Review Article

Existential Suffering in the Palliative Care Setting: An Integrated Literature Review

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Abstract

Context. Existential and spiritual concerns in relation to palliative end-of-life care have received increasing attention over the past decade.

Objectives. To review the literature specifically related to existential suffering in palliative care in terms of the significance of existential suffering in end-of-life care, definitions, conceptual frameworks, and interventions.

Methods. A systematic approach was undertaken with the aim of identifying emerging themes in the literature. Databases using CINAHL (1980–2009), MEDLINE (1970–2009), and PsychINFO (1980–2009) and the search engine of Google Scholar were searched under the key words existential suffering, existential distress, existential pain, palliative and end of life care.

Results. The search yielded a total of 156 articles; 32% were peer-reviewed empirical research articles, 28% were peer-reviewed theoretical articles, and 14% were reviews or opinion-based articles. After manually searching bibliographies and related reference lists, 64 articles were considered relevant and are discussed in this review. Overall analysis identifies knowledge of the following: 1) emerging themes related to existential suffering, 2) critical review of those identified themes, 3) current gaps in the research literature, and 4) recommendations for future research. Findings from this comprehensive review reveal that existential suffering and deep personal anguish at the end of life are some of the most debilitating conditions that occur in patients who are dying, and yet the way such suffering is treated in the last days is not well understood.

Conclusion. Given the broad range of definitions attributed to existential suffering, palliative care clinicians may need to be mindful of their own choices and consider treatment options from a critical perspective. J Pain Symptom Manage 2011;41:604–618. © 2011 U.S. Cancer Pain Relief Committee. Published by Elsevier Inc. All rights reserved.

Key Words
Palliative care, hospice care, existential suffering, end of life, research review
Introduction

Existential and spiritual concerns at the end of life have received increasing attention over the past decade. Terminally ill patients are frequently confronted with severe existential symptoms and spiritual distress that challenge palliative care providers. Existential and spiritual suffering are among the most debilitating conditions in dying patients and yet are a neglected area of palliative care because of the confusion over definition, lack of conceptual understanding, few documented interventions, and the absence of appropriate training for palliative care providers.

In this article, we identify palliative care literature related to existential suffering in terms of its definition, conceptual frameworks, and interventions, as well as how palliative care providers care for patients experiencing existential suffering. We focused specifically on the concept of existential suffering because of the following: 1) there is a substantial literature citing multiple definitions, 2) an increasing body of literature differentiates between existential and spiritual suffering, 3) the concepts of spirituality and existential issues are often used interchangeably, 4) there is conceptual ambiguity of the term spirituality and debate on its meaning in relation to existential issues, and 5) reports on interventions for existential suffering refer to this condition as a single concept entity.

Existential suffering is related to a number of different factors, and in caring for patients toward the end of life, this phenomenon can be difficult to understand and heal. Existential suffering is associated with other domains at end of life, many of which are interwoven within the broader complexity of suffering. In this discussion, existential suffering toward the end of life is examined as a separate concept. Although issues such as spirituality, hope, transcendence, and meaning and sources of suffering, such as pain and depression, were considered, we chose to examine existential suffering and existential distress to provide an opportunity for further development of knowledge specifically about this aspect of patient suffering.

The emerging interest in existential suffering follows several themes that have been represented to include the following: definitional understandings, the needs of patients, interventions, theories of existential suffering, methods and designs, and responses of palliative providers who care for patients at end of life. Literature on palliative and end-of-life care has begun to address this interest, particularly by recognizing existential suffering as a misunderstood condition for which there is no consensus on treatment. Therefore, the aims of this review are to 1) identify emerging themes related to existential suffering, 2) provide a critical review of those themes, 3) identify gaps in the research literature, and 4) recommend future research.

Methods

To review the most relevant literature on existential suffering or existential distress as a single conceptual entity, a systematic approach was undertaken with the aim of identifying emerging themes in the literature. Databases using CINAHL (1980–2009), MEDLINE (1970–2009), and PsychINFO (1980–2009) and the search engine of Google Scholar were searched under the key words existential suffering, existential distress, existential pain, palliative and end of life care. The search yielded a total of 156 articles, 32% of which were peer-reviewed empirical research articles, 28% were peer-reviewed theoretical articles, and 14% were reviews or opinion-based articles. Articles reporting on the sole concept of spirituality or religion, without explicitly referring to the existential domains in palliative care, were excluded for the purpose of our review. After examination of these articles and manually searching bibliographies and related reference lists, 64 articles were considered relevant and are discussed in this review. Most papers focused on conceptual definitions of existential suffering, approaches, and interventions from a medical and nursing perspective. The articles included in this review discussed patients with an advanced cancer illness or a terminal illness resulting from other conditions and health care providers practicing in palliative or chronic care facilities.

Seven broad themes emerged within the palliative care literature: 1) significance of existential suffering in palliative and end-of-life care, 2) definitions and conceptual understanding of
the term, 3) study designs used to investigate existential suffering, 4) theories related to existential suffering, 5) needs of patients suffering with existential concerns, 6) perspectives of palliative care providers toward existential suffering, and 7) assessment and management of existential suffering.

Significance of Existential Suffering

The primary goal in the provision of palliative care is to improve patients’ quality of life (QOL). Quality-of-life research that focuses on the importance of the patient’s existential well-being has confirmed that effective relief of existential and spiritual suffering can be achieved within the palliative care setting, alongside psychological and physical symptoms,1 through comfort and compassionate care of the dying. Palliative care aims to provide a comprehensive and compassionate approach toward the alleviation of suffering from physical, psychosocial, spiritual, and existential symptoms for people whose illness is not curable. The World Health Organization defines palliative care as “an approach that improves the quality of life of individuals and their families facing problems associated with a life limiting illness, through prevention and relief of suffering by means of identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual.”6 Yet, in spite of attempts to better understand existential suffering as a fundamental requirement of competent palliative care, this debilitating and distressing symptom remains a poorly understood and neglected area of palliative care.7–9 The significance of existential suffering at end of life is, however, clear. Documented reasons for patients wanting to end their lives include depression, social isolation, hopelessness, fear of the future, fear of being a burden to others,10–12 and existential suffering.11,13 Although the importance of existential suffering is well established in the literature, it is rarely the focus of care planning.14,15

Over the past decade, studies have attempted to address the gap in clinicians’ understanding and treatment of existential suffering. Increasing emphasis has been placed on the principles of whole person care and the existential domain as an important factor of QOL in the palliative care setting and throughout the disease trajectory of life-threatening illness.5,16–19

Definitions and Conceptual Understanding

Although research related to spirituality and health has developed from relative obscurity to a thriving field of study over the past 20 years,20 there remains a paucity of research as to how existential issues are understood, managed, and treated in palliative care settings. The concepts of spiritual and existential issues are sometimes used interchangeably in the literature21–23 and are conflated in meaning.24 Existing literature referring to spiritual and existential issues does not always make clear distinctions between how these two concepts are understood. Multiple definitions of existential suffering are evident. In the course of this review, we have identified 56 definitions of the term including those that were simultaneously linked to spirituality.

Descriptors of existential issues with similar definitions to those relating to spirituality generally focus around common themes and include the following: finding meaning; the loss of meaning or purpose in life; and an ultimate sense of wanting to find an answer to the questions “Why am I here?,” “What is the purpose of my life?,” and “What will happen to me after I die?” Other themes include a sense of connectedness, hope or hopelessness, feelings of loneliness, fear of being a burden to others, a sense of isolation, and an intense fear or terror of dying (Table 1).14,21,25–33 The issue of how to address patients’ existential needs may be linked to how well the phenomenon of existential suffering is understood or whether it is viewed as a concept distinct from that of spirituality. Fagerstrom and Eriksson34 aimed to understand the patient’s experience of caring needs and concluded that if nurses had greater awareness and knowledge of the existential/spiritual needs and desires of the patient, it would help to understand and interpret the patients’ care needs. Although this study offers extensive discussion of the caring needs of patients and claims that “an awareness of human existential/spiritual needs opens new possibilities where illness and suffering can involve inner growth” (p. 985), the concepts of spiritual
Table 1  
Overview of Literature on Descriptors of Spiritual and Existential Issues

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<thead>
<tr>
<th>Descriptors of Existential Issues</th>
<th>Descriptors of Spiritual Issues</th>
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<tr>
<td>Experience of “meaning or lack of meaning …” “relations with close relatives and significant others,” “thoughts about the future, in particular the dying process,” “the absurdity of life…why me? why now?”</td>
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<tr>
<td>A semantic philosophy of life and being, finding meaning and purpose and fulfillment in all of life’s events.</td>
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<tr>
<td>Existential mechanisms concern processes of initiating a tangible resource, finding meaning in life events, and evaluating elements of self.</td>
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<tr>
<td>A sense of purpose, freedom, and authenticity in life (are) the fundamental existential attributes.</td>
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<td>Meaninglessness, burden, hopelessness. Life after death. Faith: patients have concerns over a specific faith or religion.</td>
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<tr>
<td>“Psychoexistential suffering” is pain caused by extinction of the being and the meaning of human beings: loss of relations (with others), loss of autonomy (independence, control over the future, continuity of self), and loss of temporality.</td>
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<td>“Within the secular realm spirituality invokes a search for significance and meaning. Although the source of such inspiration will vary from person to person, what they hold in common is their ability to imbue life with an over arching sense of purpose and meaning including a sustained investment in life itself.”</td>
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<td>Spirituality is a personal search for meaning and purpose in life that may or may not be related to religion.</td>
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<tr>
<td>Meaning and purpose in life, self transcendence, transcendence with a higher being; … feelings of communion and mutuality; … hope.</td>
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<tr>
<td>Spirituality is the aspect of humanity that refers to the way individuals seek and express meaning and purpose and the way they express their connectedness at the moment to self, to others, to nature, and to the significant or sacred.</td>
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| Spirituality is the search for meaning to one’s life and includes the living of one’s understanding of that meaning. It may involve some or all of the following: having or finding.  
1. Sustaining relationships with oneself or others  
2. Meaning beyond one’s self  
3. Meaning beyond immediate events  
4. Expectations for events and/or experiences |

and existential suffering are neither discussed separately nor acknowledged as having different meanings. Another example of this duality of meaning is seen in a qualitative study by McGrath, in which interviews were conducted with survivors of hematological malignancies. In this study, it was found that individuals need to have a strong sense of being able to make meaning out of their lives as well as a sense of connection with life and that such a connection can be threatened by a break with relationships through (loss of) physical identity as well as relational and existential losses. It is unclear in this context what is meant by “existential losses.” The study concludes that “when a sense of disconnection is acutely painful… it is then experienced as spiritual pain.” The notion of meaning making and connectedness in the research literature, however, also has been associated with existential suffering. It is unclear how “existential losses” are being defined in this particular study; the authors do conclude, however, that a new language is needed for spiritual care.

In a similar vein, Mako et al. conducted a study with 57 patients with advanced cancer in a combined quantitative evaluation of participants’ intensity of spiritual pain, physical pain, depression, and illness with a qualitative focus on the nature of the patients’ spiritual pain and the kinds of interventions patients believed would ameliorate their spiritual pain. These researchers conclude that “the identification of self with the physical body can often initiate a sense of crisis or spiritual pain in the face of an embodied experience of loss or deterioration” (p. 1110). Yet, drawing on existential vocabulary, they state: “This sense of existential annihilation is a powerful realization that one is separating from life as one ebbs toward death” (p. 1110). In this report, spiritual and existential issues appear to be presented as if they have the same meaning. In other reports, existential and spiritual issues appear to be presented as completely
separate concepts. This is especially clear when spirituality is equated with religion. Bolmsjo\(^3\) points to the fact that existential questions, such as guilt, loss, anxiety, and fear of death, are universal and independent of religion (p. 499).

Berlinger\(^3\) notes that “spiritual,” similar to the word “existential,” is a word that is poorly or inconsistently defined in clinical medicine, but that the both words “signify something about that “broken patient” who remains a whole person” (p. 109).

Existential issues are sometimes cited to include a broad range of concerns. Blinderman and Cherny\(^9\) noted that when existential concerns cause morbid suffering in patients, the diagnosis of existential distress may be a consideration. They also state that existential issues “include concerns related to hopelessness, futility, meaninglessness, disappointment, remorse, death anxiety, and a disruption of personal identity” (p. 371).

Existential suffering or distress also has been referred to in the context of psychological symptoms. Distinguishing between depression and existential suffering is challenging for clinicians because there are no well-established strategies for defining existential suffering and assessing this condition.\(^4\) Although the American Psychiatric Association’s *Diagnostic and Statistical Manual, Fourth Edition* makes reference to symptoms of depression and anxiety disorders,\(^4\) there is no explicit reference to existential pain, distress, or suffering.

Morita et al.\(^2\) conducted a systematic review of the medical literature and listed all psychological distress considered to be spiritual pain or existential distress. Based on a consensus among the researchers, these authors redefined these into 13 categories, including meaningless in present life, meaningless in past life, loss of social role functioning, feeling emotionally irrelevant, dependency, fear of being a burden on others, hopelessness, grief over imminent separation, “why me” questions, guilt, unfinished business, life after death, and faith (p. 190).

Another challenge in definition is the appearance in similarity between existential suffering and psychological suffering, such as the manifestation of clinical depression. Although there are multiple definitions of existential suffering or distress, it has been argued that the presence or absence of a desire for death cannot sufficiently distinguish between existential distress or depression as it is common in such mental and emotional states.\(^4\) Nevertheless, there are also attempts to reconcile existential suffering within a framework of psychological conditions. For example, Williams\(^3\) reports on a qualitative study drawing on in-depth interviews with 33 low socioeconomic status terminally ill patients examining how using a sociological framework can provide insights on existential suffering at end of life. Williams states that existential suffering is typically understood as a psychological or spiritual condition that robs individuals of their capacity for peace in their present state of being (p. 27). Although this study claims to raise awareness about attending to the social component of existential suffering, it is unclear how existential suffering is understood and defined as either a psychological or a spiritual condition. In other literature that lists definitions of existential suffering, the concept of spirituality is also included in such lists. For example, Blondeau et al. argue that existential suffering as cited in the literature evokes expressions such as “existential distress,” “psychical distress,” “mental anguish,” “emotional psychological” and “spiritual distress.”\(^4\) It has been proposed that suffering may exist even in the absence of specific or concrete pain.\(^4\) However, there are also reports that existential issues may be defined within the context of physical pain depending on the caregiver’s perspective. In one study with chaplains, palliative care physicians, and pain specialists on the definition of existential pain, Strang et al.\(^4\) found that each group defined this concept differently. The chaplains stressed the importance of guilt issues, the palliative care physicians emphasized its association with “annihilation and impending separation,” whereas pain specialists stressed that “living is painful.” These authors conclude that a division between general existential suffering and physical pain might be helpful in addressing the ambiguity around the concept of existential pain.

Definitions of existential suffering cited in the literature also include loss of personal meaning, loss of purpose in life, fear of death, anxiety, hopelessness, fear of being a burden to others, loss of dignity, and loneliness.\(^9,14,21\) Fundamental themes concerning life and death, hope and despair, and relation and
isolation are pervasive in the care of the dying. It has been argued that existential issues are more deeply evident in end-of-life care than in any other area of medicine.\textsuperscript{8} Existential anguish also has been described as the fear of facing death, the fear when faced with the possibility that human existence will cease abruptly after life has ended, and the agony and distress arising from an unbearable state of existence.\textsuperscript{37,45} Arman and Rehnsfelt,\textsuperscript{46} in a review of the literature between 1990 and 2000 on breast cancer and suffering, observe that in the existential dimension of suffering, one is searching for one’s own way of giving the suffering meaning and, with the fight against symbolic death, of reaching a new life. These authors conclude that “love and purpose in life are therefore crucial to the person” (p. 522).

**Study Designs Used to Investigate Existential Suffering**

Cassell\textsuperscript{47} began the work on human suffering at end of life; however, there are few empirical studies since Cassell’s early seminal work specifically addressing existential suffering in the palliative care setting.\textsuperscript{14,44,48–50} There are few research studies that clarify how best to care for people with existential suffering,\textsuperscript{7–9} what kinds of interventions are appropriate for individual concerns,\textsuperscript{14,21,29} and what are the appropriate frameworks concerning treatment options in the palliative care context.\textsuperscript{28} There are wide variations in the literature on the types of study designs used to understand and treat existential suffering or pain. Study designs used include randomized controlled studies, case study methods, pre- and post-test quantitative designs, descriptive randomized controlled studies, and quasi-experimental pre- and post-test designs. However, it has been indicated that qualitative research is the methodology of choice to better understand subjective experience relating to meanings, patterns, and relationships,\textsuperscript{5,20,31} and few such studies exist. For the most part, research on existential suffering lacks an empirical base; is theoretical and opinion focused; and indicates multiple layers of meaning depending on individual interpretation,\textsuperscript{52} as is evident in the approximate 54,800 citations that yield when the words existential suffering and palliative and end-of-life care are entered into CINAHL, MEDLINE, or PsychINFO databases.

Most of the existing qualitative research on existential concerns was conducted in Sweden, Belgium, the United Kingdom, Canada, and Israel. Qualitative and quantitative studies have been conducted in Japan, primarily in relation to existential suffering and palliative sedation. Little qualitative research has been conducted on the process by which existential suffering is expressed by dying patients or how this condition is understood and responded to in an effective way by palliative care providers in the palliative care setting. For the most part, research in North America has focused largely on related concepts, such as hope, meaning, spirituality, and healing, and on the broader concepts of suffering and healing. Studies to date on existential concerns and interventions to treat them include prospective cohort studies, randomized controlled trials, case studies, and descriptive studies. There are currently multiple instruments to measure existential concepts, and several existing instruments incorporate existential meaning as part of a more complex construct.\textsuperscript{53} Qualitative studies on the actual processes of how existential suffering is communicated and managed within the patient and caregiver encounter are few. In one exception, an interpretive-hermeneutic study conducted in a Swedish palliative care population, the researchers investigated the progression of suffering in the encounter between the suffering person and the caregiver.\textsuperscript{3} However, although this study appears to examine the caregivers’ perspective in terms of their vulnerability in the patient-caregiver encounter, it does not address the actual processes by which caregivers manage and engage with existential suffering or how patients and their family members experience and perceive existential suffering within their relationship with caregivers.

**Theories Related to Existential Suffering**

There are few empirical studies that draw on traditional theoretical perspectives on the existential domains at end of life. There is growing literature, however, advocating psychotherapeutic intervention grounded in theories of
existentialism. Such literature is derived primarily from the movement of existentialism advocated by philosophers such as Søren Kierkegaard, Victor Frankl, Jean Paul Sartre, Martin Heidegger, and Irving Yalom. These authors offer a broad philosophical stance on our understanding of existential suffering, and perhaps what is most significant is that there is a decided absence of any fixed definition within their teachings. The prevailing theme in all these works is the notion of suffering as a personal, dynamic, moving, and emergent process.

Human suffering as an individual experience is a central theme in the thinking and writing of all existentialists. Kierkegaard points to the importance of creativity within our suffering and argues that one must become an independent force and an individual, which demands the ability to be alone and to reflect quietly within ourselves and within an intimate knowledge of our own suffering. Frankl draws on his own suffering experience in a concentration camp to show how people can find meaning in extremely adverse circumstances. Frankl's logotherapy is within the tradition of humanistic psychotherapy and outlines broad existential issues, such as meaning in life, death, suffering, and love, with an emphasis on individual choice. He points out that what is important is not an action in and of itself, but the way action is experienced, the intensity with which life is lived, and the notion that a person has the ability to choose freely his or her response to a given situation (p. 92). Yalom outlines the four basic issues of the existential struggle as the process of a personal struggle: death, which creates anxiety; freedom, which involves choices, responsibility, and guilt; isolation, the unbridgeable gulf between the self and others; and meaninglessness, which forces human beings to seek or create personal meaning.

Sartre's understanding of existence within existential philosophy is grounded in the idea that no fixed or universal account can be given on what it means to be human because meaning is decided through the process of existence itself. Existence is self in the making. What makes a person is not determined by type, but by who he or she becomes, and it is within this understanding that facticity, transcendence, alienation, and authenticity must be understood.

In a similar vein, Heidegger proposes that the human entity is “to be,” and consequently what it means to be an entity cannot be collapsed into a notion of facticity or any prescriptive framework. Similarly, Heidegger shows us that human existence is never static or complete. It cannot be fixed or made steadfast as an external object. For Heidegger, each person must take death and death anxiety as something that must be unique and personally experienced. “The existential meaning of our coming-to-an-end is utterly personal and must be seized by us as an ending as a grieving, which can constitute our wholeness or potency.” In Heidegger’s philosophy, death is nonrelational and, therefore, must be taken over alone. Death reveals paradoxically our fundamental aloneness in the world, and it is always “mine.”

The Needs of Patients Suffering with Existential Concerns

The scope of literature on patients’ self-reported existential concerns is limited. Of the few existing qualitative studies, the themes of existential loneliness, the need to be in the “presence” of others, and a sense of “connectedness” appear as predominant themes. Sand and Strang conducted in-depth interviews with 20 patients and 20 family members and reported self-expressed loneliness that was common not only among patients but also among family members. Both patients and family members felt unable to share their fears and thoughts with others. The patient participants in this study also expressed feelings of existential loneliness when their bodies were not touched in an empathic way. In a mixed method study by Mako et al., the qualitative findings revealed that the issue of “presence” of others carried significant spiritual and existential meanings for patients as they face a terminal illness.

Few in-depth studies exist that have explored the subjective inner life experience of patients as they perceive it over the time before and during their illness. One such phenomenological study by Mount et al. was conducted with patients from inpatient and ambulatory facilities. The aim was to understand the individual inner life experiences of spiritual and existential
suffering, and/or sense of well-being, throughout life and during their current illness from the patients’ own perspective. Common themes revealed a sense of isolation and disconnection in those participants experiencing suffering and anguish. “A sense of meaning was evident in those able to find a sense of well-being and wholeness in facing serious illness, while a sense of meaningless was common to those experiencing suffering and anguish” (p. 376). This study identified four types of “healing connections” involving a sense of bonding to Self, others, the phenomenal world, and ultimate meaning” (p. 372). In another phenomenological study on the experience of nursing home residents in chronic pain, conducted by Gudmannsdottir and Halldorsdottir,37 patients experienced existential pain and a loss of connectedness, in the loss of a loved one. The study concluded the importance of caregiver support in the grieving process and the need for staff to be aware of those patients who “suffer in silence.”

There is very little research on cultural issues in relation to patients’ existential concerns. In one exception, Blinderman and Cherny9 conducted an assessment of 40 patients with advanced cancer in a culturally diverse Middle Eastern Jewish population using qualitative interviews. The findings suggested that in this population, existential distress with features of demoralization was noted in only four of 40 patients.

Existential suffering and its correlates have been associated with patients’ will to live.15 Drawing on their extensive empirical work on dying and dignity, Chochinov et al.68 argue that the field of palliative care would be well served by a clinically relevant self-report instrument with sufficient relevance to explore a variety of sources of distress facing patients nearing death. To define the scope of this type of instrument, these researchers developed the Patient Dignity Inventory (PDI).68 Patients’ reports on the factor of existential distress in this model denoted issues such as “not feeling worthwhile,” “not being able to carry out important roles,” “feeling life no longer has meaning,” and “feeling a burden.”68(p. 569)

**Perspectives of Palliative Care Providers on Existential Suffering**

In a review of the literature on spirituality within palliative care, Sinclair et al.20 observe that, although palliative care patients have expressed the importance of compassion, respect, self-awareness, empathy, and nonabandonment as qualities in their caregivers, research on how professionals develop these skills is lacking. There are similar views in the literature on existential suffering, and there is limited documentation on how caregivers themselves respond to the existential concerns of their patients.

Research on the personal impact and coping mechanisms of palliative care providers in the face of patients’ expressed existential suffering is limited, and little is known about this issue. One qualitative study with 10 physicians exploring how participants coped with aspects of their clinical work concluded that physicians’ vulnerability in facing life and death issues has been underestimated, and that the need to belong to a caring community was a way of coping with the loneliness and powerlessness of their position.69

Ekedahl and Wengstrom,70 in another qualitative study with Swedish nurses in hospices, oncology wards, and outpatient services, examined stress levels of nurses in response to patients’ existential suffering. These researchers found that nurses’ stress levels were multifaceted when related to their own death anxiety, and that nurses perceived that they could not satisfactorily alleviate patient suffering. Bolmsjo et al.14 conducted a focus group study to gather and examine reflections from people with firsthand experience of existential issues in the palliative care setting and concluded that there are no general solutions in the care of people experiencing existential pain. These authors14 concluded that there are problems in training, insofar as palliative care professionals are not trained in end-of-life issues relating to concepts, such as autonomy, meaning, guilt relationships and dignity, and communication related to existential issues (p. 186). Few clinicians are trained in the treatment of existential pain,71 and moreover, it remains controversial because different groups of clinicians define it differently. It has been asserted that this lack of training is due to the general opinion that existential and spiritual questions fall under the category of the chaplain or clergy person, and that the realities of time limitations because of late admissions (to a palliative care unit) may be a factor in
having time to deal with existential and spiritual concerns.72 There is also evidence that lack of understanding by palliative care professionals of some elements of existential suffering exacerbates its symptoms. This is evident in the study conducted by Sand and Strang,67 where the patient’s sense of existential loneliness was compounded when the patient was left alone and treated disrespectfully in a way that made him feel invisible when staff avoided contact. “Skin hunger” was the description that patients used in this study when their body was touched disrespectfully.67(p. 1385) Similarly, Albinsson and Strang73 conducted a phenomenological study drawing on 31 semi-structured interviews to investigate how staff caring for patients with dementia deal with existential issues, the dying process, and bereavement follow-up with next of kin. The research points to the need for improved communication in the process of clinician’s understanding of patients’ existential concerns. This study reported patterns of responses that included staff perceptions that existential issues were difficult to handle and that they felt lost. Moreover, some staff attempted to ignore or minimize issues in relation to those patients who felt out of control over issues concerning life or death. The study findings further indicate that certain patients expressed a longing for death that can be related to existential issues, meaningless, isolation, and death. These authors conclude that a central factor in staff-patient communication involves “daring to listen” and not “shutting out” difficult questions (p. 173).

Other reports suggest that nurses’ and physicians’ vulnerability in their response to pain and fear may play a part in the reasons that health care professionals have difficulty understanding and assessing existential suffering. Using data from an ethnographic study to illustrate nurses’ vulnerability, as reflected in emergency room narratives, Malone74 describes strategies used by nurses to cope with vulnerability that included “distancing” and “wallowing off” as ways to cope with the demands of bearing witness to patients’ vulnerability. He states “this distancing stance acknowledges some level of vulnerability in both the patient and the nurse, but regards it as something to be avoided, and thus fails to make the connection between them… each remains isolated from the other and the vulnerability it requires nurses to experience is never addressed” (p. 7). Drawing on clinical experience and education and a review of the literature on clinical communication, Weiner and Roth25 have argued that, unlike firmly established methods of communication around physical examination and diagnostic thinking, sophisticated practices of communication related to patient suffering have yet to be included in the patient-clinician encounter. The authors observe the link between how the physician conducts medical discussions with cancer patients and the resultant anxiety, depression, and levels of hope. They note, “of importance, the patient’s will to live has been highly correlated with the patient’s satisfaction in their (sic) health care provider and the sense of support provided by the clinician (p. 457) [and] that such communication is important at end of life because many medical decisions are determined by emotional consideration and personal values” (p. 452).

Assessment and Management of Existential Suffering

Existential issues in the palliative care context have remained a widely used and yet ill-defined concept,67 a neglected symptom of suffering,7,8 and little is known about the efficacy concerning interventions.14,21 Lack of conceptual understanding also reveals considerable confusion as to how to treat this debilitating form of suffering.28,36 The management of this domain is seldom systematically explored, perhaps because existential issues are difficult for clinicians to understand and assess,14,48 and perhaps because of the multiple variations in conceptualization. The challenges of assessing and treating the existential domains include consideration of the subjective nature of its expression and the personal experiences of vulnerability by clinicians who witness their patients’ suffering.70 Existing literature points to the importance of sensitivity and trust relations, as well as to an awareness of the individual nature of patients’ existential concerns. In one example, Houtepen and Hendrix76 conducted an exploratory qualitative study drawing on semi-structured interviews with six Dutch nurses.
and six Belgian nurses to explore the problems they encounter when providing existential support to dying patients. The findings concluded that nurses are confronted with four types of questions when assessing patients’ existential concerns. These include whether the patient has actually asked for support with existential concerns, the importance of assessing the patient’s question, the need to decide on a procedure for offering support, and the question of being able to provide adequate self-care. The conclusion was that patients’ ability to express existential concerns depends on the relationship between the nurse and the patient with respect to trust issues, listening, receptiveness, and the nurse’s ability to understand the nature of the concern. These authors note, “It takes discernment to assess the nature of a question balancing between a general preconceived view and an unguided sensitivity for the unique features of each situation” (p. 382).

There is no clear theoretical framework for understanding how existential suffering is treated outside of psychiatric and psychoanalytic approaches. Emerging psychotherapeutic interventions are, for the most part, grounded in meaning-centered psychotherapy, cognitive behavioral interventions, hypnotically facilitated therapy, or psychoeducational counseling. Kearney, drawing on experiences of working with dying patients, shows how a psychotherapeutic response to suffering and “soul pain” can help people by attending to “inner” or “depth” work. Kearney developed a model in which he differentiates between “surface work” and “depth work.” At the surface level, the process involves interventions aimed at “doing” or attending to the concrete, conscious acts of trying to alleviate pain and discomfort. Depth work “is any approach or intervention that might bring an individual into an experience of soul.” It is about being able to reconnect with simple aspects of life that have brought depth and significance. This might involve sharing an old memory, spending time with loved ones, or visiting a special place of personal meaning. In a further extension of this work, Kearney and Mount emphasize the importance of obtaining a clinical biography, examining the person’s fears, exploring sources of meaning, redefining hope, and celebrating the transcendent through meditation or prayer in their advocacy to bring the dying person to a place of peace and to a greater sense of wholeness.

Despite existing research on attempts to understand existential suffering better, and to provide multiple variations of its definition and meaning by patients and clinicians, there continues to be no consensus on how to treat this debilitating and distressing symptom. Hirai et al. aimed to explore the underlying structure of psychosocial interventions recommended by psychiatrists, psychologists, and palliative care nurses. Drawing on questionnaires and using vignette scenarios representing terminally ill patients with anxiety, guilt feelings, and dependency-related meaninglessness, these authors explored the perceived effectiveness of health professionals’ recommendations with respect to their specialties. Although the three groups concluded that “a supportive expressive approach” was an important intervention, they differed in what was considered effective, and moreover different specialists perceived the effectiveness of the interventions differently.

Although there is a paucity of empirical research on the effectiveness of interventions for existential suffering, one of the few exceptions is the research work on Dignity Conserving therapy conducted by Chochinov et al. Dignity Conserving therapy refers to the sense of esteem and inalienable worth of the individual. Patients enrolled in dignity therapy are asked to record aspects of their life they would most want their loved ones to remember. Chochinov et al. reported on results of testing the PDI, which is designed to test various sources of dignity-related distress among patients nearing the end of life. These authors report that the PDI is a valid and reliable instrument that could assist clinicians to detect dignity-related distress routinely. These authors conclude that identifying these sources of distress is a critical step toward understanding human suffering and should help clinicians treat existential and spiritual suffering through the provision of dignity conserving care at end of life.

There are few studies on the actual effect of palliative care as an interventional approach aimed at improving QOL and spiritual and existential well-being, and there is a paucity of research on how the provision of care in a palliative care unit impacts existential concerns.
One exception is a mixed method study conducted by Cohen et al., which studied the responses of 88 patients admitted to five palliative care units in two regions of Canada. In this study, the McGill Quality of Life Questionnaire was used to study self-rated QOL of patients after admission to palliative care units. The result revealed significant improvements in the patient’s QOL, including physical, psychological, and existential well-being.

Qualitative research conducted by Mount et al. suggests strategies for improving QOL and relieving existential suffering: identify sources of meaning, both positive and negative before and during the patient’s illness; explore the creation of a life narrative and possible legacies for loved ones; explore sources of existential anguish before and during illness; attend to dreams as clues to sources of existential distress; identify sources of healing connections before and during illness; minimize uncertainty; identify and support expression of fears; identify ego defense mechanisms that increase distancing, denial, and closeness to others; promote a calming atmosphere characterized by efficiency, accompaniment, and caring; and promote strategies that bring the person into the present moment, such as music, meditation, or discussion of cherished interests (p. 386).

Other attempts to treat existential suffering have reported on successful use of the Life Tape Project as a brief existential intervention for cancer patients and their families, using self-reflective techniques derived from one to two hours of videotaped interviews of patients and their family members. Recently, there are reports on the existential impact of starting corticosteroid treatment as symptom control in patients who are experiencing distressing symptoms of hopelessness, deterioration, and diminished autonomy. Lundstrom and Furst conducted a qualitative study with 10 patients with advanced cancer using corticosteroid treatment. They concluded that corticosteroid treatment can have profound consequences and contributes to feelings of a normalized life symbolizing health, hope, and autonomy. It is unclear, however, from these latter studies how existential suffering is defined, what specific symptoms of existential suffering were targeted, and how or whether the identified symptoms were considered severe and intractable. There is also an absence of clarity about whether any of these interventions may be considered feasible in daily practice.

There is a new emerging literature suggesting that palliative sedation may be an acceptable intervention for existential suffering when current treatments have failed. Rousseau notes that existential suffering can be just as refractory and agonizing as physical symptoms, and he has proposed guidelines for treating existential suffering, which include the following: “1) the patient must have a terminal illness; 2) a do-not-resuscitate order (DNR) must be in place; 3) all palliative treatments must be exhausted, including treatments for depression, delirium, anxiety and any other contributing maladies; 4) a psychological assessment by a skilled clinician must be completed; and 5) an assessment for spiritual issues by a skilled clinician or clergy member should be completed” (p. 152). Rousseau notes that palliative sedation for existential symptoms can be emotionally and morally challenging for health professionals and families as the patient is frequently awake, cognitively intact, and socially interacting prior to the initiation of sedation (p. 151). Reports of treatment of existential suffering through palliative sedation, however, are varied and generally controversial in the literature. Seymour et al. conducted informal interviews with palliative care clinicians and researchers in the United Kingdom, the Netherlands, and Belgium with the aim of eliciting particular understandings and experiences of palliative sedation at end of life. The U.K. participants identified the challenges of being able to interpret suffering correctly and manage complex symptom problems without having to resort to palliative sedation.

Blondeau et al. in a study of Quebec physicians’ and pharmacists’ attitudes toward sedation at end of life, using participants’ reflections on clinical vignettes, found that clinicians were not in favor of palliative sedation if the suffering was existential. In this study, clinicians were not comfortable when confronted with their patients’ existential suffering. The study concludes that very few indicators currently exist on how to approach existential suffering, and it is important to consider an approach that respects the human dignity of the person who is suffering.
Nevertheless, there are studies citing palliative sedation as a treatment for existential suffering. Claessens et al.,87 in a review of the literature on palliative sedation, reported that 27% of the studies reviewed mentioned existential suffering besides physical suffering as a reason for sedating a patient. Most frequently mentioned were anxiety, mental anguish, and psychoexistential suffering. Literature citing alternative management of existential suffering largely points to the need for spiritual and psychological support and improved efficacy in multidisciplinary team assessment and planning for patients experiencing suffering.36,42,88

**Conclusion**

The most prevalent finding in this review has been a lack of consistency in the way existential suffering is defined and understood. Different groups define existential concerns differently, and there are evident ambiguities between what may be understood to be a spiritual concern and what may be understood as a symptom of existential suffering or distress. Although ambiguity in these definitions may be justifiable given the broad range of similarity in terminology, clinical clarity may be necessary given the current challenges of treating this form of suffering, and a general consensus that it has not been well defined or treated is also required. This is especially critical when there are emerging trends to prescribe palliative sedation specifically for existential concerns. The current lack of consensus on assessing, defining, and treating existential suffering suggests that palliative care clinicians need to be mindful of their own choices and consider treatment options from a critical perspective.

Existential suffering and deep personal anguish at the end of life are some of the most debilitating conditions that occur in patients who are dying, and yet the way we attend to this suffering in their last days is not well understood.

Research is needed to ascertain in depth how patients experience existential suffering and the actual communication processes that take place between caregiver, patient, and family members. Further research is also needed to determine how decisions are made regarding assessment and various treatments for existential concerns. While patients’ existential concerns pervade much of our care of the dying, understanding this complex domain presents an enormous challenge and demands much of the caregiver. As Frank states: “Suffering is the unspeakable as opposed to what can be spoken... it remains in darkness, eluding illumination; and it is dread beyond what is tangible even if hurtful.”89(p. 17) For the caregiver, it involves “generosity”... the giving of the self in the willingness to recognize the other as human—as the one with whom vulnerabilities and hopes are shared.90 Knowing how to provide compassionate care requires an awareness that this may involve embracing personal and emotional risks.91 The notion of whole person care calls for attention to all domains, including the physical, psychological, spiritual, and existential, with skills that demand much more from our own person and that may move beyond our training in scientific and technical skills.92

The existential mode of self is both immanent and transcendent.93 Qualitative research may be the method of choice when studying the inner life dimension of illness, and subjective experience related to meaning, patterns, and relationships may be better understood when drawing on qualitative methodologies.20,51 The phenomenological studies identified in this review suggest the possibility of studying patients’ existential concerns in the fullest breadth and depth. Phenomenological methods are ideal because they are specifically designed to elucidate the experience of people as life is lived, rather than how it is conceptualized as a set of procedures or techniques. As the landscape of palliative care shifts to encompass continuing advances in pain and symptom management, palliative care research has shown increasing success in its ability to discover symptom relief for complex and intractable pain using pharmacological and sophisticated technological measures.94 Research, however, is increasingly focused on the biomedical model, which demands diligence in the way we pursue the principles of whole person care.

A further finding in this review is the need for research on palliative care providers’ self-reflective responses to existential suffering. It is not always easy to accompany or to remain present to a person who is experiencing...
suffering and anguish during the last days of life.\(^9\) But with a fuller understanding of empathy, “presence,” and compassionate care, it may be possible for us to more fully achieve whole person care for our patients and their families. In this way, our attention to the existential domain may be better served within the vision of the late Dame Cicely Saunders:

If we can come not only in our professional capacity but in our common vulnerable humanity, there may be no need of words on our part, only for concerned listening. For those who do not wish to share their deepest concerns, the way care is given can reach the most hidden places.\(^9\)

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