strongly disagree, to 5 = strongly agree. Scores of the MUIS-C can range from 23-115, with higher scores indicating greater perceived uncertainty. The scale has questions pertaining to the following uncertainty factors: ambiguity, complexity, inconsistency and unpredictability (Mishel, 1997b).

Reliability and validity.

Scores of the MUIS-C can range from 23 to 115, with 69 being the midrange score in the combined 20 studies. The reliability of the MUIS-C has been supported by Cronbach's alphas ranging from 0.74 to 0.92 across 20 studies according to the manual, but data tables indicated two other coefficient alpha scores of 0.53 and 0.65 (Mishel, 1997b).

Construct validity was demonstrated by testing the tool on a variety of patient populations and situations (Mishel, 1997b). Initial efforts to support the validity included factor analysis work which confirmed the MUIS to be multi-dimensional, while the MUIS-C form was uni-dimensional. Convergent validity was tested through correlating the MUIS with another questionnaire, and while the author reports that there was "significant correlation," no specifics are provided. Several other relationships have been verified through testing in various populations. These include the sensitivity of the MUIS to reflect differences between groups and show the passage of time. Theoretical antecedents of uncertainty were also underscored by responses to the MUIS, as was the connection between uncertainty and emotion-focused coping, and uncertainty and anxiety. Studies also supported the idea that psycho-social distress could be predicted by the degree of uncertainty experienced. Finally the MUIS is purported to be "significantly related to theoretically proposed outcomes" (Mishel, 1997b, p. 43); however no data was provided by the author.

Intolerance of Uncertainty Scale.

The Intolerance of Uncertainty Scale was originally written in French and developed to measure an individual's intolerance of uncertainty (Freeston, Rhéaume,

Letarte, Dugas, & Ladoucer, 1994). This French scale is composed of 27 items and measures five factors: "Unacceptability and avoidance of uncertainty, Negative social evaluation caused by uncertainty, Uncertainty-related frustration, Uncertainty causes stress, and Uncertainty preventing action" (Freeston et al., 1994, p. 797). Each item is answered on a 5-point Likert scale. The choices range from 1 = not at all characteristic of me, to 5 = entirely characteristic of me. Scores on this scale can range from 27-135 with higher scores indicating greater intolerance of uncertainty.

An English translation of the Intolerance of Uncertainty Scale was completed in 2002 by Buhr and Dugas (Buhr & Dugas, 2002). It was translated using the back translating method. Testing revealed four factors: "Uncertainty leading to inability to act, Uncertainty being stressful and upsetting, Unexpected events are negative and should be avoided, and Uncertainty being unfair" (Buhr & Dugas, 2002, p. 940). This English version also consists of 27 items with each one being answered on a 5-point Likert scale. The choices range from 1 = "not at all characteristic of me", to 5 = "entirely characteristic of me." Scores on this scale can range from 27-135 with higher scores indicating greater intolerance of uncertainty.

Carleton, Norton and Asmundson's scale (2007) is a shortened version of the Intolerance of Uncertainty Scale. Through confirmatory factor analyses, the 27 item scale was reduced to 12 items. The original five factors were reduced to two: Prospective anxiety and Inhibitory anxiety (Carleton, Norton, & Asmundson, 2007, p. 113). Each of the 12 items is answered on a 5-point Likert scale. The choices range from 1 = "not at all characteristic of me" to 5 = "entirely characteristic of me," Scores on this scale can range from 12-60, with higher scores indicting greater intolerance of uncertainty.

Reliability and validity.

The original French version had very high internal consistency (a = 0.91) and a good test-retest reliability (r = .74) (Freeston et al, 1994). Convergent validity was tested and confirmed through correlations to several other well-known scales (r = 0.52-0.63, p < .0001).

Buhr and Dugas' English version also had a high internal consistency (a = 0.94) and a good test-retest reliability (r = .74) (Buhr & Dugas, 2002). Convergent validity was tested and confirmed through correlations with several other well-known scales (r = 0.55-0.60, p < .001).

The shortened version of the Intolerance of Uncertainty Scale has a high internal consistence (a = .91) (Carleton et al., 2007). Cross validation was confirmed through correlating the 12 item scale with original 27 item scale (r = .96). Convergent validity was tested through correlations with scales used in the 1994 and 2002 versions and results were significant (r = 0.54 – 0.61, p < .01). Regression techniques also confirmed that the 12 item scale measured the same domains as the 27 item scale.

Quality of Life

Quality of life is not a one-dimensional static concept, but rather a multi-dimensional dynamic concept. Each individual has his own unique definition of quality of life based on his values, needs and experiences. What brings meaning to one individual may not bring meaning to another. Therefore the only true way to measure someone's quality of life is to ask him (Osoba, 1994).

According to Andrews and Withey (1976), the term 'quality of life' became part of the American vocabulary sometime after World War II. They proposed that the term

suggested a change in thinking; that 'having it all' referred to more than just having possessions but instead included the totality of one's life. Webster's Online Dictionary (2009) defines quality of life as one's "personal satisfaction (or dissatisfaction) with the cultural or intellectual conditions under which you live (as distinct from material comfort)" (p. 1). Ferrans and Powers (1992) defined quality of life as the marriage of satisfaction with various life domains and the importance placed on those same domains.

Why is quality of life important? Quality of life speaks to the essence of life, to what gives someone hope and pleasure, to what gives life meaning for that individual.

General quality of life.

Quality of life is a dynamic topic in psychology, medicine, nursing, and sociology. In 2009, a search of the term "quality of life" in MEDLINE produced 107,504 hits taken from the years 1950-2009. A similar search of CINAHL, Academic Search Premier, PsycInfo, PsycARTICLES, and Master File Premier produced 115,272 hits, taken from the years 1818-2009. While combining these lists might take out some duplicates, and weeding out irrelevant articles may reduce the number still further, the number left would still be impressive.

A plethora of psychology articles were located which looked at various aspects and populations with regard to their quality of life. Studies were found on college students (Xiao, Tang, & Shim, 2009; Zullig, Huebner, & Pun, 2009), and the elderly (Palacios, Torres, & Mena, 2009). Other articles described parents juggling the balance of work and home responsibilities (Jang, 2009), and made suggestions on how organizations could be more family friendly (Fatimah, Jemain, Ibrahim, Nasir, & Anuar, 2009). One article described a tool to measure life's meaning by looking at one's accomplishments,

values and principles, and how one balances having a purposeful life with a need for excitement (Morgan & Farsides, 2009).

Articles in medicine and nursing focused more on health-related quality of life issues. Quality of life was an outcome watched closely in randomized controlled trials for drugs (Araujo et al., 2009), surgical treatments (Müller-Stich et al., 2009) and medical treatments (Cohen, Firth, Biddle, & Lewis, 2009). Articles were found describing quality of life issues for patients (Carroll et al., 1999; Eastwood et al., 2008), their family members (Elliot & Berry, 2009) and sometimes comparing the two (Holm, Schonberger, Poulson, & Caetano, 2009). Quality of life has become an important outcome in health care and is part of the mission statement for Healthy People 2010 (U.S. Department of Health and Human Services, 2000). Quality of life issues such as patient-assisted suicide and when to terminate life-saving treatments are complex and controversial and continue to be debated around this country.

Researchers have not reached consensus on how quality of life should be defined or measured. Ferrans and Powers (1985) identified three areas of difficulty encountered in creating a tool to measure quality of life: 1) there was no agreement on which items best describe quality of life; 2) there was no agreement on how to measure quality of life, as to whether it should be measured subjectively or objectively; and 3) a critical piece of information was lacking if the importance of the quality of life items were not assessed (p. 16). Ferrans and Powers compiled a list of factors taken from tools which have been created to measure an individual's quality of life. These included: socioeconomic status, physical health, friendships and family, marriage, perceived stresses, satisfaction with where they live as well as the nation as a whole, satisfaction with themselves and with

their life, and feelings of depression and means of coping (Ferrans & Powers, 1985, p.22). Obviously there is potential for much variability in tools and their scores (Osoba, 1994). It is the researcher's job therefore to search for or create the tool which best measures the aspect or aspects which he or she is studying.

Quality of life and cancer.

For much of history, medical research focused on increasing the quantity of life: discovering and inventing vaccines, anesthetics and antibiotics, finding cures for diseases - or at least treatment options which could prolong life, and perfecting surgical procedures. Now that individuals are living longer after a cancer diagnosis, it has become more important to focus on their quality of life during the treatment phase and when they earn the title of "survivor." Research also continues to be done on quality of life and palliative care. Over the last 40 years there has been an increasing interest in exploring individuals' perceptions of their quality of life.

Articles abound in cancer research on patients' quality of life. While there are articles on quality of life as specifically related to new drugs, treatment options and surgical procedures, quality of life issues are also becoming a top priority and a more common discussion point between the oncologist and the patient. An acknowledgement of quality of life issues signals a more holistic way of caring for each patient (Padilla & Grant, 1985). Quality of life issues are similar, yet unique to each individual and do not seem to depend on the diagnosis (Visser et al., 2006).

Quality of life in the newly diagnosed patient.

Two studies found those individuals with the highest distress were those who were newly diagnosed (Ferrell et al., 2005; Visser et al., 2006). These individuals

experienced ‘global distress’ - significant distress across the physical, psychological and social subscales. Visser (2006) also found that neither the diagnosis nor cancer site affected the distress registered in the tool. Another study on newly-diagnosed patients reported that those who lived alone had a lower quality of life than those who lived with someone (Rustoen, Moum, Wiklund, & Hanestad, 1999). In addition, the data also suggested that older patients (age 60-78) who lived alone reported greater quality of life than younger patients (age 19-39) who lived alone.

An examination of qualitative research studies gave a unique and perhaps more comprehensive view of patients’ experiences (Beatty et al., 2008; Boehmke & Dickerson, 2006; Ferrell, Smith, Cullinane & Melancon, 2003a; Hjörleifsdóttir et al., 2008; Hochwald, 2008). While the majority of these studies were on breast cancer, the quality of life issues faced are similar for most cancer diagnosis. Patients battled physical effects from the cancer and the treatments including nausea and appetite changes, fatigue, numbness and tingling, pain, menopausal symptoms, specific cancer symptoms, constipation and diarrhea, loss of hair, sleep problems, and skin changes. Psychological issues included loss of control, changes in memory or “chemo brain,” changes in body-image and self-concept, fertility issues, attempts to cope, intense emotions of fear, anguish/distress, shock, disbelief, anger, self-blame, uncertainty and isolation. Social issues included changes in social roles and support, and managing expectations and emotions of family and friends. Family issues included changes in home roles and dealing with expectations and emotions of spouse/significant other and children. Spiritual issues raised included a need to pray and to be involved in their religion. Financial issues

were also raised, from fear of losing a job and insurance to fear of not being able to afford treatments (Bradley et al., 2007).

Quality of life in the cancer survivor.

Survivors faced their own issues. Some issues were left over from the treatment phase; others developed once they were determined "cancer free" and a survivor. Survivors were often torn between wanting to celebrate beating the cancer and living in fear of recurrence (Ferrell et al., 2003b). They celebrated the return to "normal" life and activities and the return of their hair. At the same time though, they also expressed distress, anxiety, vulnerability and the feeling of "living on borrowed time" (Ferrell et al., 2003b, p. 1065).

Four qualitative studies revealed intimate details about quality of life in the survivor phase (Ferrell, Grant, Funk, Otis-Green, & Garcia, 1997, 1998; Ferrell et al., 2003b; Wonghongkul et al., 2006). Physically, survivors faced weight gain and fatigue, menopause (for women), permanent side effects of the cancer or treatments, and many sources and types of pain. They also spoke of the relief of getting their strength back after treatments were done. Psychologically, survivors continued to struggle with distress over their initial diagnosis, surgery and treatments, fears of cancer recurrence or a new cancer, financial issues, anxiety and depression, uncertainties, and attempts to balance the fear of death with reality and hope. On the positive side, survivors also spoke of regaining control, positive coping and a focus on living, improvements in their moods, hope, and a return to normalcy. They learned the importance of expressing their emotions and of humor. Socially, the main concerns were fears that their relatives would get cancer, distress over the way their illness had affected their family, and distress over changes in

the area of their sexuality. Positive social issues included the importance of social and family support, and returning to work and their other roles. Spiritually, survivors spoke of being plagued by uncertainty. Not all survivors became spiritual or religious, yet many spoke of a deepening of their faith and a return to their religious upbringing. They spoke of hope, reorganized priorities, a new appreciation of life, and a new meaning to life.

Several studies looked for connections between demographic data and quality of life. A recent study of ovarian cancer survivors found that higher quality of life was associated with being over the age of 60 and still working, living with someone, having a household income of $50,000 or more, and having no sign of recurrent cancer (Ferrell et al., 2005). Sammarco (2001), in a study of younger breast cancer survivors, found strong positive correlations between perceived social support and reported quality of life. Another study of breast cancer survivors found that uncertainty, perception of harm and years of survival influenced the quality of life (Wonghongkul et al., 2006).

Quality of life in the dying patient.

One of the recommendations put forth by the Institute of Medicine (IOM) in its 1997 report on end of life care was to "strengthen methods for measuring the quality of life and other outcomes of care for dying patients and those close to them," and to "develop better tools and strategies for improving the quality of care" (Field & Cassel, 1997, p. 267). This report highlighted the inadequacies in end of life care and resources, and the lack of health care provider education and research in this area.

Quality of life issues for dying patients are in some sense more simplified and yet just as important (McCahill, Ferrell, & Virani, 2001). Physically, they need relief from pain and other sequela of their disease processes. They need help managing their fatigue

and weakness, difficulties breathing and eating, sexuality problems, and skin and bowel problems. They need knowledgeable care providers who can give comprehensive and compassionate care up and through the time of death. Psychologically, they need comfort and some sense of control over their treatments. They need care which is culturally sensitive and honesty regarding treatment options and prognosis. Socially, they may have issues with roles again, need help dealing with emotional distress from their family and friends or feelings of isolation, and have financial worries. They may need assistance to do things which they enjoy. Spiritually, some patients struggle, others give up and get angry at God, and finally there are those who accept their prognosis and are at peace with it (Ferrell et al., 2003b).

In response to the 1997 IOM report, City of Hope investigators in collaboration with the American Association of College of Nursing created a program entitled The End of Life Nursing Education Consortium (ELNEC) in 2000. The goal of this program was to "enhance understanding" among nurses of end of life issues and how to give quality and compassionate care to the dying (American Association of Colleges of Nursing, 2009). A year earlier, a similar program was initiated for physicians and healthcare professionals called The End of Life Physician Education project (EPEC) (The EPEC Project, 2009).

As the movement grows to create a better death, hospice organizations are becoming more common and accepted. Some are found in hospitals, others are free-standing. In Auburn, Alabama, there is one free-standing hospice associated with East Alabama Medical Center called Bethany House. There are also several local home health businesses which also serve hospice patients.

Quality of life for the caregivers.

Spouses, significant others, and family members are not immune to effects of the cancer illness. While they may not be experiencing things themselves, they do experience them through watching and living with their loved one. Northouse et al. (2007) found that a spouse's "risk for distress" was the same as that of the patients. Spouses also reported "significantly less self-efficacy and social support compared with patients in managing the effects of prostate cancer across all phases of illness" (p. 4176). Based on this data, a suggestion was made to include spouses in the patient's program of care and assist them to be more open in communicating how they were feeling.

Caregivers can experience some of the same quality of life issues as the patient (McCahill et al., 2001; Ferrell, Ervin, Smith, Marek, & Melancon, 2002). Physically, they too battle fatigue and have changes in sleep patterns and appetite. Psychologically, they feel uncertain, anxious, depressed, fearful, distracted, helpless and distressed. They too long to be in control and have their "normal" life back. They may have difficulty coping. Socially, they may feel isolated and tired from caring for their loved one. Some have financial and work problems caused by the illness. Roles change and families often go through a period of distress. They are in need of a support system. Spiritually, they may be struggling between their feelings of uncertainty and their hope and faith in God. Resources for caregivers can be found through the local American Cancer Society and often also through many religious organizations.

Quality of life and uncertainty.

Literature has indicated that there is an inverse relationship between uncertainty and quality of life. Studying these two concepts in the area of cardiology, and using

variations of the same tools being used in the current research study on expressive writing, data suggested that the higher the uncertainty, the greater impact there was on quality of life, even up to six months after a life-threatening arrhythmia (r = -0.61, p = .001) (Carroll et al., 1999) and up to one year after a coronary angiography (adjusted r^2 = 0.54, p <.001) (Eastwood et al., 2008). In a study conducted on patients and their spouses before coronary artery bypass surgery, uncertainty was found to be inversely related to both hope and quality of life, with spouses reporting more uncertainty about the illness than the patient (patients r = -0.30, not statistically significant at the 95% level; spouses r = -0.49, p < .01) (Staples & Jeffery, 1997).

Cancer nursing has also looked at these two concepts together. Two studies were located that used the scales which will also be used in this research project; one study was on patients with prostate cancer (Wallace, 2003), and the other was on young breast cancer survivors (Sammarco, 2001). Data indicated that for the breast cancer patients, quality of life was positively correlated with perceived social support (r = .418, p = .000) and negatively correlated with uncertainty (r = -.436, p = .000) (Sammarco, 2001). The data also indicated a negative correlation between social support and uncertainty (r = -.288, p = .002). Men with prostate cancer who were undergoing watchful waiting experienced uncertainty which was positively correlated with the health functioning domain of quality of life (r = 0.601, p = .008) (Wallace, 2003).

Measuring quality of life.

A search of the literature revealed more than twenty quality of life tools. They ranged from one question to over 130 questions. Some were to be completed by the physician or health care provider, others were to be answered by the individual. Some

focused only on those items which fell under a nurses' control, others were more broad and asked about anything which might affect quality of life.

Grant, Padilla, Ferrell and Rhiner (1990) suggested several reasons for the importance of assessing quality of life in cancer patients. First, tools can record patient reactions to their cancer. Secondly, tools can record patient responses to symptom interventions. Thirdly, responses on tools can be used to compare different treatment options. Finally, tools can record the effects of different rehabilitation options (p. 262). By measuring a patients' quality of life and basing treatment plans on the results, health professionals are caring for that patient in a more holistic manner.

Spitzer Quality of Life Index.

The Spitzer Quality of Life Index (QL-Index) was developed in 1981 (Spitzer et al., 1981). It was created to be simple, comprehensive and applicable to numerous people groups and settings. While originally designed to be completed by a health care professional, the index is now self administered by the patient. This index has been used to measure quality of life in cancer patients (Corn et al., 2008; Perez, McGee, Campbell, Christensen, & Williams, 1997), those with lower back pain (Beaulieu, Wood-Dauphinee, Abenhaim, & Arahmowicz, 1997; Toledo, Alexandre, & Rodrigues, 2008), stem-cell recipients (Loberiza et al., 2002), and others. The QL-Index is composed of 5 items which measure an individual's social support, psychological status and activity level. Each item is rated on a 3-point Likert scale, where 0 = a more negative response. Scores of the index can range from 0-10, with lower scores indicating less quality of life.

Reliability and validity.

The reliability of the index was supported by Cronbach's a = .775 (Spitzer et al., 1981). Inter-rater comparison was also performed which supported the reliability of the index (Spearman rank 0.81, $p < .001$; 0.84, $p < .001$; and 0.74, $p < .005$).

Construct validity was demonstrated by testing the index on a variety of patient populations and situations (Spitzer et al., 1981). Initial efforts to support validity included factor analysis work which confirmed the QL-Index to be multi-dimensional. Convergent validity was tested through correlating the QL-Index with other questionnaires and in five different population groups. Data correlations were consistently significant in three groups: chronically diseased ($r = 0.42$-0.60, $p < .001$), cancer patients ($r = 0.46$-0.72, $p < .001$), and seriously ill ($r = 0.34$-0.53, $p < .005$). Discriminant construct validity was verified through a gradient of diminishing mean quality of life scores. Scores ranged from high scores for healthy people, to a mix of scores for those who had diseases or cancer, to low scores for those who were seriously ill.

City of Hope Quality of Life- Cancer Patient Version.

Ferrell developed the City of Hope Quality of Life- Cancer Patient Version (QOL-CS) in 1995 (Ferrell, Hassey-Dow, & Grant, 1995). It is described as multi-dimensional scale which measures psychological, physical, social, and spiritual well-being in a cancer patient. The tool, based on previous versions created by researchers at the City of Hope National Medical Center, grew out of research on pain and was revised to its current form (Ferrell et al., 1989; Padilla & Grant, 1985; Padilla et al., 1983). It has been adapted for long-term cancer survivors and translated into Spanish. A small sampling of studies which have utilized this tool includes studies on cancer survivors

(Ferrell et al., 2005; Ferrell et al., 1997,1998; Wonghongkul et al., 2006), and cancer patients (Juarez, Ferrell, & Borneman, 1998). The QOL-CS consists of 41 items set on an ordinal scale with 0 = worst outcome and 10 = best outcome. Scores can range from 0-410, with higher scores indicating better quality of life.

Reliability and validity.

The reliability of the QOL-CS is supported by Cronbach's alpha of .93 (Ferrell & Grant, n.d.). Cronbach's alpha scores for the subscales were spiritual (a = .71), physical (a = .77), social (a = .81) and psychological (a = .89). Test-retest reliability had an overall score of .89, with subscales scores of spiritual (r = .90), physical (r = .88), social (r = .81), and psychological (r = .88).

Construct validity of this scale was demonstrated by having it reviewed by a panel of nurses and physicians who were experts in the cancer field (Ferrell & Grant, n.d.). Step-wide multiple regressions were used for factor analysis and identified 17 factors which were statistically significant. Validity was also tested and confirmed through correlating the QOL-CS with another scale, showing an overall correlation of r = .78. Subscale correlations ranged from r = 0.44 – 0.74. Tests on the QOL-SC have also revealed a sensitivity to discriminate between known groups of cancer survivors (Ferrell & Grant, n.d.).

Quality of Life Index – Cancer Version III.

Ferrans and Powers (1985) created a Quality of Life Index (QLI) to measure an individual's satisfaction with various domains in life, and the importance of those same domains to that individual. While originally designed for healthy adults, variations of the scale have since been created to look at specific disorders and illnesses. All variations

were created from the same original scale but with items specific for the disorder or illness. The Quality of Life Index – Cancer Version (QLI-C) was developed in 1990 (Ferrans, 1990). In the past twenty years the QLI and QLI-C have been revised twice and now are in their third versions and currently identical. A recent sampling of studies which have utilized the scale with cancer populations includes studies on breast cancer survivors, both younger and older (Sammarco, 2001, 2003), women undergoing a mastectomy (Xiaokun, 2002), patients with prostate cancer (Schneider, Hsieh, Sprod, Carter, & Hayward, 2007), patients undergoing stem cell transplantation (Hacker et al., 2006) and patients with thyroid cancer (Huang, Lee, Chien, Liu, & Tai, 2004). Permission was obtained from Ferrans to use this scale for research purposes (A. All, personal communication, May 1996).

The QLI-C consists of a total of 66 items on two forms (Ferrans & Powers, 1998a). The first form consisting of 33 items measures how satisfied an individual is with various domains of their life, and the second form, again 33 items, measures the importance of those same domains to the individual. Each item is answered on a 6-point Likert scale. On the first form the choices range from 1 = very dissatisfied, to 6 = very satisfied. On the second form the choices range from 1 = very unimportant, to 6 = very important. Scores can total 33 to 198 per form. The scores of satisfaction are weighted by the scores of importance giving a range of scores from 0-30. The highest scores indicate high satisfaction with those things of high importance, and thus greater quality of life. The lowest scores are those of low satisfaction with things of high importance, and point to lower quality of life. The scales can be broken down into subscales which look

specifically at health and functioning, social and economic, psychological/spiritual, and family or significant others.

Reliability and validity.

Currently the QLI and the QLI-C scales are identical; thus reliability and validity can be drawn from either tool being used with the cancer population. The reliability of the QLI tool is high, with Cronbach's alphas ranging from 0.87 to 0.97 across nine studies (Ferrans & Powers, 1998b). Internal consistency reliability for the QLI has been demonstrated in eight studies through measurement of the four subscales (Ferrans & Powers, 1998b). Alphas ranged from 0.77 - 0.92 for health and functioning, 0.71 - 0.88 for the social and economic subscale, and 0.77-0.96 for the psychological/spiritual subscale. Alphas for family subscale were more in the mid range, 0.66 - 0.83, with one outlier of 0.18.

Content validity was demonstrated through extensive literature reviews and reports from patients regarding their quality of life (Ferrans & Powers, 1985). The QLI was also tested with the Content Validity Index and received an "acceptably high rating," though no scores were given (Ferrans & Powers, 1998b). Construct validity was tested through correlation of QLI with another questionnaire and the *r* scores ranged from 0.61 to 0.93. Construct validity was also verified through testing of the subscales in a contrasting-groups approach. The QLI scores correlated with each specific group. Factor analysis was performed which supported the four subscales or factors and the overarching factor of quality of life.

Expressive Writing/Reflective Journaling

Writing has been used for centuries to express emotions. In the Bible, David wrote songs expressing a range of emotions from praise, to fear, anger, and remorse. There are many songs (also known as psalms) which start out with David ranting at God or his enemies, and end with him being comforted and acknowledging the sovereignty of God. It was through the penning of thoughts, the acknowledgement of emotions and the wrestling through them, that comfort came.

Diaries are a private means of expressing thoughts and emotions. Consider *The Diary of Ann Frank* (Frank, 1989) or other famous memoirs written by those who have gone through horrific experiences, whether war, death, imprisonment, cancer, or a multitude of other painful experiences. Memoirs often chronicle not only particular events, but also the emotions which accompanied and helped define the events and the individual. Some diaries are written to be read by others. Some diaries are written and locked away for the writer's eyes only.

Letter writing can also be a method of communicating with oneself. The discipline of psychology has used letter writing to complement one-on-one therapy with individuals needing medical or surgical interventions and who are dealing with emotions of anger and grief (Rancour & Brauer, 2003). Psychologists have found letter writing to be a healing strategy, allowing session work to continue after the individual leaves the office.

A more recent public version of a journal or letter is called a blog. A blog is a type of online journal which is typically available for anyone in the world to read. Blogs can be found on any subject, whether it be cooking, politics, caring for plants or

parenting. What was almost unheard of 10 years ago has now become mainstream with blogging conferences and a proliferation of blogging websites. Blogs can be set up to only allow the creator to write, or the set up can allow comments to be added by readers.

In scholarly literature, writing can be found in two main areas: academia and psychology/medicine. In both settings the purpose of writing is to explore events and emotions and a means with which to chart change. In academia the writing process is referred to "reflective journaling," in psychology/medicine the process is most often referred to as "expressive writing."

Reflective journaling.

There were many examples found in the literature of academia utilizing reflective journaling in classes ranging from psychology to computer science. For example, West Point used journaling in its General Psychology for Leaders class to help the students learn and retain their course concepts (Hampton & Morrow, 2003). Management undergraduate teams used journaling when conducting project management research projects to help foster honest self appraisals, identify areas that the student needed improvement in, and ultimately improved both individual and team performance (Loo, 2002). Choral students used open or group journaling to help them with the transition from student to teacher (Williams & Watkins, n.d.). Nursing students have used journaling to track the development of their critical thinking skills, as well as the progress made in their comfort and skill level over the course of a semester (Hayes, 2005; Morgan, Johnson, & Garrison, 2005; Schaefer & Curley, 2005).

Reflective journaling has been found to enhance nursing students' critical thinking skills (Hubbs & Brand, 2005; Morgan et al., 2005). Journaling helped students

"bridge the gap between theory and practice" (Morgan et al., 2005, p. 110). Journaling did this by providing students an opportunity to reflect on the way they practiced nursing, allowed them to reflect on events, and make connections between what they already knew and the new knowledge they were learning (Morgan et al., 2005).

Hampton and Morrow (2003) and Dunlap (2006) noted that by keeping a journal, students were allowed the opportunity to reflect back over what they had learned, and thus see how much they had grown and developed. If the journal was started at the beginning of their academic time, then the student was given a wonderful overview of how far they had come both in knowledge as well as competence. Thorpe and Loo (1999) found a link between journaling and empowerment through what the student had learned, and Loo (2002) later did another study on journaling that documented recurrent themes including "personal criticisms and improvement" and "lessons learned and future actions to improve one's performance" (p. 62). Journaling also allowed a student to voice questions or doubts in a safe environment, reflect on an event, and praise themselves on an accomplishment.

Through feedback, the instructor could assess the level of comprehension and mastery of the class content and goals (Hubbs & Brand, 2005), identify problems and suggest recommendations to solve them, (Loo, 2002), and give the student advice garnered through living and working outside of the classroom (Cyboran, 2005). Also, through the giving of feedback, a mentoring relationship has the potential to develop between the student and instructor (Cyboran, 2005).

General expressive writing.

In the psychology/medical literature writing was most often referred to as "expressive writing" but also could be found under the title of "emotional disclosure." Pennebaker and Beall (1986) are generally credited with igniting the interest on studying the connections between writing and its outcomes. Pennebaker had conducted prior studies (Pennebaker & O'Heeron, 1984; Pennebaker & Hoover, 1986) searching for a relationship between the inhibition of emotions and health outcomes. In one study spouses who had lost their spouse to suicide or an accidental death were more likely to become sick in the year following the death if they did not tell others about their experience (Pennebaker & O'Heeron 1984). In a second study, Pennebaker and Hoover (1986) found that college students who had experienced a childhood trauma and had not told anyone about it were more likely to experience health problems as compared to those who had told others about the trauma. The results of these two studies led to the hypothesis that disclosing traumatic events - and the emotions which accompany those events - through writing has health benefits. The writing experiment was conducted on college students who were randomly put into one of four groups: control group (no writing); trauma-fact group; trauma-emotions group, and trauma-combination group. Blood pressure readings and mood assessments taken immediately after completing the writing were negatively impacted in the trauma-combination and trauma-emotions group. However, data taken over the next two years indicated that the students who wrote about traumatic events and their emotions were healthier than were those who wrote about trivial things (control group and trauma-fact) (Pennebaker & Beall, 1986).

The results were intriguing enough to encourage Pennebaker to continue to explore the relationship between writing and health outcomes. College employees who wrote about traumatic events showed a significant decrease (p <0.05) in their liver enzymes, as well as a positive change in their uric acid, cholesterol numbers, and two enzymes linked to immune function (Francis & Pennebaker, 1992). The study also revealed that writing benefits were greater for those with low emotional inhibition than those who had high emotional inhibition. A subsequent study noted that newly fired professionals who did emotional writing were reemployed more quickly than those who did not write or who wrote without emotion (Spera, Buhrfeind, & Pennebaker, 1994).

In 1998 Smyth did a meta-analysis of expressive writing studies to look for overall significance and effect size (Smyth, 1998). Various outcome measures were also examined for effect size and specific moderators were examined for their positive or negative effect on writing outcomes. Inclusion criteria for this meta analysis were as follows: each study had to use some variation of the Pennebaker prompt, have a control and experimental writing group, have outcomes which fell under five health types, contain statistical information needed to calculate an effect size, and be a randomized experiment. After applying the inclusion criteria, 13 studies out of 19 remained in the analysis. All 13 studies had been conducted on healthy adults or college students. After combining the results, the five outcomes types reported in these studies were: "reported health, psychological well-being, physiological functioning, general functioning and health behaviors" (Smyth, 1998, p. 177). Moderators in these studies included the characteristics of the participants, what they were asked to write, the writing session number, length and duration, the outcome type, and type of publication in which the

study was located. Smyth reported overall significant health benefits to those who participated in the studies. The overall effect size was $d = 0.47$, (r = .23) significant at the $p < .000$ level. All health outcomes were statistically significant for those who wrote, except for health behaviors.

Expressive writing in clinical groups.

While studies continue to be done with healthy volunteers, other researchers have experimented with writing in clinical diagnostic groups and looked for similar health benefits. One such study examined the effects on patients with asthma or rheumatoid arthritis (Smyth et al., 1999). This study followed patients over a four month period, and at the end of that time both experimental groups showed a statistically significant reduction in their symptoms and disease process compared to those in the control groups. Those with asthma who were in the experimental group showed improvements in lung function (measured by the mean percentage of predicted forced expiratory volume in 1 second), from a baseline of 63.9% to 76.3% after four months ($p < .001$). The rheumatoid arthritis experimental group measured symptoms on a scale where 0 = asymptomatic to 4 = severe and improved in overall disease activity from a baseline mean of 1.65 to a four month mean of 1.19 ($p = .001$). There was no improvement in either of the control groups. Two of the earliest studies of breast cancer patients found conflicting results. While Walker, Nail and Croyle (1999) did not find any significant effect of writing, Stanton et al. (2002) reported that those women who participated in the expressive writing group complained of fewer physical symptoms and had fewer medical appointments for cancer-related morbidities at the end of three months. It should be mentioned however that the studies were set up differently, including the amount and

timing of the writing, and having different writing prompts. A study of writing with prostate cancer patients found improvements in physical symptoms and health care utilization, but no change in psychological variables or immune factors (Rosenberg et al., 2002).

As a follow up to the Smyth analysis, Frisina, Borod and Lepore (2004) analyzed nine expressive writing studies done with diagnostic clinical populations to see if the same health effects would be found. Smyth's methodology was duplicated in the analysis, however these nine studies only assessed for physical and psychological outcomes, therefore no comparison could be made to the other three outcome types mentioned in the Smyth analysis. The results of the 2004 analysis revealed significant changes in physical health outcomes ($d = .21$, $p < .01$), but not in psychological health outcomes ($d = .07$, $p > .10$). While the overall effect size ($d = 0.19$, $r = .101$, $p < .05$) was less than what Smyth had found ($d = 0.47$, $r = .23$, $p < .000$), the data did suggest physical health improvements in both chronic and potentially fatal diseases. And while no significant effect was seen in the overall psychological domain, the subscales of depression, mood, anxiety and sleep quality did show improvement.

The most recent meta-analysis of expressive writing was published in 2006 and was the largest to date with almost 11,000 participants (Frattaroli, 2006). It included 146 published and unpublished studies, combining studies of healthy adults with those of chronically-ill and potentially fatally-ill populations. Statistical computations for each study included an overall effect size in addition to an effect size for each of the six outcome types: "psychological health, physiological functioning, reported health, health behaviors, subjective impact of the intervention, and general functioning/life outcome"

(Frattaroli, 2006, p. 841). The overall effect size (d = .151, r = .075, p < .000) was statistically significant. Effect sizes of the health outcome types were statistical significance for psychological health (r = .056, p < .000), physiological health (r = .060, p < .01), reported health (r = .072, p < .000), general functioning/life outcomes (r = .046, p < .01), and subjective impact of intervention (r = .159, p < .000). Congruent with the Smyth analysis, the health outcome type of health behaviors did not show changes which were statistically significant (r = .007, p > .44).

A more recent study conducted by Gellaitry, Peters, Bloomfield and Horne (2009) looked at the effect of expressive writing on perceptions of emotional support in women with breast cancer. After six months, the data suggested that women who wrote expressively perceived their actual emotional support to be closer to their desired ideal support. The discrepancy between the actual and ideal emotional support decreased from 0.91 at baseline to 0.70 at the end of six months. This was compared to the control group which revealed a widening gap between their ideal and actual emotional support. The discrepancy between actual and ideal emotional support climbed from 1.27 at baseline to 1.53 at six months. Additional insights were found in participants' comments. Some participants noted that writing gave them a venue to say things which they were afraid to say to anyone else for fear of upsetting the listener. Others were even afraid to admit things to themselves, but through writing they were able to be honest with themselves about their reality and work through the experiences in their journal.

Methods of expressive writing.

Researchers continue to search for the perfect combination of moderating variables which will produce optimum health outcomes for writing participants.

Differences in moderators can make it difficult to compare studies head-to-head. Below is a sampling of just a few moderators and the variations which have been experimented with in different studies.

There have been variations in the participants of the study. Initial studies were conducted on healthy volunteers such as college students (Pennebaker & Beall, 1986) university employees (Francis & Pennebaker, 1992), professionals who had just lost their jobs (Spera et al., 1994) and those employed (Barclay & Skarlicki, 2009). Studies have been conducted on those with psychiatric health problems such as inmates in a psychiatric prison (Richards, Beal, Seagal, & Pennebaker, 2000), college students with suicidal behaviors (Kovac & Range, 2002) and those with posttraumatic stress disorder (Gidron, Peri, Connolly, & Shalev, 1996). Studies have also been conducted on those with chronic health problems such as asthma and rheumatoid arthritis (Smyth et al., 1999), as well as more acute and potentially fatal health problems such as breast cancer (Gellaitry et al., 2009; Kállay & Băban, 2008), prostate cancer (Rosenberg et al., 2002; Zakowski, Ramati, Morton, Johnson, & Flanigan, 2004), and metastatic renal cell carcinoma (de Moor et al., 2002). According to Frattaroli (2006), those studies which had participants with physical health problems had larger health effects sizes (health criteria, r =.131; no health criteria, r = .054).

There have been variations in the location in which the writing takes place. Studies have been conducted in a lab or college classroom (Pennebaker & Beall, 1986; Burton & King, 2008), in the participant's homes (Schoutrop, Lange, Hanewald, Davidovich, & Salomon, 2002), in a cancer clinic (Morgan et al., 2008) and in a location of the participant's choosing (Laccetti, 2007). Frattaroli (2006) analysis suggested that a

higher psychological health effect size was produced when participants wrote at home (home, r = .122; controlled setting, r = .034) and writing privately affected the overall effect size (private room, r = .085; public room, r = .034).

There have been variations on the writing instructions given to the experimental groups. Pennebaker's original study placed participants into one of four groups (Pennebaker & Beall, 1986). The control group wrote on assigned trivial topics, one experimental group wrote on the facts of a trauma, another experimental group wrote on just the emotions evoked by a trauma, and the third group wrote about the whole experience. Burton and King (2008) randomly assigned participants to write about a control topic, a trauma, or a positive experience. Another study asked participants to write about their "worst" or "happiest" experience (Lyubomirsky et al., 2006). Sometimes participants have been asked to write on a specific event such as an injustice done to them by a manager (Barclay & Skarlicki, 2009), but in most studies participants were given some latitude to their topic as long as it stayed within the set guidelines. Giving participants a direct question to answer made a difference in the overall effect size (directed questions, r = .090; no directed questions, r = .052), and in the psychological health effect size (directed questions, r = .094; no directed questions, r = .011) (Frattaroli, 2006).

The amount of time spent writing is another variable. Perhaps the least amount of writing was requested by Burton and King (2008), who designed their experiment to see if writing for just two minutes a day for two consecutive days could make a difference in the participant's health. Examples of more moderate requests include one study which asked participants to write for 15 minutes a day for three consecutive days (Lyubomirsky

et al., 2006), and another which asked for 20 minutes once a week for four consecutive weeks (Francis & Pennebaker, 1992). On the longer side of writing is a study in which participants were asked to write for 45 minutes five different times over a two week period (Schoutrop et al., 2002) and a study which asked their participants to write three times a week for 12 weeks (Smith et al., 2005). Data from the Frattaroli analysis (2006) revealed that larger effect sizes were found when participants had to write at least 15 minutes (less than 15 minutes, r = -.007; at least 15 minutes, r = .080).

Frattaroli (2006) examined a comprehensive list of moderating variables and summarized the findings on the moderators as such: "The successful study tended to use participants with a health problem or with a history of trauma, to make sure participants were very comfortable during disclosure (e.g. by allowing them to disclose at home), to pay participants, to administer a large dose of disclosure (e.g. by requiring at least three disclosure sessions), to have participants disclose events that had yet to be fully processed (e.g. more recent events), to provide very detailed and specific disclosure instructions (e.g. directed questions), and to have relatively short followup periods (e.g. less than one month)" (p. 860). Consequently, these findings impacted and guided the design of the current research study on expressive writing.

Theoretical Framework

This research study was guided by the empowerment theory. Most definitions of empowerment are similar to that of Gutiérrez (1994): "a process of increasing personal, interpersonal or political power so that individuals, families, and communities can take action to improve their situations" (p. 202). However, Rappaport (1984) asserted that empowerment cannot or should not be defined, as empowerment changes to fit each

unique person and context. This theory was chosen for several reasons. These reasons included the belief that by participating in expressive writing, individuals were doing something proactively which could improve their health. In addition, participants potentially could make a positive difference in their psychological state without needing to turn to medication. Finally, by exploring their emotions and all that is being impacted by their cancer, they might be able to identify that which is important to them and brings them satisfactions, and be empowered to work with intention towards living their own unique fulfilled life.

This theory, first written about by Freire (1970) when describing oppressed peoples in Brazil, was later used to describe movements of social and political reform (Napier, 2006). Empowerment is often associated with progress being made in improving the status of women and minorities (Busch & Valentine, 2000; Hutchinson & Wexler, 2007; Lisovicz et al., 2006).

Lee (1996) presented some basic assumptions of empowerment. One assumption is that if empowerment is needed, there must be a situation with an absence of power or control. The ripple-effects of oppression are far-reaching, extending to individuals as well as to communities. Secondly, oppressed individuals must be viewed as being capable of change, of becoming empowered. They have within themselves the strength and ability to identify problems, come up with solutions, and join with other like-minded individuals to force action. By participating in this process, individuals empower themselves. Thirdly, empowerment takes action. One is not empowered through inaction; rather empowerment comes by standing up, taking personal responsibility and working hard with others towards a common goal (p. 229).

Swift and Levin (1987) compared the concept of empowerment to that of prevention. Viewed in that context, the description of empowerment is compelling. The word empowerment suggests that something positive is developing; it focuses primarily on the process not the outcome; it is a dynamic state; it is connected with a holistic world view; it requires individuals to participate; it necessitates change and with change comes more control for the individual; and empowered individuals create goals and are future minded (Swift & Levin, 1987, p. 89).

According to Lee (2001), there are "three interlocking dimensions of empowerment: 1) the development of a more positive and potent sense of self, 2) the construction of knowledge and capacity for a more critical comprehension of the web of social and political realities of one's environment, and 3) the cultivation of resources and strategies, or more functional competence, for attainment of personal and collective goals" (p. 34.). From this description, empowerment can be divided into three interrelated levels. The first level was referred to by several terms: psychological, micro or intrapersonal. This level represented the empowerment of the individual. Increasing self efficacy, learning skills, and developing a consciousness of his or her history and place in society (both present and future) was an important part of this level (Gutiérrez, 1994). Knowledge of how the individual had adapted to oppression and what coping mechanisms had been utilized in the past was also important (Lee, 2001).

The second level was the interpersonal or mezzo level. Here the individual joined with their family, special interest group or community to plan and take action towards a common goal. Participants empowered themselves as they connected with their group and experienced "collective action" (Lee, 2001).

The highest level was the political level. Communities and groups, united and empowered through their common goals and ability to cause action, became involved in the political arena in order to raise awareness about their specific oppression issue or situation, and work to alleviate the problem. In order to be effective politically, groups had to develop the knowledge, skills and network affiliations necessary to make their voices heard and spur on political action (Lee, 2001).

Empowerment and Health Promotion

More recently empowerment has been used as a foundation for health promotion (Lisovicz et al., 2006; Rissel, 1994; Wallerstein, 1992). The World Health Organization (1986) defined health promotion as "the process of enabling people to increase control over, and to improve, their health" (p. 1). While this definition describes a potential outcome of the current research project on expressive writing, it is the definition proposed by Page and Czuba (1999) which most closely matches the elements of this research project: "Empowerment is a multi-dimensional social process that helps people gain control over their own lives" (para. 11).

Since Page and Czuba's quote acts as a guiding light to this study on expressive writing, it is important to examine the three descriptors within the quote and how they apply to this study. "Multi-dimensional": this speaks to the many dimensions which impact each person, as well as the different levels in which they interact (Page & Czuba, 1999, para. 12). In the same way, the diagnosis of cancer impacts many - if not all - aspects and dimensions of a person's life. Multi-dimensional can also refer to the care which is given a patient. Treatments, tests, and medications all focus on the physical, whereas listening and writing focus more on the emotional and psychological, thus giving

the patient more holistic care. "Social": empowerment is seen as occurring in and through relationships with others (Page & Czuba, para. 12; also Lee, 1996). While expressive writing in this study may primarily be done in private, the emotions worked through on paper can impact real people and relationships. "Process": empowerment is seen as a journey, as well as an outcome (Page & Czuba, para. 12; also Rissel 1994; Swift & Levin, 1987). It can also been described as an intervention (Gutiérrez, DeLois, & GlenMaye, 1995). Likewise, receiving a diagnosis of cancer starts a person on a journey - a journey not of their choosing, but one which must be traveled none the less. Writing also takes a person on a journey; one through emotions to a place of better understanding and positive functioning (Frattaoli, 2006).

In order to stay true to the definition of empowerment, one acting as a "health promoter" must not be a director, but rather more of a facilitator (Rissel, 1994). Lee (1996) agreed that the empowerment process originates from within the individual, not through anyone on the outside. In this research study, the investigator will be facilitating the writing and providing a broad writing prompt but offering no other directions. In the discipline of social work, social workers have four empowering roles, those of enabling, catalyzing, priming and linking (Lum, 1996, p. 253). Of these four, enabling is most applicable to this research study. An enabler provides information, knowledge, or contacts which the recipient uses to gain more control over their life. Likewise, in this research study the investigator will be introducing participants to writing, which according to the literature, can help them influence their own overall health functioning (Frattaroli, 2006).

Literature has suggested some specific ways in which writing has been empowering. It gave patients something to do which could have a positive impact on their health – physical outcomes as well as psychological health (Frattaroli, 2006). Writing was found to decrease the need for pain medications in prostate cancer patients (Rosenberg et al., 2002), decrease physical symptoms and associated doctor visits in breast cancer patients (Stanton et al., 2002), and help patients with renal cell cancer have a better night's sleep (de Moor et al., 2002). Hypothetically writing might also provide a patient with the opportunity to explore their goals and dreams and assess their priorities. With this new self awareness, they will be empowered to make informed decisions when given treatment options which impact their priorities and future (Swift & Levin, 1987). Knowing what is important to them and making choices based on that knowledge increases their feelings of power and control over their lives (Zimmerman, 1995).

Summary

In this chapter, the investigator introduced the population and characteristics which define those newly-diagnosed with cancer. The concepts of uncertainty and specifically uncertainty in illness were also explored. The concept of quality of life was examined, both in general and as it is measured in clinical populations. Finally, the history and benefits of expressive writing were identified. The results of this study will contribute to the expanding knowledge of the benefits of expressive writing in a general cancer population, as well as writings' specific influence on perceptions of uncertainty and quality of life.

CHAPTER III

METHODOLOGY

This chapter describes and explains the research methodology used during this study of expressive writing and cancer patients. Methods for this study included the: (1) research approach and design, (2) study questions, (3) a description of the setting, population, and sample, (4) details about the tools used to measure the variables, (5) ethical considerations, (6) steps and procedures followed to conduct the research, and (7) data analysis plan. The chapter concludes with the expected outcomes of this study based on the review of literature.

Research Design and Approach

The causal comparative research design was utilized in this study. This design's purpose was to explain phenomena through an investigation of cause and effect relationships (Gall et al., 2007). The use of a causal comparative design enabled the researcher to examine the cause and effect relationship between expressive writing and feelings of uncertainty and perceived quality of life. This design enabled the researcher to look for changes in the outcome variables by comparing the pre-writing or baseline measurements with post-writing outcome measurements.

The approach to this study was completion of tools prior to beginning to journal, followed by completion of tools after journaling for three months. Participants were randomly put into two groups: the control and the intervention group. Pretest measurements for each group included demographic data and completion of the MUIS-C

and QLI-C tools. These were collected when the participant entered the study. At three months, these same tools were sent to each participant for completion, in addition to an expressive writing information sheet. The data received from these tools was analyzed to determine if changes in perceptions of uncertainty and quality of life had occurred individually and as a collective group over the course of the study.

Study Questions

The emotions experienced by cancer patients, feelings of uncertainty in illness, perceptions of quality of life, and the act of expressive writing were all explored in the review of literature. However, there was a gap in the literature with regard to exploring the effects of expressive writing on feelings of uncertainty and perceived quality of life in a general cancer population. Therefore this study explored these relationships through the following questions:

1. Does expressive writing cause a difference in cancer patients' perceived level of uncertainty after writing for three months?
2. Does expressive writing cause a difference in cancer patients' perception of their quality of life after writing for three months?
3. Does expressive writing affect the relationship between quality of life and uncertainty in the intervention group as compared to the control group?

Setting, Population, and Sample

To be successful and produce valid results, careful selection of the setting, population and sample is imperitive. For this study, two local cancer treatment facilities were chosen as the setting. (A third local facility was approached but declined to participate.) Conducting research in these settings allowed for easier access to the

population of interest: those newly diagnosed with cancer. The research sample was chosen through a volunteer, convenience method.

Setting

The settings chosen for this research project were ones in which the target population was most easily accessible, and where inclusion criteria could be met. Due to time constraints and the desire to have a sample size of at least 60, two local cancer treatment facilities were approached as settings for the research study: the Cancer Center at East Alabama Medical Center and the Montgomery Cancer Center.

East Alabama Medical Center (EAMC) is a public, non-profit 352-bed regional referral center located in Opelika, Alabama. It has served the local community for over fifty years. It is serviced by over 140 physicians, many of whom also see patients in the cancer center. The Cancer Center was opened to the public in 1992 and earned the designation of Community Cancer Center by the American College of Surgeons Commission on Cancer in 1995. Due to its proximity to EAMC, the Cancer Center offers the services of surgeons and regular medical physicians, as well as medical and radiation oncologists.

Opened in 1990, Montgomery Cancer Center (MCC) is a state-of-the-art freestanding facility located in Montgomery, Alabama. It offers advanced diagnostic services, advanced radiation therapy and chemotherapy for cancer, as well as treatments for diseases of the blood. It also hosts the Montgomery Breast Center, a diagnosis and treatment facility for breast cancer. The center is staffed by 10 medical and radiation oncologists, as well as 7 nurse practitioners. The center also staffs three satellite facilities

in neighboring cities, offering patients the convenience of seeing an oncologist closer to home.

Population

At the time this study was conducted, it was estimated that within the year approximately 1.5 million adults living in America would be diagnosed with cancer (American Cancer Society, 2009) and with the diagnosis would experience "global" distress (Visser, 2006). Of those, nearly 24,000 would be from Alabama (American Cancer Society, 2009). A portion of those from Alabama would be treated at the two local cancer centers involved in this study. MCC generally sees approximately 100 newly-diagnosed cancer patients a month (L. Hamilton, personal communication, March 30, 2010). The majority of patients seen in the infusion room come in with a diagnosis of breast, lung or colon cancer. This corresponds to data reported by the American Cancer Society (2009) which shows the most prevalent cancers in Alabama are female breast, colon/rectal, lung/bronchus and prostate. EAMC's cancer patient numbers ranged from 40-70 per month, with the lower numbers in November and December due to the holidays (C. Tate, personal communication, April 1, 2010). EAMC too reported the majority of their chemotherapy patients having a cancer diagnosis involving the breast, lung, colon, or head/neck.

Sample

The sample consisted of participants selected through the method of convenience sampling. From October through December 2009. all newly-diagnosed patients at EAMC and MCC were given a flyer about the project by their physician or nurse practitioner on the days the investigator was at the facility. Patients then had the option of approaching

the investigator in the waiting room to get more information. All participants who met the inclusion criteria were invited to join the study.

Inclusion criteria.

Several criteria were identified as necessary in order for patients to participate and provide meaningful data for this study (Gall et al., 2007). These inclusion criteria included:

1. Participants must be over 19 years old (per Alabama law),
2. Participants could not be pregnant or prisoners,
3. Participants must be within the first three weeks of chemotherapy or radiation treatment,
4. Participants must be able to complete a written or typed journal.

Exclusion criteria.

Several criteria were also identified which would exclude patients from participating in this study. These exclusion criteria included:

1. Patients who did not meet the inclusion criteria,
2. Patients who cognitively could not give their consent, and
3. Patients who could not speak or read English and had no access to a translator.

Data Collection Tools

After the review of literature, the following tools were rejected for use in this study. Hilton's Uncertainty Stress Scale was a valid scale to use with this research project; however few studies were found which had used it, despite the scale being available for over 15 years. Therefore, it was not chosen. The shortened version of the Intolerance of Uncertainty scale has only been tested to detect anxiety disorders in

college students, not in any clinical populations. Therefore, this scale was not chosen. The Spitzer Quality of Life Index was not chosen because this investigator believed it was not as comprehensive a measure as others. The City of Hope Quality of Life-Cancer Patient Version has been widely used and has established reliability and validity. However, this investigator believed that the importance of certain aspects of life should also be taken into consideration in a quality of life scale, therefore this scale was not chosen.

Four tools were utilized in this study, all self-administered. These tools included a demographic information sheet, the expressive writing information sheet, the Mishel Uncertainty in Illness Scale – Community form (MUIS-C) (Mishel, 1989), and the Quality of Life Index – Cancer Version III (Ferrans & Powers, 1998a). The use of self-administered tools as a data collection technique offered the following benefits: patients could pick a convenient time to fill out the tools, choose to fill them out all at once or over several sittings, and determine for themselves what order to fill out the questions (Gall et al., 2007). Self-administered tools are also cheaper to administer and do not require a time commitment from the participants to meet with the interviewer (Gall et al., 2007).

Demographic Information Sheet

Demographic data is commonly collected in order to identify trends. The Demographic Information sheet was created by the investigator and requested the following data: gender, age, marital status, race, highest level of education (number of years of education), primary employment status (full-time, part-time, not employed), cancer type, first cancer diagnosis, and cancer diagnosis as first major illness.

Expressive Writing Information Sheet

The Expressive Writing Information sheet was created by the investigator to ask how often the participant did expressive writing. This researcher-designed information sheet was included with the three-month follow-up packet. The tool comprised the following three questions: "Did you do any expressive writing? How many times a week? Did it help you feel differently?" The participants were also given the opportunity to share any additional comments under the "Comments" section at the end of the sheet.

Mishel Uncertainty in Illness Scale

The Mishel Uncertainty in Illness Scale – Community form is reported to measure the areas of ambiguity, complexity, inconsistency and unpredictability in a non-hospitalized ill individual or their family member (Mishel, 1997b). This scale looks specifically at individuals' levels of uncertainty as they progress through their illness. This scale had been used with various patient populations including those with cancer, multiple sclerosis, rheumatoid arthritis and others. Due to its specific measuring of uncertainty in an ill population, this scale was chosen to be used in this research study.

Quality of Life Index

Ferrans and Powers (1985) believed the best way to measure an individual's perceived quality of life was by considering an individual's satisfaction with certain variables coupled with how important those same variables were to that individual. Ferrans and Powers (1992) developed the Quality of Life Index – Cancer Version III with the goal of helping physicians and other health care providers identify problem areas (areas of low quality of life) and then plan interventions for those identified areas. This multi-dimensional tool looks at the subscales of family, psychological/spiritual, social

and economic, and health and functioning. It appeared to measure an individual's quality of life most comprehensively; therefore it was chosen to be used in this research study.

Ethical Considerations

Participants in research studies should be able to participate without fear of physical or psychological harm (Gall et al., 2007). Careful consideration was taken to protect the anonymity and confidentiality of each participant. Prior to meeting with the patients, packets of information were assembled. Included in these packets were two consent forms (one for the patient to keep and one for the investigator), a personal address sheet, the demographic information sheet and the QLI-C and the MUIS-C data tools. On the packet itself and on each of the sheets within – except the consents - was written a number. This number became the identifier of the participant in the study. As individuals agreed to participate, they were assigned the next number in sequence. For instance, the first individual who agreed to participate was given the packet with the number "one" on it. The second individual who agreed to participate was given the packet with the number "two" on it, and so on. Those with an odd number (one, three, five, seven…) were assigned to the intervention group. Those with an even number (two, four, six, eight…) were assigned to the control group.

The consent forms, personal address sheets, completed data tools, coding sheet and demographic information sheets were kept in a locked home filing cabinet by the investigator. The investigator kept a calendar recording when each participant entered the study, and when their three-month marks would be. At the three-month mark, the investigator sent out the data tools and expressive writing information sheet to the participant. The completed data tools and information sheet were returned in

preaddressed and stamped envelopes to the investigator at a post office (P.O.) box address.

The investigator next entered the data into the SPSS software program. An outside statistician was employed to review the study's design, data collection methods, perform statistical calculations and help with the interpretation of the results. The statistician only saw the identifier numbers, thus protecting the anonymity of the participants.

There were no anticipated physical risks for the participants; however there were some psychological risks including becoming emotional (crying) or very upset by stirred memories and associated emotions (Pennebaker, 2003). These were explained in the initial meeting and included on the consent form. Participants were warned of these potential risks and instructed that if the negative emotions lasted more than four weeks or got progressively worse, it was recommended they seek professional help. To address this risk, participants were given a list of local counselors. Potential benefits included an improved perception of quality of life and decreased feelings of uncertainty.

Data Collection Steps and Procedures

Review of other studies utilizing both tools (Sammarco, 2001; Staples & Jeffrey, 1997; Wallace, 2003) assisted in guiding the procedures used in this study. Careful documentation was kept in order to allow others to critique, repeat or improve upon this study.

Step One

Step one was approval of the research project by the thesis committee. Approval was then requested of and granted by the Institutional Review Boards of EAMC

(Appendix A), MCC (Appendix B), and Auburn University (Appendix C). The investigator also met with the oncologist or nurse practitioner in charge of each cancer clinic to provide an overview of the project and proposed benefits for their patients. These oncologists and nurse practitioners also gave verbal approval for the study to be conducted in their facility.

Step Two

The original plan was for the investigator to visit each site once a week and sit in a specific spot in the waiting room along with the patients. Oncologists or their staff would give each new patient an informational flier about the study (Appendix D) during their office visit and the patient was then given the choice to seek out the investigator on their way out or just leave. If patients were interested in being a part of the study, they could come to the investigator for more information.

Once recruitment actually began however, it became apparent that the plan would have to change and would be different at each facility. At the first facility, patients were approached by their physician and were given a study flier. If the patient was interested, the physician notified the investigator and the investigator called the patient to set up a meeting at the facility during a regularly scheduled infusion. Care was taken to remain within the initial three week window of the inclusion criteria. At the meeting, the investigator described the study in more detail.

At the second facility, the patient educator gave each new patient a study flier in their information packet. On the days the investigator was at the facility, the investigator asked each infusion nurse if they had a new patient that day or one which would fall within the three week window criteria. If there were new patients, the investigator met

with them and inquired of their interest in participating in the study. If they were interested, the investigator then described the study in more detail.

Each interested patient was given an explanation of the research project by the investigator as per the recruitment script (Appendix E): what would be expected of them, what data would be collected and how it would be used, and what risks and benefits would be faced by participating (Gall et al., 2007). Risks for participating included potentially experiencing some psychological distress. Potential benefits included an improved perception of quality of life and decreased feelings of uncertainty, among other benefits. After being given the opportunity to ask questions, each patient could consent or not consent. Those who wanted to participate and met the inclusion criteria signed a written consent form with the stated understanding that they could leave the study at any time without fearing any negative consequences. Those at EAMC signed the EAMC consent form (Appendix F) and those at MCC signed the MCC consent (Appendix G). Patients were given a copy of their consent form.

The consent forms were inside a numbered folder which also contained a personal address sheet, the demographic sheet, and the two data tools, each numbered with the same number as was on the folder, except the consent forms which had no numbers so as to protect participants' anonymity. The number on the folder became the participant's personal identifier number. Odd numbers were assigned to the intervention group; even numbers were assigned to the control group.

Step Three

Once consent had been given the participant filled out the personal address sheet (Appendix H). Then the investigator read the demographic tool (Appendix I), the MUIS-

C (Appendix J) and the QLI-C (Appendix K) to each participant. This enabled the investigator to explain how the data tools were to be filled out and to ensure no data points were left blank. The investigator then recorded the participant's answers on the data tool forms.

For those in the intervention group (odd numbers), a verbal explanation of expressive writing was given and questions were answered at this time. Participants in this group were given a Pennebaker prompt to help start their writing:

> Over the next three months I would like for you to write about your very deepest thoughts and feelings about an extremely important emotional issue that has affected you and your life. In your writing, I'd like you to really let go and explore your very deepest emotions and thoughts. You might tie your topic to your relationships with others, including parents, lovers, friends or relatives; to your past, your present, or your future; or to who you have been, who you would like to be, or who you are now. You may write about the same general issues or experiences on all days of writing or on different topics each day. All of your writing will be completely confidential. Don't worry about spelling, sentence structure or grammar (Pennebaker, 2003, p. 362).

Participants were assured they could write about anything, negative or positive, as long as they included honest thoughts and emotions. They could write in a journal or type on a computer or typewriter. Participants were asked to write a minimum of twice a week, with no specific amount of time set per episode. Each participant was given a written instruction sheet which covered the same information (Appendix L) as well as a list of local counselors for them to call if they became psychologically distressed. Those

at EAMC received a list of Auburn facilities (Appendix M) and those at MCC received a list of Montgomery facilities (Appendix N). They were also offered a journal in which to write. These participants were told that the journals were theirs to keep and that the journals would not be requested by the investigator at the end of the study. While the investigator would never read what had been written, the participant could choose to allow others to read the journals or could keep their writings private.

Participants in the intervention group were informed that the MUIS-C and the QLI-C tools plus an expressive writing information sheet (Appendix O) would be sent to them after three months for them to self-administer and return to the investigator at a P.O. Box address in pre-addressed and stamped envelopes. Participants were given two weeks to fill out and return the tools. If the tools were not received within two weeks post-mailing, a second set of surveys was sent.

Participants in the control group (even numbers) were told they were in the non-journaling group, but the investigator could not ask them to abstain from any type of journaling for the next three months while participating in the study. They too were told that at three months they would be sent the MUIS-C and QLI-C tools and the expressive writing information sheet for them to self-administer and return to the investigator at a P.O. Box address in pre-addressed and stamped envelopes. Participants were given two weeks to fill out and return the tools. If the tools were not received within two weeks post-mailing, a second set of surveys was sent. The control group participants were also offered a journal, but theirs would be sent to them once the investigator had received their three-month surveys. If they accepted the journal offer, they picked one out of the assortment provided by the investigator and it was put aside for them.

Data Analysis Plan

All data analysis for this causal-comparative study was done using SPSS version 17.0 software. All tests had a significance level set at $p < 0.05$. Descriptive statistics including group means and standard deviations were performed first on all tools and variables. The following are the research study questions and the statistical tests which were used to measure the data.

1. Does expressive writing cause a difference in cancer patients' perceived level of uncertainty after writing for three months?

There are certain statistical tests which are commonly used with a causal-comparative research design, one of which is the repeated measure analysis of variance (ANOVA) (Gall et al., 2007). ANOVA is used to measure and compare the amount of variance within a group and between groups by looking at their means. If the variance proves statistically significant, then there is more variance between groups than there is within each group. With repeated measures ANOVA, the test is repeated on the same group of subjects more than once, often as a pre and post test. (The original plan was to use the ANOVA but due to the small sample size the statistical test had to be changed to a paired *t*-test.) Scores from the MUIS-C scale (Mishel, 1997b) were utilized to answer this question. The investigator tested the intervention group and control group and compared the means of their levels of uncertainty at baseline and three months later.

2. Does expressive writing cause a difference in cancer patients' perception of their quality of life after writing for three months?

Originally, the data from a repeated measures ANOVA was also supposed to answer this question, however again due to the small sample size the statistical test had to

be changed to a paired *t*-test. Scores from Ferrans and Power's QLI-C tool (Ferrans & Powers, 1998a) were measured in the intervention and control group, and the means of their perceptions of quality of life were compared at baseline and three months later.

3. Does expressive writing affect the relationship between quality of life and uncertainty in the intervention group as compared to the control group?

Relationships require statistical tests which look at correlations, therefore Pearson's *r* was chosen to answer this question. It measured the strength of the relationships between each of the two tools and the intervention and control groups.

Expected Results

Literature reported that many who have participated in expressive writing have experienced decreased levels of uncertainty. Expressive writing has also been found to increase many writing participant's perceptions of their quality of life. Accordingly, this study expected data to show decreasing levels of uncertainty and increasing levels of quality of life in those of the intervention group who participated in the writing exercise. If any positive changes were noted in the control group, they would not be as significant as those of the intervention group.

CHAPTER IV

ANALYSIS OF DATA

This chapter will give an overview of the process and procedures utilized in conducting this research study. The study sample will be described based on the data collected on the demographic form. Each research study question, the statistical procedures utilized to measure that question, and the results from the data collected will be presented.

Data Collection

As described earlier, data was collected at two different facilities and the data collection procedure differed slightly between the facilities. At both facilities though, once consent was given, the patient filled out the personal address form and the demographic sheet and the investigator administered the MUIS-C and QLI-C tools. The patient was then randomized into either the intervention or control group based on their folder number.

The participants who were in the intervention group were given the writing instructions verbally as well as on a written sheet to take home, and were given a list of local counselors to call if they experienced prolonged psychological distress. They were also invited to choose a journal provided by the investigator in which to write. Both groups were told they would receive another set of tools at three months to fill out and return. The participants in the control group were promised a journal once their three-month forms were returned to the investigator.

At the end of three months, each participant was sent the MUIS-C and QLI-C tools as well as the expressive writing information sheet and a pre-addressed and stamped envelope. The forms were returned to the investigator at a local P.O. Box address. Seven participants returned their forms on time. The other seven did not respond within two and a half weeks and were sent a second complete set of forms. Two participants responded from that second group. Those who responded from the control group were sent their journal as promised. Once the forms were returned, the investigator entered all of the data into an SPSS version 17.0 software program. The data was then sent to a statistician to run the required statistical analysis tests with the significance level set at $p < .05$. Of the nine returned three-month survey forms, six were from the intervention group and three were from the control group. Due to the small total number and control group response, the repeated measures ANOVA tests originally planned were replaced by paired *t*-tests.

Description of Sample

Fourteen patients - one male and thirteen females - made up the study sample and were recruited during the time period of October through December, 2009. Nine were being treated at the Cancer Center at East Alabama Medical Center and five at the Montgomery Cancer Center. The age range of the total sample was 35-88, with 55.9 being the mean age (see Table 1). The majority of the participants were married (n=9) and Caucasian (n=12). The level of education ranged from 9 years to 24 years, with a mean of 15.4 years. More than half were currently working (n=9). For all but two this was their first major illness. Nearly half of the participants had a diagnosis of breast cancer (n=6), with the rest evenly split between colon/rectal and head/neck (under

"other"). Finally, only one fifth of the sample (n=3) stated they normally did some type of journaling.

The intervention group consisted of six females and the only male, all Caucasian. The majority were married (n=5) and employed full time (n=6), and all had at least some college education. Six of the seven returned their three-month survey forms (see Table 1).

The control group consisted of seven females, five Caucasians and two African Americans. The majority were married (n=4) and unemployed (n=4), and most had at least some college education (n=5). Three of the seven returned their three-month survey forms (see Table 1).

TABLE 1

Comparison of Intervention and Control Group Demographics

Demographic	**Intervention Group**	**Control Group**
Age		
31-45 years	2	2
46-60 years	2	1
61-75 years	2	4
76-90 years	1	0
Gender		
Male	1	0
Female	6	7
Marital Status		
Married	5	4
Divorced	1	1

Widowed	1	1
Separated	0	1
Race		
Caucasian	7	5
African American	0	2
Level of Education		
7-12 years	0	2
13-16 years	5	3
17+ years	2	2
Employment Status		
Full time	6	2
Part time	0	1
Not employed	1	4
First Major Illness		
Yes	6	6
No	1	1
Cancer Type		
Breast	2	4
Colon / rectal	4	0
Other	1	3
Normally Journal		
Yes	1	2
No	6	5

Reliability of Instruments

Cronbach's alphas are calculated to estimate the internal consistency of a tool (Polit & Beck, 2008). The higher the reliability, the higher the Cronbach's alpha. Accordingly, Cronbach's alphas for both tools were examined at baseline and three months. In previous studies, Cronbach's alphas for Mishel's Uncertainty in Illness scale – Community form ranged from 0.74 to 0.92 (Mishel, 1997b). For this study, at baseline, the MUIS-C tool's Cronbach's alpha was comparable and acceptable at 0.86, but it decreased to 0.64 at three months. This decrease could be attributed to the smaller three-month sample size. Ferrans and Powers reported Cronbach's alphas from 0.87 to 0.97 for the Quality of Life Index – Cancer Version III (Ferrrans & Powers, 1998b). For this study, the QLI-C Cronbach's alphas remained high throughout, with 0.93 at baseline and reducing very slightly to 0.91 at three months. Both of these alphas were comparable to those previously reported.

Results

The results are organized by responses to each study question. Statistical results are presented for each question as well as tables illustrating the findings.

Response to Research Study Questions

Research question one.

Research question one: Does expressive writing cause a difference in cancer patients' perceived level of uncertainty after writing for three months? Every participant in the study filled out Mishel's Uncertainty in Illness scale – Community form. This scale assessed the respondent's feelings of uncertainty as it pertained to their illness, which in this case was their cancer diagnosis, by exploring four characteristics of uncertainty:

"inconsistency, unpredictability, ambiguity, and complexity" (Mishel, 1997b, p. 6). The scale consists of 23 questions answered with a 5-point Likert-like scale, where 1 = strongly disagree and 5 = strongly agree. The higher the score, the more uncertainty the person is feeling. Scores can range from 23-115, with mean scores from previous studies ranging from 42.4 - 85.5 (Mishel, 1997b). To assess for any changes in their level of uncertainty and to answer this study question, a comparison was made between the baseline and three-month data of the intervention group. Setting the significance value at $p < .05$, a paired *t*-test was performed. The results were $t_{(5)} = -0.583$, $p = .56$. While there was a three point increase in the mean of the intervention group from baseline to three months (see Table 2), due to the small sample size no significant statistical difference was found in the perceived level of uncertainty after expressively writing for three months. For comparison purposes, data from the total group and control group were also included in the table.

Table 2

Group Total, Mean and Standard Deviation for Uncertainty in Illness Scale

Groups	n	M	S.D.
Intervention Group			
Baseline	6	46.8	11.8
Three Months	6	49.8	5.5
Control Group			
Baseline	3	54.3	5.1
Three Months	3	55.3	6.5
Total Group			
Baseline	9	49.3	10.3
Three Months	9	51.7	6.1

Research question two.

Research question two: Does expressive writing cause a difference in cancer patients' perception of their quality of life after writing for three months? Every participant in the study filled out Ferrans and Power's Quality of Life Index – Cancer Version III. This index is composed of 66 questions looking at the domains of "health and functioning, psychological/spiritual, socioeconomic, and family" (Ferrans & Powers, 1998a). The first 33 questions ask how satisfied the individual is with an item in their life, and the second 33 questions ask how important that same item is to them. A 6-point Likert-type scale is used in this survey, with 1 = very dissatisfied or very unimportant, and 6 = very satisfied or very important. The answers are weighted so that the scale

ranges from 0 - 30, with higher numbers indicating higher quality of life. Those items which have high satisfaction and importance give a higher score indicative of greater quality of life, and those items which have high importance but low satisfaction get a lower score indicating a lower quality of life. To answer this study question, a comparison was made between the intervention group's data collected at baseline and three months (see Table 3). The table also includes the data from the total group and control group for comparison. Setting the significance value at $p < .05$, a paired *t*-test was performed on the data. The results were $t_{(5)} = 1.01$, $p = .36$. Therefore, after writing expressively for three months, no statistically significant difference was found between the two sets of quality of life data for either the total index or the subscales.

Table 3

Group Total, Mean and Standard Deviation for Quality of Life Index

Groups	**n**	**M**	**S.D.**
Intervention Group			
Baseline	6	24.6	2.9
Three Months	6	23.6	2.8
Control Group			
Baseline	3	21.4	1.3
Three Months	3	20.4	3.9
Total Group			
Baseline	9	23.6	2.9
Three Months	9	22.5	3.4

Research question three.

Research question three**:** Does expressive writing affect the relationship between quality of life and uncertainty in the intervention group as compared to the control group? A Pearson's *r* correlation was used to test for relationships between the variables and they were not statistically significant. Therefore, the data did not support the question. However, when asked if expressive writing had helped them "feel differently," five out of the six intervention group members who finished the study answered "yes." One participant clarified the "yes" by writing, "I feel that it always helps to express your inner feelings by putting it down on paper. It has helped me with my stress of being sick and the hope of a better future!" Another commented, "The more chemo I had and the worse the side effects, the less I wrote. But I did not give up my spirit."

Summary

Fourteen participants consented to be in the study and were randomly placed into either the intervention group or the control group. However, only nine returned the three-month data tools and completed the study. Of those who completed the study, six were in the intervention group and three were in the control group. Due to the small sample and even smaller response size, a change was made in the statistical tests done to analyze the data. In order to run a repeated measures ANOVA, a group needs at least 30 people. Therefore a paired *t*-test was substituted for the ANOVA and was used to answer the first and second research questions. The uncertainty *t*-test was not statistically significant, though examining the means of the intervention and control groups at baseline and three months revealed an increase in both groups at three months over baseline. This suggests an increase in all respondent's levels of uncertainty during the course of the study. The

quality of life *t*-test was also not statistically significant. Examination of the control and intervention group means at baseline and three months showed a slight decrease in both group means at three months compared to baseline. This indicates a slight decrease in perceived quality of life for each group. Pearson's *r* was also not statistically significant, showing no correlation between expressive writing, uncertainty and perceived quality of life. While the quantitative data was insignificant, the qualitative data was interesting and will be discussed further in the next chapter.

CHAPTER V

DISCUSSION, IMPLICATIONS, SUMMARY

The time period following a cancer diagnosis and start of treatment is fraught with uncertainty and a decrease in perceived quality of life. Expressive writing has the potential to improve cancer patients' mood, anxiety and depression (Frisina, 2004). This study looked at a general cancer population through the method of convenience sampling to see if expressive writing would be beneficial to them – changing their perception of their quality of life and amount of uncertainty. Despite non-significant statistical findings, the majority of the intervention group stated that they felt differently after writing. This last chapter explored the qualitative data obtained from the study, as well as the encountered limitations, implications for further research and practice, and a summary of the study.

Discussion

A non-significant *t*-test or Pearson's *r* indicates that the research questions are not supported by the data. In this study there were several factors which could have affected or caused this outcome including the small sample size and resulting low power of the study, high attrition rate which led to an even smaller response size, the length of the study time being too long (contributing to attrition rate), or the study time being too short to capture a true change in uncertainty or perceived quality of life caused by expressive writing. Or perhaps no matter what, expressive writing would not have made a statistically significant difference in this samples' feelings of uncertainty and perceived

quality of life. Despite the lack of statistical significance however, some interesting qualitative information about this sample was gleaned after a closer inspection of the data.

Mishel's Uncertainty in Life Scale – Community form

All fourteen participants completed a MUIS-C tool at the beginning of their time in the study. The reported mean at baseline was 48.6 (S.D. = 11.6) where the possible scores could range from 23-115. This original sample appears to be moderately uncertain. The study mean falls between two means reported by Mishel (1997b) also from studies with mixed type cancers: M = 44.6 (S.D. 10.9) and M = 85.5 (S.D. = 6.9). Their sample numbers were larger however with N=55 and N=70 respectively.

Based on the current study's baseline data, the items which received the highest scores for uncertainty were: "The course of my illness keeps changing; I have good and bad days" (M = 3.7, S.D. = 1.3); "I am certain they will not find anything else wrong with me" (M = 3.4, S.D. = 1.9); and "It is unclear how bad my pain will be" (M = 3.0, S.D. = 1.2). These statements echo statements made by newly diagnosed breast cancer patients (Beatty et al., 2008; Boehmke & Dickerson, 2006; Hochwald, 2008). Paring the group total down to only those who returned the three-month forms (n= 9), uncertainty due to the changing illness course remained the number one cause of uncertainty in both groups at baseline and three months (see Tables 4 and 5). Another issue producing high uncertainty in both groups was how treatments affected what they could or could not do.

Table 4

Comparison of Item Means of Highest Uncertainty and Lowest Uncertainty in Intervention Group at Baseline and Three Months

Baseline	Three Months
Greatest Uncertainty • Course of illness keeps changing (3.5) • Certain to find nothing else wrong (3.2) • Unclear how bad pain will get (3.2)	Greatest Uncertainty • Course of illness keeps changing (4.0) • Hard to know if treatments are helping (2.8) • Unsure if illness is better or worse (2.7) • Treatment effectiveness undetermined (2.7) • Treatment affects what I can do/not do (2.7)
Least Uncertainty • Don't know what's wrong with me (1.2) • Explanations are hazy (1.5) • Purpose of treatment is unclear (1.5) • Drs' explanations have many meanings (1.5) • Treatments too complex to understand (1.5) • Differing opinions on what is wrong (1.5)	Least Uncertainty • Don't know what's wrong with me (1.2) • Purpose of treatment is unclear (1.7) • Drs' explanations have many meanings (1.7) • Differing opinions on what is wrong (1.7) • No specific diagnosis (1.7) • Drs don't use everyday language (1.7)

- Test results inconsistent (1.5)
- Treatments don't have known probability of success (1.5)
- No specific diagnosis (1.5)

Table 5

Comparison of Item Means of Highest Uncertainty and Lowest Uncertainty in Control Group at Baseline and Three Months

Baseline	**Three Months**
Greatest Uncertainty • Course of illness keeps changing (4.0) • Unpredictability of illness affects ability to plan for future (3.7) • Treatment affect what I can do/not do (3.3)	Greatest Uncertainty • Course of illness keeps changing (4.0) • Treatments affect what I can do/not do (4.0) • Symptoms change unpredictably (3.3)
Least Uncertainty • Treatments don't have known probability of success (1.3) • No specific diagnosis (1.3) • Seriousness of illness is undetermined (1.3) • Drs don't use everyday language (1.3)	Least Uncertainty • Don't know what's wrong with me (1.3) • Unsure if illness is better or worse (1.3) • Unpredictability of illness affects ability to plan for future (1.7) • Treatments don't have known probability of success (1.7) • Seriousness of illness is undetermined (1.7)

In looking at the above statements, some reflect the normal unpredictable side of the disease and treatment process. For instance, unfortunately, it is normal for a course of illness to change; it is normal to wonder how bad the pain will get – whether caused by the disease or side effects; it is normal for treatments to affect - sometimes dictate - ones daily life, and to wonder if treatments are working and one is getting better. Even though these are normal concerns, they can and should be addressed by health care providers. Patients may not necessarily expect or receive an answer, but they need someone to ask how they are feeling, acknowledge the uncertainties and address them as valid concerns (Boehmke & Dickerson, 2006; Vitek, Rosenzweig, & Stollings, 2007).

Examining the amount of change in responses on the uncertainty tool from baseline to three months also revealed some interesting details. The intervention group (n = 6) had two questions whose scores showed a significant downward change from baseline to three months. The change indicated a decrease in uncertainty about anticipated intensity of pain (U4) and fear of additional health problems (U19). The decrease in uncertainty in pain may be explained by the passage of time: patients are usually past needed surgeries and they have had enough treatments that they know what to expect for side effects. The uncertainty regarding the chance of something else being found wrong is also reported among breast cancer survivors (Beatty et al., 2008). Three questions' scores that increased the most at three months indicated a greater uncertainty about illness progression (U3), effectiveness of treatments (U11), and potential success of treatments (U20) (see Figure 1). These uncertainties were supported by statements from breast cancer survivors who told of fears of reoccurrence, yet were also challenged by the

same survivors who also spoke of the importance of staying positive and seeing cancer as a temporary problem (Beatty et al., 2008), This positive viewpoint was echoed by other cancer patients still in the middle of their treatments who spoke of their hopes and belief that the treatments would work (Hjörleifsdóttir & Gunnarsdóttir, 2008).

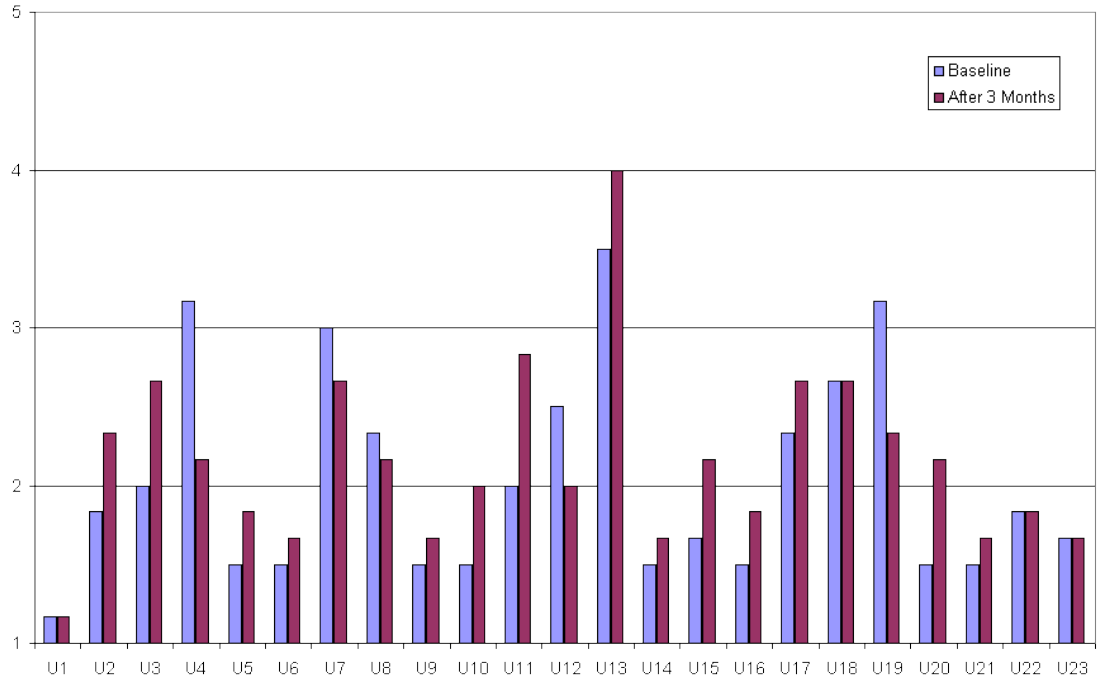

Figure 1. Comparison of Mean Uncertainty Tool Question Scores from Baseline to Three Months for Intervention Group

There were three questions for the control group (n = 3) which were significantly higher at baseline than three months. This change indicated a decrease in uncertainty about illness prognosis (U3), anticipated intensity of pain (U4), and inability to plan for the future (U12). By three months into treatments, patients have gotten into a routine with their treatments and are learning to live their life around them (Hjörleifsdóttir & Gunnarsdóttir, 2008). Three other question's scores were much higher at three months. These indicated an increase in uncertainty related to symptom unpredictability (U7), and

not understanding explanations, apparently due to doctors and nurses lack of using everyday language in their explanations (U8 and U23) (see Figure 2). One explanation for the symptom unpredictability could be the compounding intensity of side effects from chemotherapy which often worsens over time (Hochwald, 2008). The inability to understand explanations is troubling however, since open communication between a patient and their health care provider can minimize uncertainties and provide hope (Hjörleifsdóttir & Gunnarsdóttir, 2008).

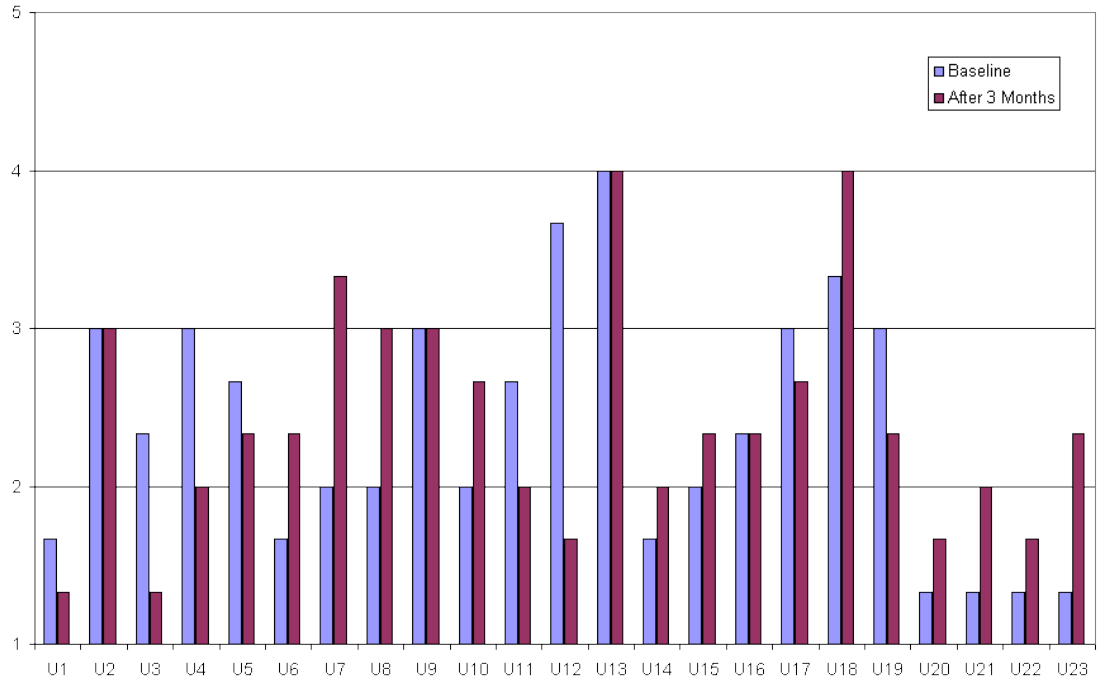

Figure 2. Comparison of Mean Uncertainty Tool Question Scores from Baseline to Three Months for Control Group

Ferrans and Powers Quality of Life Index – Cancer Version III

All fourteen participants filled out the QLI-C tool when they entered the study. The group mean at baseline was 22.5 (S.D. = 3.8) which is considered moderately high (range was 0-30). This was comparable to another study with newly diagnosed cancer

patients in Norway which reported a mean score of 21.5 (S.D. = 3.8) (Rustoen et al., 1999), and a sample of American breast cancer survivors (M = 21.96, S.D. = 4.5) (Sammarco, 2001). A closer look at the individual questions revealed that the top three items the fourteen participants were most satisfied with were their health care, emotional support from their family, and their faith in God (all tied with M = 5.9). The top three items they felt were most important were their family's health, children, and their family's happiness (all tied with M = 6.0). Faith in God was a close fourth (M = 5.9).

Closer examination of the intervention group's data revealed that the family subscale had the highest mean at both baseline (M = 27.6, S.D. = 4.8) and three months (M = 26.7, S.D. = 2.8). Within the family subscale, the items related to highest quality of life were family's happiness, children, emotional support from family, and family's health. The health and functioning subscale had the lowest mean at both baseline (M = 21.8, S.D. = 3.2) and three months (M = 19.7, S.D. = 4.2). Health, energy level, and worries were the items which received the lowest scores. These ratings were not surprising as most participants were in the middle of their chemotherapy treatments at their three month survey time. Other studies reported similar mean ratings with newly diagnosed cancer patients (Rustoen et al., 1999) and young breast cancer survivors (Sammarco, 2001).

Across the board, the intervention group had higher means than did the control group, though there are many factors besides expressive writing which could have influenced the difference in the scores. While the intervention means were higher, it is interesting to note that all but the psychological/spiritual subscale mean decreased at three months (see Table 6). In contrast, the control group's psychological/spiritual and

family subscales were both increased at three months. A decrease in the quality of life scores was similar to two other studies which did not use the Ferrans and Powers Quality of Life Index but did measure quality of life with a different tool over a period of time. Both studies looked at the effects of expressive writing with breast cancer patients and reported an initial decrease in quality of life followed later by an increase which surpassed the baseline mean (Gellaitry et al., 2009; Stanton et al., 2002).

Table 6

Comparison of Subscale Means of Intervention Group and Control Group at Baseline and Three Months

Subscales	**Baseline**	**Three Months**
Intervention Group		
QLI - total	24.6 (S.D. = 2.9)	23.6 (S.D. = 2.8)
Health/functioning	21.9 (S.D. = 3.2)	19.7 (S.D. = 4.2)
Social/economic	25.9 (S.D. = 2.9)	25.5 (S.D. = 3.7)
Psychological/spiritual	26.5 (S.D. = 2.9)	26.7 (S.D. = 3.3)
Family	27.6 (S.D. = 4.8)	26.7 (S.D. = 2.8)
Control Group		
QLI - total	21.4 (S.D. = 1.3)	20.4 (S.D. = 3.9)
Health/functioning	19.5 (S.D.= 3.3)	16.7 (S.D. = 5.3)
Social/economic	23.4 (S.D. = 0.9)	21.9 (S.D. = 5.2)
Psychological/spiritual	21.4 (S.D. = 2.3)	23.3 (S.D. = 1.0)
Family	24.1 (S.D. = 2.7)	26.0 (S.D. = 3.2)

Examining individual question weighted ratings revealed some items in common between the two groups as well as others unique to each group. All participants rated their faith in God as the number one item at both measurement times. This might have to do with the location of the study – deep south in the Bible belt – since a Norwegian study of a similar population reported faith in God as the least important item (Rustoen et al., 1999). Other items which received high ratings included their health care and emotional support from family (see Tables 7 and 8), which were both mentioned as important in other studies (Beatty et al., 2008; Hjörleifsdóttir & Gunnarsdóttir, 2008). Participants rated their lack of energy as their lowest quality of life item which indicated they thought it was very important but were very dissatisfied with it. This is to be expected as they were in the midst of chemotherapy treatments and the resulting side effects. Other items which received a low quality of life rating in both groups included their health and their current amount of worries. Interesting to note that the intervention group – in which five out of the six were employed – listed "not having a job" as one of their three lowest quality of life items. Perhaps they were concerned that the cancer would cause them to lose their job.

Table 7

Comparison of Weighted Means Showing Items with Highest Importance and Satisfaction in Intervention and Control Groups at Baseline and Three Months

Baseline	**Three Months**
Intervention Group	Intervention Group
• Faith in God (30.0) • Health care (29.6) • Children (29.0) • Emotional support from family (29.0)	• Faith in God (30.0) • Health care (29.6) • Job (28.1)
Control Group	Control Group
• Faith in God (30.0) • Health care (30.0) • Emotional support from family (29.2)	• Faith in God (30.0) • Emotional support from family (29.2) • Peace of mind (28.9)

Table 8

Comparison of Weighted Means Showing Items with Highest Importance but Lowest Satisfaction in Intervention and Control Groups at Baseline and Three Months

Baseline	**Three Months**
Intervention Group • Health (11.6) • Not having a job (15.0) • Amount of worries (16.8)	Intervention Group • Energy (9.9) • Not having a job (11.6) • Amount of worries (14.1)
Control Group • Energy level (7.8) • Personal appearance (9.8) • Health (12.0)	Control Group • Energy level (6.3) • Health (12.0) • Ability to fulfill family responsibilities (12.0) • Usefulness to others (12.0)

Examination of the change in quality of life ratings over time revealed much less variance within the intervention group than the control group. This could have been attributed to many factors including difference in group sizes, differences in chemotherapy and radiation treatment regimes, or individual disease progression. The biggest change in scores recorded for the intervention group was the drop in satisfaction of their energy level (Q4) (see Figure 3). The next three largest drops were a decrease in satisfaction with their ability to manage family responsibilities (Q16), the amount of pain they were experiencing (Q3), and their ability to be independent with self care (Q5). All

of these were to be expected considering where these patients were in their treatment regimes. The largest jump in ratings was due to an increase of both importance and satisfaction with their health (Q1) and ability to care for their needs financially (Q24). While being more satisfied with their health seems odd, it may reflect their recovery from pre-chemotherapy surgeries, or perhaps the participants were expressing more of an appreciation for health now that their health status had changed. The third highest jump was in satisfaction with their home, apartment or wherever they lived (Q20).

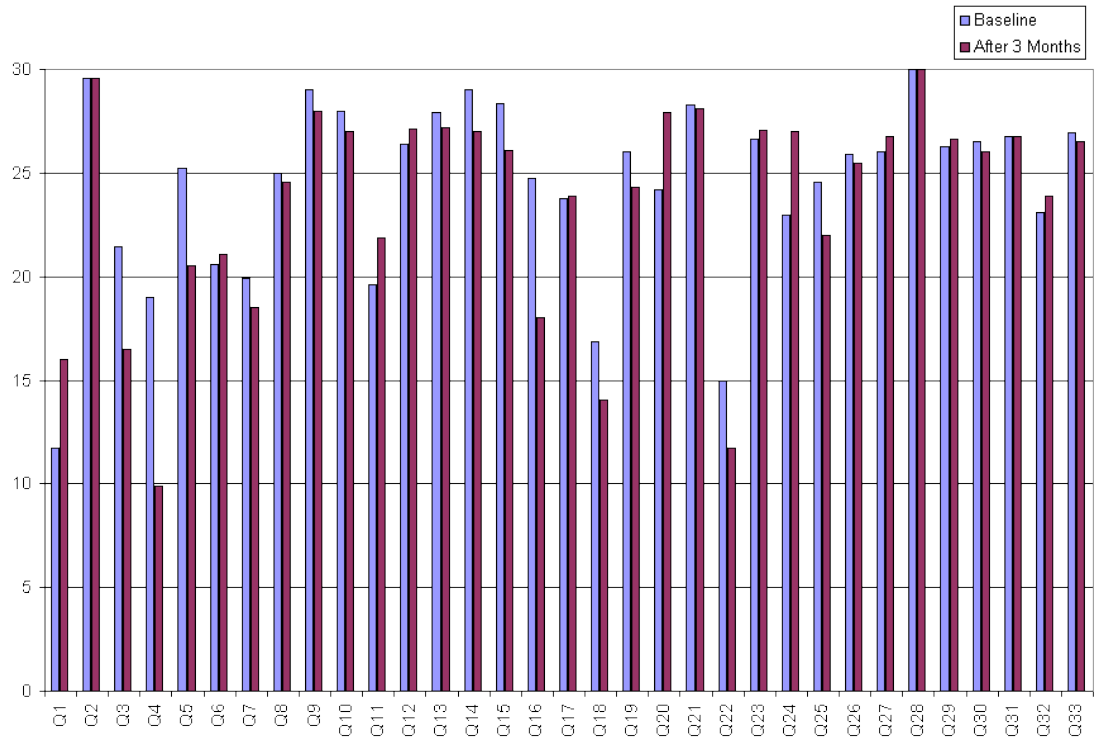

Figure 3. Comparison of Weighted Mean Quality of Life Question Scores from Baseline and Three Months for Intervention Group

The control group showed much more variance in their ratings. As suggested above, this variance could be attributed to the smaller group size, difference in disease treatments or progression, or many other factors. The most dramatic drop was caused by

a decrease in both satisfaction with and importance of their neighborhood (Q19) (see Figure 4). A large drop in satisfaction was also noted in the amount of control they had over their lives (Q6), the amount of pain they were in (Q3), and their home, apartment or place where they lived (Q20). Interestingly, at three months, being useful to others went up in importance yet they were less satisfied with it (Q17). The most significant jump was seen in their satisfaction with their children (Q9), followed by their peace of mind (Q27) and themselves in general (Q33). Friends (Q13) and their personal appearance (Q32) increased in both importance and satisfaction.

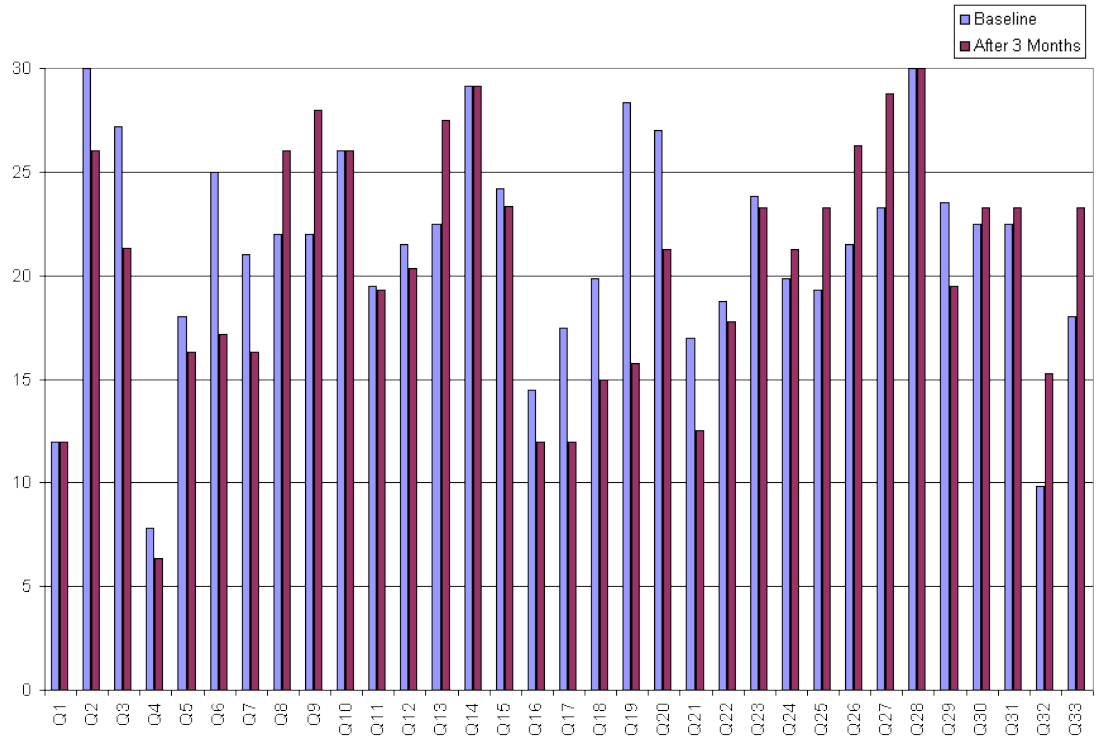

Figure 4. Comparison of Weighted Mean Quality of Life Question Scores from Baseline and Three Months for Control Group

Correlations between Uncertainty and Quality of Life

Pearson's *r* was used to test the relationship between expressive writing, uncertainty and quality of life in the intervention group and in the control group. There are several factors which could have caused the results to be statistically non-significant, including having multiple diagnoses and thus different chemotherapy drugs and treatment protocols, the small sample size and resulting low power of the study, the length of the study not allowing adequate time to process effects of writing, each participant's life situations, and many other unknown factors.

Figure 5 graphically portrays the changes in combined uncertainty and quality of life scores for each participant from baseline to three months. This illustrates the unique response of each participant to their cancer experience. Four participants experienced a drop in their uncertainty over the time period. This could be attributed to being over their initial shock and settling down into a treatment routine, or being completely over with their treatments. Five showed an increase in uncertainty. This could be due to the appearance of new side effects, treatments not going well, or having a difficult time performing at their job or fulfilling family responsibilities. Four reported an increase or no change in their perceived quality of life. This could be credited to a reprioritizing of their lives, a change in focus of what they thought was important. This increase could also speak to their coping skills. Five reported a drop in their quality of life. Treatments could have been one contributing factor, but also the global impact of cancer on their life (Ferrans, 1990).

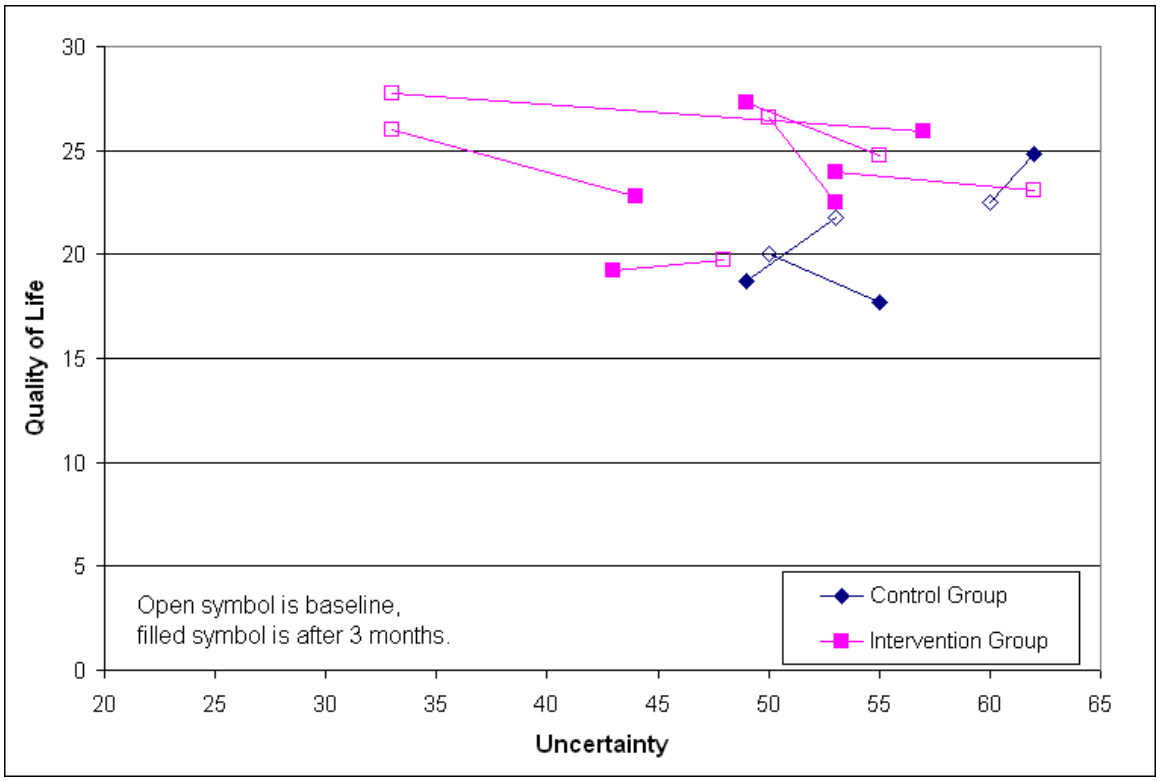

Figure 5. Changes in Combined Uncertainty and Quality of Life Scores of Each Participant from Baseline and Three Months

Limitations

Limitations are those things over which the researcher has no control, but which can affect the accuracy or purity of the study findings and which must be taken into account during the interpretations of the findings. A list of potential limitations was included in chapter one. The following three limitations are discussed in more detail here due to their obvious impact on the study. The first limitation encountered almost immediately was a difficulty in obtaining buy-in from all providers at the facilities. Some actively encouraged patients to join the study, whereas other providers merely included the study flier in the large stack of information given to each newly-diagnosed patient. Obviously patients who just received a flier in a stack of papers were unlikely to respond compared with those whose providers encouraged their participation. This lack of buy-in

may have contributed to the small total sample size, which in turn affected the results obtained through the statistical analysis.

Another limitation encountered was the attrition rate. Five participants did not return the three-month data tools, thus effectively dropping out of the study. This attrition rate may be explained by progression of their disease, metastasis or death; treatment regime and intensity of side effects; presence or lack of a support system; or current life situations including previous and ongoing uncertainties or issues pertaining to their quality of life. The attrition rate might also have been impacted by the fact that the investigator met with the participants at baseline and had them fill out the data forms at that time, whereas the three-month forms were mailed out and participants did not have the investigator there in person encouraging them to complete the forms. Perhaps more participants would have responded if the investigator had offered to meet with them face-to-face at three months to fill out the forms or had contacted them through a personal telephone call. This attrition rate significantly affected the control group data and made it difficult to compare the control group to the intervention group.

A third limitation in this study worth noting was the lack of control over what the control group participants did while in this study. Since the participants were randomized into their groups, the investigator was unable to ensure that those who usually journal were put into the expressive writing group. In fact, two of the three participants who said they already did journaling were randomized into the non-writing control group. Of the three control group participants who responded at three months, one said that they did some journaling during the study time period. While the control group did not receive the writing prompt, just the act of journaling may have impacted their response data.

Implications for Further Research

Frattaroli (2006) demonstrated that expressive writing can have a positive effect on a person's psychological health, physiological health, reported health, general functioning, and life outcomes. Specific benefits of expressive writing for cancer patients with regard to their uncertainty and perceived quality of life, both as a general cancer patient population as well as by specific diagnosis, have yet to be determined. Repeating this study with a larger sample size may provide sufficient power to produce valid data. Additionally, limiting the sample to one type of cancer population would allow results to be compared more equally. A lack of uniformity of this sample meant that some participants were in the middle of their treatments at three months but others might have been finished – two very different spots psychologically. Reading the journals and doing word and content analysis might also provide researchers with data enabling them to draw correlations between the content in the journals and the data results. Furthermore, investigators might want to experiment with different writing instructions, such as varying the number of days participants are asked to write or requiring a specific amount of time spent writing.

Implications for Practice

Alternative and complementary therapies are beginning to be researched and accepted by health care providers and insurance companies. In today's uncertain economy, having an intervention which is inexpensive, non-invasive and proven beneficial should be welcomed by both providers and patients alike. It is important to understand the potential benefits of expressive writing and the impact writing might have on a patient's uncertainty and perceived quality of life. This knowledge and use of a

writing intervention can assist health care providers in providing more holistic care by addressing the psychological effects associated with a cancer diagnosis.

Summary

The first goal of Healthy People 2010 is to "increase quality and years of healthy life" (U.S. Department of Health and Human Services, 2000, para.1). Oncologists have developed cancer treatment regimes to fight for a patient's chance at a longer life, but do not always include treatments or interventions to address their patient's perceived uncertainties and quality of life. By recommending expressive writing to patients, health care professionals acknowledge the psychological ramifications of the disease and treat each patient in a more holistic manner (Laccetti, 2007). Expressive writing empowers patients to improve their own positive functioning by freeing themselves of bondage from past and current traumas.

Participants in this research study were given the opportunity to practice expressive writing and through the completion of the two tools give voice to their uncertainties and quality of life. This sample was most uncertain about disease progression – the disconcertion caused by fluctuations in how they felt and what they were able to do, and the possibility of a "cure". The uncertainty data served health care professionals a reminder to use vocabulary easily understood by their patients when giving explanations. This sample revealed the high importance they placed in their faith in God and their family. Not surprisingly, as a whole they were also frustrated over their lack of energy and good health. The responses revealed the uniqueness of each person manifested by their response to illness and their choices of what mattered most when they considered their quality of life.

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APPENDIX A

EAST ALABAMA MEDICAL CENTER INSTITUTIONAL REVIEW BOARD APPROVAL

LETTER OF APPROVAL
Institutional Review Board

TO: Naomi Crouse
Principal Investigator

FROM: Michael J. Lisenby, M.D.
Chairperson, IRB

DATE: July 10, 2009

The research project submitted for Expedited Review and approval entitled, "The Power of the Written Word", was reviewed and approved with the following stipulations:

A. Investigators acknowledge and accept their responsibility for protecting the rights and welfare of human research subjects and for complying with all applicable thereof.

B. Investigators must report promptly to the IRB:

(1) Any proposed changes in IRB approved research and acknowledge such research may not be initiated without IRB review and approval except where necessary to eliminate apparent immediate hazards to the human subjects.
(2) Any unanticipated problems involving risks to human subjects or others.
(3) Any instance of serious or unexpected adverse events arising during the research.

C. The above titled project is approved July 10, 2009 through July 9, 2010.
If the project is to continue beyond the ending date of approval, application for renewal must be made as of May 9, 2010 to be further approved by the IRB.

D. Approval is contingent upon modifications, if any, of the protocol or consent form and approved documentation of such modifications.

IRB Chairperson — Date: 7/10/09

Please acknowledge your agreement to abide by these stipulations by your signature, keep a copy and return the original to the IRB office.

Principal Investigator — Date: July 23 2009

APPENDIX B

MONTGOMERY CANCER CENTER INSTITUTIONAL REVIEW BOARD APPROVAL

Medical Oncology
Harry M. Barnes III, M.D.
Keith A. Thompson, M.D.
Stephen L. Davidson, M.D.
Stephen A. White, M.D.
Phatama Padavanija, M.D.
Scott A. McDaniel, M.D.

Montgomery Cancer Center

Radiation Oncology
William W. Helvie, M.D.
R. Lee Franklin III, M.D.
Michael L. Ingram, M.D.
David T. Vega, M.D.

October 21, 2009

Naomi Crouse
Nursing Student, Auburn University
634 Monticello Ct.
Auburn AL 36830

Dear Naomi,

MCC is in receipt of your IRB approval.

As we discussed, you will ensure all consents and IRB correspondence are filed in the regulatory binder in the Compliance Office.

Please call me if you have any questions during the course of the study.

Regards,

Laura Hamilton
Compliance Officer

Main Campus
5145 Carmichael Road
Montgomery, Alabama 36106-2801
Phone 334/ 273-7000
Medical Oncology Fax 334/ 260-2010
Radiation Oncology Fax 334/ 260-5010

East
7085 Sydney Curve
Montgomery Alabama 36117
Phone 334/ 244-4000
Fax 334/ 244-4053

Prattville
545 McQueen Smith Road North
Prattville, Alabama 36066
Phone 334/ 358-3374
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Selma
1023 Medical Center Parkway, Suite 110
Selma, Alabama 36701
Phone 334/ 872-9300
Fax 334/ 872-3919

Medical Oncology
Harry M. Barnes III, M.D.
Keith A. Thompson, M.D.
Stephen L. Davidson, M.D.
Stephen A. White, M.D.
Phatama Padavanija, M.D.
Scott A. McDaniel, M.D.
John E. Reardon, M.D.

Montgomery Cancer Center

Radiation Oncology
William W. Helvie, M.D.
R. Lee Franklin III, M.D.
Michael L. Ingram, M.D.
David T. Vega, M.D.

August 31, 2009

Naomi Crouse
Nursing Student, Auburn University
634 Monticello Ct.
Auburn AL 36830

Dear Naomi,

You have approached Montgomery Cancer Center, LLC (MCC) to allow you to invite MCC patients to participate in a research project to support your thesis in working toward your Clinical Nurse Specialist degree. The study is described as,

> "This study will investigate if expressive writing makes a difference in those newly diagnosed with cancer with regards to their feelings of uncertainty and perceived quality of life. Participants will be recruited from local cancer treatment centers in Alabama. Each participant will fill out a demographic information sheet, Mishel's Uncertainty in Illness scale and Ferrans and Powers Quality of Life index, Cancer Version III. Participants will then be randomly placed into one of two groups: a control or an intervention group. Those in the control group will fill out these same tools at the end of three months, but do nothing else. Those in the intervention group will be asked to write expressively at least twice a week during the three months in the study and fill out the same tools as at the beginning, as well as an expressive writing information sheet. Research findings will contribute to the growing body of literature on expressive writing, and may introduce nurses and physicians to a non-invasive, inexpensive and beneficial intervention which they can recommend to their patients."

As we've discussed, you are working with Kristi Springer, CRNP to get approval of physician(s) with whom you would work to recruit patients.

In terms of Institutional Review Board (IRB) oversight, MCC does not currently maintain an IRB. Therefore for studies conducted at MCC, MCC currently contracts as needed with one of several professionally managed IRBs (e.g., Western Institutional Review Board or New England IRB). The fees for professional IRBs may be referenced on the internet; it's possible that they offer fees designed for student studies.

In your case, if Auburn University's IRB agrees to oversee your research at MCC, that would be acceptable, with a written approval letter from Auburn IRB provided.

Main Campus
4465 Carmichael Road
Montgomery, Alabama 36106-2801
Phone 334/ 273-7000
Medical Oncology Fax 334/ 260-2010
Radiation Oncology Fax 334/ 260-5010

East
7085 Sydney Curve
Montgomery, Alabama 36117
Phone 334/ 244-4000
Fax 334/ 244-4053

Prattville
645 McQueen Smith Road North
Prattville, Alabama 36066
Phone 334/ 358-3374
Fax 334/ 358-3375

Selma
1023 Medical Center Parkway, Suite 110
Selma, Alabama 36701
Phone 334/ 872-9300
Fax 334/ 872-3919

Before conducting research at MCC, MCC requires the following:

- To approve the IRB chosen
- A letter from IRB stating their approval of MCC as a site
- A copy of the IRB approved protocol, including all forms to be used in study
- A copy of the IRB approved consent, including required HIPAA language
- A signed copy of the each patient's consent
- A copy of all IRB correspondence and approval letters

For the duration of the project and at its conclusion, MCC require periodic IRB follow reports.

An original copy signed and dated consent must be placed on the respective patient's chart, and a copy must be maintained in the study binder described below. Each consent form must be signed by the patient, you, and a MCC MD or CRNP.

To facilitate communication and record keeping regarding this project, the information required as described in this letter should be organized in a "study binder". The study binder must be organized in the following manner: a 2" binder, labeled spine and front, with the following tabs: Protocol, Consent, Forms, IRB Approvals, IRB Correspondence, General Correspondence, List of Participants, Signed Consents. The study binder must be maintained in the MCC Compliance Office by you during the course of the study.

I look forward to working with you.

Regards,

Laura Hamilton
Compliance Officer

APPENDIX C

AUBURN UNIVERSITY INSTITUTIONAL REVIEW BOARD APPROVAL

AUBURN

UNIVERSITY

Office of Human Subjects Research
307 Samford Hall
Auburn University, AL 36849

Telephone: 334-844-5966
Fax: 334-844-4391
hsubjec@auburn.edu

September 29, 2009

MEMORANDUM TO: Naomi Crouse
Nursing

PROTOCOL TITLE: "The Power of the Written Word"

IRB AUTHORIZATION NO: 09-249 EP 0909

APPROVAL DATE: September 28, 2009
EXPIRATION DATE: September 27, 2010

The above referenced protocol was approved by IRB Expedited procedure under 45 CFR 46.110 (Category #7):

> "Research on individual or group characteristics or behavior (including, but not limited to, research on perception, cognition, motivation, identity, language, communication, cultural beliefs or practices, and social behavior) or research employing survey, interview, oral history, focus group, program evaluation, human factors evaluation, or quality assurance methodologies."

You should report to the IRB any proposed changes in the protocol or procedures and any unanticipated problems involving risk to subjects or others. Please reference the above authorization number in any future correspondence regarding this project.

If you will be unable to file a Final Report on your project before September 27, 2010, you must submit a request for an extension of approval to the IRB no later than September 10, 2010. If your IRB authorization expires and/or you have not received written notice that a request for an extension has been approved prior to September 27, 2010, you must suspend the project immediately and contact the Office of Human Subjects Research for assistance.

A Final Report will be required to close your IRB project file. You are reminded that you must use the stamped, IRB-approved informed consent when you consent your participants. Please remember that you must keep signed informed consents for three years after your study is completed.

If you have any questions concerning this Board action, please contact the Office of Human Subjects Research at 844-5966.

Sincerely,

Kathy Jo Ellison, RN, DSN, CIP
Chair of the Institutional Review Board
for the Use of Human Subjects in Research

cc: Dr. Barbara Witt
Dr. Anita All

AUBURN UNIVERSITY INSTITUTIONAL REVIEW BOARD for RESEARCH INVOLVING HUMANSUBJECTS

RESEARCH PROTOCOL REVIEW FORM

For Information or help contact THE OFFICE OF HUMAN SUBJECTS RESEARCH, 307 Samford Hall, Auburn University
Phone: 334-844-5966 e-mail: hsubjec@auburn.edu Web Address: http://www.auburn.edu/research/vpr/ohs/

Complete this form using Adobe Acrobat Writer (versions 5.0 and greater). Hand written copies not accepted.

1. PROPOSED START DATE of STUDY: Oct 1, 2009

PROPOSED REVIEW CATEGORY (Check one): ☐ FULL BOARD ☑ EXPEDITED ☐ EXEMPT

2. PROJECT TITLE: The Power of the Written Word

3. Naomi Crouse (PRINCIPAL INVESTIGATOR) | RN, BSN (TITLE) | Nursing (DEPT) | 334-502-8923 (PHONE) | crousnl@auburn.edu (AU E-MAIL)
634 Monticello Ct. Auburn, AL 36830 (MAILING ADDRESS) | (FAX) | naomi@thecrouses.com (ALTERNATE E-MAIL)

4. SOURCE OF FUNDING SUPPORT: ☑ Not Applicable ☐ Internal ☐ External Agency: _____ ☐ Pending ☐ Received

5. LIST ANY CONTRACTORS, SUB-CONTRACTORS, OTHER ENTITIES OR IRBs ASSOCIATED WITH THIS PROJECT:
The Cancer Center at East Alabama Medical Center and the Montgomery Cancer Center

6. GENERAL RESEARCH PROJECT CHARACTERISTICS

6A. Mandatory CITI Training

Names of key personnel who have completed CITI:
Naomi Crouse — Graduate Student
Dr. Anita All — Professor / Advisor

CITI group completed for this study: ☐ Social/Behavioral ☑ Biomedical

Protocol-Specific modules completed:
☐ Genetic ☐ Vet.'s Administration
☐ International ☐ Prisoner Research
☐ Public School Students ☐ Pregnant Women/Fetuses
Other _____

6B. Research Methodology

Please check all descriptors that best apply to the research methodology.

Data Source(s): ☑ New Data ☐ Existing Data

Will data be recorded so that participants can be directly or indirectly identified? ☑ Yes ☐ No

Data collection will involve the use of:

☐ Educational Tests (cognitive diagnostic, aptitude, etc.)
☑ Surveys / Questionnaires
☐ Internet / electronic
☐ Audio / Video / Photos
☐ Interview / Observation
☐ Physical / Physiological Measures or Specimens (see Section 6E.)
☐ Private records or files

The Auburn University Institutional Review Board has approved this document for use from 9/25/09 to 9/27/10 Protocol # 09-249 EP 0909

6C. Participant Information

Please check all descriptors that apply to the participant population.
☑ Males ☑ Females ☐ AU students

Vulnerable Populations
☐ Pregnant Women/Fetuses ☐ Children and/or Adolescents (under age 19 in AL)
☐ Prisoners

Persons with:
☐ Economic Disadvantages ☐ Physical Disabilities
☐ Educational Disadvantages ☐ Intellectual Disabilities

Do you plan to compensate your participants? ☐ Yes ☑ No

6D. Risks to Participants

Please identify all risks that participants might encounter in this research.
☑ Breach of Confidentiality* ☐ Coercion
☐ Deception ☐ Physical
☑ Psychological ☐ Social
☐ None ☐ Other _____

RECEIVED SEP 2009 Office of Human Subjects Research IRB

*Note that if the investigator is using or accessing confidential identifiable data, breach of confidentiality is always a risk.

6E. Institutional Biosafety Approval

Do you need IBC Approval for this study? ☑ No ☐ Yes - BUA # _____ Expiration date _____

FOR OHSR OFFICE USE ONLY

DATE RECEIVED IN OHSR: 9/25 by AKH
DATE OF IRB REVIEW: 9/28/09 by KE
DATE OF IRB APPROVAL: 9/28/09 by KE
COMMENTS: original received 9/4/09 IRB reviewed 9/28/09

PROTOCOL # 09-249 EP 0909
APPROVAL CATEGORY: 45 CFR 46.110 (#7)
INTERVAL FOR CONTINUING REVIEW: 1 year

7. PROJECT ASSURANCES

PROJECT TITLE: The Power of the Written Word

A. PRINCIPAL INVESTIGATOR'S ASSSURANCES

1. I certify that all information provided in this application is complete and correct.
2. I understand that, as Principal Investigator, I have ultimate responsibility for the conduct of this study, the ethical performance this project, the protection of the rights and welfare of human subjects, and strict adherence to any stipulations imposed by the Auburn University IRB.
3. I certify that all individuals involved with the conduct of this project are qualified to carry out their specified roles and responsibilities and are in compliance with Auburn University policies regarding the collection and analysis of the research data.
4. I agree to comply with all Auburn policies and procedures, as well as with all applicable federal, state, and local laws regarding the protection of human subjects, including, but not limited to the following:
    a. Conducting the project by qualified personnel according to the approved protocol
    b. Implementing no changes in the approved protocol or consent form without prior approval from the Office of Human Subjects Research
    c. Obtaining the legally effective informed consent from each participant or their legally responsible representative prior to their participation in this project using only the currently approved, stamped consent form
    d. Promptly reporting significant adverse events and/or effects to the Office of Human Subjects Research in writing within 5 working days of the occurrence.
5. If I will be unavailable to direct this research personally, I will arrange for a co-investigator to assume direct responsibility in my absence. This person has been named as co-investigator in this application, or I will advise OHSR, by letter, in advance of such arrangements.
6. I agree to conduct this study only during the period approved by the Auburn University IRB.
7. I will prepare and submit a renewal request and supply all supporting documents to the Office of Human Subjects Research before the approval period has expired if it is necessary to continue the research project beyond the time period approved by the Auburn University IRB.
8. I will prepare and submit a final report upon completion of this research project.

My signature indicates that I have read, understand and agree to conduct this research project in accordance with the assurances listed above.

Naomi Crouse	Naomi Crouse	9/4/09
Printed name of Principal Investigator	Principal Investigator's Signature	Date

B. FACULTY ADVISOR/SPONSOR'S ASSURANCES

1. By my signature as faculty advisor/sponsor on this research application, I certify that the student or guest investigator is knowledgeable about the regulations and policies governing research with human subjects and has sufficient training and experience to conduct this particular study in accord with the approved protocol.
2. I certify that the project will be performed by qualified personnel according to the approved protocol using conventional or experimental methodology.
3. I agree to meet with the investigator on a regular basis to monitor study progress.
4. Should problems arise during the course of the study, I agree to be available, personally, to supervise the investigator in solving them.
5. I assure that the investigator will promptly report significant adverse events and/or effects to the OHSR in writing within 5 working days of the occurrence.
6. If I will be unavailable, I will arrange for an alternate faculty sponsor to assume responsibility during my absence, and I will advise the OHSR by letter of such arrangements. If the investigator is unable to fulfill requirements for submission of renewals, modifications or the final report, I will assume that responsibility.
7. I have read the protocol submitted for this project for content, clarity, and methodology.

Anita C. Hall		8/31/09
Printed name of Faculty Advisor / Sponsor	Signature	Date

C. DEPARTMENT HEAD'S ASSSURANCE

By my signature as department head, I certify that I will cooperate with the administration in the application and enforcement of all Auburn University policies and procedures, as well as all applicable federal, state, and local laws regarding the protection and ethical treatment of human participants by researchers in my department.

Barbara S Witt	Barbara S Witt	8/31/09
Printed name of Department Head	Signature	Date

8. **PROJECT OVERVIEW: Prepare an abstract that includes:**
(400 word maximum, in language understandable to someone who is not familiar with your area of study):

I.) A summary of relevant research findings leading to this research proposal, *(Cite sources; include a "Reference List" as Appendix A.)*
II.) A brief description of the methodology,
III.) Expected and/or possible outcomes, and,
IV.) A statement regarding the potential significance of this research project.

Receiving a diagnosis of cancer can catapult a person into a time period dominated by uncertainty (Mishel, 1988). Emotions such as anxiety, depression, fear, distress and helplessness are all common during this time (Boehmke & Dickerson, 2006; Ferrell & Coyle, 2008; Hochwald, 2008; Morgan et al., 2008). As people experience these negative emotions, they perceive their quality of life decreasing (Ferrell et al., 2005; Stanton et al, 2002; Wallace, 2003). Literature supports that being honest and writing about emotions associated with traumas may address and reverse these negative emotions and increase people's positive functioning (Fratarolli, 2006; Frisina, Borod, & Lepore, 2004; Pennebaker & Chung, 2007; Stanton et al, 2002).

This study will investigate if expressive writing makes a difference in those newly diagnosed with cancer with regards to their feelings of uncertainty and perceived quality of life. Participants will be recruited from local cancer treatment centers in Alabama. Each willing and eligible participant will fill out a consent form, demographic information sheet, Mishel's Uncertainty in Illness scale and Ferrans and Powers Quality of Life index, Cancer Version III. Participants will then be randomly placed into one of two groups: a control or an intervention group. Those in the control group will do nothing. Those in the intervention group will be asked to write at least twice a week during their three months in the study. At the end of the three months, participants in both groups will fill out the same tools as at the beginning, as well as an expressive writing information sheet. Journals will not be read or collected by the investigator. Data from the tools will be entered into a SPSS statistics program and will be analyzed through descriptive statistics and the statistical tests of repeated measure ANOVA, and Pearson's r correlations. The data will be included in the PI's master's thesis and possibly at some later date other scholarly papers or presentations. No personal identification will be included in the thesis, papers or presentations.

Expected outcomes include reported perceived increases in quality of life and decreases in uncertainty. Research findings will contribute to the growing body of literature on expressive writing, and may introduce nurses and physicians to a non-invasive, inexpensive and beneficial intervention which they can recommend to their patients.

9. **PURPOSE.**
   a. **Clearly state all of the objectives, goals, or aims of this project.**

The overall goal of this research project is to see if writing can affect uncertainty and perceived quality of life in those newly diagnosed with cancer. Specific questions which will be looked at during this study include:
1. Does expressive writing cause a difference in cancer patients' perceived level of uncertainty at time of treatment commencement and in the following three months?

2. Does expressive writing cause a difference in cancer patients regarding their perception of quality of life at time of treatment commencement and in the following three months?

3. Is there an association between increased perception of quality of life and decreased feelings of uncertainty between the group that did expressive writing and those who did not write at three months?

   b. **How will the results of this project be used? (e.g., Presentation? Publication? Thesis? Dissertation?)**

The results of this study will be used to complete the writing of a masters thesis. It is possible at some later date, that the data might also be written up in a publication or be part of a presentation. Regardless of how this data will be used, no identifiable data will be disclosed.

10a. **KEY PERSONNEL.** Describe responsibilities. Include information on research training or certifications related to this project. **CITI is required. Be as specific as possible.** (Attach extra page if needed.) *All non AU-affiliated key personnel must attach **CITI certificates of completion.***

Principle Investigator Naomi Crouse **Title:** RN, BSN **E-mail address** crousnl@auburn.edu
Dept / Affiliation: School of Nursing, Auburn University

Roles / Responsibilities:

Naomi Crouse is a graduate student and the principle investigator of this project. She was responsible for the literature review and research design. She will be meeting with the physicians, putting together the tool packets, interviewing potential participants, participating in all aspects of data collection and coding, and will eventually write up the data for a masters thesis and later possibly a publication or presentation.

Individual: Dr. Anita All **Title:** Professor/Advisor **E-mail address** aca0001@auburn.edu
Dept / Affiliation: Director and professor in School of Nursing, Auburn University

Roles / Responsibilities:

Dr. Anita All is the PI's thesis chair and will have an advisory role in this project.

Individual: _____ **Title:** _____ **E-mail address** _____
Dept / Affiliation: _____

Roles / Responsibilities:

Individual: _____ **Title:** _____ **E-mail address** _____
Dept / Affiliation: _____

Roles / Responsibilities:

Individual: _____ **Title:** _____ **E-mail address** _____
Dept / Affiliation: _____

Roles / Responsibilities:

Individual: _____ **Title:** _____ **E-mail address** _____
Dept / Affiliation: _____

Roles / Responsibilities:

11. **LOCATION OF RESEARCH. List all locations where data collection will take place.** (School systems, organizations, businesses, buildings and room numbers, servers for web surveys, etc.) **Be as specific as possible. Attach permission letters in Appendix E.**
(See sample letters at http://www.auburn.edu/research/vpr/ohs/sample.htm)

Data will initially be collected at the Cancer Center at East Alabama Medical Center and the Montgomery Cancer Center. The second set of tools will be completed by the participants at their homes.

12. PARTICIPANTS.

a. **Describe the participant population you have chosen for this project.**
(If data are existing, check here ☐ and describe the population from whom data were collected.)

According to the American Cancer Society (2009), approximately 24,000 people living in Alabama will be diagnosed with cancer this year. The most common cancer sites are breast, prostate, lung or bronchus, and colon or rectal (not including skin or in-situ cancers). This study is interested in recruiting patients from both the Cancer Center at East Alabama Medical Center and Montgomery Cancer Center who have been newly diagnosed with cancer and are just starting their treatment phase.

b. **Describe why is this participant population is appropriate for inclusion in this research project.** (Include criteria for selection.)

When a person is diagnosed with cancer, they experience a myriad of intense emotions. The negative emotions and the uncertainty which causes them can have a negative effect on a person both physically and psychologically. Literature suggests that having patients journal about their emotions can produce outcomes of positive health functioning (Stanton et al., 2002), decreased feelings of anxiety and depression (Kállay & Băban, 2008), and increased quality of life (Morgan, Graves, Poggi, & Cheson, 2008).
Inclusion criteria for this study include the person being over the age of 19, not pregnant or a prisoner, being within the first three weeks of chemotherapy or radiation treatment, and being able to complete a written or typed journal.

c. **Describe, step-by-step, all procedures you will use to recruit participants.** *Include in Appendix B a copy of all e-mails, flyers, advertisements, recruiting scripts, invitations, etc., that will be used to invite people to participate.*
(See sample documents at http://www.auburn.edu/research/vpr/ohs/sample.htm.)

Participants will be recruited from local cancer treatment centers in Alabama. On the day that the investigator is at their facility, each new patient seen that day by the physicians will receive a flyer about the study. Patients then have the option of stopping by and seeing the investigator or leaving. Those interested in the study and who meet the inclusion criteria will fill out a consent form, personal address sheet, demographic information sheet, Mishel's Uncertainty in Illness scale and Ferrans and Powers Quality of Life index, Cancer Version III. Participants will then be randomly placed into one of two groups: a control or an intervention group.

What is the minimum number of participants you need to validate the study? 60

Is there a limit on the number of participants you will recruit? ☑ **No** ☐ **Yes – the number is** _____

Is there a limit on the number of participants you will include in the study? ☑ **No** ☐ **Yes – the number is** _____

d. **Describe the type, amount and method of compensation and/or incentives for participants.**
(If no compensation will be given, check here ☐.)

Select the type of compensation: ☐ Monetary ☑ Incentives
☐ Raffle or Drawing incentive (Include the chances of winning.)
☐ Extra Credit (State the value)
☑ Other

Description:

Participants will all be offered a journal. Those in the intervention group will be offered one at the beginning of the study; those in the control group will be offered one which will be sent to them at the end of the study.

13. PROJECT DESIGN & METHODS.

a. Describe, step-by-step, all procedures and methods that will be used to consent participants.
(☐ Check here if this is "not applicable"; you are using existing data.)

Participants will be recruited from two local cancer treatment centers in Alabama. The PI will meet with physicians and other office personnel before beginning the recruitment process in order to explain the study and give them fliers to hand to the patients. On the day that the investigator is at their facility, each new patient seen that day by the physician will receive a flyer about the study. Patients then have the option of stopping by and seeing the investigator after their office visit or leaving. Those who are interested will meet with the PI and the PI will read through the recruitment script and answer any questions the participant might have. If the participant remains interested and meets the inclusion criteria, then the consent form will be signed and the other data forms filled out.

Careful consideration will be taken to protect the anonymity, when possible, and confidentiality of each participant. Prior to meeting with the patients, packets of information will be assembled. Included in these packets will be two consent forms (one for the patient to keep and one for the investigator), a personal address sheet, the demographic information sheet and the Quality of Life Index and Mishel's Uncertainty in Illness Scale-Community data tools. (At the Montgomery Cancer Center there will be three consents: one for the patient, one for their chart, one for the investigator, and then a copy will be made to be placed in the study binder.) On the packet itself and on each of the sheets within – except the consents – will be written a number. This number becomes the identifier of the participant in the study. As individuals agree to participate, they are assigned the next number in sequence. For instance, the first individual who agrees to participate will be given the packet with the number "one" on it. The second individual who agrees to participate will be given the packet with the number "two" on it, and so on. Those with an odd number will be assigned to the intervention group and even numbers will be assigned to the control group.

b. Describe the procedures you will use in order to address your purpose. Provide a step-by-step description of how you will carry out this research project. Include specific information about the participants' time and effort commitment. (*NOTE: Use language that would be understandable to someone who is not familiar with your area of study. Without a complete description of all procedures, the Auburn University IRB will not be able to review this protocol. If additional space is needed for this section, save the information as a .PDF file and insert after page 6 of this form.*)

Those in the control group will fill out a personal address sheet, demographic information sheet, Mishel's Uncertainty in Illness scale and Ferrans and Powers Quality of Life index, Cancer Version III when they enter the study. They will do nothing else until at the end of three months when they will be sent these same tools again plus the expressive writing information sheet. Tools will be returned to the PI in pre-addressed and stamped envelopes. If the tools aren't returned within two weeks, the PI will send a reminder postcard to that participant. Once the tools are returned, the PI will enter the second data set into the SPSS program, and send a journal to the participant.

Those in the intervention group will fill out a personal address sheet, demographic information sheet, Mishel's Uncertainty in Illness scale and Ferrans and Powers Quality of Life index, Cancer Version III when they enter the study. They will then be asked to write at least twice a week during their three months in the study. They will be given the following writing prompt which they can choose to follow or not. "Over the next three (months) I would like for you to write about your very deepest thoughts and feelings about an extremely important emotional issue that has affected you and your life. In your writing, I'd like you to really let go and explore your very deepest emotions and thoughts. You might tie your topic to your relationships with others, including parents, lovers, friends or relatives; to your past, your present, or your future; or to who you have been, who you would like to be, or who you are now. You may write about the same general issues or experiences on all days of writing or on different topics each day. All of your writing will be completely confidential. Don't worry about spelling, sentence structure or grammar." (Pennebaker, 2003, p. 362). Participants will be offered a journal in which to do their writing. At the end of the three months, they will fill out the original tools again, as well as an expressive writing information sheet. These will be returned to the PI in a pre-addressed and stamped envelope.

Data from the original tools will be entered into an SPSS program by the PI. At the three month mark for each participant, the PI will send a set of tools to the participant and have them fill them out and return them in pre-addressed and stamped envelopes. If the tools aren't returned within two weeks, the PI will send a reminder postcard to that participant. Once the tools are returned, the PI will enter the second data set into the SPSS program.

13c. List all data collection instruments used in this project, in the order they appear in Appendix C.
(e.g., surveys and questionnaires in the format that will be presented to participants, educational tests, data collection sheets, interview questions, audio/video taping methods etc.)

Personal address sheet
Demographic information sheet
Mishel's Uncertainty in Illness scale
Quality of Life index
Expressive writing information sheet
Writing instruction sheet
Postcard reminder

d. Data analysis: Explain how the data will be analyzed.
Data will be entered into SPSS version 17.0 software program. All tests will have a significance level set at $p<0.05$. Descriptive statistics including group means and standard deviations will be performed first on all tools and variables. Repeated measures ANOVA and Pearson's r correlations will also be performed.

14. RISKS & DISCOMFORTS: List and describe all of the risks that participants might encounter in this research. ***If you are using deception in this study, please justify the use of deception and be sure to attach a copy of the debriefing form you plan to use in Appendix D.*** *(Examples of possible risks are in section #6D on page 1.)*

There were no anticipated physical risks for the participants; however there is a risk of breach of confidentiality as well as some psychological risks including becoming emotional (crying) or very upset by stirred memories and associated emotions (Pennebaker, 2003). These were explained in the initial meeting and included on the consent form. Participants were warned of these potential risks and told that if the negative emotions lasted more than four weeks or got progressively worse, that it was recommended they seek professional help. A psychological referral plan based on the facility location will be given to each participant.

15. **PRECAUTIONS.** Identify and describe all precautions you have taken to eliminate or reduce risks as listed in #14. If the participants can be classified as a "vulnerable" population, please describe additional safeguards that you will use to assure the ethical treatment of these individuals. ***Provide a copy of any emergency plans/procedures and medical referral lists in Appendix D.***

Participants will be warned of the risks in the initial description of the study, and the risks will also be included in the consent form. A psychological referral plan based on the facility location will be given to each participant in the study.
Participants will be randomly placed into either the control group or the intervention group based on the order in which they sign up for the study. There will be a sheet of paper with consecutive numbers on it, starting with number "one". The first person who signs up will be given number "one", the second person to sign up will be assigned number "two" and so on. All odd numbers will be assigned to the intervention group; all even numbers will be assigned to the control group. The PI will be the only one with this coding list.

If using the Internet to collect data, what confidentiality or security precautions are in place to protect (or not collect) identifiable data? Include protections used during both the collection and transfer of data.
(These are likely listed on the server's website.)

N/A

16. **BENEFITS.**
    a. **List all realistic direct benefits participants can expect by participating in this specific study.**
    (Do not include "compensation" listed in #12e.) Check here if there are no direct benefits to participants. ☐

Potential benefits included an improved perception of quality of life and decreased feelings of uncertainty. They might experience more positive physical functioning and improved psychological health (Frattaroli, 2006).

    b. **List all realistic benefits for the general population that may be generated from this study.**

Results of this study will add to the literature on the benefits of expressive writing. Few studies have been done on a general cancer population, and very few have been done which specifically looked at the combination of uncertainty and quality of life. Additionally, if participants feel the writing has been beneficial to them, they might encourage others to write who are also going through a traumatic life situation.

17. PROTECTION OF DATA.

a. **Will data be collected as anonymous?** ☐ Yes ☑ No *If "YES", skip to part "g".*
("Anonymous" means that you will not collect any identifiable data.)

b. **Will data be collected as confidential?** ☑ Yes ☐ No
("Confidential" means that you will collect and protect identifiable data.)

c. **If data are collected as confidential, will the participants' data be coded or linked to identifying information?**
☑ Yes (If so, describe how linked.) ☐ No

Participants will sign two consent forms, one for the PI to keep, and the other for them to keep. The participant will also sign a personal address sheet which has their identifier number on it. This sheet will be kept by the PI. That same identifier number will be on both sets of tools which the participant fills out.

d. **Justify your need to code participants' data or link the data with identifying information.**

Identifier information – participants' names and addresses – is necessary in order to send them the tools to complete at the end of three months.

e. **Where will code lists be stored?** (Building, room number?)
Consent forms will be stored in Miller Hall in the faculty advisor's locked filing cabinet. Personal address sheets, the code list and completed tools will be kept by the PI in a locked filing cabinet in her office.

f. **Will data collected as "confidential" be recorded and analyzed as "anonymous"?** ☑ Yes ☐ No
(If you will maintain identifiable data, protections should have been described in #15.)

g. **Describe how and where the data will be stored** (e.g., hard copy, audio cassette, electronic data, etc.), **and how the location where data is stored will be secured in your absence. For electronic data, describe security. If applicable, state specifically where any IRB-approved and participant-signed consent documents will be kept on campus for 3 years after the study ends.**

PI will keep the code list, personal address sheets, completed data tools and demographic sheets in a locked filing cabinet in her office for the duration of the study. Once the study has ended, these forms will be transferred to the faculty advisor's office in Miller Hall.
The faculty advisor will keep the completed consent forms in a locked filing cabinet fin her office or the duration of the study.

All SPSS data will be stored on a USB storage device and backed up on CDROM. The USB storage device and back up CDs will be stored with the completed tools in the PI's locked filing cabinet. This data will not be able to be tied to any participant.

h. **Who will have access to participants' data?**
(The faculty advisor should have full access and be able to produce the data in the case of a federal or institutional audit.)

Dr. Anita All is the PI's faculty advisor and will have full access to all forms and data. The PI will have access to the code list, personal address sheets and consent forms (until they are given to the faculty advisor,) completed data tools and demographic sheets, and the entered data. The statistician will only see the entered data.

i. **When is the latest date that confidential data will be retained?** (Check here if only anonymous data will be retained. ☐)
The consent forms, data tools and demographic sheets will be kept for 5 years and then shredded. The address sheets and envelopes will be kept until the data has been analyzed and the thesis written and then they will be shredded. The SPSS data will be stored on a USB storage device and backed up on CDROMs. Five years after the conclusion of the study, the USB device and CDROMS will be physically destroyed.

j. **How will the confidential data be destroyed?** *(NOTE: Data recorded and analyzed as "anonymous" may be retained indefinitely.)*
A paper shredder will be used to shred all consent forms, data tools, demographic sheets, address sheets and return envelopes at the proper times. A hammer will be used to smash the USB device and CDROMs.

PROTOCOL REVIEW CHECKLIST

All protocols must include the following items:

1. ☑ Research Protocol Review Form (All signatures included and all sections completed)

FROM THIS SECTION ON, FOR FULL BOARD REVIEW,
PLEASE NUMBER YOUR APPENDICES CONSEQUETIVELY FROM THIS PAGE ON, BEGINNING WITH PAGE 11.

(Examples of appended documents are found on the OHSR website: http://www.auburn.edu/research/vpr/ohs/sample.htm)

2. ☑ **Consent Form or Information Letter** and any Releases (audio, video or photo) that the participant will sign.

3. ☑ **Appendix A**, "Reference List"

4. ☑ **Appendix B** if e-mails, flyers, advertisements, generalized announcements or scripts, etc., are used to recruit participants.

5. ☑ **Appendix C** if data collection sheets, surveys, tests, other recording instruments, interview scripts, etc. will be used for data collection. Be sure to attach them in the order in which they are listed in # 13c.

6. ☑ **Appendix D** if you will be using a debriefing form or include emergency plans/procedures and medical referral lists (A referral list may be attached to the consent document).

7. ☑ **Appendix E** if research is being conducted at sites other than Auburn University or in cooperation with other entities. A **permission letter** from the site / program director must be included indicating their cooperation or involvement in the project. NOTE: If the proposed research is a multi-site project, involving investigators or participants at other academic institutions, hospitals or private research organizations, a letter of **IRB approval** from each entity is required prior to initiating the project.

8. ☐ **Appendix F -** Written evidence of acceptance by the host country if research is conducted outside the United States.

APPENDIX D

STUDY FLIER

Expressive Writing Research Study

Be a part of an important study on how writing can affect your feelings of uncertainty and quality of life

Are you over the age of 19?

Are you able to complete a written or typed journal?

Are you newly diagnosed with cancer?

Have you just begun your treatment phase?

If you answered YES to these questions, you may be eligible to participate in this writing research study.

The purpose of this research study is to determine the effectiveness of writing at changing your feelings of uncertainty and perceived quality of life. Benefits include less distress, anxiety, anger and uncertainty, and an increased perception of quality of life. Risks include feeling sad or angry over past or present emotional issues. Participants will be offered a journal, and all writings will be kept private. The journal will not be asked for nor read by the investigator. This research study will last for three months.

This study is being conducted by Naomi Crouse, RN, BSN, at Auburn University, College of Nursing.

Please contact Naomi Crouse at crousnl@auburn.edu or 334-821-8618 for more information.

APPENDIX E

RECRUITMENT SCRIPT

RECRUITMENT SCRIPT

My name is Naomi Crouse, and I am a graduate student in the Department of Nursing at Auburn University. I would like to invite you to participate in my research study. I want to see if writing makes a difference in your feelings of uncertainty and perceived quality of life. You may participate if you are over 19, newly diagnosed with cancer, just starting your treatment phase, not pregnant or a prisoner, and able to complete a written or typed journal. Please do not participate if you do not meet the inclusion criteria, cannot give legal consent, and cannot speak or read English.

As a participant, you may be asked to write in a journal twice a week for three months. You will be asked to fill out three survey tools when you enter the study and again at the end of three months. I will not read any journals nor will I ask for them at the end of the study. The information gathered from the survey tools will be analyzed and written up in my master's thesis, and perhaps later in a publication or presentation. Nothing will be said or written that can be linked to you.

Risks of being in this study include experiencing emotional distress, sadness or anger as you write about emotional issues of your choice. Benefits may include feeling less uncertain and distressed, and perceiving a better quality of life. Compensation includes being given a journal, and there will be no costs encountered by you if you agree to participate.

If you would like to participate in this research study, please request a consent form and read through it.

Do you have any questions now? If you have questions later, please contact me at crousnl@auburn.edu or (334) 821-8618 or you may contact my advisor, Dr. Anita All, at (334) 844-6135 or aca0001@auburn.edu

APPENDIX F

EAST ALABAMA MEDICAL CENTER INFORMED CONSENT

AUBURN UNIVERSITY

SCHOOL OF NURSING

INFORMED CONSENT
for a Research Study entitled
"The Power of the Written Word"

You are invited to participate in a research study to investigate if expressive writing affects feelings of uncertainty and perceived quality of life in those newly diagnosed with cancer. The study is being conducted by Naomi Crouse, under the direction of Dr. Anita All, director of the masters program and professor in the Auburn University Department of Nursing. You were selected as a possible participant because you are newly diagnosed with cancer, just starting your treatment phase, able to complete a written or typed journal, are age 19 or older, and are receiving treatment at the East Alabama Cancer Center.

What will be involved if you participate? If you decide to participate in this research study, you may be assigned to a journal-writing group or to a group that will not be asked to write in a journal. Those who are assigned to write in a journal will be asked to write a minimum of twice a week for the next three months. Your total time commitment will be approximately three months. The investigator will never read your journal and the journals will not be collected at the end of the study.

Are there any risks or discomforts? The risks associated with participating in this study include emotional distress caused by writing about past or present emotional issues. If negative emotions last more than four weeks or get progressively worse, it is recommended you seek professional help. You are responsible for any costs associated with medical treatment. A psychological referral list will be provided when entering this study.

Are there any benefits to yourself or others? If you participate in this study, you can expect to potentially experience decreased uncertainty, depression and anxiety, and improved perceived quality of life. We/I cannot promise you that you will receive any or all of the benefits described.

Will you receive compensation for participating? To thank you for your time you will be offered a journal. Those who are to journal for the next three months will receive it when they enter the study; those who are not writing will receive the journal at the end of the three months.

Participant's initials _____

107 Miller Hall, Auburn, AL 36849-5505; Telephone: 334-844-5665; Fax: 334-844-4177
w w w . a u b u r n . e d u

If you change your mind about participating, you can withdraw at any time during the study. Your participation is completely voluntary. If you choose to withdraw, your data can be withdrawn as long as it is identifiable. Your decision about whether or not to participate or to stop participating will not jeopardize your future relations with Auburn University, the School of Nursing, or the East Alabama Cancer Center.

Your privacy will be protected. Any information obtained in connection with this study will remain confidential. Completed questionnaires and personal information will be kept in a locked filing cabinet. Information obtained through your participation will be used to write a master's thesis and possibly later an article to be published in a professional journal. No personal identification will be included in the thesis or journal article.

If you have questions about this study, *please ask them now or* contact Naomi Crouse at (334) 821-8618, Dr. Anita All at (334) 844-6135 or Dr. Michael Lisenby at (334) 528-1326. A copy of this document will be given to you to keep.

If you have questions about your rights as a research participant, you may contact the Auburn University Office of Human Subjects Research or the Institutional Review Board by phone (334) 844-5966 or e-mail at hsubjec@auburn.edu or IRBChair@auburn.edu.

HAVING READ THE INFORMATION PROVIDED, YOU MUST DECIDE WHETHER OR NOT YOU WISH TO PARTICIPATE IN THIS RESEARCH STUDY. YOUR SIGNATURE INDICATES YOUR WILLINGNESS TO PARTICIPATE.

_____		_____	
Participant's signature	Date	Investigator obtaining consent	Date
_____		_____	
Printed Name		Printed Name	

The Auburn University
Institutional Review Board
has approved this document for use
from 9/28/09 to 9/27/10.
Protocol # 09-349 EP 0909

APPENDIX G

MONTGOMERY CANCER CENTER INFORMED CONSENT

AUBURN UNIVERSITY

SCHOOL OF NURSING

INFORMED CONSENT
for a Research Study entitled
"The Power of the Written Word"

You are invited to participate in a research study to investigate if expressive writing affects feelings of uncertainty and perceived quality of life in those newly diagnosed with cancer. The study is being conducted by Naomi Crouse, under the direction of Dr. Anita All, director of the masters program and professor in the Auburn University Department of Nursing. You were selected as a possible participant because you are newly diagnosed with cancer, just starting your treatment phase, able to complete a written or typed journal, are age 19 or older, and are receiving treatment at the Montgomery Cancer Center.

What will be involved if you participate? If you decide to participate in this research study you may be assigned to a journal writing group or to a group that will not be asked to write in a journal. Those who are assigned to write in a journal will be asked to write a minimum of twice a week for the next three months. Your total time commitment will be approximately three months. The investigator will never read your journal and the journals will not be collected at the end of the study.

Are there any risks or discomforts? The risks associated with participating in this study include emotional distress caused by writing about past or present emotional issues. If negative emotions last more than four weeks or get progressively worse, it is recommended you seek professional help. You are responsible for any costs associated with medical treatment. A psychological referral list will be provided when entering this study.

Are there any benefits to yourself or others? If you participate in this study, you can expect to potentially experience decreased uncertainty, depression and anxiety, and improved perceived quality of life. We/I cannot promise you that you will receive any or all of the benefits described.

Will you receive compensation for participating? To thank you for your time you will be offered a journal. Those who are to journal for the next three months will receive it when they enter the study; those who are not writing will receive the journal at the end of the three months.

Participant's initials _____ Page 1 of 2

107 Miller Hall, Auburn, AL 36849-5505; Telephone: 334-844-5665; Fax: 334-844-4177
www.auburn.edu

If you change your mind about participating, you can withdraw at any time during the study. Your participation is completely voluntary. If you choose to withdraw, your data can be withdrawn as long as it is identifiable. Your decision about whether or not to participate or to stop participating will not jeopardize your future relations with Auburn University, the School of Nursing, or the Montgomery Cancer Center.

Your privacy will be protected. Any information obtained in connection with this study will remain confidential. Completed questionnaires and personal information will be kept in a locked filing cabinet. Information obtained through your participation will be used to write a master's thesis and possibly later an article to be published in a professional journal. No personal identification will be included in the thesis or journal article.

If you have questions about this study, *please ask them now or* contact Naomi Crouse at (334) 821-8618, Dr. Anita All at (334) 844-6135 or Dr. Stephen Davidson at (334) 273-7000. A copy of this document will be given to you to keep.

If you have questions about your rights as a research participant, you may contact the Auburn University Office of Human Subjects Research or the Institutional Review Board by phone (334) 844-5966 or e-mail at hsubjec@auburn.edu or IRBChair@auburn.edu.

HAVING READ THE INFORMATION PROVIDED, YOU MUST DECIDE WHETHER OR NOT YOU WISH TO PARTICIPATE IN THIS RESEARCH STUDY. YOUR SIGNATURE INDICATES YOUR WILLINGNESS TO PARTICIPATE.

Participant's signature	Printed Name	Date
Investigator obtaining consent	Printed Name	Date
Montgomery Cancer Center	Printed Name	Date

The Auburn University
Institutional Review Board
has approved this document for use
from 9/28/09 to 9/27/10
Protocol # 09-249 EP 0909

APPENDIX H

PERSONAL ADDRESS SHEET

AUBURN UNIVERSITY

SCHOOL OF NURSING

"The Power of the Written Word"

Personal Address Sheet

_____

_____

_____

_____

_____

Personal Identifier #_____

107 Miller Hall, Auburn, AL 36849-5505; Telephone: 334-844-5665; Fax: 334-844-4177

www.auburn.edu

APPENDIX I

DEMOGRAPHIC SURVEY

AUBURN UNIVERSITY

SCHOOL OF NURSING

"The Power of the Written Word"

Demographic survey

Please answer each question and circle that answer which most closely resembles you.

What is your age? 18-30 31-45 46-60 61-75 76-90 90+

What is your gender? Male Female

What is your marital status? Single Married Divorced Widowed Separated

What is your race? Asian African American Hispanic Caucasian other_____

What is your highest level of education? 0-6 yrs 7-12 yrs 13-16 yrs 17+ yrs

Primary employment status? Full time Part time not employed

Cancer first major illness? Yes No

Cancer type: Breast Prostate Lung/Bronchus Colon/Rectal Other_____

Do you normally journal? Yes No

107 Miller Hall, Auburn, AL 36849-5505; Telephone: 334-844-5665; Fax: 334-844-4177

www.auburn.edu

APPENDIX J

MISHEL UNCERTAINTY IN ILLNESS SCALE – COMMUNITY FORM

MISHEL UNCERTAINTY IN ILLNESS SCALE – COMMUNITY FORM

INSTRUCTIONS:

Please read each statement. Take your time and think about what each statement says. Then place a "X" under the column that most closely measures how you are feeling TODAY. If you agree with a statement, then you would mark under either "Strongly Agree" or "Agree". If you disagree with a statement, then mark under either "Strongly Disagree" or "Disagree". If you are undecided about how you feel, then mark under "Undecided" for that statement. Please respond to every statement.

1. I don't know what is wrong with me.

Strongly Agree (5)	Agree (4)	Undecided (3)	Disagree (2)	Strongly Disagree (1)
_____	_____	_____	_____	_____

2. I have a lot of questions without answers.

Strongly Agree (5)	Agree (4)	Undecided (3)	Disagree (2)	Strongly Disagree (1)
_____	_____	_____	_____	_____

3. I am unsure if my illness is getting better or worse.

Strongly Agree (5)	Agree (4)	Undecided (3)	Disagree (2)	Strongly Disagree (1)
_____	_____	_____	_____	_____

4. It is unclear how bad my pain will be.

Strongly Agree (5)	Agree (4)	Undecided (3)	Disagree (2)	Strongly Disagree (1)
_____	_____	_____	_____	_____

5. The explanations they give about my condition seem hazy to me.

Strongly Agree (5)	Agree (4)	Undecided (3)	Disagree (2)	Strongly Disagree (1)
_____	_____	_____	_____	_____

6. The purpose of each treatment is clear to me.

Strongly Agree (5)	Agree (4)	Undecided (3)	Disagree (2)	Strongly Disagree (1)
_____	_____	_____	_____	_____

7. My symptoms continue to change unpredictably.

Strongly Agree (5)	Agree (4)	Undecided (3)	Disagree (2)	Strongly Disagree (1)
_____	_____	_____	_____	_____

8. I understand everything explained to me.

Strongly Agree (5)	Agree (4)	Undecided (3)	Disagree (2)	Strongly Disagree (1)
_____	_____	_____	_____	_____

9. The doctors say things to me that could have many meanings.

Strongly Agree (5)	Agree (4)	Undecided (3)	Disagree (2)	Strongly Disagree (1)
_____	_____	_____	_____	_____

10. My treatment is too complex to figure out.

Strongly Agree (5)	Agree (4)	Undecided (3)	Disagree (2)	Strongly Disagree (1)
_____	_____	_____	_____	_____

11. It is difficult to know if the treatments or medications I am getting are helping.

Strongly Agree (5)	Agree (4)	Undecided (3)	Disagree (2)	Strongly Disagree (1)
_____	_____	_____	_____	_____

12. Because of the unpredictability of my illness, I cannot plan for the future.

Strongly Agree (5)	Agree (4)	Undecided (3)	Disagree (2)	Strongly Disagree (1)
_____	_____	_____	_____	_____

13. The course of my illness keeps changing. I have good and bad days.

Strongly Agree (5)	Agree (4)	Undecided (3)	Disagree (2)	Strongly Disagree (1)
_____	_____	_____	_____	_____

14. I have been given many differing opinions about what is wrong with me.

Strongly Agree (5)	Agree (4)	Undecided (3)	Disagree (2)	Strongly Disagree (1)
_____	_____	_____	_____	_____

15. It is not clear what is going to happen to me.

Strongly Agree (5)	Agree (4)	Undecided (3)	Disagree (2)	Strongly Disagree (1)
_____	_____	_____	_____	_____

16. The results of my tests are inconsistent.

Strongly Agree (5)	Agree (4)	Undecided (3)	Disagree (2)	Strongly Disagree (1)
_____	_____	_____	_____	_____

17. The effectiveness of the treatment is undetermined.

Strongly Agree (5)	Agree (4)	Undecided (3)	Disagree (2)	Strongly Disagree (1)
_____	_____	_____	_____	_____

18. Because of the treatment, what I can do and cannot do keeps changing.

Strongly Agree (5)	Agree (4)	Undecided (3)	Disagree (2)	Strongly Disagree (1)
_____	_____	_____	_____	_____

19. I'm certain they will not find anything else wrong with me.

Strongly Agree (5)	Agree (4)	Undecided (3)	Disagree (2)	Strongly Disagree (1)
_____	_____	_____	_____	_____

20. The treatment I am receiving has a known probability of success.

Strongly Agree (5)	Agree (4)	Undecided (3)	Disagree (2)	Strongly Disagree (1)
_____	_____	_____	_____	_____

21. They have not given me a specific diagnosis.

Strongly Agree (5)	Agree (4)	Undecided (3)	Disagree (2)	Strongly Disagree (1)
_____	_____	_____	_____	_____

22. The seriousness of my illness has been determined.

Strongly Agree (5)	Agree (4)	Undecided (3)	Disagree (2)	Strongly Disagree (1)
_____	_____	_____	_____	_____

23. The doctors and nurses use everyday language so I can understand what they are saying.

Strongly Agree (5)	Agree (4)	Undecided (3)	Disagree (2)	Strongly Disagree (1)
_____	_____	_____	_____	_____

APPENDIX K

FERRANS AND POWERS QUALITY OF LIFE INDEX – CANCER VERSION III

Ferrans and Powers
QUALITY OF LIFE INDEX©
CANCER VERSION - III

PART 1. For each of the following, please choose the answer that best describes how ***satisfied*** you are with that area of your life. Please mark your answer by circling the number. There are no right or wrong answers.

HOW *SATISFIED* ARE YOU WITH:	Very Dissatisfied	Moderately Dissatisfied	Slightly Dissatisfied	Slightly Satisfied	Moderately Satisfied	Very Satisfied
1. Your health?	1	2	3	4	5	6
2. Your health care?	1	2	3	4	5	6
3. The amount of pain that you have?	1	2	3	4	5	6
4. The amount of energy you have for everyday activities?	1	2	3	4	5	6
5. Your ability to take care of yourself without help?	1	2	3	4	5	6
6. The amount of control you have over your life?	1	2	3	4	5	6
7. Your chances of living as long as you would like?	1	2	3	4	5	6
8. Your family's health?	1	2	3	4	5	6
9. Your children?	1	2	3	4	5	6
10. Your family's happiness?	1	2	3	4	5	6
11. Your sex life?	1	2	3	4	5	6
12. Your spouse, lover, or partner?	1	2	3	4	5	6
13. Your friends?	1	2	3	4	5	6
14. The emotional support you get from your family?	1	2	3	4	5	6
15. The emotional support you get from people other than your family?	1	2	3	4	5	6

(Please Go To Next Page)

HOW *SATISFIED* ARE YOU WITH:	Very Dissatisfied	Moderately Dissatisfied	Slightly Dissatisfied	Slightly Satisfied	Moderately Satisfied	Very Satisfied
16. Your ability to take care of family responsibilities?	1	2	3	4	5	6
17. How useful you are to others?	1	2	3	4	5	6
18. The amount of worries in your life?	1	2	3	4	5	6
19. Your neighborhood?	1	2	3	4	5	6
20. Your home, apartment, or place where you live?	1	2	3	4	5	6
21. Your job (if employed)?	1	2	3	4	5	6
22. Not having a job (if unemployed, retired, or disabled)?	1	2	3	4	5	6
23. Your education?	1	2	3	4	5	6
24. How well you can take care of your financial needs?	1	2	3	4	5	6
25. The things you do for fun?	1	2	3	4	5	6
26. Your chances for a happy future?	1	2	3	4	5	6
27. Your peace of mind?	1	2	3	4	5	6
28. Your faith in God?	1	2	3	4	5	6
29. Your achievement of personal goals?	1	2	3	4	5	6
30. Your happiness in general?	1	2	3	4	5	6
31. Your life in general?	1	2	3	4	5	6
32. Your personal appearance?	1	2	3	4	5	6
33. Yourself in general?	1	2	3	4	5	6

(Please Go To Next Page)

PART 2. For each of the following, please choose the answer that best describes how ***important*** that area of your life is to you. Please mark your answer by circling the number. There are no right or wrong answers.

HOW *IMPORTANT* TO YOU IS:	Very Unimportant	Moderately Unimportant	Slightly Unimportant	Slightly Important	Moderately Important	Very Important
1. Your health?	1	2	3	4	5	6
2. Your health care?	1	2	3	4	5	6
3. Having no pain?	1	2	3	4	5	6
4. Having enough energy for everyday activities?	1	2	3	4	5	6
5. Taking care of yourself without help?	1	2	3	4	5	6
6. Having control over your life?	1	2	3	4	5	6
7. Living as long as you would like?	1	2	3	4	5	6
8. Your family's health?	1	2	3	4	5	6
9. Your children?	1	2	3	4	5	6
10. Your family's happiness?	1	2	3	4	5	6
11. Your sex life?	1	2	3	4	5	6
12. Your spouse, lover, or partner?	1	2	3	4	5	6
13. Your friends?	1	2	3	4	5	6
14. The emotional support you get from your family?	1	2	3	4	5	6
15. The emotional support you get from people other than your family?	1	2	3	4	5	6

(Please Go To Next Page)

HOW *IMPORTANT* TO YOU IS:	Very Unimportant	Moderately Unimportant	Slightly Unimportant	Slightly Important	Moderately Important	Very Important
16. Taking care of family responsibilities?	1	2	3	4	5	6
17. Being useful to others?	1	2	3	4	5	6
18. Having no worries?	1	2	3	4	5	6
19. Your neighborhood?	1	2	3	4	5	6
20. Your home, apartment, or place where you live?	1	2	3	4	5	6
21. Your job (if employed)?	1	2	3	4	5	6
22. Having a job (if unemployed, retired, or disabled)?	1	2	3	4	5	6
23. Your education?	1	2	3	4	5	6
24. Being able to take care of your financial needs?	1	2	3	4	5	6
25. Doing things for fun?	1	2	3	4	5	6
26. Having a happy future?	1	2	3	4	5	6
27. Peace of mind?	1	2	3	4	5	6
28. Your faith in God?	1	2	3	4	5	6
29. Achieving your personal goals?	1	2	3	4	5	6
30. Your happiness in general?	1	2	3	4	5	6
31. Being satisfied with life?	1	2	3	4	5	6
32. Your personal appearance?	1	2	3	4	5	6
33. Are you to yourself?	1	2	3	4	5	6

APPENDIX L

WRITING INFORMATION SHEET

"The Power of the Written Word"

Writing Instruction Sheet

Please write at least twice a week. The length of time spent writing is up to you.

You can write about anything positive or negative, just make sure you include honest thoughts and emotions. The following is a writing prompt which might help you start out your writing.

> "Over the next three months I would like for you to write about your very deepest thoughts and feelings about an extremely important emotional issue that has affected you and your life. In your writing, I'd like you to really let go and explore your very deepest emotions and thoughts. You might tie your topic to your relationships with others, including parents, lovers, friends or relatives; to your past, your present, or your future; or to who you have been, who you would like to be, or who you are now. You may write about the same general issues or experiences on all days of writing or on different topics each day. All of your writing will be completely confidential. Don't worry about spelling, sentence structure or grammar" (Pennebaker, 2003, p. 362).

These journals will not be read nor collected at the end of the study. They are yours to keep.

APPENDIX M

AUBURN PSYCHOLOGICAL REFERRAL LIST

"The Power of the Written Word"

Auburn Psychological Referral List

Auburn University Psychological Services Center
1122 Haley Center, Auburn University
Call for appointment: 334-844-4889

Auburn University Student Counseling Center
2086 Medical Clinic, Auburn University
Call for appointment: 334-844-5123

Wellspring Counseling Center
2813 Pepperell Parkway, Opelika, AL
Call for appointment: 334-741-8007

Auburn/Opelika Psychology Clinic
2127 Executive Park Dr., Opelika, AL
Call for appointment: 334-742-9555

The Pastoral Care and Counseling Center
1922 Professional Circle, Auburn, AL
Call for appointment: 334-501-7829

Clinical Psychologists PC
248 E. Glenn Ave., Auburn, AL
Call for appointment: 334-821-3350

For Emergencies:
East Alabama Mental Health Center
2300 Center Hills Dr., Opelika, AL
Call 334-742-2877

Crisis Center
Call 334-821-8600

APPENDIX N

MONTGOMERY PSYCHOLOGICAL REFERRAL LIST

"The Power of the Written Word"

Montgomery Psychological Referral List

AUM Student Counseling Center
319 Taylor Center, Auburn University Montgomery
Call for appointment: 334-244-3469

Samaritan Counseling Center, Inc
2911 Zelda Rd., Montgomery, AL
Call for appointment: 334-262-7787

Montgomery Psychology
1736 Taliaferro Trail, Montgomery, AL
Call for appointment: 334-270-9000

Lighthouse Counseling
3580 McGehee Place Drive South, Montgomery, AL
check phone book or call office for other locations
Call for appointment: 334-284-6416

Frazer Counseling Clinic
6000 Atlanta Highway, Montgomery, AL
Call for appointment: 334-272-8622

APPENDIX O

EXPRESSIVE WRITING INFORMATION SHEET

AUBURN UNIVERSITY

SCHOOL OF NURSING

"The Power of the Written Word"

Expressive Writing Information Sheet

Please answer each question and circle that answer which most closely resembles your writing experience

Did you do any expressive writing? Yes No

How many times a week? 1-2 3-4 5-6 7+

Did it help you feel differently? Yes No

Additional comments:

107 Miller Hall, Auburn, AL 36849-5505; Telephone: 334-844-5665; Fax: 334-844-4177

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