



A concept analysis of the existential experience of adults with advanced cancer

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ABSTRACT

Background: Attention to the existential dimension of an individual's experience during serious illness is important. However, existential concerns continue to be poorly defined in literature, leading to neglect in the clinical realm.

Purpose: This concept analysis seeks to clarify the concept of the existential experience within the context of adults with advanced cancer.

Methods: Rodgers' evolutionary method of concept analysis was used.

Discussion: Existential experience in adults with advanced cancer is a dynamic state, preceded by confronting mortality, defined by diverse reactions to shared existential challenges related to the parameters of existence (body, time, others, and death), resulting in a dialectical movement between existential suffering and existential health, with capacity for personal growth. Personal factors and the ability to cope appear to influence this experience.

Conclusion: These findings can drive future research and enhance clinician ability to attend to the existential domain, thereby improving patient experience at end-of-life.

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Being diagnosed with a serious illness, such as cancer, can be a deeply unsettling experience with potential to bring existential concerns to the fore (Greisinger, Lorimor, Aday, Winn, & Baile, 1997; Kissane, 2012; Lee & Loiselle, 2012; LeMay & Wilson, 2008; Sand, Olsson, & Strang, 2009; Strang, 1997). Weisman and Worden (1976) refer to the increase in thoughts about life and death an individual may experience following a diagnosis of cancer as the “existential plight.” The medical community has increasingly recognized that the management of cancer entails attention to the whole person, including existential concerns (Piderman et al., 2015). Unfortunately, cancer patients continue to report a high degree of unmet existential needs (Greisinger

et al., 1997; Moadel et al., 1999; Strang, 1997). These needs are amplified due to the increasing incidence of cancer worldwide in the setting of an aging population, as well as patients with advanced cancer living longer with incurable disease as a result of more effective cancer treatments, leaving individuals with longer to wonder about their impending death (Hui, Hannon, Zimmermann, & Bruera, 2018; Kissane, 2012).

Absence of a clear definition of existential experience has led to confusion in clinical practice (Hench & Danielson, 2009; Morita, 2004; Rodrigues, Crokaert, & Gastmans, 2018). Clinicians working with individuals with serious illness report understanding the importance of addressing existential issues (Browall,

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Melin-Johansson, Strang, Danielson, & Henoch, 2010; Strang, Henoch, Danielson, Browall, & Melin-Johansson, 2014), but perceive existential concerns as too vague to comprehend and thus, too complicated to approach (Bolmsjo, Hermeren, & Ingvar, 2002; Hirai, Morita, & Kashiwagi, 2003; Leung & Esplen, 2010; Sand & Strang, 2006; Sand, Olsson, & Strang, 2018; Strang, Strang, & Ternestedt, 2002; Strang, Strang, Hultborn, & Arner, 2004; Whitehead, 2003). Their confusion reflects a literature which includes several clarifications of components of existential experience (e.g., existential loneliness (Bolmsjo, Tengland, & Ramgard, 2018; Ettema, Derksen, & van Leeuwen, 2010), existential suffering (Boston, Bruce, & Schreiber, 2011), existential concerns and interventions (Henoch & Danielson, 2009; Lee & Loiselle, 2012; LeMay & Wilson, 2008), and existential health (Whitehead, 2003)). However, these reviews are inconsistent to the way existential experience is understood. In fact, a recent literature review of existential suffering found 56 different definitions of the term in 64 articles (Boston et al., 2011).

The subjective and heterogenous nature of the existential experience makes it a challenge for researchers to define and clinicians to recognize. While some individuals may experience a persistent state of demoralization when confronting mortality consistent with the original formulation of “existential plight” (Kissane, 2000; Weisman & Worden, 1976), others may experience increased attention to existential issues without significant distress (Blinderman & Cherny, 2005), and still others may experience a heightened sense of meaning and purpose, or an improved state of existential health (Cohen, Mount, Tomas, & Mount, 1996). Yet, studies are limited that explore how the full spectrum of existential experience, inclusive of existential suffering as well as existential health, is expressed in the clinical setting.

The purpose of this analysis, therefore, is to clarify the concept of existential experience in adults with advanced cancer. This is a vital first step to assist researchers in the study of existential experience and clinicians in recognizing and addressing the existential needs of patients with advanced cancer. To avoid perpetuating linguistic ambiguity, in this analysis “existential experience” will encompass all of the existential needs, issues, concerns, and aspects of patient experience, including existential suffering and existential health. This concept analysis of the existential experience of adults with advanced cancer adds to the literature in two important ways. First, it builds upon previous work investigating components of existential experience to include the full spectrum of existential experience. Second, given the subjective and heterogenous nature of existential experience, this analysis looks to the voice of the patient for conceptual clarity, focusing on the qualitative literature as these methodologies can illuminate the subjective inner life of the illness experience (Boston, Mount, Orenstein, & Freedman, 2001).

Methods

We used Rodgers' (2000) evolutionary method of concept analysis because of its rigorous and inductive methodology. This methodology uses the published literature as the source of data and requires the investigator to present quality criteria for inclusion or exclusion of material, contributing to the validity of this method (Toftagen & Fagerstrom, 2010). Rodgers' (2000) evolutionary method of concept analysis was also chosen due to its philosophical underpinnings which recognize concepts as dynamic in time and contextually bound. As the concept of existential experience is represented in the literature as dynamic and context-dependent over the course of illness (Lee & Loiselle, 2012), these characteristics call for using Rodgers' (2000) evolutionary approach.

Rodgers' (2000) evolutionary method calls for the completion of six activities: identification of the concept of interest, selecting an appropriate realm for data collection, data collection, data analysis, identification of an exemplar, and identification of implications for the process of concept development. The remainder of this paper will be outlined according to these six activities. The first phase in Rodgers' (2000) evolutionary method is to identify the concept of interest. As described above, existential experience was chosen for analysis given the lack of clarity surrounding this concept in the literature and clinical realm, as well as limited exploration of the full spectrum of existential experience during serious illness in the literature.

Data Sources

Rodgers (2000) emphasizes selecting an appropriate setting and sample for data collection. We searched four databases (PubMed, CINAHL, PsycINFO, and Scopus) combining the concept of existential experience with the context of cancer and end-of-life and the methodology of interest, qualitative methods, with no timeframe specified. This search was completed with the assistance of an experienced librarian. We chose these major pertinent databases for their scope to best capture the concept of existential experience. A building blocks search strategy was used (Figure 1). Search tools, such as MeSH terms, truncation, and Boolean operators were used according to the particular thesaurus in each database.

We selected articles according to whether they were empirical works using qualitative methods focused on adults with advanced cancer and their ability to clarify the concept of existential experience (inclusion and exclusion criteria are described in Table 1). The age range of participants in the studies was set at a limit because it is likely existential experience differs between children and adults, as some authors situate existential concerns within a developmental framework (Wright, Grant, Depner, Donnelly, & Kerr, 2015). We decided to focus on qualitative explorations of this

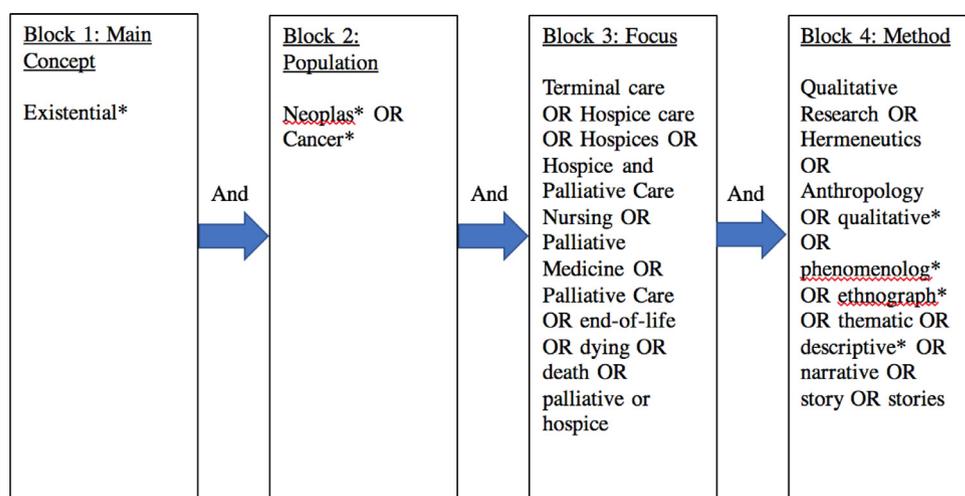


Figure 1 – Building blocks search strategy. Terms within blocks were combined with “OR” and blocks were combined with “AND”. The concept “existential” was searched within the title and abstract of the articles. The purpose of this analysis was to include articles that helped to clarify the concept of existential experience; all other terms were searched anywhere within the article.

concept from the perspective of the seriously ill individual, given that qualitative research is best suited to uncovering the meaning of a multifaceted concept from the perspective of the individuals experiencing it (Patton, 2001). Furthermore, quantitative studies of the existential domain frequently utilize investigator-developed tools which may narrow the breadth and depth of individual experience that can be investigated (Cohen et al., 1997). Lastly, there are many different aspects of existential experience along the cancer continuum (e.g., occurring with initial diagnosis (Lee & Loiselle, 2012)). However, since the aim of this paper was to investigate the existential experience of individuals with advanced cancer nearing end-of-life, papers were limited to individuals that were in their

final phase of life. The authors conferred with a clinical oncology/palliative care expert on articles related to specific cancer diagnoses to ensure that the “advanced” cancer being discussed fit these criteria. Sources that used quantitative methods, focused on populations other than adults with advanced cancer, empirical works that were not peer-reviewed, and those not published in English were excluded from this study.

Synthesis of Results

The literature search yielded an initial article count of 453. Duplicates were removed and articles were screened according to the inclusion and exclusion

Table 1 – Selection Criteria for the Articles

Inclusion Criteria	Exclusion Criteria
Original empirical research focusing on the perspective of the seriously ill individual*	Dissertations, book chapters, commentaries, or letters to the editor
Qualitative research studies that focused on existential experience	Articles using quantitative methodology
The population of focus was adults with “advanced cancer” which includes individuals over the age of 18 years with cancer described by authors as “advanced,” “metastatic,” “late-stage,” “terminal,” or receiving palliative or hospice care	Primarily focused on psychometric tool evaluation
Written in English	Primarily focused on interventions to address the existential experience
	The population of focus was not adults (e.g., children or parents of sick children)
	The population of focus was not “advanced cancer” (e.g., conditions other than cancer or focused on another part of the disease trajectory such as diagnosis or survivorship)
	Explored existential experience from a perspective other than the seriously ill individual (e.g., caregiver or health care provider perception) or focused on the existential experience of someone other than the seriously ill individual (e.g., caregiver or health care provider)
	Articles reporting on the sole concept of spirituality or religion, without explicitly referring to the existential domains
	Published in a language other than English

* Articles were included if they sought the explicit voices of the seriously ill individual as it is considered that studies presenting from the family’s or professional’s perspective show a different vision from those with a patient perspective (see also Ambrosio et al. (2015)).

criteria (Figure 2). The full texts of included papers were uploaded into Atlas.ti 8.2.4 data management software program and each paper was read at least twice, summarized, and coded. The articles were read in their entirety and analyzed using thematic analysis to identify antecedents, attributes, consequences, and surrogate terms of existential experience (Rodgers, 2000; Tofthagen & Fagerstrom, 2010). For case exemplars, Rodgers (2000) emphasizes focusing on identifying real, as opposed to constructed, cases. Therefore, similar to other authors conducting concept analyses of qualitative studies (Weathers, McCarthy, & Coffey, 2016). This analysis presents participant quotations to support the results and exemplify the existential experience of adults with advanced cancer.

Results

We included 21 articles for analysis (Table 2). Overall, the term “existential” was used as part of over 50 different terms in the literature with references to “existential distress/suffering” and “existential issues/concerns” being the most common phrases. Table 2 provides an overview of the studies included in this concept analysis and lists definitions of various aspects of existential experience present in these studies. Table 3 presents major findings, organized by themes, including citations for studies where each theme was present.

Antecedents

Confronting Mortality and Awareness of Death

A commonality across the majority of studies included in this concept analysis was the idea that existential

experience in advanced cancer is preceded by being confronted with mortality and becoming aware of one’s imminent death.

Due to Terminal Diagnosis. Some authors emphasize that this confrontation with mortality begins at the moment of terminal diagnosis. Authors referred to this confrontation with mortality due to terminal diagnosis as an “existential turning point” (Missel & Birkelund, 2011, p. 298) or an “existential transformation,” (Sand, Strang, & Milberg, 2008, p. 858). Participants became more aware of the seriousness of their situation, realizing their own life was threatened and existence was no longer secure, leading them to face existential challenges.

Due to Physical Changes. Other authors emphasized that confronting mortality occurred not solely due to terminal diagnosis, but to the physical changes that occur with disease progression evident in advanced cancer which can disrupt daily life and lead to facing existential challenges. For example, Sand et al. (2008) relate that participants experienced “existential limitations” from the disease or treatment side effects, such as fatigue preventing individuals from doing everyday activities, reminding them of their “fragile situation and impending death,” (p. 857).

Known on a Deeper Level. Regardless of whether entering the existential experience of advanced cancer begins at the moment of terminal diagnosis or is initiated due to physical changes related to disease progression, most authors relay that individuals experiencing advanced cancer become aware of their mortality on a deeper level than before. Though participants may have experienced existential concerns throughout their lives, when facing death in the setting of advanced illness, these concerns appeared in a more intense way (Asgeirsdottir et al., 2014; Ekwall, Ternstedt, & Sorbe, 2007; Lovgren, Hamberg, & Tishelman, 2010). As one patient put it:

The only thing I can think of is that I’m going to die. And that’s the only certainty that I have. I know we do all have that and I know people say (...) you could cross the street and be run over by a bus. But you live your life not thinking about it. I have to deal with it. My bus is here. All the time. (Willig, 2015, p. 420)

Influences

The literature suggests that a variety of personal factors can shape existential experience including age, gender, ethnicity, religious or spiritual beliefs, cultural background, disease characteristics (e.g., time since terminal diagnosis), socioeconomic status, and military experience. The most commonly noted factors of these included cultural background (Aoun, Kristjansson, Oldham, & Currow, 2008; Bentur, Stark, Resnizky, & Symon, 2014; Blinderman & Cherny, 2005; Carter, MacLeod, Brander, & McPherson, 2004; Lee et al., 2016; Moestrup & Hansen, 2015), religious beliefs

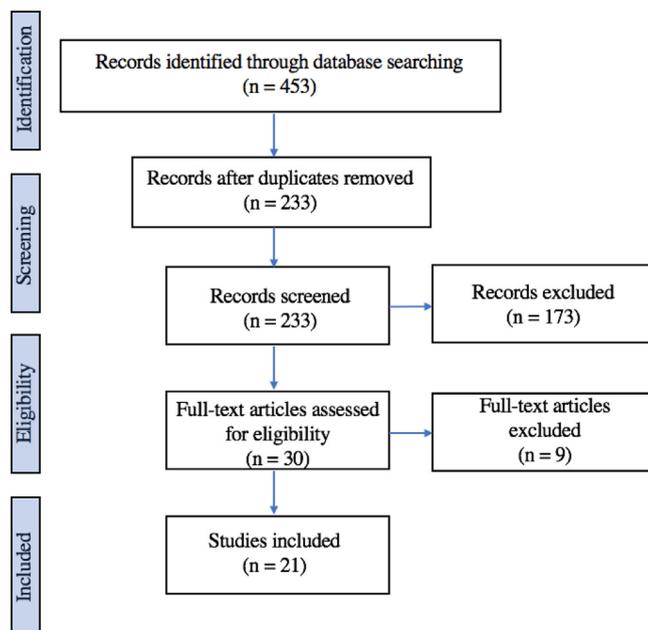


Figure 2 – PRISMA flow chart.

Table 2 – Definitions of Existential Experience in the Published Health Literature

Author(s) and Year	Research Design and Sample	Relevant Definitions of Existential Experience in the Article	Philosophical Basis/Sources Cited for Definitions
Adorno and Brownell (2014)	Qualitative exploratory design using semi-structured interviews (grounded theory approach to analysis) Older (age > 55 years) veterans with advanced/late-stage lung cancer in the United States (n = 12)	Existential issues: include “meaning, purpose, and value,” specifically “our sense of self and identity,” (p. 141). Existential suffering: a “profound shift;” can occur when “illness and debility preclude one’s ability to continue life ‘as usual’” resulting in “profound loss ‘of the person we know ourselves to be’ compounded by the environment’s inability to support or embrace new ways of knowing and valuing oneself,” (p. 141). Existential domain: includes concepts such as “integrity of self and personhood;” a part of quality of life.	Charmaz (1983) and Mako et al. (2006) Mount (2003) and Mount et al. (2007)
Aoun et al. (2008)	Qualitative descriptive design using semi-structured interviews Patients terminally ill with advanced cancer in hospice in Australia (n = 11)	Existential considerations: “A pragmatic approach to life, the importance of choice and the need for dignity,” (p. 8).	
Asgeirsdottir et al. (2014)	Hermeneutic, phenomenological design Patients with advanced cancer receiving palliative care in Iceland (n = 10)	Existential challenges: Major forms include: “(1) death anxiety, (2) loss and change, (3) freedom with choice, (4) dignity of the self, (5) fundamental aloneness, (6) altered quality of relationships, (7) meaning, (8) mystery,” (p. 1502). Existential despair: can be recognized as “demoralization syndrome,” which entails “the loss of meaning, purpose, and hope that sustains the will to live or the loss of any potential for future joy,” (p. 1504).	Typology of existential suffering according to Kissane (2012) Kissane et al. (2001)
Bentur et al. (2014)	Qualitative phenomenological design Patients with advanced-stage cancer in Israel (n = 22)	Existential suffering: “No universal definition. . . consistently understood as a complex phenomenon related to emotional distress and potentially threatening to individual integrity,” (p. 1).	Boston et al. (2011), Krikorian and Limonero (2012), LeMay and Wilson (2008), and Wilson et al. (2007)
Blinderman and Cheney (2005)	Qualitative descriptive study using semi-structured interviews Patients with advanced/incurable cancer in Israel (n = 40)	Existential issues: “Concerns related to hopelessness, futility, meaninglessness, disappointment, remorse, death anxiety and disruption of personal identity,” (p. 371). Existential distress: “When existential concerns cause morbid suffering,” (p. 371).	Cassell (1982), Kissane et al. (2001)
Carter et al. (2004)	Qualitative exploratory design using interviews (incorporated principles of narrative analysis and grounded theory during analysis) Patients with terminal cancer in hospice in New Zealand (n = 10)	No explicit definitions	
Ekwall et al. (2007)			

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Table 2 – (Continued)

Author(s) and Year	Research Design and Sample	Relevant Definitions of Existential Experience in the Article	Philosophical Basis/Sources Cited for Definitions
	Qualitative phenomenological design Patients 5–10 months after learning of their recurrent ovarian cancer in Sweden (n = 12)	Existential loneliness: characterized by participants feeling “alone with their thoughts” despite having a social network; valuing relationships in a new way due to the threat of death, wanting to “feel that they belonged” and being “afraid of being rejected;” assuming “great responsibility for their own health and for the well-being of those around them” wanting to protect those closest to them by “not spreading their worry,” (p. 275). Existential homelessness: “A condition in which the world is no longer experienced as familiar,” (p. 275).	Svenaeus (2001)
Friedrichsen et al. (2011)	Qualitative interpretive study using semi-structured interviews (employed hermeneutic analysis) Patients with terminal cancer receiving palliative care in Sweden (n = 45)	Existential survival: “Despite the awareness of approaching death. . . their nonexistence. . . [participants] struggled to find ways to cope with thoughts about their continuing to exist as a person and a self,” (p. 177).	
Griffiths et al. (2002)	Qualitative descriptive study using in-depth interviews Patients with advanced/late-stage cancer in England (n = 21)	Existential concerns: “Contemplation of life, death and dying with or without a change in a person’s personal meaning of life; a tried or untried spiritual, religious, or philosophical search for existential meaning within the context of illness, death and dying,” (p. 244).	Weisman and Worden (1976) and O’Connor et al. (1990)
Karlsson et al. (2014)	Qualitative phenomenological design (analysis according to hermeneutic interpretive principles) Patients with advanced gastrointestinal cancer receiving palliative care in Sweden (n = 14)	Existential uncertainty: living in uncertainty “of the prospect of the disease trajectory, about being able to survive or not and how life will be before death” due to awareness of one’s own mortality/mortal threat of the body as a result of serious illness (p. 2). Existential certainty: “Having a fresh take on life, getting to know themselves better and appreciating their families in a different way;” existential uncertainty can transform into existential certainty “in relation to patients’ quest for knowledge in order to deal with advanced cancer,” (p. 2).	Cassell (1982), Ohlen (2002), Westman et al. (2006), and Källerwald (2007) Corbeil et al. (2009) and Friberg and Ohlen (2007)
La Cour and Hansen (2012)	Qualitative design using a combination of methods including diaries, interviews, and participant observation with phenomenological analysis Patients with advanced cancer for which cure was no longer expected in Denmark (n = 7)	“Authentic” existence: “To be true to oneself,” can occur when “confronted with one’s own mortality,” “involves progressive attunements that may be promoted by the immediate presence of existential issues such as life and death,” (p. 127).	Defines “authentic” and “inauthentic” being and analyzed the empirical data according to the philosophy of Heidegger (1962)

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Table 2 – (Continued)

Author(s) and Year	Research Design and Sample	Relevant Definitions of Existential Experience in the Article	Philosophical Basis/Sources Cited for Definitions
Lee et al. (2016)	Qualitative descriptive study (in-depth interviews and focus group discussions) Ethnic-Chinese patients with advanced solid cancer in Singapore (n = 46)	Existential pain and suffering: a part of health-related quality of life (HRQoL) within the domain of “pain and suffering,” related to the “meaning of suffering” e.g. “Pain and suffering took on existential meanings described by the participants as meaningless or a solitary experience. The participants faced it essentially alone, probably at the most vulnerable time of their lives,” (p. 1110). Existential well-being/health: a part of HRQoL within the domain of “spiritual health” which is understood as encompassing “religious and existential aspects such as an appreciation of life, relationship with God/Higher Power, self, hope, meaning, and purpose in life,” includes “death and dying concerns, meaning of death, meaning of illness, and meaning of life,” (p. 1113–1114).	Edwards et al. (2010)
Lovgren et al. (2010)	Qualitative descriptive study (open interviews) Patients 1 year after diagnosis with inoperable lung cancer in Sweden (n = 35)	No explicit definitions	
Melin-Johansson et al. (2008)	Qualitative descriptive study (narrative interviews) Patients with incurable/metastatic cancer approaching death receiving palliative care in Sweden (n = 8)	Existential experience: concerns “reflections about life and death” and “the importance of retaining a sense of hope and meaning in life,” (p. 232).	Thome, Dykes, Gunnars, & Hallberg, 2003 and Greisinger et al. (1997)
Missel and Birkelund (2011)	Hermeneutic, phenomenological design Patients incurably ill with esophageal cancer in Denmark (n = 5)	Existential turning point: Becoming “aware of the seriousness of the situation,” (p. 298).	They cite Kierkegaard (1964), Løgstrup (2011), Merleau-Ponty (1962), and Ben-ner and Wrubel (1989) as theoretical inspiration during interpretation of the findings
Moestrup and Hansen (2015)	Qualitative descriptive design using semi-structured interviews Patients (all but 2) terminally ill with advanced cancer in hospice in Denmark (n = 17)	Existential conditions: “No single commonly accepted definition;” “four recurrent basic conditions that always challenge human existence: (1) that we all must die, (2) that we all are alone in critical moments, (3) that we have the freedom to choose our lives, and (4) that we are struggling to make sense of the world,” (p. 427). Existential awakening: “To assimilate death in life,” (p. 434).	Existential domains categorized according to Yalom (1980) Yalom (1980)
Philip et al. (2014)	Qualitative exploratory design using interviews (grounded theory analysis) Patients with high-grade primary malignant glioma in Australia (n = 10)	No explicit definitions	

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Table 2 – (Continued)

Author(s) and Year	Research Design and Sample	Relevant Definitions of Existential Experience in the Article	Philosophical Basis/Sources Cited for Definitions
Saeteren et al. (2011)	Gadamerian hermeneutical design Patients with advanced cancer in Norway (n = 15)	Existential upheaval: “Takes the patients through demanding phases filled with contradictory emotions and uncertainty,” (p. 811).	Use the existential philosophy of Kierkegaard (1964) as a framework for interpretation during analysis
Sand et al. (2008)	Mixed methods (survey with qualitative questions; the qualitative part was the main focus of the questionnaire) Patients with disseminated cancer receiving palliative care in Sweden (n = 103)	Demoralization syndrome: Emphasize helplessness as one of several core phenomena in “a condition that comes from a persistent inability to cope,” (p. 854).	Clarke and Kissane (2002)
Williams (2004)	Qualitative interpretive investigation using semi-structured interviews Patients terminally ill with cancer of low socioeconomic status in the United States (n = 33)	Existential transformation: when “one’s own life was threatened, and the earlier existence did not rest on the same solid ground that had previously been taken for granted;” “scary and difficult to cope with,” (p. 858). Existential suffering: “the experience of agony and distress arising from an unbearable state of existence;” “a psychological or spiritual condition that robs individuals of their capacity to find solace or peace in their present state of being;” “rooted in incoherence and disruption of relations with self and others,” (p. 27). From a sociological perspective it “emerges out of the symbolic process of interaction with others and has its roots in the capacity of human beings to reflect upon the experience of dying and interpret its meaning in light of the social reality of their lives,” (p. 29).	Frank (1991) and Charmaz (1980)
Willig (2015)	Qualitative investigation using semi-structured interviews & object elicitation together with existentially informed hermeneutic phenomenological analysis Patients with advanced (metastatic) cancer in England (n = 10)	Existential challenge: “Demands that the individual concerned finds a way of coming to terms with the very parameters of human existence,” (p. 417); “requires an immediate response,” (p. 422). Existential paradox: “Struggling to live while preparing for death,” (p. 418). Existential concerns: “Time, our embodied nature, and our being-in-the-world-with-others,” (p. 419). Existential slap: The moment individuals “realized that their own death was imminent,” (p.422).	Coyle (2006) Willig and Billin (2012) and Ashworth (2003) Coyle (2004)

(Asgeirsdottir et al., 2014; Bentur et al., 2014; Blinderman & Cherny, 2005; Moestrup & Hansen, 2015), and age (Adorno & Brownell, 2014; Aoun et al., 2008; Lovgren et al., 2010; Williams, 2004). These are considered antecedents to existential experience as authors describe how these factors play a role in how an individual conceptualizes life, death, and the afterlife, thus shaping concerns and coping strategies related to these domains. For example, the quotes in Table 3 related to age reveal how advanced illness in an individual's life course may alter the meaning of the experience.

Attributes

The literature revealed three core attributes of existential experience, reflecting the shared existential challenges individuals face when confronting mortality, and the diversity of characteristics of coping with these challenges. As many authors noted, these themes are interconnected and overlapping, reflecting the dynamic nature of existential experience (Adorno & Brownell, 2014; Carter et al., 2004; Saeteren, Lindstrom, & Naden, 2011).

Facing Existential Challenges: Redefining Existence in Relation to Body, Time, Others, and Death

The literature describes individuals redefining their existence in relation to their body, time, others, and their approaching death. As individuals face challenges in these different dimensions, they may suffer or may find ways to adapt and thrive.

Relationship to the Body. Individuals with advanced cancer face existential challenges in relation to their body. They may experience physical changes due to progressing disease which may result in feelings of loss of control, loss of dignity, loss of identity, and alienation from the body and therefore, the self. Patients described feeling like “prisoners in their own bodies,” as their physical status restricted their ability to do the things that make them who they are and make their lives meaningful (Melin-Johansson, Odling, Axelsson, & Danielson, 2008, p. 234).

Relationship to Time. Individuals with advanced cancer face existential challenges in the realm of their relationship to time, as being given a terminal diagnosis unsettles one's experience of time in the present, past, and future. Individuals discuss their hopes and fears in light of an uncertain future (especially hopes for more time), their regrets and guilt over events of the past, and their search for meaning and purpose in a tenuous present. For example, Blinderman and Cherny (2005) included one patient who stated, “Nobody knows what will happen. As long as I am living and I am fine today, then I don't have to think about tomorrow,” (p. 377).

Relationship to Others. Individuals with advanced cancer face existential challenges in relation to others, as they experience increasing dependency and struggle with resulting loss of autonomy which challenges their dignity, integrity, and identity, and can lead to fear of being a burden. Additional challenges in this realm include feelings of grief or guilt over leaving loved ones behind and the existential isolation and loneliness that can come with being seriously ill. One patient summarized existential loneliness stating, “Your family, your friends, might be beside you, still, the suffering is yours,” (Lee et al., 2016, p. 1110). Many authors discuss how existential loneliness can be exacerbated by lack of communication (e.g., quote in Table 3).

Relationship to Death. Individuals with advanced cancer also face existential challenges in relation to their death. Themes included fears, hopes, and feelings of uncertainty surrounding their impending death, as well as searching for meaning in the event of death and what comes next. While confronting mortality and negotiating a fragile existence in various domains in light of looming nonexistence, a common refrain was simply stated by one patient, “I do not at all want to die yet,” (Asgeirsdottir et al., 2014, p. 6).

Characteristics of Existential Experience

Ambivalence. Many authors describe existential experience as a “hovering between” (Ekwall et al., 2007, p. 273) more negative thoughts and feelings (e.g., despair, pain, grief, sorrow, loss, meaninglessness, uncertainty, anxiety, fear, doubt, guilt, regret, shame, anger, insecurity, powerlessness, isolation, loneliness, and hopelessness) and more positive thoughts and feelings (e.g., hope, meaning, certainty, security, connectedness, joy, happiness, love, peace, calm, gratitude, openness, and relief). Individuals with advanced cancer live existential experience as a state of mixed and fluctuating thoughts and feelings, a state of ambivalence and oscillation. More than one patient described this experience as “a roller coaster ride,” (Asgeirsdottir et al., 2014, p. 5; Carter et al., 2004, p. 616).

Negative and Positive Thoughts and Feelings. Most commonly, participants in the articles described their existential experience as colored by isolation, uncertainty, grief or sorrow over the myriad of losses they faced, and fear of the future. This experience was punctuated by moments of profound despair, as one patient describes, “I was going to put on panty hose and discover that it's a garment (it's made) for healthy women, not sick ones. Then I experienced a sense of impotence, powerlessness, and helplessness. Death must come as a relief,” (Sand et al., 2008, p. 858). Though described with less frequency in the articles, individuals also described more positive aspects of existential experience, most commonly related to feeling hope and finding meaning. As the quote in Table 3 reveals, many

Table 3 – Elements of Existential Experience Extracted From Studies, n = 21

Antecedents	Subtheme	Selected Supporting Evidence	Articles Identified
Confronting mortality and awareness of death	Due to terminal diagnosis	“After diagnosis, patients described an awareness of having a limited lifespan and gaining a new perspective on life in general. Many patients explicitly said ‘now time is running out...’” (Lovgren et al., 2010, p. 60).	12 (57%) (Blinderman & Cherny, 2005; Carter et al., 2004; Ekwall et al., 2007; Griffiths, Norton, Wagstaff, & Brunas-Wagstaff, 2002; Karlsson et al., 2014; Lee et al., 2016; Lovgren et al., 2010; Missel & Birkelund, 2011; Saeteren et al., 2011; Sand et al., 2008; Williams, 2004; Willig, 2015)
	Due to physical changes	“Periods when severe side-effects of treatments, cancer symptoms or general debility were reported as times when respondents felt vulnerable and existential thoughts of death and dying emerged,” (Griffiths et al., 2002, p. 245)	11 (52%) (Adorno & Brownell, 2014; Asgeirsdottir et al., 2014; Bentur et al., 2014; Blinderman & Cherny, 2005; Carter et al., 2004; Ekwall et al., 2007; Griffiths et al., 2002; Karlsson et al., 2014; Melin-Johansson et al., 2008; Philip et al., 2014; Sand et al., 2008)
	Known on a deeper level	“Suddenly I have started getting the kind of thoughts like, okay, even if I am still alive, things are going to change. You know, all of a sudden it’s over for everyone, right, and how strange, what’s going to happen then, you know? You can sort of get an ‘aha’ experience from, from stuff that you know intellectually, but you get the feeling of it too somehow, you know,” (Lovgren et al., 2010, p. 60).	18 (86%) (Adorno & Brownell, 2014; Aoun et al., 2008; Asgeirsdottir et al., 2014; Bentur et al., 2014; Carter et al., 2004; Ekwall et al., 2007; Friedrichsen, Lindholm, & Milberg, 2011; Griffiths et al., 2002; Karlsson et al., 2014; la Cour & Hansen, 2012; Lovgren et al., 2010; Melin-Johansson et al., 2008; Missel & Birkelund, 2011; Moestrup & Hansen, 2015; Saeteren et al., 2011; Sand et al., 2008; Williams, 2004; Willig, 2015)
Influences	Personal factors	E.g. age: “As a 37-year-old patient with breast cancer so poignantly expressed, “This is a young life we’re talking about here. I don’t want to die young. I’m scared that the cancer will go somewhere else, and I’ll have to spend the rest of my life getting ready to die...before I’ve even had a chance to live,” (Williams, 2004, p. 32); “As one 78-year-old man said, ‘At this age your future is behind you, and I am not worried about it at all. Yes, we are living on overtime,’” (Lovgren et al., 2010, p. 60).	13 (62%) (Adorno & Brownell, 2014; Aoun et al., 2008; Asgeirsdottir et al., 2014; Bentur et al., 2014; Blinderman & Cherny, 2005; Carter et al., 2004; Lee et al., 2016; Lovgren et al., 2010; Melin-Johansson et al., 2008; Moestrup & Hansen, 2015; Sand et al., 2008; Williams, 2004; Willig, 2015)
Attributes	Subtheme	Selected Supporting Evidence	Articles Identified
Facing existential challenges	Relationship to body	“I could hardly recognise my body after the chemotherapy. It was so different. I was really afraid of myself – my body is decaying and I can’t do anything about it,” (Missel & Birkelund, 2011, p. 298). “What’s it like, life on your back? It’s not nice. Every day it gets progressively worse, it sort of creeps. Each morning you wake up with a little bit extra and it’s as if overnight, something goes into your brain and starts to scratch little bits away,” (Philip et al., 2014, p. 392).	18 (86%) (Adorno & Brownell, 2014; Asgeirsdottir et al., 2014; Bentur et al., 2014; Blinderman & Cherny, 2005; Carter et al., 2004; Ekwall et al., 2007; Friedrichsen et al., 2011; Griffiths et al., 2002; Karlsson et al., 2014; la Cour & Hansen, 2012; Lovgren et al., 2010; Melin-Johansson et al., 2008; Missel & Birkelund, 2011; Moestrup & Hansen, 2015; Philip et al., 2014; Sand et al., 2008; Williams, 2004; Willig, 2015)
	Relationship to time	“I don’t think too far into the future. I think it’s kind of sad that you (sighs)... even these retirement information letters that come in the mail (upset)... I don’t want to look at it. I think I won’t even exist then (crying); honestly, I’m not sure if I will. What if I’m not alive in 6 months; it’s no use buying a new dress...but then I think that you can’t think that way! You can just have it as long as you can (upset),” (Ekwall et al., 2007, p. 273). “I wish I had the energy to do the things I used to do...each day it seems to be less that I can do...it’s just the inability to do what I thought I would do, [what] I would have liked to have done...I was busy with interesting work – now I can’t do anything,” (Carter et al., 2004, p. 614).	19 (90%) (Adorno & Brownell, 2014; Asgeirsdottir et al., 2014; Bentur et al., 2014; Blinderman & Cherny, 2005; Carter et al., 2004; Ekwall et al., 2007; Friedrichsen et al., 2011; Griffiths et al., 2002; Karlsson et al., 2014; la Cour & Hansen, 2012; Lovgren et al., 2010; Melin-Johansson et al., 2008; Missel & Birkelund, 2011; Moestrup & Hansen, 2015; Philip et al., 2014; Saeteren et al., 2011; Sand et al., 2008; Williams, 2004; Willig, 2015)
	Relationship to others	“One of the things that strike me is how difficult it is to come to terms with feeling incapacitated. Going from an able bodied person, to suddenly having someone cut up your meal and feed you or shower you – that’s very hard to come to terms with,” (Philip et al., 2014, p. 392). “It’s important for me to talk with my kids, that they’ll know...but we always talk about everyday things and we don’t talk about life. We pushed life aside. And that’s wrong,” (Bentur et al., 2014, p. 3).	19 (90%) (Adorno & Brownell, 2014; Aoun et al., 2008; Asgeirsdottir et al., 2014; Bentur et al., 2014; Blinderman & Cherny, 2005; Carter et al., 2004; Ekwall et al., 2007; Griffiths et al., 2002; Karlsson et al., 2014; la Cour & Hansen, 2012; Lee et al., 2016; Melin-Johansson et al., 2008; Missel & Birkelund, 2011; Moestrup & Hansen, 2015; Philip et al., 2014; Saeteren et al., 2011; Sand et al., 2008; Williams, 2004; Willig, 2015)
			21 (100%)

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Table 3 – (Continued)

Antecedents	Subtheme	Selected Supporting Evidence	Articles Identified	
	Relationship to death	<p>“I have one fear. I am afraid I will die alone in my apartment and nobody will know until after my body starts to smell from decay, then they will know,” (Blinderman & Cherny, 2005, p. 378).</p> <p>“You know it’s a terminal illness, but is the end coming quick or is it slow, is it going to be long and drawn out and painful...not knowing, I think initially, is the hardest part,” (Carter et al., 2004, p. 615).</p>	(Adorno & Brownell, 2014; Aoun et al., 2008; Asgeirsdottir et al., 2014; Bentur et al., 2014; Blinderman & Cherny, 2005; Carter et al., 2004; Ekwall et al., 2007; Friedrichsen et al., 2011; Griffiths et al., 2002; Karlsson et al., 2014; la Cour & Hansen, 2012; Lee et al., 2016; Lovgren et al., 2010; Melin-Johansson et al., 2008; Missel & Birkelund, 2011; Moestrup & Hansen, 2015; Philip et al., 2014; Saeteren et al., 2011; Sand et al., 2008; Williams, 2004; Willig, 2015)	
Characteristics of existential experience	Ambivalence	<p>“I’m secure and hopeful and insecure and not hopeful, all at the same time. It goes up and down... then I think more that it’s the healthy part of me that makes it go up and down, but even so, it’s... (sighs deeply)... the hope... that it’s at least a little bigger than hopelessness,” (Ekwall et al., 2007, p. 273).</p>	8 (38%)	(Asgeirsdottir et al., 2014; Carter et al., 2004; Ekwall et al., 2007; Lovgren et al., 2010; Missel & Birkelund, 2011; Moestrup & Hansen, 2015; Saeteren et al., 2011; Willig, 2015)
	Negative thoughts and feelings	<p>“I am becoming more reserved. That is why it is so difficult (sad). I daren’t be open about my feelings anymore. It is as if people dislike me even more when I am (sad). And then I cry more (sad),” (Melin-Johansson et al., 2008, p. 234).</p> <p>“I felt that my life was at an end, why me?, why now?”, “what’s going to happen?”, “am I going to die?” (Missel & Birkelund, 2011, p. 298).</p> <p>“There is both fear and anxiety. First there was fear and then anxiety. First it was complete fear. I was just so...you can say terribly afraid...” (Asgeirsdottir et al., 2014, p. 5).</p>	20 (95%)	(Adorno & Brownell, 2014; Aoun et al., 2008; Asgeirsdottir et al., 2014; Bentur et al., 2014; Blinderman & Cherny, 2005; Carter et al., 2004; Ekwall et al., 2007; Friedrichsen et al., 2011; Griffiths et al., 2002; Karlsson et al., 2014; Lee et al., 2016; Lovgren et al., 2010; Melin-Johansson et al., 2008; Missel & Birkelund, 2011; Moestrup & Hansen, 2015; Philip et al., 2014; Saeteren et al., 2011; Sand et al., 2008; Williams, 2004; Willig, 2015)
	Positive thoughts and feelings	<p>“um, I’m more happy with life...Yeah, eh, where I used to take a lot for granted, I don’t now...I’m grateful for every little thing now... I wake up every morning, I’ve got, I’ve got my life...you know, see my Grandson, love and kisses and everything,” (Griffiths et al., 2002, p. 245).</p> <p>“Last week I heard that the doctor had given up, the illness has spread everywhere, the chemo isn’t helping, and all that’s left for me to do is start having some good times and enjoy life. That’s it. I left, and then I said ‘No! I’ll show them they’re wrong, and I’ll fight!’ [Smiling] And I am fighting,” (Bentur et al., 2014, p. 3).</p>	20 (95%)	(Adorno & Brownell, 2014; Aoun et al., 2008; Asgeirsdottir et al., 2014; Bentur et al., 2014; Blinderman & Cherny, 2005; Carter et al., 2004; Ekwall et al., 2007; Friedrichsen et al., 2011; Griffiths et al., 2002; Karlsson et al., 2014; la Cour & Hansen, 2012; Lee et al., 2016; Lovgren et al., 2010; Melin-Johansson et al., 2008; Missel & Birkelund, 2011; Moestrup & Hansen, 2015; Philip et al., 2014; Saeteren et al., 2011; Williams, 2004; Willig, 2015)
Coping with existential challenges	Strategies	<p>“Humour is what I try to survive on,” (la Cour & Hansen, 2012, p. 129).</p> <p>“I live from day to day because I really don’t know how long these things take,” (Aoun et al., 2008, p. 7).</p> <p>“I have had to make sure that everything is in order, because I know that I am going to die,” (Missel & Birkelund, 2011, p. 298).</p> <p>“I try to live my everyday as happy as I can,” (Lee et al., 2016, p. 1114).</p> <p>“I think it will be something beautiful when death arrives. I think it will be something beautiful. I will be welcomed by my own family,” (Asgeirsdottir et al., 2014, p. 8).</p>	21 (100%)	(Adorno & Brownell, 2014; Aoun et al., 2008; Asgeirsdottir et al., 2014; Bentur et al., 2014; Blinderman & Cherny, 2005; Carter et al., 2004; Ekwall et al., 2007; Friedrichsen et al., 2011; Griffiths et al., 2002; Karlsson et al., 2014; la Cour & Hansen, 2012; Lee et al., 2016; Lovgren et al., 2010; Melin-Johansson et al., 2008; Missel & Birkelund, 2011; Moestrup & Hansen, 2015; Philip et al., 2014; Saeteren et al., 2011; Sand et al., 2008; Williams, 2004; Willig, 2015)
	Obstacles	<p>“It’s always been out of my hands. It just happened the way it happened. I never really had a real choice, you know. Being sick was never anything I claimed,” (Williams, 2004, p. 33).</p> <p>“I won’t worry about it. I don’t want to worry about what may happen tomorrow and what can happen in the next...I simply will not spend my time on that—it may happen that it comes to mind,” (Moestrup & Hansen, 2015, p. 431).</p>	16 (76%)	(Adorno & Brownell, 2014; Asgeirsdottir et al., 2014; Bentur et al., 2014; Blinderman & Cherny, 2005; Carter et al., 2004; Ekwall et al., 2007; Friedrichsen et al., 2011; Griffiths et al., 2002; Karlsson et al., 2014; Missel & Birkelund, 2011; Moestrup & Hansen, 2015; Philip et al., 2014; Saeteren et al., 2011; Sand et al., 2008; Williams, 2004; Willig, 2015)

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Table 3 – (Continued)

Antecedents	Subtheme	Selected Supporting Evidence	Articles Identified
Consequences	Subtheme	Selected Supporting Evidence	Articles Identified
Existential suffering vs. health	Existential suffering	<p>"I thought I cannot cope with this any longer and then I actually cried. I was crying when the physicians were here. I said, I do not want to live. I do not want to live if I am going to feel like this. I do not want to live like this," (Melin-Johansson et al., 2008, p. 234)</p> <p>"She evokes a sense of being caught up in something terrible ("a nightmare", "a horrendous situation") without the means of dealing with it; she concludes "Yes, you're in it and, yes, you can't get out of it," (Willig, 2015, p. 420).</p>	<p>(Adorno & Brownell, 2014; Asgeirsdottir et al., 2014; Bentur et al., 2014; Blinderman & Cherny, 2005; Ekwall et al., 2007; Karlsson et al., 2014; la Cour & Hansen, 2012; Lee et al., 2016; Lovgren et al., 2010; Melin-Johansson et al., 2008; Missel & Birkelund, 2011; Moestrup & Hansen, 2015; Philip et al., 2014; Saeteren et al., 2011; Sand et al., 2008; Williams, 2004; Willig, 2015)</p>
	Existential health	<p>"I have never experienced love so strongly before, and love is what is really important," (Saeteren et al., 2011, p. 815).</p> <p>"All my priorities and my perspective on life changed, I say those who haven't been there don't even understand what life is... I think people these days are too busy with material things and confuse the unimportant things with the essence. I'm saying there's nothing stronger than the power of daily routine. For me, managing to keep the routine going, waking up in the morning with the kids and putting them to bed, sending them off to kindergarten with a smile, reading them a story... [is] supreme bliss. Supreme," (Bentur et al., 2014, p. 4).</p> <p>"Yes, you take charge of it. I think something good can come from this, that I've grown as a person too. I have a completely different awareness now," (Karlsson et al., 2014, p. 6).</p>	<p>17 (81%)</p>
	Existential health		<p>14 (67%)</p>

participants voiced hoping for more time, or hope for cure/a miracle, despite being aware of their prognosis.

Coping With Existential Challenges

Strategies. Coping strategies described in the literature include using humor, practicing acceptance, focusing on the here and now, seeking support from family, friends, and health care professionals, employing active coping (e.g., through preparing for death), and positively reframing existential experience, primarily through making meaning (whether through religious, spiritual, or secular beliefs). The most frequently discussed strategies in the literature related to using active coping strategies to prepare for death (in this way regaining control in a situation marked by loss of control) and reframing existential challenges to make meaning in the time remaining. For instance, authors discuss individuals renegotiating their relationship with time to make the most of their time left. As one patient residing in a hospice facility states, "We look forward to every day now," (Moestrup & Hansen, 2015, p. 433).

Obstacles. Whether due to limited personal resources or environmental support, the literature illustrates how some individuals face obstacles to coping with existential challenges. Limited personal resources are marked by lacking effective coping strategies, either employing denial or struggling with lack of control throughout life as a result of systemic disempowerment. Insufficient environmental support was the most frequently reported obstacle to coping, with participants voicing feeling unsupported by friends, family, or health care professionals. For instance, Philip et al. (2014) describe that patients report their existential needs are neglected by the health care team, with one patient stating, "I'd be very happy to have an opportunity to talk with someone about what I'm going through and what it all means," (p. 394).

Consequences

Existential Suffering vs. Existential Health

Consequences of existential experience are identified in the literature as existential suffering vs. existential health. Existential suffering "disturbs the entity of body, soul and spirit," (Saeteren et al., 2011, p. 816) resulting from an individual being unable to cope with their existence and identity being challenged relative to their relationship to their body, time, and others as well as being overwhelmed by thoughts of death. Individuals may experience a "profound loss 'of the person [they] know [themselves] to be'" (Adorno & Brownell, 2014, p. 141); individuals in this state experience uncertainty, meaninglessness, grief, and loneliness. Conversely, existential health is described as "a movement towards a deeper unity of becoming... toward wholeness and integrity," (Saeteren et al., 2011, p. 816). Authors describe this state as characterized by personal growth, a new or a renewed appreciation of daily life,

new meaning, increased fulfillment, a sense of connectedness to others, and improved well-being.

However, the relationship between these two states remains unclear. While some authors describe these states as dichotomous (Bentur et al., 2014; Blinderman & Cherny, 2005; Willig, 2015), other authors describe these states as continuous, where there is a “dialectical movement” between suffering and health (Karlsson, Friberg, Wallengren, & Ohlen, 2014; la Cour & Hansen, 2012; Melin-Johansson et al., 2008; Moestrup & Hansen, 2015; Saeteren et al., 2011, p. 816; Sand et al., 2008). Still other authors explain a movement through suffering toward health (Carter et al., 2004; Missel & Birkelund, 2011), suggesting a progression that evolves over time and perhaps suggesting these are not two distinct states, but instead, two parts of one process. Thus, it remains unclear how these consequences coexist.

Related Concepts

Review of the literature revealed concepts related to existential experience. These included spirituality (Breitbart, 2002; Brennan, 2006; McSherry & Cash, 2004), dignity (Chochinov, Hack, McClement, Kristjansson, & Harlos, 2002; Guo & Jacelon, 2014), hope (Broadhurst & Harrington, 2016), meaning (Frankl, 1985), transcendence (Coward, 1989), and post-traumatic growth (Tedeschi, Cann, Taku, Senol-Durak, & Calhoun, 2017), as well as hopelessness and futility (Parker, 2011), suffering (Cassell, 1982; Ferrell & Coyle, 2008), demoralization syndrome (Kissane, Clarke, & Street, 2001; Parker, 2004; Robinson, Kissane, Brooker, & Burney, 2015, 2016), and death anxiety (An, Lo, Hales, Zimmermann, & Rodin, 2018). A full review of these related concepts was beyond the scope of this paper.

Discussion

This concept analysis provides a foundation for clarifying the concept of existential experience of adults with advanced cancer. It can be understood as a dynamic and fluid state, preceded by confronting mortality and becoming aware of death. Whether this “existential turning point,” (Missel & Birkelund, 2011, p. 298) occurs due to receiving a terminal diagnosis or experiencing the physical changes associated with progression of disease, the fragility of existence is known in a deeper way than before. Existential experience is shaped by personal factors, such as age, cultural background, and religious beliefs. It is defined by the process of facing shared existential challenges related to the parameters of existence (body, time, others, and death) and coping in idiosyncratic ways—most commonly through preparing for death and reframing existential challenges to make meaning in the time remaining. However, this ability to cope with existential challenges can be hindered by limited

personal resources or environmental support. The feeling of ambivalence permeates this experience, characterized by a constant fluctuation between positive and negative thoughts and feelings such as hope and meaning along with isolation, uncertainty, grief, and sorrow. Existential experience results in a dialectical movement between existential suffering and existential health, with capacity for personal growth. The model for the existential experience of adults with advanced cancer is presented in Figure 3. [Antecedents are represented in gray boxes. Attributes are represented in gray text, with positive and negative thoughts and emotions displayed between existential challenges and either existential suffering or existential health, as well as along the spectrum from existential suffering to existential health. It should be noted that particular affective and cognitive attributes are not necessarily associated with coping strategies, obstacles, or dialectical coping; rather, these attributes are characteristics of the existential experience overall and are displayed in this way for visualization purposes only. Coping strategies are represented as assisting individuals in facing existential challenges and moving toward existential health. Obstacles to coping are represented between existential challenges and existential suffering as these factors may make existential suffering more likely; dialectical coping is also on the spectrum between existential suffering and existential health. Consequences are represented in boxes with dashed outlines, representing the fluidity of these states. The consequences of existential experience are represented as points on a pendulum, illustrating the dialectical movement between existential suffering and existential health.]

This concept analysis builds upon previous philosophical work surrounding existential experience. For instance, the findings of this analysis support Yalom's (1980) emphasis on four key existential concerns: (1) freedom, (2) meaninglessness, (3) isolation, and (4) death, each of which is dualistic, with positive and negative dimensions. These themes are woven through the existential challenges described herein and this concept analysis particularly supports the ambivalent nature of existential experience. Perhaps more clearly, it underscores van Manen's “existentials”—spatiality, temporality, corporeality, and relationality—which structure how we experience ourselves and our world in relation to lived space, time, the body, and in connection to others (Van Manen, 2014). As this concept analysis reveals, during advanced illness, individuals find their relationship to these aspects of existence challenged, and they must cope with these changes or else existential suffering may result.

Strengths and Limitations

This analysis focused on the existential experience of adults with advanced cancer, which may limit

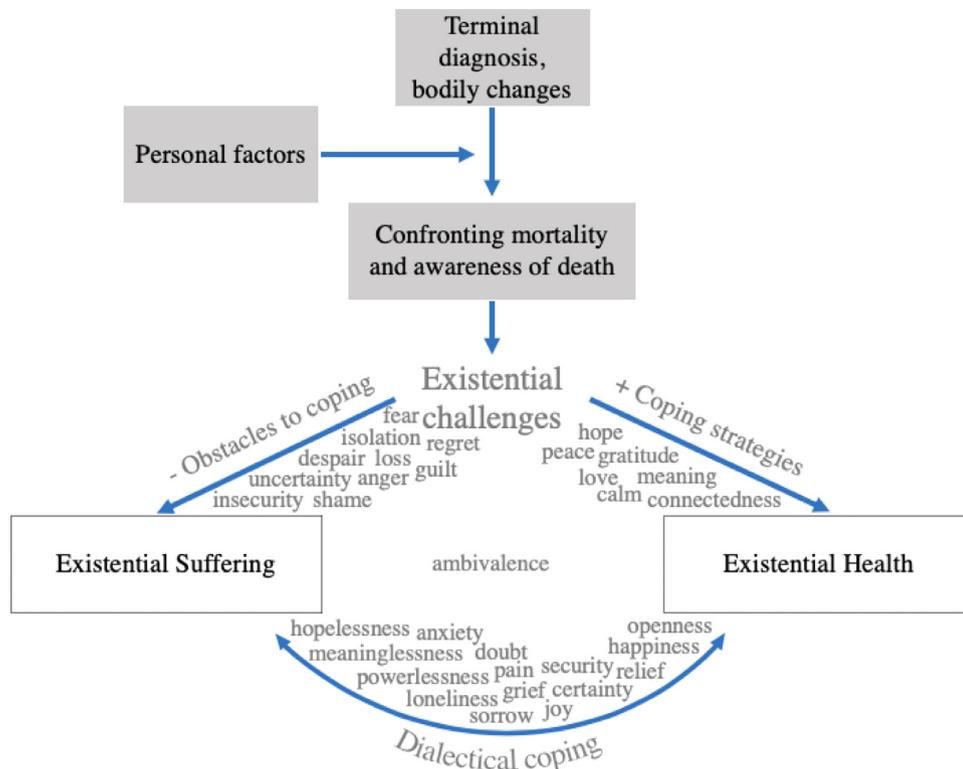


Figure 3 – The model of existential experience in adults with advanced cancer.

applicability to other illnesses and age ranges. Methodologically, to improve sensitivity of the literature search, articles were included if they mentioned “existential” in the title or abstract. This approach may have potentially missed articles that could have added to the understanding of the concept. Furthermore, synthesizing qualitative findings from studies using different methods could be a concern due to the distinct ways these methods approach analysis (Noblit & Hare, 1988). Thus, as much as possible, this analysis focused on the patient accounts from the included articles in order to interrogate the first-hand experience of adult persons with cancer.

One strength of this analysis is that the full spectrum of existential experience was investigated in comparison to the research related to existential experience which focuses on aspects of experience (e.g., suffering). As this concept analysis reveals, the existential experience of individuals with advanced cancer is dynamic and so exploring the totality of experience, rather than demarcating it into investigator-defined buckets, honors its essence. An additional strength of this analysis is the focus on qualitative research to pay explicit attention to the patient’s voice and attempt to capture this heterogenous and highly subjective experience. Lastly, the studies included in this analysis span from many different countries (Australia, Denmark, England, Iceland, Israel, New Zealand, Norway, Singapore, Sweden, and the United States), suggesting the universality of existential experience and relevance of this concept analysis.

Implications

This concept analysis has important implications for both research and clinical practice. First, this concept analysis helps elucidate the full spectrum of existential experience and highlights the capacity for personal growth within this experience. Yet, the literature exploring existential experience is limited as the majority of studies are cross sectional and focus on existential suffering. To improve understanding of how individuals move between existential suffering and health, and uncover whether these are two distinct states or perhaps part of the same developmental process (Emanuel, Reddy, Hauser, & Sonnenfeld, 2017), increasing longitudinal research studying the full spectrum of existential experience is vital.

Additionally, education programs for clinicians working with individuals with serious illness to understand and attend to existential concerns are evolving (Sand et al., 2018). However, these educational strategies continue to stress existential crisis (Sand et al., 2018). The conceptual model presented here can offer clinicians a broader view, highlighting the importance of acknowledging and addressing existential suffering, as well as identifying and fostering existential health. This is significant as some linguistic anthropologists argue that having more language to describe a phenomenon affects the perception, understanding, and outlook of that phenomenon (Ahearn, 2011; Young & Rushton, 2017). Thus, emphasizing the full spectrum of existential experience gives clinicians the language necessary to expand their

gaze beyond existential suffering and feel confident supporting possibilities for growth at end-of-life.

Conclusion

When an individual faces serious illness, such as advanced cancer, this experience “tears a rent in the curtain of defenses,” and individuals confront the reality of their impending nonexistence much more intensely (Yalom, 1980, p. 44). This concept analysis sheds light on this critical life situation, revealing the antecedents, attributes, and consequences of existential experience, to more fully describe how adults with advanced cancer live while approaching death. Clarifying the concept of existential experience can drive future research, empirically refining the model presented here. It is our hope that this concept analysis can serve as the first step toward facilitating deeper understanding of existential experience on the part of clinicians, enhancing attention to this neglected domain of serious illness management and improving the care of patients at end-of-life.

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