

The existential plight of cancer: meaning making as a concrete approach to the intangible search for meaning

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Abstract

Introduction Despite modern advances that have led to improved prognoses and symptom management, a cancer diagnosis continues to evoke images of pain, suffering, and death.

Discussion The current literature suggests that the “existential plight of cancer” refers to what is now commonly known as the “search for meaning” following a cancer experience. Mounting 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. It provides the motivation for people with cancer to reengage in life amongst a bewildering array of physical, psychosocial, social, spiritual, and existential changes imposed by the disease. Health care providers are inherently involved in their patients’ search for global meaning. Yet, few empirical

studies have operationalized how this search can be achieved.

Conclusion The meaning-making intervention is presented as one concrete approach to address the normative distress associated with the search for meaning within the context of cancer.

Keywords Existential plight · Cancer · Meaning-making coping · Psychological adjustment

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Introduction

Supportive care for cancer patients takes on many forms. Medical, technological, pharmacological, and epidemiological advances have dramatically increased our understanding, treatment, and care of the person diagnosed with cancer. However, despite these modern advances that are leading to earlier detection and treatment, better symptom management, and longer survival times, cancer is still one of the most feared diseases.

The purpose of this paper is to provide an overview of the current understanding about the existential plight of cancer and to suggest that the emerging evidence around meaning-making coping in the context of cancer will provide a useful framework to understand and manage cancer-related existential distress.

The existential plight of cancer

Historically, the fear of cancer can be traced to medieval times when people died shortly after diagnosis from advanced disease or from limited medical knowledge in which the only available treatment was surgery under very

poor conditions [32]. In the early to mid 1900s, the discovery of chemotherapy and radiotherapy offered hope in terms of longer survival from cancer, but people came to fear the pain, physical suffering, and disfigurement that were common side effects of these treatments [32].

The inevitability of death associated with cancer is often one of the first confrontations that people have with their own mortality. From the perspective of terror management theory, people are innately motivated towards self-preservation and actively try to avoid reminders of one's tenuous existence [2]. When juxtaposed with the unique human ability to contemplate time and causal relationships as well as the instinctual drive to find a concrete purpose to one's existence [24], an awareness of one's imminent death often initiates an "existential plight." The term 'existential plight,' coined by Weisman and Worden [63], describes the exacerbation of thoughts about one's existence and potential for nonexistence following a diagnosis of cancer. Since then, the existential plight of cancer has become a major focus in the psychosocial oncology literature. A recent proliferation of studies indicates that the existential plight of cancer is not culturally dependent. Numerous studies have explored the profound existential issues faced by cancer patients from Australia [38, 48, 49], Japan [51], Norway [42], Sweden [5, 37], Israel [3, 4], UK [30], and North America [6, 9, 31, 45, 59].

While the existential plight of cancer may be a common phenomenon, variations exist in the level of distress associated with such contemplation. Thoughts about one's mortality and purpose in life following a cancer diagnosis can range from a normative awareness of one's existence that does not necessarily result in psychological suffering [4] to a persistent state of demoralization that is characterized by severe, unrelenting feelings of hopelessness, helplessness, isolation, pessimism, and a sense of being trapped towards a meaningless future [38]. Variation also exists in the onset, occurrence, and duration of the existential plight. Although the landmark study by Weisman and Worden [63] circumscribed the existential plight of cancer to begin with diagnosis and last until the distress subsides approximately 100 days later, indeed, some patients may experience a more obscure phenomenon that waxes and wanes throughout the individual's journey with cancer, heightening at transition points that are characterized with greater uncertainty [64].

To explain these variations, researchers suggest that the degree of distress experienced by the patient is not related to the objective prognosis indicated by the histological stage of cancer but rather to the appraisal of life threat that is associated with cancer [43]. Meaning theory posits that people hold a "global meaning" which is a personalized life schema built upon a set of beliefs and assumptions to provide a sense of order and purpose in life [53, 60]. Global

meaning allows individuals to get up in the morning, go about a daily routine, and strive for long-term goals. This overall global meaning is based on a set of illusions that are characteristic and essential for normal mental health. Such illusions include overly positive beliefs about the self and expectations that there will always be tomorrow, that good people deserve good things happening to them, that it is possible to plan ahead into the future, and that the future looks bright [2, 36, 58]. This set of positive illusions generally remains unexamined until something goes wrong such as being diagnosed with cancer.

When cancer strikes, the belief system that once provided a sense of stability, familiarity, and security are called into question. The goals that were set out for the future may no longer appear realistic or attainable. It appears that the 'existential plight of cancer' may be referring to what is now known in the current literature as the "search for meaning"—a normative but distressing psychological process in which the individual attempts to appraise the impact of cancer on his or her life and understanding of the world [44, 53]. This is the process by which patients struggle to retain what is personally meaningful when virtually every aspect of their life will be threatened by changes imposed by the cancer and its management. In an effort to assimilate or accommodate the reality of the cancer experience, patients undergo a cognitive process that may involve exposure to recurrent and intrusive thoughts about aspects of the cancer experience, and avoidant behaviors when the distress associated with this exposure becomes overwhelming and respite is needed [14]. The cognitive process is reported to be a necessary, though psychologically and emotionally difficult, phase. Studies have shown that frequency of intrusive thoughts or the use of avoidant-type coping styles has been associated with greater psychological distress [19, 62]. However, a number of studies also indicate that not all patients with cancer search for meaning [16, 25, 57]. More research is needed to understand the individual variations of the process of searching for meaning, for example, when it is initiated, when it is revisited, and how it is affected by the patient's changing clinical status as the individual transitions along the cancer trajectory.

Individuals who successfully complete the process of searching for meaning often emerge with a sense of renewal, greater self-awareness and personal growth, as well as a greater appreciation for life, nature, and compassion to others [44, 59]. This phase of the meaning-making process is theorized to occur when the limitations imposed by the cancer becomes incorporated into a newly reconstituted life schema that once again provides a sense of order and purpose. Although it might appear paradoxical and even contradictory to expect that the mortality salience and struggle that follows a diagnosis of cancer may act as a

catalyst for positive changes in an individual's life, the body of literature related to post-traumatic growth and benefit finding following cancer continues to grow at a steady pace [55, 56, 59].

Meaning-oriented interventions

The empirical evidence is rapidly emerging to suggest that meaning-making coping is a critical mediator between cancer-related distress and psychological well-being and may be the possible mechanism to explain the coexistence of positive and negative psychological states following cancer [22, 23, 53]. In light of this growing knowledge base about meaning-making coping, and by virtue of our privileged position to accompany patients in their journey from diagnosis to death, clinicians are inherently implicated to help the patient make sense of their existential plight. Cancer patients often turn to health care professionals to help them make sense of the overwhelming array of information that confronts them. With the exception of one randomized controlled trial [47], early recommendations for the use of meaning-oriented interventions to address the existential questions and issues associated with cancer were more clinically and intuitively based, rather than theoretically or empirically based [20, 35, 52]. Meaning-oriented strategies have evolved in the past decade and are commonly embedded in multi-modal supportive care interventions for cancer patients [10–12, 15, 29, 39, 40] or as the sole focus of newer psychological interventions [28, 13]. Although the effectiveness of psychological interventions for cancer patients has been established [1, 18, 21, 50, 61], several challenges confront the development of interventions that are specifically dedicated to meaning-making coping strategies: (1) the ability to generalize across the many variations of the cancer experience needs to be counter-balanced with the ability to individualize to each patient's particular life situation, (2) the need to be complementary and not in competition with current treatments, and (3) the need for acceptability and relevance by the patient.

The Meaning-Making intervention

The meaning-making intervention (MMi) for cancer patients is a novel psychological intervention that was designed specifically for health care professionals to address their patients' cancer-related existential issues. The phased development and testing of the MMi represents one of the first published attempts to quantify the effect of meaning-making coping on psychological well-being. The theoretical underpinnings to the MMi was based on Park and Folkman's [53] extension of the "Transactional Model of Stress and

Coping" as well as the results from a systematic literature review of studies related to meaning in the context of cancer from the nursing, medical, and psychological disciplines [44]. The clinical component of the MMi was premised on the McGill Model of Nursing [26, 27] which is a collaborative approach to engage patients in a process of learning about their own strengths and skills in order to become active participants in their own care and development as human beings. The MMi for cancer patients [Lee 2004, unpublished manual] was developed following completion of a pilot study which adapted an existing intervention that had been initially created for trauma patients with life-threatening injuries [Grossman and Lee, unpublished manuscript]. The purpose of the pilot study was to determine (1) the relevant themes for cancer patients undergoing the meaning-making process, (2) the most appropriate method of introducing each theme and in what sequence, and (3) the patient outcomes that were the most responsive to the effects of the MMi [45]. Thus, a thoughtfully established theoretical basis provided the potential for the MMi to generalize to a spectrum of cancer experiences, while a collaborative nursing model structured its format and delivery to be situation responsive and tailored to each individual's unique life context. The pilot study validated the content for the cancer population, determined the timing and number of sessions, and suggested measurable outcomes that were sensitive to the effects of the MMi.

The application of the MMi is based on three tasks using a "Lifeline" exercise that is completed in a collaborative partnership between the patient and the clinician. The three tasks are sequentially ordered (1) to recognize the normative distress and facilitate the grieving process associated with coming to terms with a cancer diagnosis [59], (2) to avoid forcing an inappropriate and untimely burden on patients to "think positively" [33, 54], and (3) to prepare the patient to gradually confront that which is considered to be the more threatening aspects of their particular situation. However, situation responsiveness is also a key feature of the MMi that would allow for flexibility within the ordered tasks. That is, although the clinician is following the suggested format of the MMi, the clinician must be attentive to the cues from the patient who is ultimately responsible for guiding the pace and timing of the MMi. For example, progression through the tasks may necessitate immediately addressing elements that occur later in the tasks, revisiting previously completed tasks, or attending to the patient's physical comfort and concerns regarding symptom management issues before returning to the recommended sequence of tasks.

'Lifeline exercise' and task completion of the MMi The results of the pilot study suggested that the 'Lifeline'

exercise (see Fig. 1) was considered a systematic but natural and acceptable approach by patients to initiate a nonthreatening discussion about the personal impact of cancer and to facilitate a personal reflection about the purpose of one's existence in relation to the cancer diagnosis. Patients receive a brief introduction that includes information about the normative reactions expected during life-threatening illness, the process of moving through life transitions [7], and the influence of beliefs and past experiences on present and future responses. Patients are then presented with a blank piece of paper on which a single horizontal line is printed across the middle of the page. Patients are asked to imagine that the left side of the line represents when they were born, the right side of the line represents the end of their physical life, and to draw a circle on the lifeline to represent their "self" and where they think they are now given the cancer diagnosis. Patients are free to adjust this linear representation of life depending on their personal belief systems.

In the first task, patients are encouraged to "tell their story" from the point of diagnosis to the present. The clinician enriches the recall of the patient's experience by asking the patient to consider the symptoms that led to seeking medical attention, their immediate and ensuing thoughts, feelings, actions, and who they told or did not tell, as well as what has changed and not changed in their life since the diagnosis and subsequent management of cancer. The purpose of this session is (1) to facilitate the grieving process by acknowledging the losses and the gravity of their situation, (2) to demonstrate that there are still aspects of their lives that they continue to retain control over, and most importantly (3) to introduce the idea that positive elements can coexist with the negative aspects of their lives.

In the second task, patients are asked to identify other critical turning points prior to the diagnosis of cancer. These are sequentially labeled to the left of their circle ("the self") for discussion. As patients continue with their narrative of each of these life-turning events, the clinician encourages the patient to explicitly identify the strengths and coping strategies that had previously been used to deal with these past challenges that were equally as unexpected as the present situation with cancer. The purpose of this task is to remove the sense of being engulfed by the threat of cancer and to embed the cancer experience within an existing framework of past coping strategies and strengths that may be carried over to the present situation with cancer. This task also affords an opportunity to introduce new coping strategies that might be experimented in the present situation.

Finally, in the third task, patients are encouraged to think about how to live life as fully as possible given their experience of cancer. Important life goals and activities are identified and labelled to the right of the circle. This third

task is presented as an opportunity for patients to discuss their thoughts about the uncertainty of the future against a backdrop of strengths that has allowed them to master past challenges and now includes survival since the cancer diagnosis. For those who are ready and willing, this third task usually leads to more in-depth discussions about confronting future unknowns that may include not meeting expectations, worries or plans about death and dying, or the fear of recurrence. The stark realization that they may not live as long as they had previously thought often serves as an impetus to make realistic short-term and long-term goals given the uncertainty of the future. It is not unusual for some patients to only allude to a shortened lifespan and purposefully avoid use of the word "death" but most patients willingly participate in discussions about what they look forward to in a future-oriented timeframe that they are comfortable with (e.g., the next day, week, month, and year).

Ethical considerations The need to respect the patient's wish to temporarily withdraw from discussing emotionally difficult issues is paramount throughout the duration of the intervention, particularly when patients begin to address the more threatening aspects of their situation such as uncertainty about their future, potential for recurrence, or thoughts about their mortality. Some patients may not wish to explore the deeper existential meaning of their situation with cancer because the implications may be considered too overwhelming and they may not feel emotionally ready. Although there is a small risk of eliciting some emotional distress from the MMi discussions when the patient is not willing to consider the topic introduced by the clinician, or when the topic of benefit or psychological growth is raised prematurely or inappropriately, the storytelling approach that is used within the MMi would allow the patient the right to choose to delve into only those areas that he feels ready to discuss. Ostensibly, the MMi could not create a greater emotional burden than what is already generated by the cancer situation. On the contrary, the MMi would be a useful tool to alert the clinician to provide proper treatment and follow-up if it was discovered during the MMi discussions that a patient had long-standing psychological issues or that a patient's level of demoralization included thoughts of hastened death or suicidal ideation. In such cases, referrals for additional psychological or psychiatric support may be necessary.

Research directions The efficacy of the MMi had been initially tested in a randomized controlled trial with 74 newly diagnosed breast and colorectal cancer patients who were actively receiving anticancer treatment in an ambulatory care clinic [46]. All participants completed pre-test measures for self-esteem, optimism, and self-efficacy prior to being randomized to either the experimental group ($n=35$) or the

Fig. 1 Hypothetical example of a completed “Lifeline exercise”

FIRST TASK: ACKNOWLEDGE THE PRESENT

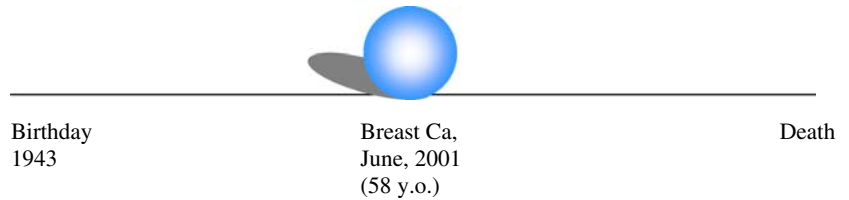
Patients are encouraged to “tell their story” from diagnosis to present

Rationale:

Facilitates grieving within safe, non-judgmental context

Preserves a sense of control by acknowledging what was and what is, what can and cannot be changed.

Demonstrate the co-existence of negative and positive in life

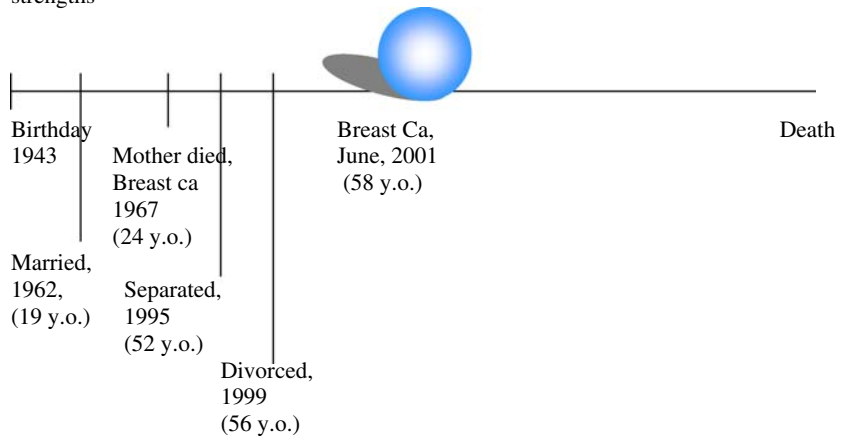


TASK 2: CONTEMPLATE THE PAST

Patients are encouraged to talk about pivotal life events prior to their diagnosis of cancer.

Rationale:

Embeds the cancer experience within existing framework of past coping strategies and strengths

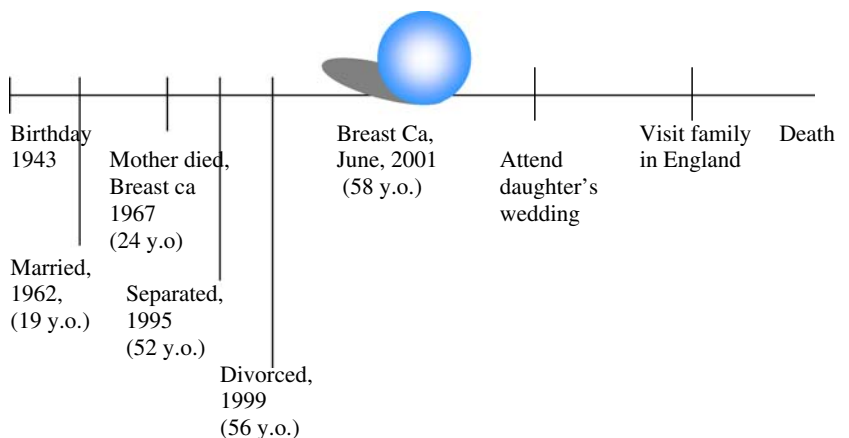


TASK 3 : LIVE THE PRESENT, FOR THE FUTURE

Patients are encouraged to talk about how to live life as fully as possible in the context of cancer

Rationale:

Awareness of a shortened lifespan can lead to concrete plans to achieve important life goals



control group ($n=39$). On average, participants in the experimental group completed the three MMi tasks within two to three sessions that ranged from 15 to 120 min in length. Post-test measures were completed within 24 h of the last session. After controlling for baseline pretreatment scores, results from an analysis of covariance indicated that participants who received the MMi significantly improved on each outcome variable compared to the participants who received usual care. Given the encouraging results from the completed trial, two randomized controlled trials are currently in progress to adapt and further test the efficacy of the intervention with newly diagnosed advanced-stage ovarian cancer patients, as well as with the caregivers of patients with late-stage cancer (Henry, Cohen, Lee, & Mayo, in progress). Future research directions include exploratory studies to determine the relationships between meaning-making coping and common cancer-related symptoms such as level of physical activity, fatigue, sleep disturbance, and the perception of pain.

Currently, effectiveness studies are being planned to adapt the MMi into a shorter version to determine the dose (number, duration, and frequency of sessions), timing (when to deliver in terms of patient readiness and nurse workload), approach (which strategies are most feasible to deliver at bedside), delivery by whom (what type and level of preparation is needed on the part of the nurse who delivers the MMi), and potential outcomes. It is considered a priority that the format and use of the MMi be tested for feasibility in order to complement, and not compete with, other clinical priorities in the everyday context. For example, currently at the McGill Cancer Nutrition Rehabilitation Program, the MMi and the “Lifeline” are being explored as a clinical framework from which to understand the individuals’ responses and reactions in order to help them reengage in a life that is meaningful despite the limitations imposed by the cancer and its management. The treatment plan is jointly determined by an interdisciplinary team composed of an oncologist–palliative care physician, two nurses, physiotherapist, nutritionist, occupational therapist, clinical psychologist, and social worker. Each health care professional assesses the particular symptom(s) that are within their respective domains of expertise and skill and purposefully explores the patients’ previous, current, and anticipated life context. Treatment recommendations are framed and communicated to the patient with reference to their life context and goals in order to remove a sole focus away from the cancer and towards what gives purpose and meaning to the individual.

Conclusion

Meaning-oriented existential interventions are increasingly promoted as compelling clinical approaches that have the

potential for conferring dramatic insight and self-awareness into one’s life affected by cancer. A broadened life perspective that positive and meaningful experiences can co-occur with the turmoil of the cancer experience can paradoxically follow from discussions that include an acknowledgement of one’s shortened lifespan. Creative, evidence-based approaches are needed to facilitate a dialog with patients so that quality of life, and not always the treatment and management of the illness, becomes one of the guiding forces in their search for meaning following cancer. The MMi is presented here as one approach that may bring us one step closer to this goal.

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