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Research

Mindfulness, Death and Dying Distress, Pain, and Breast Cancer

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Abstract

Cancer patients experience distress that likely will be exacerbated at some point by pain and death concerns. Abundant research indicates that mindfulness-based stress reduction (MBSR) interventions benefit cancer populations in terms of different types of distress. The primary purpose here was to investigate the effects of a mindfulness intervention on death-related and pain measures. Indeed, this was the first MBSR study to explore intervention effects using a new death and dying distress measure developed specifically for those with cancer as well as explore the view or attitude of death as an escape. Scores were collected for death anxiety, pain anxiety, existential well-being and the death attitude of escape before and after the eight-week intervention program. Statistical analyses revealed significant improvements for death anxiety, pain anxiety and existential well-being. Scores for the death attitude of escape, however, did not change significantly. In sum, this was the first mindfulness-based study to investigate effects on 1) death-related distress using a new instrument; and, 2) explore the attitude of death as an escape in women with breast cancer. Continued complementary research is needed in the areas of pain and thanatology for patients whose diagnoses involve dealing with such issues.

Keywords: MBSR; Mindfulness and Death; Death Anxiety; Death and Dying Distress; Pain; Breast Cancer; Pain Anxiety

Introduction

Cancer patients experience distress that likely will be exacerbated at some point by pain [1]. Indeed, a diagnosis of cancer likely elicits greater distress than any other diagnosis, regardless of prognosis [1]. Humans fear pain and death and the fear of a painful death, for they are threats to our human existence [2]. The combined issues of pain and mortality are frequently shared by those with a chronic and/or "terminal" illness [3]. While there have been tremendous advances in the cancer treatment over past decades as indicated by improved survival rates, cancer-related pain is under-treated, and opioids remain the medical standard for treatment despite psychological factors such as pain anxiety [2, 3]. Surveys show that up to 60% of cancer patients experience poor pain control especially during their last year of life which sadly attests to the significant problem of pain control in this population as they near death [3]. No known study has examined the mindfulness based stress reduction (MBSR) intervention effects on death and dying distress or death attitudes in cancer patients experiencing cancer related pain. Thus, the purpose here was to investigate the effects of the cognitive based program on scores for: death and dying distress, existential well-being, pain anxiety, and death [as an] escape attitude in women with cancer.

Death Distress and Existential Well-Being

Death is the ultimate threat to life, and mortality salience is no more profound than when facing a disease like cancer, the word alone, of which, used to be considered a death sentence [4]. The term "existential plight" was coined to refer to intensifying thoughts one experiences about existence vs nonexistence after receiving a cancer diagnosis [4]. Originally, existential plight referred to the first one hundred days of a new cancer patient to capture one's understandable focus on mortality [5]. Evidence also suggests that such distress is not culturally bound [6]. Specifically, heightened death distress and existential intensity in new cancer patients have been documented around the globe; also beneficial effects of a mindfulness intervention have been reported on existential well-being in a single study with breast cancer patients [6]. Therefore, the purpose here was to investigate the effects of a mindfulness-based intervention program on death and dying distress by use of a new instrument developed specifically to measure death anxiety in those with cancer, and to replicate findings on existential well-being in women with breast cancer.

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Pain Anxiety and Death Attitudes

Death anxiety is associated with pain and physical distress, and pain anxiety is an important factor in chronic pain, which plays a major role in fear avoidance models Asmundson, G.J.G., Norton, P.J. and Norton, R.G., 1999. Beyond pain: the role of fear and avoidance in chronicity. *Clin. Psychol. Rev.* **19**, pp. 97–119. **Article** | PDF (252 K) | View Record in Scopus | Cited By in Scopus (183)[7, 8]. Fear–anxiety–avoidance models of chronic pain view pain anxiety as salient in the development and maintenance of chronic pain [9]. Indeed, fear–anxiety–avoidance models of chronic pain involve patterns and processes similar to anxiety models; that is, anxiety disorders either follow from, or are exacerbated by unpleasant experiences associated with behavioral avoidance, catastrophic cognitions, and major distress [7]. Studies investigating pain anxiety have been conducted primarily on non-malignant pain populations, however results from a recent MBSR study involving women with breast cancer found significant improvement in pain related anxiety after the intervention [10]. Pain, over time, may elicit such fear of pain that views about death change (ref). For example, pain and suffering may lead to an escape orientation towards death where death becomes attractive in the face of psychological, existential pain and physical suffering [11,12]. No MBSR study has investigated the death attitude or orientation of escape in those with cancer.

Mindfulness and Cancer

Kabat-Zinn's eight week mindfulness stress reduction and relaxation program originated at the University of Massachusetts Medical Center [13]. Basically, mindfulness is the disciplined practice of discipline fosters detached, nonjudgmental observation or witnessing of thoughts, perceptions, sensations, and emotions, which provides a means of self-regulating one's arousal and awareness (ref). Investigations to mindfulness-based intervention effects on cancer populations began nearly two decades ago (ref). Data from a plethora of studies indicate that the MBSR is effective in significantly reducing scores on stress levels and symptoms, anxiety and depression, symptoms of cancer distress, insomnia and fatigue [14]. Also, mindfulness-based interventions in those with cancer have found significant improvements pre-post in quality of life, positive mood shifts, improved coping, mental adjustment to cancer, and health locus of control [14,17]. In contrast, a single study has examined death related factor s such as grief and loss [6], and scant literature exists as to the effects of the MBSR on and pain related factors such as pain anxiety in individuals diagnosed with cancer [10].

Again, in cancer populations, death anxiety is associated with pain and physical distress as well as impaired spiritual wellbeing, and quality of life [7,8,18]. To address the paucity of studies in this area, the aim here is to investigate the effects of a mindfulness-based intervention on death and dying distress, existential well-being, pain-related anxiety and the death attitude of escape in women with breast cancer and related pain (ref). Since this was the first study to explore MBSR effects on death and dying distress and death attitudes in a cancer population, no hypotheses were made. Based on limited findings, it was hypothesized that: 1) existential well-being scores would increase significantly post-intervention; and 2) pain anxiety scores would decrease significantly following the intervention.

Materials and Methods

Design

A one group pre-test/post-test design was used to assess changes in death and dying distress, existential well-being, and pain-related anxiety before and after the eight-week MBSR intervention.

Recruitment

Following Human Subjects Approval, participants were recruited through medical facilities via fliers, media advertisements, referrals from physicians and the American Cancer Society in a community of approximately 200,000 residents. Consent forms were explained and signed before the start of the study intervention.

Intervention

The MBSR program of Kabat-Zinn was held in a hospital counseling center for 1.5 hours/week over eight-weeks. Participants were trained in the mindfulness practices of: body scan, sitting meditation, hatha yoga, and walking meditation [13]. The body scan involves a gradual sweeping of attention throughout the body with non-critical acceptance of sensations or feelings, and suggestions of breath awareness and relaxation. Sitting meditation involves mindful attention of the breath and nonjudgmental awareness of distractions. Hatha yoga involves simple stretches and postures to develop mindful movement of the body or meditation in motion. Walking meditation involves walking mindfully while paying attention to all sensations. An aspect of the intervention included in Kabat-Zinn's curriculum is homework practice; thus, participants received compact discs to facilitate daily homework of the learned techniques [13]. Weekly homework sheets, distributed to the participants in binder form, were turned in each week to indicate the amount of homework conducted for each mindfulness technique daily. A section was available on the homework sheets for participants to write any major life occurrences such as family deaths, major condition or treatment changes (positive or negative), etc. No such major life events were recorded. At the end of the intervention program, participants again completed questionnaires.

Outcome Measures

Four standardized instruments were administered before (pre) and after (post) the eight-week MBSR intervention to evaluate intervention effects on the following outcome factors.

Death and Dying Distress

The Death and Dying Distress Scale (DADDS) has been developed recently for use in cancer patients with an advanced or complicated disease course [19], consequently, cancer pain is viewed as a factor that heightens mortality-related distress and complicates the subjective disease process [4]. Thus, the instrument assesses death distress so as to provide psychosocial interventions and support. This 15 item measure states "Over the past two weeks, how distressed did you feel about with responses ranging from 0 (not distressed) to 5 (extremely distressed). Total DADDS scores range from 0 to 75, with higher scores indicating greater death anxiety: none or little death anxiety (<15); little to mild (15 - 29); mild to moderate (30 - 44); moderate to great (45 - 59); great to extreme (60 - 75). The DADDS is reported to be a reliable and valid measure [19].

Existential Distress

Existential distress is viewed as the stressful state of an individual confronting his/her mortality due to feelings of meaninglessness, death anxiety, remorse, powerlessness and futility with a disrupted sense of purpose in and engagement with life [20]. The Existential Well-being measure is a 10 item subscale of the Spiritual Well-being Scale that rates items on a 6 point Likert scale from 6 (strongly agree) to 1 (strongly disagree) (e.g., *Life doesn't have much meaning)*. Higher scores indicate greater well-being with a range from 10 – 60. This instrument has reported reliability and validity [20, 21].

Pain Anxiety

The Pain Anxiety Symptoms Scale 20 (PASS-20) was used to measure pain related anxiety [22]. The PASS-20 is a 20 item instrument that measures fear of pain indirectly via pain-related anxiety (e.g., *Pain seems to cause my heart to pound or race*). Each item is responded to using a 6-point Likert scale from 0 (never) to 5 (always); scores range between 0–100 with higher scores indicating greater levels of anxiety. The PASS-20 consists of four distinct components of pain-related anxiety: (1) cognitive anxiety (e.g., *I can't think straight when in pain*); (2) pain-related fear (e.g., *Pain sensations are terrifying*); (3) escape and avoidance (e.g., *I try to avoid activities that cause pain*), and; (4) physiological anxiety (e.g., *Pain makes me nauseous*). The PASS-20 is internally consistent; reliability and validity of the PASS-20 are well established [22].

Escape Death Attitude

Death as an escape was measured by the escape subscale of the Death Attitude Profile-Revised (DAPR) [23]. The subscale consists of 5 items based on a seven point Likert scale (completely agree to completely disagree). An example of the escape orientation is: *Death is deliverance from pain and suffering*. The DAPR has acceptable validity and reliability [23].

Results

Paired t-test analyses were conducted to assess pre-and-post changes for each outcome variable. See Table 1.

Participants

Sixty women were approached about participating in this study, yet only 42 women (70%) agreed. Exclusion criteria included no cancer diagnosis or related pain, current primary sites other than breast, less than 18 years of age, and psychopathology. The mean age was 62 and the majority, or 28 women, were stage III (67%); the remaining 14 women in stage II (33%). The majority were: Caucasian (83%) with 17 % Hispanic women; Protestant (83%) with 17% Catholic; married (89%), with a modal income ranging between $39,000 and $75,000 (71%); and, some form of education beyond high school (64%). More than half (54%) of these women were unemployed at the time of the study. Seven women (17%) indicated a family history of cancer. Individuals with cancer related pain were confirmed during consent of the attending physician. All participants maintained standard medical care during the program.

Pre-Post Results Outcome Measures

No prediction was made for the exploratory measure of death and dying distress as assessed by the Death and Dying Distress Scale (DADDS). The total score for the DADDS was used in analysis of pre-to-post-intervention scores for death and dying-related anxiety. Pre-intervention scores ($M = 39.71$, $SD = 12.24$) decreased significantly by the end of the intervention ($M = 37.23$, $SD = 10.44$), ($t = 3.15$, $p < .05$). Pre-and-post scores remained within the mild to moderate range during this study .As predicted, the data showed that scores for existential well-being increased significantly from pre ($M = 26.34$, $SD = 9.12$) to post the intervention ($M = 28.98$, $SD = 11.54$) ($t = 3.20$, $p < .05$). Thus, the women in this investigation experienced a greater sense of well-being existentially after the mindfulness intervention. Baseline scores for pain anxiety prior to the intervention ($M = 48.17$, $SD = 11.12$) dropped significantly following completion of the intervention ($M = 45.34$, $SD = 13.41$), ($t = 3.38$, $p < .01$). Thus, results for this group of women with breast cancer showed significant improvement pre-to-post-intervention on pain associated anxiety. Another exploratory analysis where no predication was made occurred in the case of the escape death attitude. Baseline scores for the escape attitude of death ($M = 4.37$, $SD = 3.19$) did not change significantly by the end of the intervention ($M = 4.36$, $SD = 3.10$), ns. Thus, this exploration indicated that the mindfulness program did not affect this attitude of death.

Table 1. Means and Standard Deviations for Variables Preintervention-Postintervention

	Pre intervention		Post intervention		
Variable	*M*	*SD*	*M*	*SD*	*t*
Death & Dying Distress (DADDS)	39.71	12.24	37.23	10.44	3.15*
Existential Well-being (EWB)	26.34	9.12	28.98	11.54	3.20*
Pain Anxiety (PASS-20)	48.17	11.12	45.34	13.41	3.38**
Escape Death Attitude (DA-E)	4.37	3.19	4.36	3.10	ns

* $p = .05$. ** $p = .01$.

Discussion and Conclusion

This was the first known intervention study of any kind to use the Death and Dying Distress Scale (DADDS) to measure death anxiety since its development and initial validation for cancer patients [19]. This clinical population has long needed a death anxiety instrument designed with its unique issues, disease course and process in mind. Results showed that scores decreased significantly from baseline to the end of the mindfulness-based program in these women with cancer. Recall that processes in anxiety models are similar to models of chronic pain, for anxiety disorders either follow from, or are exacerbated by unpleasant experiences such as chronic pain and are associated with catastrophic cognitions and major distress [7]. Since this was the first mindfulness intervention study to assess death anxiety using this scale, there are not previous findings for comparison. It is important to assess death anxiety in pain populations given that death anxiety is associated with pain, for pain is a survival treat [7, 8]. These findings need replication as well as variation among different cancer populations, stages, and gender.

Existential well-being was investigated in this study. The confrontation of self with potential non-existence often results from a cancer diagnosis, igniting a process of spiritual exploration and existential crisis or "plight." More specifically, the "existential plight of cancer" refers to the "search for meaning" after a cancer experience [5]. Global meaning defined as the general sense that one's life has order and purpose plays a major role in overall quality of life; indeed, it can motivate cancer patients to re-engage in life amidst physiological, psychosocial, social, spiritual, and existential changes fueled by the disease [24]. In this study, scores for existential well-being increased significantly by the end of the intervention, thus replicating the single previous study [6]. These findings make logical as well as intuitive sense; that is, an increased feeling of existential well-being would parallel a decrease in death distress.

Pain anxiety was investigated in this study. In fear–anxiety–avoidance models of chronic pain, pain-related anxiety contributes to the development and maintenance of chronic pain [7, 8]. Recall that anxiety model processes are similar to models of chronic pain, for anxiety disorders either follow from, or are exacerbated by negative experiences such as chronic pain and are associated with catastrophic cognitions and major distress [7]. Results here showed that scores prior to the mindfulness program decreased significantly following the intervention in this group of women. These findings align with previous results from a recent MBSR study of women with breast cancer that found significant improvement in pain-related anxiety after the intervention [10].

In the death literature, pain and suffering have been speculated to initiate an escape orientation towards death where death becomes attractive in the face of psychological and existential pain and physical suffering. This was the first MBSR study to explore any death attitudes or orientations in those diagnosed with cancer. Results showed a slight decrease in scores pre-to-post the intervention but did not reach significance. One reason for this finding may be that the intervention was not long enough in weeks needed to induce change because ingrained attitudes and beliefs are more difficult to alter. Another possibility is that the program simply does not influence attitudes toward death.

Limitations must to be acknowledged. First, this study dealt with women with breast cancer, therefore ,findings cannot be generalized to other chronic or life-threatening disease populations such as cardio-vascular disease, or other oncology populations. Secondly, another limitation involves the passage of time. The eight weeks of intervention may have played a role in the findings, for this period of time intervention applied. Next, the participants were primarily Caucasian, which questions how results would differ in women of different ethnic origins. Lastly, participants were not randomly assigned to multiple treatment conditions.

This study adds to the paucity of literature about the efficacy of mindfulness in those diagnosed with cancer where death and dying still may be synonymous with the word "cancer." Rumination and catastrophizing are the opposite of mindfulness which exemplifies an intentional and flexible self-regulation of the present moment where an individual accepts each moment non-judgmentally. In conclusion, death and dying distress, existential well-being, and pain anxiety scores showed significant improvement after the program; the death attitude of escape scores showed no significant

changes from pre-to-post. Individuals with a life-threatening disease need not only narcotics to help them deal with physical suffering, but also, complementary options in conjunction with standard medical treatment that can ameliorate psychological distress associated with issues of pain and death.

Competing Interests

The author declares that no competing interests exist.

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