Psychotherapeutic Interventions at the End of Life: A Focus on Meaning and Spirituality

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Medical and psychological discourse on end-of-life care has steadily shifted over the years from focusing primarily on symptom control and pain management to incorporating more person-centred approaches to patient care. Such approaches underscore the significance of spirituality and meaning making as important resources for coping with emotional and existential suffering as one nears death. Though existential themes are omnipresent in end-of-life care, little has been written about their foundations or import for palliative care practitioners and patients in need. In this article, we explore the existential foundations of meaning and spirituality in light of terminal illness and palliative care. We discuss existential themes in terms of patients' awareness of death and search for meaning and practitioners' promotion of personal agency and responsibility as patients face life-and-death issues. Viktor Frankl's existential logotherapy is discussed in light of emerging psychotherapeutic interventions. Meaning-centred group therapy is one such novel modality that has successfully integrated themes of meaning and spirituality into end-of-life care. We further explore spiritual and existential themes through this meaning-oriented approach that encourages dying patients to find meaning and purpose in living until their death.

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Clinical Implications

- As they face their final stages of life, dying patients require attention to their physical, emotional, and psychological needs.
- Palliative care literature has emphasized the need for greater focus on spiritual and existential therapeutic interventions in end-of-life care.
- Spirituality and existential approaches (that is, existential foundations of meaning and spirituality) form the basis for emerging novel therapeutic modalities to meet this growing need.

Limitations

- This review bases its conclusions on limited empirical data.
- This article offers a general overview and framework for understanding existential issues in end-of-life care. It does not represent a comprehensive review of existential literature on this topic.
- This review focuses primarily on cancer populations and does not fully address the issues and needs of other populations (for example, AIDS or cardiac disease patients)

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> Whoever rightly understands and celebrates death, at the same time magnifies life.
>
> —Rainer Maria Rilke

As the struggles and needs of patients facing the end of life are better understood, long-standing concepts of adequate end-of-life care must be expanded beyond symptom control alone to include psychiatric, psychosocial, existential, and spiritual domains (1–5). Such refocusing is all the more important as we recognize that symptoms of psychological distress and existential concerns are even more prevalent than pain and other physical symptoms (6). This realization has led both medical professionals and cancer patients themselves to identify psychological and spiritual domains of end-of-life care as priorities.

For example, 40% of the respondents to a Gallup Poll (7) on spiritual beliefs and the dying process said that, if they were dying, it would be "very important" to have a doctor who was attuned to them spiritually; 50% to 60% said that, when they think of their own deaths, their greatest concerns are not being forgiven by God; not reconciling with others; and, in dying, being removed or cut off from God or a higher power. Clearly, patients require more attention to the existential crisis of meaning that serious illness engenders. Unfortunately, we health care providers often view patients as clusters of syndromes and focus our efforts on symptom relief and reduction. Although this approach may be effective on one level, it ignores the human experience of life-threatening illness.

This article reviews the foundations of meaning and spirituality at the end of life and underscores the complex existential issues that can occur at various stages of life-threatening illnesses. We discuss the issue of meaning with reference both to its existential underpinnings and to the current literature. We address spirituality in terms of patient suffering and the extent to which spiritual aspects of death and dying have been integrated into end-of-life care. We discuss emerging psychotherapeutic interventions (for example, meaning-centred group psychotherapy) to highlight novel modalities that integrate meaning and spirituality into end-of-life care.

Meaning in Palliative Care

In the nexus between cognitive reasoning and personal feeling lies the realm of meaning. The process of meaning making becomes vitally significant as one faces the physical pain of disease and the emotional suffering of separating from life and loved ones (6–11). Death punctuates life, giving it solidity and meaning. This meaning is no longer vague or trivial; rather, it becomes imbued with a sense of urgency and signification that must be discovered, not imposed. Finding meaning at the end of life is no small endeavour: it takes courage, commitment, and conviction to reflect upon and take ownership of one's own existence (12–14).

Especially at death, "meaning" reflects a certain spatiotemporal horizon of living and becoming. The space of one's diseased body (that is, Merleau-Ponty's notion of "embodiment"; 15) and the time of one's impending death (that is, Heidegger's notion of "being-toward-death"; 16) factor heavily into how patients find meaning at the end of life. For example, a woman suffering from end-stage metastatic breast cancer may find historical meaning in facing her scarred chest. In the absence of her breast, she may reflect upon past meanings imbued with the presence of her former breast (for example, feelings of femininity, motherhood, and sexuality). Her scarred chest may also elicit anxiety because it implies her impending death.

Palliative care practitioners may seize the opportunity to encourage patients to find meaning in suffering as they face death. This meaning-making process can be generative for patients: feelings of anxiety, guilt, or hopelessness that seem punishing and unrelenting at the end of life can be transformed into ways of actively exploring the relationship to self and others.

By understanding the meanings associated with suffering, patients may begin to actively transform their feelings into signals that elicit an actively engaged response to living and dying. For example, instead of feeling stifled and disempowered by overwhelming anxiety or sadness, patients may actively seek to derive meanings from these feelings. According to van Deurzen, existential anxiety is

> that basic unease which we experience as soon as we become self-conscious and aware of our vulnerability and possible death . . . It is a measure of the extent to which we face up to the basic question of whether we will be or not be (17, p 61).

The meaning of guilt may shift from not measuring up to others' expectations to not meeting one's own needs and not fulfilling one's own potential. Again, van Deurzen describes existential guilt as "a reminder of what you owe to yourself. Only to the extent that you take up this existential challenge will you experience a strong sense of being in charge of your own life" (17, p 212). By exploring the meanings associated with anxiety and guilt at the end of life, we may use our experiences as tools to integrate our life into a meaningful whole. Negative emotions change from impediments to sources of healing and instruments to promote emotional and spiritual well-being.

Spirituality and Life-Threatening Medical Illness

Both medical professionals and patients have identified spiritual domains of supportive care as priorities. The Institute of Medicine report *Approaching Death: Improving Care at the End of Life* identified the domains of quality supportive care from the professional perspective (18). These domains are overall quality of life, physical well-being and functioning, psychosocial well-being and functioning, spiritual well-being, patient perception of care, and family well being and functioning. Singer and colleagues conducted an extensive qualitative study of cancer patients' perspectives on the most important domains of supportive care (19). For cancer patients, the domains of quality care include receiving adequate treatment for pain and symptom control, avoiding inappropriate prolongation of dying, achieving a sense of spiritual peace, relieving burden, and strengthening relationships with loved ones. Clearly, for both patient and physician, spirituality issues are essential elements of quality palliative care.

Several studies have indicated great interest in the impact on health outcomes of spirituality, faith, and religious beliefs, as well as in their palliative care role (20–24). In their review of the literature, Sloan and colleagues concluded that evidence supporting an association between religion and health was weak and inconsistent and that it was premature to promote faith and religion as adjunctive medical treatments (20). Another review of the literature on the relation between religion and depression suggests that individuals with high levels of religious involvement, organizational religious involvement, religious salience, and intrinsic religious motivation are at reduced risk for depression, while private religious activity and particular religious beliefs have no relation to depression (21). Elderly men who use religious beliefs or practices as a means of coping with physical illness appear to suffer less depression than their nonreligious peers (23). Religious beliefs may help patients construct meaning in regard to suffering associated with illness, which may facilitate coping and acceptance (24). Other recent studies have shown that religion and spirituality generally play a positive role in patients' coping with illnesses such as cancer or HIV (22,25,26).

As well, several recent studies among advanced cancer patients have demonstrated that spiritual well-being and meaning have a central role as buffers against depression, hopelessness, and desire for hastened death (26–28). Although spiritual well-being, as measured by the Functional Assessment of Chronic Illness Therapy–Spiritual Well-Being Scale (FACIT-Sp) (29), seems to diminish the incidence of depression, hopelessness, and desire for death, the Meaning–Peace subscale of the FACIT-Sp has the most significant influence. These findings are important in view of the consequences of depression and hopelessness for palliative patients. Depression and hopelessness are associated with poorer survival rates in cancer patients and with dramatically higher rates of suicide, suicidal ideation, desire for hastened death, and interest in physician-assisted suicide (27,30–32). Clearly, interventions for cancer patients that address depression, hopelessness, and loss of meaning and affect desire for death or spiritual suffering (4) are needed.

Addressing Spiritual Suffering

Palliative care practitioners have begun to recognize the importance of spiritual suffering and the need to design appropriate interventions to address it (4,5). Rousseau has developed an approach for the treatment of spiritual suffering that centres on 1) controlling physical symptoms; 2) providing a supportive presence; 3) encouraging life review to help recognize purpose, value, and meaning; 4) exploring guilt, remorse, forgiveness, and reconciliation; 5) facilitating religious expression; 6) reframing goals; and 7) encouraging meditative practices focused on healing rather than on cure (4). Rousseau's approach to spiritual suffering is an interesting blend of basic psychotherapeutic principles common to many psychotherapies. He emphasizes facilitating religious expression and confession, which may be extremely useful to many patients. It is not, however, applicable to all patients, and many clinicians may not feel comfortable providing it.

The Role of Spirituality in Meaning Making

Meaning making is not just a cognitive construct. As humans, we strive to incorporate and synthesize a vast inner and outer world. Park and Folkman (33) review meaning in the context of stress and coping and describe conceptual models for meaning in relation to traumatic events and coping. They describe meaning as a general life orientation, as personal significance, as causality, as a coping mechanism, and as an outcome. Positive psychological changes and an improved sense of meaning in life have been associated with cancer (34). In their work with patients, cancer professionals witness many examples of positive life change and positive reappraisals of the value and meaning of life (35–37).

Puchalski and Romer define spirituality as "that which allows a person to experience transcendent meaning in life" (5). According to Karasu (38) and Brady and others (29), spirituality is a construct that involves concepts of faith and (or) meaning. Faith is a belief in a higher transcendent power, not necessarily identified as God and not necessarily achieved through the rituals or beliefs of an organized religion.

The importance of addressing spirituality in palliative care is becoming apparent. Spiritual well-being and a sense of meaning and peace appear to substantially benefit persons suffering psychological distress at the end of life. Brady and colleagues (29) found that cancer patients who reported a high degree of meaning in their lives were able to tolerate severe physical symptoms more than patients who reported lower scores on measures of meaning and peace. Patients with a high sense of meaning reported high satisfaction with their quality of life, despite pain and fatigue, compared with patients with a low sense of meaning.

Such findings demonstrate that levels of spiritual well-being and a sense of meaning are powerful predictors of both levels of hopelessness and desire for death in terminally ill cancer patients. Not only did these variables show a strong negative correlation with measures of hopelessness and desire for death, these associations were also independent of the effect of depression. This further supports the importance of developing and assessing interventions that focus on increasing or maintaining a sense of meaning and purpose. These interventions may substantially reduce hopelessness and desire for hastened death at the end of life. Our research group has been able to demonstrate a significant role for spiritual well-being

and meaning as a protection against depression, hopelessness, and desire for hastened death within terminally ill cancer patients; any effective psychotherapeutic intervention for meaning should include issues of spirituality.

Emerging Psychotherapeutic Interventions in the Terminally Ill

Clinicians frequently underestimate the potential benefits of psychotherapy for seriously medically ill patients, especially in patients who are months away from death (39). This bias is reflected in the dearth of clinical research on psychotherapeutic interventions within this population. However, a range of psychotherapeutic approaches have proven to be effective for patients struggling with advanced, life-threatening medical illness (11).

A small but growing literature is developing on psychotherapeutic interventions for palliative care patients. These approaches are grounded in nontraditional, alternative, or spiritually based theoretical perspectives ranging from yoga, meditation, and Buddhist philosophy (40) to perspectives based on concepts of self-transcendence (41–44) and Viktor Frankl's logotherapy (45–47). Kissane has been developing an intervention aimed at targeting "demoralization syndrome" among cancer patients (48,49). In addition, Chochinov and colleagues have conducted work on a "dignity-conserving intervention" for patients at the end of life (33). Breitbart and colleagues have developed interventions for spiritual suffering in the terminally ill that focus on increasing patients' sense of meaning and purpose in life (8–11). This meaning-centred approach is deeply rooted in existential theory and therapeutic practice. The following section briefly delineates these fundamental existential themes and their bearing on end-of-life care.

Existential Psychotherapy

> He who has a why to live for can bear with almost any how.
>
> — Friedrich Nietzsche

Existential psychotherapy emerged as an outgrowth of existentialism, which was founded by 19th-century philosophers Friedrich Nietzsche and Soren Kirkegaard and further developed by influential 20th-century philosophers Jean-Paul Sartre, Martin Heidegger, Martin Buber, Maurice Merleau-Ponty, and Emmanuel Levinas. Several key existential psychotherapists have since developed therapeutic modalities centred on the existential philosophy of being human. Medard Boss (50) developed an existential psychotherapy, "daseinsanalysis," which is based on Heidegger's philosophy of "*dasein*," a term reflecting the human way of being in the world. Viktor Frankl's "logotherapy" is based on his experiences as a prisoner in a German concentration camp (12). Most notably, he integrated Nietzsche's concepts of the "will to power" and "overcoming," which formed the basis for his concepts of "the will to meaning" and "self-transcendence" (51,52). Contemporary existential psychotherapists such as Rollo May (53), Irvin Yalom (54), Adrian Van Kaam (55), and Emmy van Deurzen (17) have all made significant contributions toward advancing the theory and practice of existential psychotherapy.

While the subject matter of existential psychotherapy is well suited to end-of-life care, surprisingly little has been written on this topic (56). Existential therapy explores what it means to be human in light of our shared human condition; that is, we may live infinite possibilities, but we are essentially finite creatures. Fischer delineated the following 6 propositions that underlie the basis of existential psychotherapy and that may help to guide and inform work with dying patients (57):

- The capacity for self-awareness (for example, we are finite, yet we have the potential to continually grow and become until we die)
- Freedom and responsibility (for example, we can make the commitment to authentically choose a life for ourselves)
- The need for centre and the need for others (for example, we can have the courage to be, as well as the experience of aloneness and relatedness)
- The search for meaning (for example, we have the capacity to discard old values, to freely choose new ones, and to continually question and challenge the meaning of life)
- Anxiety as a condition of living (for example, we can experience anxiety as a source of growth, and we can experience the escape from anxiety)
- Awareness of death and nonbeing (for example, the very realization of eventual nonbeing gives meaning to existence, because it makes every human act count).

The value of existential psychotherapy in end-of-life care is that it encourages patients to seriously explore their past, present, and future in terms of meaningful choices and the experiences that created and continue to generate their story. By challenging the notions of heightened awareness, personal freedom, and responsibility, patients begin to meaningfully reflect upon and take ownership of the lives they have chosen and of the possibilities that are still available until the moment of their death. By helping patients explore the "why" of their existence (for example, "Why am I here?") and the meaning of their lives (for example, "Did my life matter?"), existential therapists offer dying patients a way to bear the burden of their suffering and eventual death with strength and dignity.

Existential Foundations of Meaning and Spirituality at the End of Life

Nowhere in medical practice are such existential issues more profoundly evident than in end-of-life care (56). The paradoxical nature of human existence—that is, fundamental themes concerning life and death, hope and despair, relation and isolation, absence and presence—pervades work with the dying. It is therefore important to understand the existential foundations of how one finds meaning in the paradoxes of life as one faces death.

Existential psychology is rooted in a rich philosophical history that emphasizes each human being's unique capacity to freely choose to become aware of and responsible for his or her own existence. Primary existential themes such as human freedom (58), agency and responsibility (16,59), self-transcendence (12), and the quest for meaning (12,51,52) take on significant import as one comes to terms with life while confronting imminent death.

There is no greater existential crisis than that of facing one's own death. Existentialism is based on the fundamental premise that human beings have the unique capacity to question and reflect upon their own existence, that is, "to be or not to be" (16). We are fundamentally aware of our existence, as well as of our potential for nonexistence. Although we are endowed with incredible faculties to reason about and comprehend our lives, we are faced with the existential quandary that we cannot predict or control our death. The way human beings live their lives in the face of such finitude creates the framework for existential psychology. Issues related to patient anxiety (for example, Heidegger's notion of "existential angst" as "being-toward-death"; 16), guilt (for example, Heidegger's notion of "indebtedness to being"; 16), and denial (for example, Sartre's notion of "bad faith"; 58) factor heavily into this process. Finding meaning (12) and a reason for being alive (Sartre's notion of "*raison d'etre*"; 58) become pivotal existential resources for helping patients reconcile with their past, come to terms with their present, and accept an uncertain future.

Although such existential themes may seem foreboding, they hold significant potential for promoting meaningful reflection and transformation at the end of life. Frankl held the conviction that, "meaning can be found in life literally up to the last moment, up to the last breath, in the face of death" (51, p 76). He suggested that finding meaning in one's suffering created an optimistic shift that could "transform despair into triumph" (51, p ix). The existential aim is to liberate patients from being passive victims of circumstance and invite them to become active participants in their lives via heightened awareness and responsibility. Taking meaningful ownership of one's life, feelings, choices, and beliefs promotes authentic relatedness with oneself, the world, and others (16,60,61).

Frankl's "tragic triad" of suffering, guilt, and death (51) become less threatening as one actively pursues the meanings inherent within them. Feelings of anxiety and panic in the face of a poor prognosis may be quelled by bringing such feelings to active awareness and choosing one's attitude toward them. This process can be liberating and transformative for dying patients. They are encouraged to become the agents, authors, and producers of their unfolding story of life, illness, and death. The emptiness and seeming futility (Frankl's "existential vacuum"; 12,51) of facing one's suffering and death become transformed by active engagement with the meanings of life and living. Death anxiety becomes less something to avoid and evade and more something to explore and learn from. Palliative care practitioners have the privilege of promoting, witnessing, and validating patients' existential explorations within this unfolding dialogue.

Meaning-Centred Group Psychotherapy for Cancer Patients

Building upon Frankl's therapeutic framework (12), Breitbart and colleagues have applied his concepts of meaning-based psychotherapy to address issues of meaning and spiritual suffering in patients with advanced cancer (8–11). Frankl's logotherapy was not designed for the treatment of patients with life-threatening illness. However, his concepts of meaning and spirituality clearly have applications in psychotherapeutic work among patients with advanced medical illness: many seek guidance and help in understanding their illness and sustaining meaning and hope while avoiding overt religious emphasis.

This meaning-centred group psychotherapy (10) uses a mixture of didactics, discussion, and experiential exercises that focus on particular themes related to meaning and advanced cancer. It is designed to help patients with advanced cancer sustain or enhance a sense of meaning, peace, and purpose in their lives.

With this manualized group intervention, patients are assigned readings and homework tailored to each session's theme, which is then discussed in the following session. Although each session focuses on issues of meaning and (or) peace and purpose in life in the face of advanced cancer, expressions of support and emotion are inevitable in each group session (limited, however, by the focus on experiential exercises, didactics, and discussions related to themes focusing on meaning).

In general, this group aims to promote an environment of communal support among cancer patients with similar challenges at an otherwise difficult time in their lives; to facilitate a greater understanding of plausible sources of meaning both before and after the diagnosis of cancer; and, as well as

offering maintenance during illness, to assist participants to discover a sense of meaning in life.

The ultimate goal, however, is to use coping most effectively by enhancing patients' sense of meaning and purpose and to make the most of each group member's remaining time, regardless of how limited that time may be. It is fundamentally important to remember that it is up to the individual members to use the group to find sources of meaning in their lives. Therefore, they are not perceived as passive treatment recipients but, rather, as active participants in the process. This view is essential, because we conceptualize finding meaning as a creative, individual, and active process. Participants must be willing to help create meaning, both for themselves and for the other group members.

This intervention aims to help expand possible sources of meaning by teaching the philosophy of meaning on which the intervention is based; by group exercises and homework for each individual participant; and by open-ended discussion, which may include interpretive comments from group leaders. To promote a heightened sense of personal awareness and meaning in life, the 8 group sessions are categorized under the following specific meaning-centred themes:

- Session 1. Summary of concepts and sources of meaning
- Session 2. Cancer and meaning
- Sessions 3 and 4. Meaning derived from the historical context of life
- Session 5. Meaning derived from attitudinal values
- Session 6. Meaning derived from creative values and responsibility
- Session 7. Meaning derived through experiential values
- Session 8. Termination and feedback.

The Process of Meaning Making Within the Groups

Frankl's work stresses one crucial theme: the longing to find meaning within the content of our lives and within our existence is not just mere coincidence but, rather, is a primary motivating force within humans (12). Frankl believed that life has meaning and never ceases to possess this precious meaning until we die. It is our hope that attaining such a sense of purpose and meaning can help to assuage the distress experienced by group participants.

What one holds as meaningful may change over time with changing circumstances. Although we may have no control over various facets of suffering, Frankl suggests that each individual still has the freedom to choose his or her attitude toward suffering. This essential mutability of meaning has been apparent in our groups. Some common themes noted in the early sessions include helplessness, anger, betrayal, injustice, and physical concerns, as well as interpersonal concerns such as isolation, dependency, envy, and fear of death. In later sessions, we note the emergence of themes such as the afterlife, uncertainty about the future, loss of identity, meaninglessness, and previous experiences with illnesses or the sudden death of other family members and (or) close friends. This progression toward broadening the existential focus is in keeping with Frankl's conception of "human meaning making." It is this metamorphosis of meaning that likely results in the positive outcomes noted thus far in the meaning-centred group psychotherapy approach.

Conclusion

Issues of meaning and spirituality are essential components of the experience of persons facing serious illnesses. They greatly shape how individuals view themselves, their illness, and their future. Health care providers have tended to overlook these aspects of the illness experience, although this is changing as we become aware of their importance and acquire the facility to examine them critically. Meaning-centred group psychotherapy is our attempt to explore the complex relation between meaning and illness. It offers a therapeutic and healing alternative that may help patients confront the existential challenges presented by a life-threatening illness.

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Résumé : Interventions psychothérapeutiques en fin de vie : insistance sur le sens et la spiritualité

L'accent du discours médical et psychologique sur les soins aux personnes en fin de vie est passé de façon constante au fil des ans du contrôle des symptômes et de la douleur à l'incorporation d'approches des soins plus axées sur la personne. Ces approches soulignent l'importance de la spiritualité et de la recherche de sens comme étant des ressources précieuses pour composer avec la souffrance émotionnelle et existentielle à l'approche de la mort. Même si les thèmes existentiels sont omniprésents dans les soins aux personnes en fin de vie, il y a peu de documentation sur leur fondement ou leur signification pour les médecins des soins palliatifs et les patients dans le besoin. Dans cet article, nous examinons les fondements existentiels du sens et de la spiritualité sous l'angle des maladies mortelles et des soins palliatifs. Nous discutons des thèmes existentiels qui touchent la sensibilisation des patients à la mort et la recherche de sens, et la promotion par les médecins de l'action et de la responsabilité personnelles, lorsque les patients font face à des questions de vie et de mort. La logothérapie existentielle de Viktor Frankl est discutée à la lumière des nouvelles interventions psychothérapeutiques. La thérapie de groupe axée sur le sens est une de ces nouvelles modalités qui ont réussi à intégrer les thèmes du sens et de la spiritualité aux soins de fin de vie. Nous examinons ensuite les thèmes spirituels et existentiels au moyen de cette approche axée sur le sens qui incite les patients mourants à trouver un sens et un but à la vie jusqu'à leur mort.