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Mindfulness: Existential, Loss, and Grief Factors in Women with Breast Cancer

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Although a plethora of studies exist as to the efficacy of mindfulness-based interventions with cancer patients, existential, loss, and grief factors are absent. The primary purpose of this exploratory study was to add to the literature by exploring the pre–post effects of an 8-week mindfulness-based intervention on existential well-being, summed self-identified losses, and grief scores as well as assess mental adjustment to cancer; also, 6-month follow-up data as to intervention maintenance were obtained. Sixty-five women, all of whom had been diagnosed with breast cancer within the past 12 months, participated in this study. The data indicated significant improvements for existential well-being, number of self-identified losses, grief scores as well as three mental adjustment styles. Six-month follow-up revealed that of the 58 responding participants, 88% were maintaining mindfulness strategies at varying schedules on a weekly basis with mindfulness-based walking as the preferred strategy. This is the first known mindfulness-based intervention study to investigate existential, loss, and grief factors in those with cancer. Further investigations earnestly are needed in this area to provide full psychosocial care to those confronting cancer.

KEYWORDS *mindfulness, cancer, existential, loss, grief, psychosocial oncology care*

INTRODUCTION

Breast cancer is the most common type of diagnosed cancer in women worldwide, and it was estimated that 1.5 million new cases would be diagnosed in the United States in 2010 (American Cancer Society, 2010). Traditional

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cancer care focuses on and emphasizes the physical or biological, yet cancer patients can experience various types of emotional and existential distress during the course of their disease process. Indeed, a diagnosis of cancer likely elicits greater distress than any other diagnosis, regardless of the prognosis (National Cancer Institute, 1997). Relevant here is the proposal that emotional distress be elevated as a core indicator of well-being, that is, the “sixth” vital sign in cancer care (Bultz & Carlson, 2005). In the context of cancer, the terms of *loss* and *grief* tend to be used in reference to the bereaved, the loved ones left behind when a cancer patient dies (Rando, 1984). However, loss and grief are experienced by many as they come to grips with the disease, deal with the side effects of treatment, and struggle on a daily basis with a precarious future and possible death. Cancer’s uncertainty can be ever present—even years after treatment during survivorship—haunting like a ghost, making not only cancer worry common, but also existential issues (Andersen, Shapiro, Farrar, Crespin, & Wells-Digregorio, 2005; Dunn & Steginga, 2000). A plethora of studies exist as to the efficacy of mindfulness interventions with cancer patients, yet existential, loss, and grief factors are absent. The primary purpose here is to add to the literature by exploring the effects of a mindfulness-based intervention on these factors.

Existential Issues in Cancer

Existential concerns are fundamental to being human (Arlebrink, 1999), thus, to provide the best possible psychosocial care, existential well-being must be addressed in those suffering with a life-threatening disease. Cancer patients’ interest in existential and spiritual concerns stem from the notion that cancer is associated with eventual death (Strang, 1997); thus, cancer is an existential trigger that can be traced back to Medieval times when people died shortly after diagnosis from advanced disease or from limited medical knowledge (Edmondson, Park, Blank, Fenster, & Mills, 2008; Holland & Rowland, 1989). The phrase of “existential plight,” coined by Weisman and Worden (1977) to describe the course of a new patient’s first 100 days, refers to the exacerbation of thoughts about one’s existence and potential nonexistence following a cancer diagnosis (Holland & Rowland, 1989). The current literature suggests that the “existential plight” refers to what now is known as the “search for meaning” following a cancer experience (Lee, 2008, p. 779); indeed, cumulative evidence suggests that global meaning—defined as the general sense that one’s life has order and purpose—is a key determinant of overall quality of life (Lee, 2008).

The existential plight of cancer has become a focus in the supportive psychosocial oncology literature (Holland & Rowland, 1989), and studies that indicate existential plight is not culturally dependent. Specifically, some examples of studies that have explored existential issues in cancer patients from around the globe include: Australia (Kissane, 2000; Little & Sayers,

2004), Israel (Baider & de Nour, 1986; Blinderman & Cherny, 2005), Japan (Morita, Tsunoda, Inoue, & Chihara, 2000), North America (Breitbart, Gibson, Poppito, & Berg, 2004; Chochinov et al., 2005; Lee, Cohen, Edgar, Laizner, & Gagnon, 2006), Norway (Landmark, Strandmark, & Wahl, 2001), and Sweden (Bolmsjo, 2000; Jensen, Back-Pettersson, & Segesten, 2000). The evidence suggesting that existential issues are common across cultures lends logic to investigating the effects of an intervention program on existential well-being in cancer patients.

Loss and Grief Factors

Dealing with multiple losses, physical and symbolic as well as with associated grieving, can be preeminent tasks faced by a patient with a life-threatening disease like cancer (e.g., Block, 2001). Possible issues of loss and grieving can involve the patient's former self—before the diagnosis and the designated identity of being a “cancer patient” (e.g., Gillies & Johnston, 2004; Hottensen, 2010). Other potential losses may involve the loss of independence, decreased physical and cognitive functioning, or loss of one's role in the family; thus, cancer patients may experience anticipatory grief (Hottensen, 2010). Anticipatory grief is a “range of intensified emotional responses that may include separation anxiety, existential aloneness, denial, sadness, anger, disappointment, resentment, guilt, exhaustion, and desperation” (Cincotta, 2004, p. 325).

In the absence of awareness, grieving may end up being repressed or expressed as anger. Grief symptoms may be misdiagnosed as depression and possibly result in an unnecessary prescription of antidepressants, or an overuse of antidepressants when people enter the health care system (Schneider, 2000). A single study investigated the effects of mindfulness on grieving associated in patients with chronic pain (Sagula & Rice, 2004). However, no mindfulness-based stress reduction (MBSR) investigations have been conducted with cancer patients to assess its effectiveness in helping individuals deal with disease induced losses or grieving responses. That no study has examined the MBSR program's effects on existential or loss and grief factors in this population truly is surprising, given the context of a life-threatening illness. Also, in such a medically intense context, a patient's mental adjustment to cancer is of salient importance.

Mental Adjustment to Cancer

Having breast cancer is associated with feelings of helplessness, anxiety, depression, and loss of control (Watson et al., 1991). Observing this, Greer and colleagues developed a scale to determine psychological and behavioral coping responses to having cancer (Watson et al., 1988; Watson et al., 1991). The implicit assumption is that coping will reflect an enduring attitudinal or

behavioral style in individuals confronted with cancer. Five original mental and behavioral coping strategies were identified: Fighting Spirit (FS), where the patient fully accepts the diagnosis, and adopts an optimistic attitude; Helpless–Hopelessness (HH), which relates to feelings of giving up and being overwhelmed by the diagnosis; Anxious Preoccupation (AP), that is characterized by constant cancer preoccupation and anxiety; Stoic–Fatalism (FA), which reflects an attitude of resigned, passive acceptance of the cancer; and Avoidance (Denial), where patients avoid or deny the notion of having been diagnosed with cancer (Greer, Moorey, & Watson, 1989; Watson et al., 1988).

Mindfulness Meditation

Mindfulness meditation is the disciplined practice of paying attention to the present moment with uncritical, nonjudging acceptance, or a “beginner’s mind” (Kabat-Zinn, 1990). Mindfulness meditation strategies, traditionally taught in the 8-week MBSR program, encourage nonjudgmental observation or witnessing of thoughts, perceptions, sensations, and emotions, providing a means of self-monitoring and regulating one’s arousal with detached awareness. Pre–post designs with cancer populations have shown the MBSR to be effective in reducing stress levels and symptoms, scores for anxiety and depression, pain, symptoms of distress, insomnia, and fatigue (e.g., Carlson & Garland, 2005; Speca, Carlson, Goodey, & Angen, 2000; Tacón, Caldera, & Ronaghan, 2004, 2005). Mindfulness-based interventions also have shown significant improvements pre–post in quality of life, pain, positive mood shifts, improved coping and mental adjustment to cancer, and health locus of control (Carlson, Speca, Patel, & Goodey, 2003; Tacón, 2006; Tacón et al., 2004, 2005). Description of an MBSR program for cancer patients has been described elsewhere (Tacón, 2003).

The purpose of the present pilot study is to address the paucity of literature by exploring the effects of a mindfulness-based intervention program on existential well-being, self-identified losses, grieving, and mental adjustment to cancer in women with breast cancer. The program’s effects on existential well-being, self-identified losses, and grief factors are exploratory, hence, no predictions were made. Based on previous research, it was predicted that mental adjustment to cancer scores would improve positively and significantly (Tacón et al., 2004). In addition, program maintenance was assessed at 6-months follow-up.

METHOD

Participants

Following Human Subjects approval, participants were referred from oncologists’ offices to provide them with mind–body tools to enhance their cancer

coping resources. Seventy-six women were approached about participating in the study; of the original 76 women, 11 women (14.5%) declined. The resulting sample consisted of 65 women in a southwestern community of approximately 200,000. Ages ranged from 32 to 63 (mean of 45.4 years). The majority of participants were White (94%), middle class (92%) and married (60.8%), of Protestant faith (96%), with education beyond high school (68.0%). Three were working full-time (5.6%) whereas a little more than one half (52%) were working part-time during the study, and six women (11%) had a family history of cancer. All women had been diagnosed within the past 12 months and ranged from Stage 1 (68%) to Stage 2 (32%). Thirty-nine of the women (73.6%) were receiving chemo or radiation therapy; eight (15.1%) were preparing for surgery and had been referred to the program for that reason; and, the remaining six women (11.3%) were in between or not receiving treatment. All participants in this middle-aged group of women attended the eight sessions. Attendance was bolstered by an unusually strong support system that developed early on among them, which even led to the formation of transportation pools among several bands of women for attending sessions. Also, 6 months later, 58 of the original 65 participants filled out follow-up questionnaires.

Measures

Existential well-being. *Existential distress* is defined as the state of an individual confronting his or her own mortality arising from feelings of futility powerlessness, disappointment, meaninglessness, remorse, death anxiety, and disruption of one's engagement with and purpose in life (Paloutzian & Ellison, 1982). The 10-item Existential Well-Being (EWB) subscale of the Spiritual Well-Being Scale was used assess one's sense of meaning in life (Paloutzian & Ellison, 1982). The EWB subscale is rated on a 6-point Likert-type scale 6 (*strongly agree*) to 1 (*strongly disagree*) with demonstrated reliability and validity (Ellison, 1983; Kirschling & Pittman, 1989). The total summed score on the EWB ranges from 10 to 60 with higher scores indicating greater existential well-being.

Loss categories. Section B of the Grief Diagnostic Instrument (GDI) was used to assess loss that was felt to be more advantageous because it measures grief from the standpoint of multiple losses rather than a single loss of other grief measures (Clark, Marley, Hiller, Leahy, & Pratt, 2005/2006). Also, the GDI was developed for use in a medical practice context. Thirteen categories of loss can range from past or present (e.g., death of loved one, quality of life due to illness, etc.) to future events (e.g., impending death, separation, fear of own death). The measure was modified so that individuals would mark categories of loss as they pertained to the experience of having cancer. The GDI has been demonstrated to be a concise, valid, reliable, and sensitive

instrument (Clark et al., 2005/-2006). For the purpose of the current study, the summed total of categories will be used at this time.

Grief scale. Section C of the GDI determines a grief score summed from 16-items assessing grief symptoms on a 4-point Likert-type scale, and taps into the emotional, physical, social, and cognitive domains affected by grieving (Clark et al., 2005/2006). The summed clinical grief score ratings are: mild grief = 1–17; moderate grief = 18–22; and, severe grief = > 22.

Mental adjustment to cancer. The Mental Adjustment to Cancer Scale (MAC) was used to assess psychological adjustment to cancer (Watson et al., 1988). The MAC scale is a 40-item self-rating questionnaire using a 4-point Likert-type scale, which includes the following five mental and behavioral attitudinal coping styles: Fighting Spirit (FS, 16 items) where the patient accepts the diagnosis yet is determined to fight the disease with the adoption of an optimistic attitude; Helpless–Hopeless subscale (HH, six items) is related to feelings of giving up and being overwhelmed by the diagnosis, characterized by a pessimistic mind-set; Anxious Preoccupation (AP, nine items) characterized by constant preoccupation with anxiety; Fatalism (FA, eight items) shows an attitude of resigned, stoic acceptance of the cancer; and, Avoidance (Denial) (one item), is characterized by patients avoiding the notion of even having a cancer diagnosis (Greer et al., 1989; Watson et al., 1988). Items are rated on a scale ranging from *definitely does not apply to me* (1) to *definitely applies to me* (4). Acceptable psychometric properties of the MAC have been reported and replicated (Watson et al., 1988). The avoidance subscale was not included because it consists of only one item.

Mindfulness Intervention Program

The MBSR intervention was provided one night per week for 1½ hours over 8 weeks in a hospital-based counseling center setting. The participants received training in four basic mindfulness meditation practices: the body scan, sitting meditation, hatha yoga, and walking meditation. The body scan involves a gradual and thorough sweeping of attention through the geography of the body from feet to head, focusing noncritically, with periodic suggestions of breath awareness and relaxation. Sitting meditation involves mindful attention of the breath, and a heightened state of observational yet non-judging awareness of thoughts and distractions. Hatha yoga involves simple stretches and postures designed to strengthen and relax the musculoskeletal system and develop mindful movement of the body, that is, meditation in motion. Last, walking meditation consists of walking in moment-to-moment awareness, while paying attention to all physical sensations and fluctuations in awareness during the mundane activity of walking. Participants are given audiotapes for homework practice of the techniques learned during the sessions. The program, modeled after Kabat-Zinn's (1990), was adapted for

issues specific to cancer patients such as applying techniques during treatment(s), or in a doctor's waiting room, and so on (see program description, Tacón, 2003).

RESULTS

Paired *t* test analyses were conducted to assess pre- and postchanges for each of the outcome variables of existential well-being, self-identified loss categories, grief and mental adjustment to cancer scores (see Table 1).

Existential Well-Being

Total scores on the EWB subscale were used in analysis of scores at baseline and postintervention. Significant and positive changes occurred between baseline scores ($M = 28.91$, $SD = 6.12$) to scores after the end of the intervention ($M = 32.17$, $SD = 8.02$), $t = 4.63$, $p < 0.001$.

Loss Categories

The total summed scores for the number of multiple losses were analyzed preintervention ($M = 8.0$, $SD = 4.43$) and postintervention ($M = 6.0$, $SD = 4.57$). Results showed that the number of troubling losses decreased significantly from baseline to post completion of the MBSR intervention ($t = 2.47$, $p < 0.05$). The women in this study documented multiple categories of loss specific to their cancer experience. The loss category with the greatest frequency was separation (pre and post), followed by the following categories in frequency: fear of own death, quality of life, personal or body integrity, and independence.

TABLE 1 Means and Standard Deviations for Dependent Variables Preintervention and Postintervention

Variable	Preintervention		Postintervention		<i>t</i>
	<i>M</i>	<i>SD</i>	<i>M</i>	<i>SD</i>	
Existential well-being	28.91	6.12	32.17	8.02	4.63***
Self-identified losses (summed total)	8.0	4.43	6.0	4.57	2.47*
Grief (summed total)	20.12	6.75	17.72	6.34	3.56**
Anxious preoccupation adjustment	22.32	4.34	17.38	3.20	5.74***
Fatalism/stoicism adjustment	13.15	6.23	12.93	6.11	ns
Fighting spirit adjustment	7.11	4.01	8.94	5.32	2.43*
Helpless-hopelessness adjustment	14.92	4.24	12.02	4.80	3.49**

* $p < 0.05$, ** $p < 0.01$, *** $p < 0.001$.

Grief

Total scores for grief significantly dropped from preintervention high moderate grief ($M = 20.12$, $SD = 6.75$) to mild grief after completion of the MBSR program ($M = 17.72$, $SD = 6.34$), $t = 3.56$, $p < 0.01$.

Mental Adjustment to Cancer

Three types of psychological responses to cancer—*anxious preoccupation*, *fighting spirit*, and *helplessness–hopelessness*—showed significant changes in scores before and after the MBSR intervention. Specifically, scores on the AP subscale ($M = 22.32$, $SD = 4.34$) dropped significantly by the end of the 8-week period ($M = 17.38$, $SD = 3.20$), $t = 5.74$, $p < 0.001$. Scores for FS subscale showed a significant increase from pre ($M = 7.11$, $SD = 4.01$) to postintervention ($M = 8.94$, $SD = 5.32$), $t = 2.43$, $p < 0.05$. Last, scores on the HH subscale decreased significantly from preintervention ($M = 14.92$, $SD = 4.24$) to postintervention ($M = 12.02$, $SD = 4.80$), $t = 3.49$, $p < 0.01$. These findings indicate that, after completing the MBSR program, the women experienced statistically significant changes in scores of the *fighting spirit*, *anxiously preoccupied*, and *helpless and hopeless orientation* to their condition. Although *fatalistic scores* decreased from pre- to post-period, the change was not statistically significant.

Six-Month Follow-Up

Six months after the mindfulness program intervention, the 65 participants were mailed a follow-up questionnaire to assess their adherence to mindfulness skills learning during the intervention. Of the 65 women, 58 (89%) completed and returned the questionnaires. In response to how many of them had continued practicing mindfulness strategies taught in the intervention, 51 (88% of the 58) answered in the affirmative. In response to many days/week that mindfulness techniques were practiced, 15 women (29%) answered 5 to 6 days, 24 women (47%) answered 3 to 5 days, and 12 women (24%) answered 1 to 3 days/week. Last, the participants were to state which of the major mindfulness techniques (*body scan*, *sitting meditation*, *yoga*, *walking meditation*) they most preferred. *Walking meditation* was by far the most preferred strategy (50.6%); *yoga* was the second (32.2%) followed by *sitting meditation* (10.1%), and the *body scan* (7.1%).

DISCUSSION

This was the first known study to explore the effects of a mindfulness intervention program on existential well-being, loss, and grief factors in any

population, including those with the life-threatening disease of cancer. These preliminary data showed that existential well-being scores improved significantly from pre- to postintervention. It is possible that this finding may have centered on the women finding social support and comfort in being with others “in the same boat” with which to explore profound existential interpretations about their cancer experiences. For example, themes of genuine and blunt discussions that continued over the course of the 8 weeks included the search for meaning as to why the cancer had “reared its ugly head,” and if any gifts or lessons could be gleaned from such a frightening and painful encounter. Another theme was the feeling of an utter aloneness unlike any other life experience that best could be summed up by what one of the participant’s described as “being alienated from everything in the universe . . . for the first time, I realized I was just a small speck on the edge of a dark cliff . . . I don’t know what was worse, the sheer terror of being destroyed or feeling so alienated and trivial.”

Another woman shared her despair and loneliness about her family not being able to fully comprehend what she was going through and instead were being absurdly upbeat, not wanting to fill her need of having any “deep” talks.

They are so damn scared that they’re not able to be there for me . . . and I just want to scream at them and say, “hey, I may not exist on this planet next year—so cut me some frigging slack!”

Also, a surprising theme that emerged was the failing of support from religious personnel, a frequent solution suggested to several of them by others who felt uncomfortable and didn’t know what to say to a “cancer” patient.

I know he means well, but hearing about heaven and hell and the bible is not where I’m at or what I need right now—I’m still trying to wrap my head around the possibility of me not being around anymore, you know, my family and *no me*. How can that be?

Without a doubt, however, the topic that fostered the greatest group cohesion derived from a shared search for discovering a new self or identity, and what it meant to be a “cancer survivor” as well as where they were to go from here, and what they were to do with their lives: “I can’t just go back and be cookie-cutter miss homemaker anymore—that woman is gone—I’ve been through too much.” Because no MBSR study has investigated existential issues or well-being, no data are available for comparison with this study’s findings.

This MBSR study was also the first to explore self-identified losses and grieving among cancer patients. These data showed a significant drop in the quantitative number of domains or categories of loss before and after the program that were predominant to this group of women. As stated

previously, the most frequently specified category of loss was separation, followed by fear of own death, quality of life, and loss of personal or body integrity, respectively. It is surprising that separation—not fear of own death—was the most frequently endorsed loss domain. From an attachment theory perspective, death can be viewed as the ultimate separation from attachment figures and loved ones, thus the proximity of these two categories is understandable. Also, being that mindfulness in principle and practice focuses on being in the reality of now, it is interesting to note that the two leading domains are future based rather than anchored in a present moment orientation; a possible explanation is that attachment relations were predominant regardless of intervention focus. A suggestion for future research would be additionally to examine attachment styles in the participants to see relations among existential well-being and quantitative/qualitative loss domains. Again, there are no previous findings for comparison since this is the first identified MBSR study to explore loss in any population.

Grieving was another novel factor explored. The grief scores decreased significantly from before to after the intervention 8 weeks later. Indeed, the scores for grief significantly improved from the clinical rating of moderate grief at the start of the program to the mild grief classification after the program ended. These preliminary data suggest, at least for this group of women, that a mindfulness intervention may provide useful skills for dealing with self-specified losses and grief associated with cancer. However, these results are a first step, for replication is needed, especially given that there are no known data with which to compare findings. Future studies will need to investigate gender effects and cancer type on program outcomes; for example, conducting this intervention with men diagnosed with prostate cancer.

As predicted, positive and significant changes in mental adjustment to cancer scores occurred pre–post intervention. Specifically, scores for the anxious preoccupation and hopeless–helplessness subscales improved significantly over the course of the 8-week intervention; also, fatalistic scores decreased but did not reach significance. These findings are consistent with previous results (Tacón et al., 2004). However, a novel finding with this data is that the fighting spirit coping response increased significantly by the end of the intervention.

Follow-up information at 6 months indicated that 88% (51 of 58) of the women still were practicing mindfulness strategies learned during the intervention, and the order of the preferred strategies were, from most to least preferred: walking meditation, yoga, sitting meditation, and the body scan. These findings differ slightly from previous data. In an earlier study involving 24 women at 3 months follow-up, the preferred strategies were first, yoga, next the body scan, and third, sitting meditation (Tacón et al., 2004). Unfortunately, this study did not include walking meditation among the rating of preferred mindfulness techniques.

Limitations

The initial findings must be interpreted cautiously because there were several limitations that must be acknowledged. First, this study dealt with women with breast cancer, and thus findings cannot be generalized to other chronic or life-threatening disease populations such as cardiovascular disease, or other oncology populations. Second, another limitation involves the passing of time. The 8 weeks may have played a role in the findings, for this time period, itself, may have been significant for the continuing adjustment of these participants, regardless of the intervention. Next, the participants were primarily White, which begs the question about how results would differ in women of other ethnic origins. Last, participants were not randomly assigned to multiple treatment conditions; instead, the pressing psychosocial needs of these women, as indicated by physicians and staff, took priority. Based on these pilot data, future investigations consisting of randomized conditions appear feasible. The bottom line is that individuals in the context of a life-threatening illness need as many intervention options as possible with which to help them and their loved ones cope with their presenting biopsychosocial-existential circumstances.

Themes

The earnest themes that evolved over the 8 weeks proved especially enlightening in terms of distinguishing between religious versus existential needs—at least as specified by this particular group of women. It could be said that “self the experiential” came before that of “salvation the eternal.” Dealing with the immediacy of their present human experience appeared to be foremost in processing for the majority of these participants before transitioning to life-after-death and past deeds evaluative considerations. Future qualitative studies in this area could provide rich and informative data of perspectives.

In conclusion, profound distress in terms of psychosocial suffering in those with cancer must be matched with equally effective psychosocial care and therapeutic interventions. Existential, loss, and grief concerns are common bedfellows to the oncology experience, and they must not be forgotten in either the clinical or empirical domains of psychosocial oncology.

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