AFTER BREAST CANCER DIAGNOSIS: MEANING PROCESSES, QUALITY OF LIFE, AND HEALTH IN THE CONTEXT OF ONLINE INTERVENTIONS

by

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ABSTRACT

AFTER BREAST CANCER DIAGNOSIS: MEANING PROCESSES, QUALITY OF LIFE, AND HEALTH IN THE CONTEXT OF ONLINE INTERVENTIONS

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This study explores meaning processes in the wake of a women's diagnosis of breast cancer and in the context of an online psychosocial intervention developed to help patients cope with the illness. Meaning processes have been identified as a critical element of weathering the difficult and often traumatic illness of breast cancer. A review of the literature identified four constructs necessary to facilitate an integrative process of meaning. These constructs are explicitly found in the Comprehensive Health Enhancement Support System (CHESS), an online psychosocial intervention developed for use by women newly-diagnosed with breast cancer. Narrative and quantitative survey data from CHESS research were used to examine the meaning process in the context of breast cancer.

Inductive methodology based on grounded theory was used to explore the qualitative data collected from women with breast cancer using either CHESS or the Internet alone who were asked to describe how they've been changed by their illness experience. Quantitative analyses of group differences in meaning outcomes and their relationship to demographic information, health outcomes, and quality of life measures were conducted. Results inform a more comprehensive understanding of the process of meaning during illness and its integration with quality of life. Implications of the facilitation of meaning processes to enhance well-being via the use of online interventions are discussed. Possible directions for future development and use of such interventions are explored.

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This study examined the process of meaning in the wake of a woman's diagnosis of breast cancer and in the context of an online psychosocial intervention developed to help a woman cope with the illness. Meaning processes have been identified as a critical element of weathering the difficult and often traumatic illness of breast cancer. A review of the literature identified four constructs necessary to facilitate an integrative process of meaning. These constructs are explicitly found in the Comprehensive Health Enhancement Support System (CHESS), an online psychosocial intervention developed for use by women newly-diagnosed with breast cancer. Narrative data from CHESS research provided an opportunity to examine the meaning process in the context of an intervention designed to help women cope with the illness.

This study analyzed both qualitative and quantitative survey data collected from women with breast cancer who participated in a randomized control trial testing the CHESS intervention against an "Internet only" control. Participants described how they'd been changed by their illness experience 4 months after inclusion in the study (and 4 to 6 months post-diagnosis). Quantitative analyses were used to detect group differences in meaning outcomes and their relationship to demographic information, health outcomes, and quality of life. Qualitative analyses of open-ended responses were conducted using inductive methodology based on grounded theory. A more comprehensive understanding of the meaning process during illness and its correlation with quality of life and breast cancer outcomes further refines our understanding of the interconnection of meaning processes and health during illness; and provides direction for development of interventions specifically designed to facilitate meaning, thus mitigating traumatic stress for millions of women with the illness.

The Psychological Impact of a Breast Cancer Diagnosis

Breast cancer is a chronic, unpredictable, and potentially fatal illness. Being diagnosed with the disease is a stunning and frightening experience (Cordova et al., 1995), yet, sadly, one out of every 8 women in the U.S. will be told they have the illness this year (American Cancer Foundation, 2008). Clinically, it is defined as a traumatic event capable of eliciting symptoms consistent with cancer-related acute stress disorder (ASD), and, if symptoms persist, with cancer-related posttraumatic stress disorder (PTSD) (Alter et al., 1996; Cordova et al., 1995; Green et al., 1998; Kangas, Henry & Bryant, 2005). It is estimated that 22% to 50% of patients with breast cancer meet criteria for a psychiatric diagnosis of depression (Morris, Greer & White, 1977; Lasry et al., 1987); 3% to 19% meet criteria for posttraumatic stress disorder (Alter et al., 1996; Andrykowski, Cordova, Studts, & Miller, 1998; Cordova et al., 1995; Green et al., 1998; Jacobson et al., 1998); and 33% meet criteria for acute stress disorder (McGarvey et al., 1998).

Traumatic stress symptoms of breast cancer are associated with the patient's *perception of threat* to life (Cordova, Cunningham, Carlson & Andrykowski, 2001), and include dissociation, recurrent and intrusive thoughts, avoidance behavior, numbing, and increased arousal. Xuereb & Dunlop (2003) found that patients with cancer undergoing bone marrow transplant described the possibility of death in terms of a threat to the most cherished aspects of their life. At diagnosis in particular, they perceived a *threat* to the people and activities they held most dear.

Inherent in the descriptions of traumatic stress disorders is the assumption that a complex interplay of biopsychosocial forces can overwhelm one's adaptive capacity and contribute to the development of psychopathology (Briere, 1997; van der Kolk, McFarlane, & Weisaith, 1996; Wilson & Raphael, 1993). Recognizing the traumatogenic nature specific to illness has been a recent development, marked by its inclusion in the diagnostic criteria of PTSD in the DSM-IV (American Psychiatric Association, 1994; Baum & Posluszny, 2001; Green, Epstein Krupnick & Rowland, 1997).

Persons struggling with PTSD oscillate between avoidance of the event's emotional impact and the intrusion, or re-experiencing, of the emotional response to it (American Psychiatric Association, 2000). The failure to resolve or integrate traumatic experience is associated with persistent symptoms, which are diagnosed as a stress disorder when they meet specified criteria. Trauma is defined in the DSM-IV-TR as experiencing, witnessing, or learning about an event that involves either actual or threatened death or severe injury (criterion A1) when the individual responds with intense fear, helplessness, or horror (criterion A2). The DSM-IV-TR provides a list of PTSD stressors which includes life-threatening illness. Symptoms cluster in three general areas:

> *Re-experiencing/intrusion*: (i.e., nightmares, flashbacks, intrusive thoughts, emotions, or images) (criterion B);
>
> *Avoidance/numbing:* (i.e., detachment, restricted affect, and avoidance of reminder thoughts and activities) (criterion C); and
>
> *Hyperarousal:* (i.e., hypervigilance, decreased concentration, increased startle response, insomnia, and irritability) (criterion D).

Symptoms that persist from 2 days to one month after a traumatic event and that cause significant distress may meet DSM-IV-TR criteria for an acute stress disorder (ASD). ASD often precedes the development of PTSD (Koopman et al., 1995), which is then diagnosed when symptoms persist beyond one month. However, ASD and PTSD may represent only a portion of the distress spectrum from traumatic events. Subthreshold PTSD or adjustment disorders (Rothbaum & Foa, 1993; Schutzwohl & Maercker, 1999; Stein et al., 1997) have also been associated with significant social and physical impairment (Carlier & Gersons, 1995; Weiss et al., 1992) and are likely to be more common than full stress disorders in nonpsychiatric populations.

An illness such as cancer has the potential to overwhelm ordinary adaptive capacities (Baum & Posluszny, 2001; Herman, 1992). The risk, diagnosis, treatment, progression, and recurrence of cancer may constitute profoundly stressful events (Van't Spijkey, Trijsburg & Duivenvoorden, 1997; Xuereb & Dunlop, 2003). The threat to life and bodily integrity is often considerable, and the experience of disfiguration, disability, pain, and loss of social and occupational roles can trigger overwhelming feelings (Alter et al., 1996; Cordova, Andrykowski et al. 1995). *The perceived lack of control* imposed by the illness and the suddenness of the diagnosis may trigger intense fear, helplessness, or terror (Green, Epstein, Krupnick, & Rowland, 1997; Xuereb & Dunlop, 2003). Persons with prior exposure to traumatic events often regard cancer as the worst trauma experienced (Alter et al., 1996). Although in many respects the trauma of cancer resembles that of other traumatic stressors, it is distinct in that the threat is chronic, unpredictable, and emanates from within the body, rather than from an outside aggressor.

The stress of the illness is similar to the ongoing nature of threat found during war, family violence, and incest. Although the definition of posttraumatic stress is the persistence of the stress response beyond the termination of the stressor (Baum, O'Keeffe, & Davidson, 1990), in the case of cancer, it is difficult to determine when the illness "stops" versus a new (as in cancer recurrence) or ongoing threat (as in fear of recurrence). The cumulative response to such experiences may be qualitatively and quantitatively different from those that occur after more specific, time-limited events (Green, Epstein, Krupnick & Rowland, 1997). Triggers for such responses may include diagnosis, treatment procedures, witnessing the deteriorating health of other patients, psychoeducational interventions, or even routine follow-up that continually reminds one of vulnerability. Cancer recurrence may be even more traumatic than its initial presentation (Cella, Mahon, & Donovan, 1990), as the entire cycle repeats. These cumulative effects may have a significant adverse effect on later psychological functioning (Alonzo, 2000; Green et al., 2000; Turner & Lloyd, 1995).

In addition to its continual presence, breast cancer is characterized also by its unpredictability of long periods of remission punctuated with acute illness while the possibility of death lingers throughout the course of the disease (Green, Epstein, Krupnick, & Rowland, 1997). Waiting for the results of diagnostic testing has been cited as one of the most stressful periods of the cancer experience (Green et al., 1998), and breast cancer survivors are likely to remain vigilant throughout their lives for possible recurrence.

In contrast to the threat from perpetrators of sexual and physical assault, the threat from cancer originates from within one's own body, and often from unknown causes (Green, Epstein, Krupnick & Rowland, 1997). This physiological "betrayal" may affect one's perception of the threat, including its perceived inescapability. Likewise, one may be continually reminded of the illness by bodily signs or symptoms of cancer, such as surgical scars, breast pain, or physical limitations imposed by the illness. The internal, unpredictable, and often progressive nature of cancer may account for some of the overwhelming distress associated with it.

The Significance of Meaning after Breast Cancer Diagnosis

Persons newly diagnosed with cancer struggle to understand what it means to them: why they have the illness; what options they have to affect its outcome; what it means for their family, friends, work; whether they will suffer; whether they have any control over the process; what is a quality life, and whether they will be able to maintain it; whether they will survive, and whether they are prepared for death (Ryff & Singer, 2003a; Xuereb & Dunlop, 2003)? Cancer's impact is felt on all aspects of one's life, inseparable from one's core values and from what one finds meaningful. It is so "deeply embedded both in ideas and feelings about threat to physical life, and in the significance of people, events, and circumstances that comprise this life, that any subsequent action taken in relation to the illness involves all these dimensions" (Xuereb & Dunlop, 2003, p. 406).

Although cancer type, stage of cancer, and proximity to treatment have been used to define the physical illness, these *objective* disease indicators may not reflect *the subjective experience of life threat or the interpersonal meaning of cancer.* This may account for the lack of association between treatment intensity and stress responses in some studies (Green et al., 2000; Gurevich, Devins, & Rodin, 2002; Mundy et al., 2000). In fact, higher traumatic stress scores have been correlated to *high perceived life threat*, *low illness meaning*, and high perceived treatment intensity in female cancer patients (Hampton & Frombach, 2000). Global meaning, defined as one's existential belief system, has also been found to moderate the relationship between intrusive thoughts and psychological distress in both breast cancer survivors 2–15 years postdiagnosis (Vickberg, Bovbjerg, et al., 2000), and in leukemia patients who had undergone bone marrow transplantation (Vickberg, DuHamel et al., 2001).

Coping is facilitated by one's ability to integrate the process with meaningful aspects of one's life (Taylor, 1983; Taylor, Kemeny, Reed, Bower & Gruenewald, 2000). For a woman with breast cancer, the process of finding positive meaning becomes an ally, helping her cope with the unpredictability of the illness. It provides direction and focus as she navigates her way through the myriad treatment options and other distressing issues associated with the experience, such as pain and bodily disfigurement, disruption of employment, insurance challenges, the strain on family, and isolation from friends (Davis, Nolen-Hoeksema & Larson, 1998; Folkman, 1999; Xuereb & Dunlop, 2003).

Taylor (1983) found in her study of women with advanced breast cancer that a person's ability to find *any* meaning in the experience was crucial for their well-being: the ability to find meaning predicted better social, emotional, and occupational adjustment in the face of adversity. An individual's ability to find meaning is significantly associated with lower distress, greater self-esteem, and better adjustment (Coward, 1991; Fife, 1995; Lewis, 1989), while the inability to find meaning in a traumatic experience has been linked to poorer outcomes (Curbow, Somerfield, et al., 1993).

There is mounting evidence that positive psychological well-being during illness is tied to better health outcomes (Taylor, 2000). The process of meaning, as a construct, has been variously referred to throughout the literature as "benefit-finding", "making sense", or "meaning-based coping". Bower, Kemeny, Taylor, & Fahey (1998) also defined it as a major shift in values, priorities, or perspective in response to loss. Despite the variations of definition, the process may be considered an active and dynamic construct (i.e., "finding", "making", "coping", "shifting") and has been correlated with improved health outcomes and positive psychological well-being. There are theoretical bases for what may facilitate the process of meaning, and there is mounting evidence supporting this mechanism. However, what this study will explore, at a personal level, in what way meaning matters for health. What is salient to a woman as she navigates through the illness process? Does the dynamic cognitive process of meaning sustain perceptions of quality of life and the physical correlates of health? Can an intervention affect these interactions?

This study was designed to explore these questions. First, a review of the theoretical bases for why meaning *should* matter for health is presented, followed by an examination of the evidence for what facilitates the process of meaning *in practice*. Guided by this evidence and assisted by new technology, this study attempts to understand more deeply the interconnection between meaning processes, and a women's quality of life and health outcomes in the context of breast cancer.

An Integrative Model of Meaning

While examining these theoretical and evidence-based reviews of meaning and health, four themes emerged that served to organize the disparate information as well as provide the foundation from which this study emerged (see Table 1). These themes are best captured by the description of four coping skills identified by Ray (2004) as key determinants of health within the biopsychosocial model: (a) greater knowledge and information; (b) inner (psychological) resources; (c) social support; and (d) belief in something greater than oneself and connection with the future (purpose, spirituality or religious belief). Ray (2004) suggested that the balance between one's coping skills and environmental demands determines the quality of psychological equilibrium and the biological damage to the body from stress. He identified these four coping skills as being the most important to maintaining this balance. Collectively, these four concepts

Table 1

The Big Four and their related concepts in meaning theory and health

BIG FOUR	**Theories of Meaning**				**Cancer**	**Psychological Well-Being**		**CHESS**
Four coping styles that reduce allostatic load (Ray, 2004)	**Meaning-based Therapy (Frankl, 1984; Langle, 2004)**	**Four Needs for Meaning (Baumeister & Vohs, 2002)**	**Meaning-based coping (Folkman, 1999)**	**Meaning as Biology (Bolton & Hill, 2004)**	**Specific to Cancer Outcomes (Greer, 1999;Giese-Davis & Spiegel 2003)**	**Psycho-social factors of resilience (Ryff & Singer, 2003b,c)**	**SDT: Needs for Psych Well-Being (Ryan & Deci, 2000)**	**Online Services For Women with Breast Cancer**
Greater knowledge of the world	To know the world as it is, (Somatic dimension)	Seeking mastery over environment	Gathering info for planning, decision making & problem-focused coping	Understanding the environment for better survival & functioning	Those who seek control by understanding cancer have best disease outcome	Purposeful engagement	Competence	Library; Q&As; Resource Directory; Health Tracking; Ask An Expert
Inner Resources	To know oneself as unique & autonomous (Psychological dimension)	Values (sense of goodness and justify course of action)	Positive reappraisal (cognitive strategies)	Focus on what matters for optimal functioning & survival in the world	Affect regulation = increased survivorship & decreased recurrence	Flexible self-definitions	Autonomy	Decision Aid; Personal Stories; Journaling
Social Support	Network of relationships (i.e., the *dialogical* force needed to unify the dimensions of human life)	Self-worth as found in relation to *others*	Sense of connection & self-esteem bolstered by others that ordinary events become meaningful	"Rules" of meaning for optimal functioning made in biological *dialogue* with other biostructures in body.	Social support buffers endocrine response to stress; increased survivorship & decreased negative affect	Having persistently positive ties to meaningful others	Relatedness	Discussion group; Ask an Expert; Personal Stories
Something greater than oneself = Purpose or Spirituality	The future envisioned & shaped through one's choices & activities (Noetic dimension)	Purpose i.e., the present draws meaning from its connection with the future	Spiritual beliefs and practices	Greater "awareness" beyond info exchange-ties multiple rules into coherence for optimal functioning	Balancing hope of life with fear of death—expressing fears aids survivorship, decreases recurrence	Sustained religious or spiritual orientations	Natural outcome of Autonomy, Competence, & Relatedness	Discussion Group

provide the common thread that links the various theories of meaning and health with each other. For the sake of brevity, they will be referred to throughout this essay as "the Big Four."

The first of the Big Four, *greater knowledge and information,* recognizes that the more one knows about how the world works, the more one can understand and control it effectively. "With knowledge, information, comes empowerment, a belief that the world is understandable, and controllable and benign. Perhaps the most stressful situation is the ambiguity that comes from an awareness that one has inadequate and incomplete information" (Ray, 2004, p. 33). This is especially relevant to the experience of breast cancer where one searches for accurate information about her illness and treatment options in order to choose those which are best for her.

The second theme, *inner (psychological) resources*, incorporates the concepts of a psychological self, values, beliefs, assumptions and one's sense of self. The third theme, *social support*, describes one's sense of relatedness or connection to others, the quality of relationships one has developed with others, and one's social network.

The final theme, *belief in something greater than oneself,* emanates from one's sense of spirituality or greater purpose, or an awareness of and connection with the future. The field of medicine has begun to recognize spirituality as a new frontier of health exploration, proposing the need for "a broad understanding of the roles of meaning and belief" (Scheurich, 2003, as quoted in Ray, 2003, p. 33). Lower mortality rates, for example, have been found in those persons with greater social support, and in those who drew strength and comfort from religious and/or spiritual beliefs (House, Landis, & Umberson, 1988; Oxman, Freeman, & Manheimer, 1995).

Ray (2004) demonstrates that these four coping styles are associated with reducing allostatic load, and supporting allostasis. Allostasis, meaning literally "maintaining stability through change," describes the ability to adapt to change in the environment while maintaining physiological systems within normal operating ranges (McEwen & Stellar, 1993; McEwen &

Seeman, 2000). Allostatic load refers to the physical cost to the body forced to adapt repeatedly to challenges.

While allostatic load has been defined primarily by the interacting physiological systems that constitute the physical response to environmental challenge, this response is initiated by one's *perception* of the challenge. It is the perception of the stressor—its meaning to the observer and not simply the presence of the stressor itself--that determines whether physiological systems will be activated (McEwen & Seeman, 2000; Ryff & Singer, 2003a). Meaning, in this context, plays a pivotal role in the determination of whether or not a challenge is translated as "friend or foe" with corresponding physiological consequences. "If we are correct that physical health is affected to some extent by emotional health, …our capacity to make meaning from two disparate events or entities provides the connection, the plug, that creates the cascade of biological changes necessary for that effect" (Baumeister & Vohs, 2002, p. 608).

The process of meaning will be explored within the context of traumatic stress, examining its relevance and role in the process of determining whether an environmental demand, such as a serious, life-threatening illness, is considered "friend" or "foe", and how this determination relates to health. To provide a framework for the discussion, Table 1 displays the Big Four overarching themes along the vertical axis, while listing the topics reviewed----Theories of Meaning, Breast Cancer, Psychological Well-Being and CHESS Intervention--across the top. This framework organizes seemingly disparate areas into a holistic view of meaning and health.

These themes, and their relevance to current models of psychological well-being, provide the basis for an exploration of the *process* of meaning as *a cognitively-driven integrative mechanism supporting allostasis during breast cancer.* The evidence, or lack thereof, of the meaning process supporting health during the experience of breast cancer will be reviewed, providing a foundation for a new model of meaning that is grounded in biological outcomes. The model will illustrate the vital role meaning may play to sustain health as it helps one transform her perception of "illness as threat", to "illness as a force for positive change." The process of meaning may contribute a vital component to support allostasis during serious, life-threatening illness.

Theories of Meaning

Meaning has only recently been examined in clinical research. Operational definitions of meaning have been missing, or inferred, and the lack of definition has made it difficult to capture meaning's effects. This lack of definition may be a product of the variety of theoretical constructs for this concept. For this review, four constructs of meaning representative of the literature have been selected: (a) meaning as the primary motivation in life (Frankl, 1984); (b) meaning as basic human needs for optimal psychological functioning (Baumeister & Vohs, 2002; Sommer & Baumeister, 1998); (c) meaning as a cognitive process that sustains coping during negative life events (Folkman,1997); and (d) meaning as a psychological process similar to the biological processes that ensure optimal functioning of the organism (Bolton & Hill, 2003).

Frankl and the Dialogical Human Spirit: Meaning from Dialogue

Until recently, existential and/or humanistic psychologists Victor Frankl, Carl Jung, Rollo May, Abraham Maslow and others (Frankl, 1969; Jung, 1964; May, 1977) have most actively explored the importance of meaning for psychological health, most notably meaning derived from suffering. Jung (1964, p. 35) writes, "Man positively needs general ideas and convictions that will give a meaning to his life and enable him to find a place for himself in the universe. He can stand the most incredible hardships when he is convinced that they make sense; he is crushed when, on top of all his misfortunes, he has to admit that he is taking part in a 'tale told by an idiot.'"

Frankl, too, observed a similar effect during his years as a prisoner in the Jewish concentration camps of World War II. He found that what often predicted survival in those inhuman conditions was a positive shift in one's thinking that provided meaning and helped one persevere in the face of adversity. "In some way, suffering ceases to be suffering at the moment it finds a meaning, such as the meaning of a sacrifice" (Frankl, 1984, p. 135).

Frankl (1969, 1984; 2000) considered meaning the primary motivation in human life, a process of intention and choice—a choice of response, direction and attitude. He proposed that human existence had three dimensions: (a) a somatic dimension, which encompassed the biological functioning of the body and the material world within which it exists; (b) a psychological dimension, which included emotional states, learning, habits and social patterns; and (c) the noetic or spiritual dimension. Frankl used the term "spiritual" to refer to that which is unique to the human *spirit*--the faculties of intentionality, freedom of choice, creative and spiritual sensitivities, awe, intuition, inspiration, and the search for meaning.

The search for meaning was not just one item on this list. For Frankl, meaning was *the* complex achievement of the human spirit, developed for the purpose of unifying the somatic, psychological and spiritual dimensions of human existence. These dimensions were unified by *integrating four key areas* of life that are conceptually similar to the Big Four (see Table 1, Column 2): (a) knowledge about and acceptance of the world's realities, in its full range of beauty and horror; (b) knowing one's self as a unique and autonomous person; (c) one's relationships with others; and, (d) one's future envisioned by and shaped through one's choices (Langle, 2004).

Frankl (1984) believed that interaction and dialogue with others in relation to oneself was critical, because the realization of meaning was a *process* that draws connections that can only be appreciated by the human spirit. In fact, he believed the very *nature* of human spirit was *dialogical,* because only through the interaction with others, the world, and oneself could one discover the connections that revealed meaning (Langle, 2004).

From this philosophical perspective, Frankl developed logotherapy, a psychotherapeutic method developed to help one discover the meaning in one's life. Through dialogue, one explored the realities of life (death and life, suffering and joy); one's relationships; one's autonomy; and one's future shaped by choice. Meaning was a *dynamic* search for connection and resolution, found through dialogue between others or with oneself, in some form, to help one understand the world.

Meaning was not abstract or static, but was dynamic, dependent on the specific context at any given moment. Frankl (1984) compared the question "what is the meaning of life" to "what is the best move in chess": in life, as in a chess game, the answers to these questions depend on the specific context—the best move depends on the particular game, the personality of the players, etc. Meaning was *dynamic,* because it was *relative* not only to situational demands, but also to what a person thought and felt in a particular context.

Dialogue was key to this process: Frankl believed that the human spirit *itself* was dialogical. In fact, the only reason human beings were capable of meaning was because of their dialogical human spirit. Human beings were able to grasp the unseen—the possibility of a future vision or invisible connection between people or things--because this process allowed them to separate the reality of what was imposed by the environment and outside of one's control from what was possible in the future. For Frankl, the process of meaning defined the distinctly human dimension of existence (Frankl, 1985).

Evidence for Frankl's conception of a dialogical spirit comes from an unlikely source. Psychoneurological research suggests that human beings may be innately predisposed or "hardwired" to create higher order meaning from seemingly unrelated stimuli or events, and to produce a narrative reflection of the brain's inputs (Gazzaniga, 1993, 1997).

Narrative is an account of events experienced by a narrator: it is not a fixed or an absolute account, but one open to interpretation by the narrator (Harden, 2000). It is a structured story requiring reflection, and, as such, it is inherently dialogical. The narrator may reflect on, compose, interpret, and/or change salient features of an event into something that is relevant or meaningful (McAdams, 1993; Carlick & Biley, 2004). Some have also suggested that human beings are creators of meaning, and that narrative thought is the process by which meaning originates and changes (Bruner, 1986).