

Review Article

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Increasing our understanding of nonphysical suffering within palliative care: A scoping review

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Abstract

Objective. Nonphysical suffering is emotional, psychological, existential, spiritual, and/or social in nature. While palliative care is a discipline dedicated to the prevention and relief of suffering — both physical and nonphysical — little is known about existing research specific to nonphysical suffering within the context of palliative care. This scoping review helps to fill this gap.

Method. Three hundred and twenty-eight unique records were identified through a systematic search of three databases (MEDLINE, CINAHL, and PsycINFO). The following keywords were used: (suffering) AND (palliative OR “end of life” OR “end-of-life” OR hospice OR dying OR terminal* ill*). Thirty studies published between 1998 and 2019 met the inclusion criteria.

Results. Losses, worries, and fears comprise patients’ primary sources of nonphysical suffering. Patients face numerous barriers in expressing their nonphysical suffering to healthcare providers. The idea that patients can choose how they perceive their circumstances, thereby minimizing their nonphysical suffering, is pervasive in the research. The nature of nonphysical suffering experienced by family caregivers and palliative care clinicians is revealed in the review. The unique and sensitive interplay between nonphysical suffering and both palliative sedation and requests for hastened death is also evident. Overall, seven themes can be identified: (i) patients’ experiences of nonphysical suffering; (ii) patient coping mechanisms; (iii) efforts to measure nonphysical suffering; (iv) palliative sedation; (v) requests for hastened death; (vi) family suffering; and (vii) clinician suffering.

Significance of results. This is the first scoping review to map palliative care’s research specific to suffering that is social, emotional, spiritual, psychological, and/or existential in nature. Its findings expand our understanding of the nature of nonphysical suffering experienced by patients, families, and palliative care clinicians. The review’s findings have significant implications for front-line practice and future research.

Introduction

Preventing and relieving suffering lies at the heart of the definition and aim of palliative care (WHO, 2021). The word ‘suffering’ translates from the Latin verb ‘sufferer’ as ‘to undergo,’ ‘to bear,’ or ‘to carry’ (Browning, 2004). Suffering is often viewed as inherently multidimensional; that is, simultaneously physical, emotional, psychological, social, existential and/or spiritual in nature (Williams, 2004; Sacks and Nelson, 2007; Sudore et al., 2010; Krikorian et al., 2012; Montoya-Juarez et al., 2013a; Beng et al., 2014). This holistic view of suffering is akin to the concept of ‘total pain,’ coined by the founder of the modern hospice movement, Dame Cicely Saunders. ‘Total pain’ “include[s] physical symptoms, mental distress, social problems, and emotional difficulties” (Clark, 2016, p. 131); if physical pain is difficult to treat, it may be connected to nonphysical elements, resulting in ‘total pain,’ or ‘total suffering’ (Saunders et al., 1995). Saunders’ conceptualization of suffering, along with Dr. Eric Cassell’s (1982) which defines suffering as “the state of severe distress associated with events that threaten the intactness of the person” (p. 640), are widely referenced in the palliative care literature. Like Saunders, Cassell, too, believes that suffering should not be separated into physical and nonphysical realms (Cassell, 2004). Cassell is credited with moving medicine’s understanding of suffering away from a focus on solely its bodily or physical manifestations, to an understanding of suffering as that which affects — or “afflict[s]” — a ‘person,’ or one’s personhood (Cassell, 2004, p. xii).

Both research and front-line practice reveal, however, that physical suffering and nonphysical suffering do not always co-exist, and can be distinct experiences for patients, families, and clinicians alike. Nonphysical suffering includes suffering that is emotional, psychological, existential, spiritual, and/or social in nature. Increasing our understanding of nonphysical suffering is important — vital, in fact — to the work of palliative care practitioners across all disciplines, which is the aim of this scoping review.

Methods

Scoping Reviews are systematic ways of examining a large body of literature, “especially when an area is complex or has not been reviewed comprehensively before” (Arksey and O’Malley, 2005, p. 21). ‘Suffering’ is described as complex and multifaceted in the palliative care literature (Daneault et al., 2006; Sacks and Nelson, 2007; Montoya-Juarez et al., 2013a), and a scoping review specific to suffering, let alone nonphysical suffering, within palliative care has not been completed before.

Inclusion and exclusion criteria

Inclusion and exclusion criteria were developed at the review’s outset and refined as the process unfolded (Arksey and O’Malley, 2005). Levac et al. (2010) noted that in scoping reviews, “Study selection involves post hoc inclusion and exclusion criteria. These criteria are based on the specifics of the research question and on new familiarity with the subject matter through reading the studies” (p. 3). All articles had to be peer reviewed and published in English. Studies needed to have as a primary purpose either a focus on suffering that was specifically nonphysical in nature, or a focus on trying to better understand ‘suffering,’ including both nonphysical and physical elements. Studies that focused exclusively on physical suffering or did not specify the nature of suffering (whether physical and/or nonphysical) were excluded, as were studies that asked patients about their experiences of nonphysical aspects of ‘pain’ or ‘distress,’ but not ‘suffering.’ All study participants had to be themselves receiving palliative care and/or living with an advanced illness, or be caregivers/family members of patients receiving palliative care and/or living with an advanced illness. In studies focusing on clinician experiences working with nonphysical suffering, clinicians had to work specifically with individuals receiving palliative care and/or living with an advanced illness. The author of this paper chose to exclude one of their own studies that would have met the inclusion criteria.

Search strategy

A computerized search was conducted of sources published as of February 2020 in the following databases: CINAHL, MEDLINE, and PsycINFO. The following keywords were used: (suffering) AND (palliative OR “end of life” OR “end-of-life” OR hospice OR dying OR terminal* ill*). As CINAHL does not offer the option to search by ‘keyword,’ terms were searched using the ‘MJ Word’ option. This search strategy resulted in 447 records. Of the 447 records, 125 were duplicates. The total number of records rejected was 241: 11 were rejected outright because they were book reviews, conference abstracts, or on an unrelated topic, and an additional 230 articles were rejected because they were not research studies (e.g., conceptual papers, commentaries, etc.). Of the 87 research studies, including 6 that were identified through hand searching reference lists, 30 met this scoping review’s inclusion/exclusion criteria. See Table 1 for the study’s Prisma flowchart.

Data analysis

Arksey and O’Malley’s (2005) five stages framework for scoping reviews guided the review process. Stage 1 is the ‘Identification of a Research Question.’ The research question guiding this scoping study is: What is known from the research about nonphysical suffering within the context of palliative care? Its purpose is to

gain a better understanding of nonphysical suffering, to identify gaps in the research, and to consider implications for both front-line practice and future research. Stage 2 involves the ‘Identification of Relevant Studies’ and Stage 3 is ‘Study Selection’; closely following the inclusion and exclusion criteria developed for this review helped in the identification and selection of 30 relevant studies. Stage 4 involves ‘Charting the Data’; a technique that entails “sifting, charting and sorting material according to key issues and themes,” and “collecting standard information on each study” (Arksey and O’Malley, 2005, p. 26). Table 2 provides a brief summary of standard study characteristics, including study settings (e.g., inpatient and outpatient palliative care programs), study location (country), and patient diagnoses. A chart of all studies included in the review was developed to track study aims and key findings (see Table 3). From there, commonalities and differences were noted across all findings which allowed for the identification of seven themes. Stage 5 of Arksey and O’Malley’s (2005) model is summarizing and reporting the results, which is the focus of the following section.

Results

In total, 30 studies were reviewed. Seven themes can be identified: (i) patients’ experiences of nonphysical suffering; (ii) patient coping mechanisms; (iii) efforts to measure nonphysical suffering; (iv) palliative sedation; (v) requests for hastened death; (vi) family suffering; and (vii) clinician suffering.

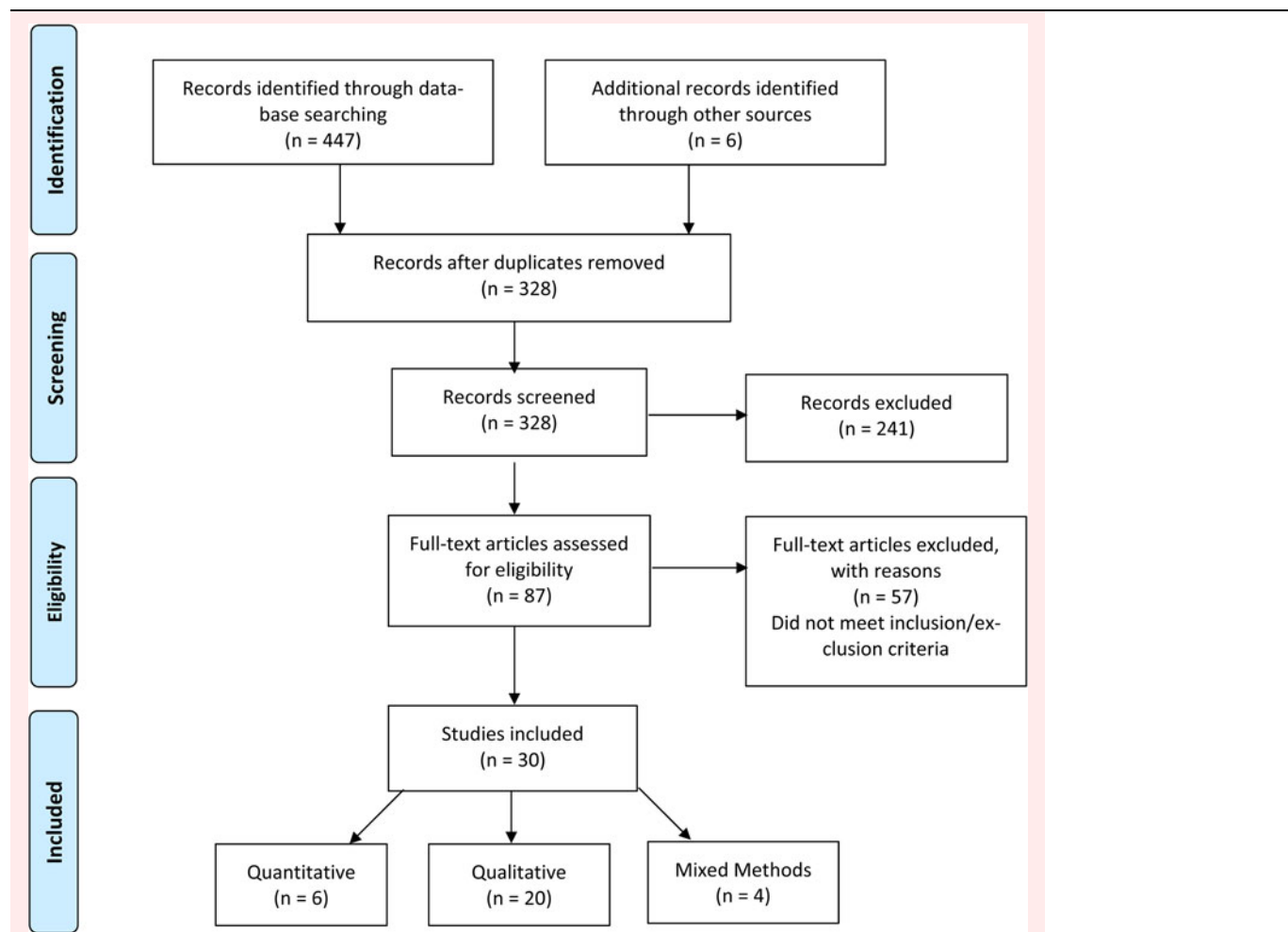
Theme 1: Patients’ experiences of nonphysical suffering

Thirteen of the 30 research studies included in the scoping review focus on trying to explain or understand patients’ experiences of nonphysical suffering.

Losses

The multiple and accumulated losses that individuals experience in the advanced stages of illness are a key component of nonphysical suffering, including loss of independence (Daneault et al., 2004; Wilson et al., 2007; Nilmanat et al., 2010; Beng et al., 2014; Ellis et al., 2015; Tan et al., 2016; Tang et al., 2016), functional losses (Kuuppelomaki and Lauri, 1998; Beng et al., 2014), and loss of control (Kuuppelomaki and Lauri, 1998; Rydahl-Hansen, 2005; Wilson et al., 2007; Rujs et al., 2012). Loss from physical changes also comes in the form of changes to one’s body image, which can be related to the effects of treatments, surgeries, and the illness itself (Kuuppelomaki and Lauri, 1998; White et al., 2004; Nilmanat et al., 2010). The loss or “erosion” of one’s social roles and/or social identity is another aspect of nonphysical suffering prominent in the research (Daneault et al., 2004, p. 9; Wilson et al., 2007; Rujs et al., 2012; Ellis et al., 2015). Participants throughout the studies experience profound social isolation, loneliness, and alienation, even when they are receiving care and are near the people in their life — another key aspect of nonphysical suffering (Kuuppelomaki and Lauri, 1998; Williams, 2004; Wilson et al., 2007; Nilmanat et al., 2010, 2015; Montoya-Juarez et al., 2013b). Loss-induced suffering is also experienced in the form of patients anticipatorily grieving their families, including chosen family. One study describes it as, “anticipated separation from family, [and] anticipated loss of all things in the end, including their own existence” (Beng et al., 2014, p. 49). The losses associated with not being able to achieve one’s goals, and, in general, grieving a future that they will not be

Table 1. Prisma flowchart



a part of is another aspect of nonphysical suffering described in the research (Daneault et al., 2004; Ellis et al., 2015).

Fears

Nonphysical suffering also comes in the form of fears. Patients' fears include fear of the future, the unknown, uncertainty, future suffering, death, and fear of being burdensome (Kuuppelomaki and Lauri, 1998; Daneault et al., 2004; White et al., 2004; Williams, 2004; Sacks and Nelson, 2007; Chio et al., 2008; Rujs et al., 2009; Montoya-Juarez et al., 2013b). Patients' nonphysical suffering comprise fears of *how* death will happen, as well as fears *that* death will happen (Daneault et al., 2004; Terry and Olson, 2004), with research participants expressing, for example: "I get caught up in fear. I don't want to have a drawn out agony [when I die]" (Daneault et al., 2004, p. 10), and "I don't want to die, I'm scared" (Terry and Olson, 2004, p. 605). One study notes that dying young or "off time" contributes to existential fears and suffering (Williams, 2004, p. 27), with another study finding that patients' prognostic awareness increases suffering (Tang et al., 2016).

Worries about family/friends

Patients' worries about their family and/or friends are another key component of nonphysical suffering. Patients' worries stem from how family members are currently coping and how they will cope

after they die (Baines and Norlander, 2000; Rydahl-Hansen, 2005; Beng et al., 2014; Ellis et al., 2015). One research participant shares: "... Umm I just feel sometimes you know the hurt that I've given to my husband and the boys. Umm ... and they're going to have to cope afterwards ... That's what hurts the most" (Ellis et al., 2015, p. 203). Additionally, patients feel "emotional pain" (Ellis et al., 2015, p. 204), grief and helplessness watching their family members experience the advanced stages of their illness, and imagining their family's future without them (Beng et al., 2014). Patients also suffer from knowing that they are causing worry for their family and friends, and leaving them to grieve (Wilson et al., 2007; Beng et al., 2014; Tan et al., 2016), as well as from "unresolved family dynamics" (White et al., 2004, p. 440).

Barriers to expressing nonphysical suffering

Patients face several barriers in expressing their nonphysical suffering to healthcare providers. Patients shared feeling too physically and mentally exhausted to articulate their suffering to healthcare providers, with one study revealing that patients were in this sense, "... at the mercy of the professionals, one's articulateness" (Rydahl-Hansen, 2005, p. 217). Patients also experience difficulty in expressing their nonphysical suffering because it is simply hard to do so; they may choose to under-report or minimize their suffering so as to not become overwhelmed by it (Daneault et al., 2004, 2006; Rydahl-Hansen, 2005). The clinical

Table 2. Summary of study characteristics

Geographic Break-Down:
USA: 5
Malaysia: 5
Canada: 5
Netherlands: 2
Australia: 2
Taiwan: 2
Spain: 2
Thailand: 2
UK: 1
Finland: 1
Denmark: 1
Japan: 1
Colombia: 1
Date Range:
1998–2019
Diagnosis (of population studied or served):
Advanced Cancer: 17
Advanced Cancer and Noncancer: 7
Does Not Specify: 6
Settings:
Inpatient Palliative Care Unit: 7
Outpatient Palliative Care: 1
Residential Hospice: 3
Inpatient Oncology Unit: 2
Outpatient Oncology Care: 2
Combination Inpatient/Outpatient Palliative Care: 5
Home Care: 3
Does Not Specify: 7

environment also contributes to patients' nonphysical suffering remaining unexpressed. The research shows that a lack of time and space within the clinical environment, and feeling rushed during clinical encounters, are additional barriers to suffering's expression (Daneault et al., 2004, 2006; Rydahl-Hansen, 2005; Schroepfer, 2007; Beng et al., 2014). Lack of information and limited attention from staff can also lead to patients experiencing "psychosocial suffering" (Schroepfer, 2007, p. 143).

Theme 2: Patients' coping mechanisms

Seven of the 30 research studies in the scoping review focus on ways that patients can respond to, cope with, and/or heal their nonphysical suffering. Five of the 7 studies note that how patients choose to view or appraise their situation is a determining factor in whether they will 'suffer.' Choosing to view one's illness in a positive light (Chio et al., 2008; Krikorian et al., 2014; Tan et al., 2016), as an opportunity for personal growth, and being hopeful and accepting of one's situation (Montoya-Juarez et al.,

2013a; Nilmanat et al., 2015; Tan et al., 2016) are identified in the research as effective ways of responding to nonphysical suffering. By changing their mindset, patients' nonphysical suffering can be transformed or transcended (Chio et al., 2008; Montoya-Juarez et al., 2013a; Krikorian et al., 2014; Nilmanat et al., 2015; Tan et al., 2016); what one study describes as "cognitive restructuring" (Krikorian et al., 2014, p. 539). As one study notes, patients' own "psychological patterns have been perpetuating their suffering; they have a choice to stop the perpetuation; and they have the full capacity to liberate themselves from being stuck in their own set patterns of perceptions" (Tan et al., 2016, p. 5). Changing patients' perceptions of suffering is the focus of another study that finds a mindfulness breathing technique helpful in this regard (Beng et al., 2019). Other research notes that adopting a religious or spiritual approach can help patients transform their nonphysical suffering, and find meaning in it (Ellis et al., 2015; Nilmanat et al., 2015).

Theme 3: Efforts to measure nonphysical suffering

Two of the 30 research studies in the scoping review focus on ways clinicians can measure a patient's suffering, including both physical and nonphysical elements. Because suffering is thought to be a subjective experience, the research reveals efforts to try to objectively measure it. In one study, the reliability of the Suffering Pictogram to detect a patient's inner experiences of suffering was confirmed; it requires patients to use Likert Scales to assess their feelings across eight domains, including worry, fear, anger, sadness, hopelessness, difficulty in acceptance, emptiness, and physical discomfort (Beng et al., 2017). Another study developed and validated a quantitative tool to measure advanced cancer patients' 'State of Suffering' across nearly 70 aspects of suffering on a five-point scale, with participants themselves distinguishing sources of suffering as having physical (e.g., weakness, tiredness, pain, loss of appetite, and not sleeping well) vs. psychological, social, and existential dimensions (e.g., "loss of function," "feelings of not any longer being the same person," "feeling lonely," and "fear of future suffering") (Rujs et al., 2009, p. 4).

Theme 4: Palliative sedation

Palliative sedation is the focus of two of the 30 research studies; both focus on clinician attitudes or experiences with palliative sedation in the context of existential suffering specifically. One study explores palliative care physicians' and pharmacists' attitudes toward palliative sedation based on prognosis (long vs. short) and type of suffering (physical vs. existential) (Blondeau et al., 2005), finding that participants were much more reluctant to support palliative sedation for existential suffering than for suffering that was physical in nature, even when a patient's prognosis was short (<10 days). The second study explores aspects of existential suffering that may lead a palliative care physician to provide a patient with palliative sedation (Morita, 2004, p. 445). The study concludes that "palliative sedation for psychoexistential suffering could be ethically permissible in exceptional cases," for such aspects of suffering as feeling worthless, burdensome, isolated, and fearful and/or anxious about death (Morita, 2004, p. 449).

Table 3. Summary of studies included in the scoping review ($n = 30$)

Article	Country	Population/Setting	Study Aims	Methods	Key Findings
Baines and Norlander (2000)	United States	92 Patients enrolled in a home-hospice program with prognoses of less than 6 months. Participants had both cancer and noncancer diagnoses.	To examine the relationship between terminally ill patients' rating of pain and their rating of suffering in three categories: physical, spiritual, and personal or family.	Quantitative study. Participants completed quantitative scales that asked them to rate both their pain and suffering experiences on a scale of 0–10.	Patients reported suffering even though they were not having pain and conversely reported minimal suffering even though they were experiencing severe pain. Of the three categories of suffering that this study explored, "Concern for loved ones" was the experience of suffering that received the highest mean score among hospice patients.
Beng et al. (2019)	Malaysia	40 Palliative care inpatients with an overall suffering score of 4+ as measured by the Suffering Pictogram.	To study the efficacy of a single session of mindful breathing on the reduction in perceived level of suffering among palliative care patients.	Quantitative study. Parallel-group, nonblinded, randomized controlled study. Participants were randomly assigned to either mindful breathing or supportive listening based on computer-generated random numbers. Suffering as measured by the Suffering Pictogram was assessed pre- and post-intervention.	A 20-min mindful breathing intervention was as effective as 20-min supportive listening intervention in the reduction of suffering among palliative care patients. Although there was no significant difference between intervention and control, the benefit of mindful breathing was experienced earlier (within 5 min) than supportive listening (before 20 min).
Beng et al. (2017)	Malaysia	91 Palliative care inpatients. Participants had both cancer and noncancer diagnoses. Nearly half had been ill for more than a year, 16 were ill for 6–12 months, and 23 were ill for less than 6 months.	To determine the reliability of the Suffering Pictogram to detect a patient's inner experiences of suffering.	Quantitative study. Participants completed quantitative scales designed to detect a patient's inner experience of suffering.	The Suffering Pictogram is a validated instrument that can be used as a screening tool to detect suffering directly across eight domains: physical discomfort, worry, fear, anger, sadness, hopelessness, difficulty in acceptance, and emptiness.
Beng et al. (2014)	Malaysia	20 Palliative care inpatients. All participants had advanced cancer.	To understand the experiences, nature and components of suffering of palliative care patients.	Qualitative study. Semi-structured interviews; coding; thematic analysis.	Multiple losses, complete dependence, poor support, intense symptoms, excessive rumination, and nonacceptance contribute to the experience of patients' suffering. Strong support, well-managed symptoms, resilience, optimism, appreciation, and acceptance are protective factors regarding patients' experience of suffering.
Beng et al. (2013)	Malaysia	15 Informal caregivers of adult palliative care inpatients. Majority of patients had advanced cancer.	To explore the experience of suffering in informal caregivers.	Qualitative study. Semi-structured interviews; coding; thematic analysis.	Family caregivers experience suffering vicariously because of the empathy they feel toward the patient. Anticipatory grief, feeling helpless, and anticipating both the patient's impending death and the patient's perceived absence in their life contribute to family caregivers' suffering. Caregivers' suffering may also be financial in nature. Family caregivers' suffering is often unacknowledged by healthcare providers, or by caregivers themselves.

(Continued)

Table 3. (Continued.)

Article	Country	Population/Setting	Study Aims	Methods	Key Findings
Blondeau et al. (2005)	Canada	124 Clinicians at 37 palliative care sites (does not specify the number that were physicians vs. pharmacists). Participants were recruited from clinical environments offering palliative care.	To understand physician and pharmacist attitudes toward palliative sedation based on prognosis (long vs. short) and type of suffering (physical vs. existential).	Mixed methods study. Participants analyzed four clinical vignettes developed to measure the dependent variable: respondents' attitudes toward end-of-life sedation. These consisted of sample situations which were used to measure the effect of the two independent variables: suffering and prognosis. Attitude to sedation was measured using a Likert scale.	Study results showed that participants were not in favor of using palliative sedation for existential suffering no matter the length of the prognosis. With physical suffering, participants were more open to using sedation and were slightly more in favor of this practice if the prognosis is shorter (<10 days) vs. a longer prognosis of 1–2 months. The study found that clinicians felt “uneasy” and “powerless” in the face of existential suffering specifically.
Bruce et al. (2011)	Canada	6 Patients, 6 family caregivers, and 10 clinicians (nurses, chaplains, social workers, physicians) who identified with having experience with existential suffering at the end of life.	To understand the process of engaging with existential suffering at the end of life.	Qualitative study. Grounded theory. Open-ended questions were used. For example, clinicians were asked: “Tell me what it is like being with patients who experience intolerable nonphysical suffering?” Patients were asked: “Tell me what it has been like since receiving your diagnosis?” As few follow-up prompts as possible were used.	Findings suggest the process of existential suffering begins with an experience of groundlessness that results in an overarching process of ‘Longing for Ground in a Ground(less) World’, a wish to minimize the uncomfortable or anxiety-provoking instability of groundlessness. ‘Longing for ground’ is enacted in three overlapping ways: by turning toward one’s discomfort and learning to let go (engaging groundlessness), turning away from the discomfort, attempting to keep it out of consciousness by clinging to familiar thoughts and ideas (taking refuge in the habitual), and learning to live within the flux of instability and unknowing (living in-between).
Chio et al. (2008)	Taiwan	21 Inpatients in a hospital’s oncology department. All participants had advanced cancer.	To examine terminally ill cancer patients’ experiences of spiritual suffering, understand their views on the change mechanism in the healing process and explore the role of Chinese cultures in shaping such experiences.	Qualitative study. Phenomenology. Semi-structured interviews and narrative analysis of transcripts.	Sources of spiritual suffering include feeling a fear of death, feeling burdensome, feeling pessimistic, and lacking support from family or friends. Sufficient social support, changing their perception of their situation, and religious philosophies helped patients endure and interpret their experience of spiritual suffering.

Daneault et al. (2004)	Canada	26 Patients (inpatient and outpatient). All participants had advanced cancer.	To further our understanding of patients' experiences of suffering.	Qualitative study. Semi-structured interviews. Content analysis of transcripts. Participants were asked to describe their experience, including what constitutes their suffering and whether, in their dealings with healthcare providers, their burden had been alleviated or added to.	The suffering experience included physical, psychological, and social spheres. Respondents defined their suffering in terms of: (i) being subjected to violence (ii) being deprived and/or overwhelmed, and (iii) living in apprehension.
Daneault et al. (2006)	Canada	26 Patients (inpatient and outpatient). All participants had advanced cancer.	To explore patients' perceptions of their own suffering in order to describe, from these patients' perspective, some elements of healthcare providers' responses to suffering.	Qualitative study. Semi-structured interviews. Content analysis of transcripts. Participants were asked to describe their experience, including what constitutes their suffering and whether, in their dealings with healthcare providers, their burden had been alleviated or added to.	The study found that, in some cases, healthcare delivery directly contributes to increased suffering. Patients reported experiencing suffering due to the medical/healthcare environment which does not allow for the expression and acknowledgement of suffering, leading to suffering remaining unexpressed.
Ellis et al. (2015)	United Kingdom	49 Palliative care day patients (outpatients) All participants had advanced cancer.	To explore what patients with advanced cancer perceived as 'suffering' and how they use their own resources to manage suffering.	Qualitative study. Focused narrative interviews analyzed by thematic analysis.	Loss is a central feature of patients' suffering, including anticipated loss of family members, and loss associated with decreased physical functioning and independence. The experience of suffering was transformative for some participants, altering their view of themselves or the world. Spirituality was a lens through which a person could understand and live with his/her own suffering, the outcome of which was to develop a more coherent self and sense of meaning.
Krikorian et al. (2014)	Colombia	98 Patients accessing a palliative care service. All participants had advanced cancer and prognoses of less than 6 months.	To understand predictors of suffering in advanced cancer; that is, what causes or leads to suffering, so as to relieve and prevent suffering?	Mixed methods study. Semi-structured interviews explored a variety of elements, including suffering levels, physical, psychological, social and spiritual symptoms, coping strategies, and level of adjustment. Instruments used included Pictorial Representation of Illness and Self Measure (PRISM), Edmonton Symptom Assessment System (ESAS), and Detection of Emotional Distress (DED). Variance-based structural equation model was used for the data analysis.	Elements such as pain and loss of autonomy influence suffering. Levels of anxiety, depression, and altered mood predict the level of adjustment problems through the type of coping strategies chosen. Hopelessness, desire for death, and loss of meaning in life are mediated by the type of coping and the magnitude of the adjustment problems.

(Continued)

Table 3. (Continued.)

Article	Country	Population/Setting	Study Aims	Methods	Key Findings
Kuuppelomaki and Lauri (1998)	Finland	32 Patients from two central hospitals and four health centers. All participants had advanced cancer. Half of the participants had been diagnosed less than 12 months previously. The shortest time since diagnosis was one week; the longest was 10 years.	To describe the nature, content, and the meaning of suffering as reported by patients with incurable cancer, so as to produce information that can help to improve the quality of cancer nursing.	Qualitative study. Phenomenology. Interviews primarily and a structured questionnaire.	Patients' suffering experiences are physical, psychologic, and social in nature. Physical suffering was divided into two categories: that caused by the illness itself and that caused by treatment of the illness. Sources of physical suffering include fatigue, pain, and treatment side effects. Sources of psychologic suffering include helplessness, growing dependence, and the imminence of death. Social suffering stems from general deterioration and fear of infections which work to restrict patients' social life, causing them to socially withdraw. Suffering changes over the course of illness and occurs early and late in the illness trajectory.
Montoya-Juarez et al. (2013a)	Spain	24 Patients (inpatient, hospital setting). Participants mostly had advanced cancer, some had noncancer illnesses including COPD.	To identify the psychological responses that terminally ill patients develop when faced with suffering at the end of life as a foundation for future nursing interventions.	Qualitative study. Phenomenology. Semi-structured interviews.	Psychological responses that patients develop when faced with suffering include: realizing that life is short and thinking of serious illness as an opportunity for growth. Nurses can encourage patients' psychological responses by helping them feel satisfied with life and ascribing a positive meaning to their illness.
Montoya-Juarez et al. (2013b)	Spain	13 Parents of hospitalized children (0–16 years old) with terminal illness.	To understand parent perspectives on the suffering experienced by their terminally ill child.	Qualitative, descriptive study. Semi-structured interviews.	Children's suffering is demonstrated through sadness, apathy, and anger toward their parents and healthcare professionals. Sources of suffering for children include: isolation from their natural environment, uncertainty about the future, and anticipation of pain. The helplessness that parents experience in the face of their child's terminal illness is a feature of parents' suffering, as is not being able to find meaning in life.
Morita (2004)	Japan	81 Physicians working in palliative care units.	To understand the existential suffering patients experienced that required palliative sedation.	Quantitative Study. On a questionnaire, participants were requested to report the number of patients who received continuous deep sedation for refractory psychoexistential suffering during the past year, and to provide details of the two most recent patients.	Palliative sedation for psychoexistential suffering was performed in exceptional cases in specialized palliative care units wherein the patient condition was generally poor, and the suffering was refractory to intermittent sedation and specialized psychiatric, psychological, and/or religious care. Patients' existential suffering that led to the use of palliative sedation included feelings of meaninglessness/worthlessness (61%), being a burden/dependency on others (48%), death anxiety/fear/panic (33%), wishing to control the time of death (24%), isolation/lack of social support (22%), and economic burden (8.7%).

Nilmanat et al. (2010)	Thailand	15 Patients. All participants had advanced cancer.	To describe the suffering that patients with advanced cancer experience in their everyday life.	Qualitative study. Longitudinal, descriptive study. Thematic analysis.	Patients described their overarching experience at the end of life as living with suffering. Five inter-related subthemes regarding the experience of suffering were identified: (i) physical symptom distress, (ii) feeling of isolation/alienation, (iii) sense of worthlessness, (iv) sense of burden to others, and (v) desire for hastened death. Loss and distress related to body image changes from cancer treatments, and loss of ability to perform daily activities and increased dependency were also sources of psychological and spiritual suffering.
Nilmanat et al. (2015)	Thailand	15 Patients. All participants had advanced cancer.	To explore how patients with advanced cancer move beyond suffering at the end of their life.	Qualitative study. Coded thematic analysis. Interviews and observations of 15 patients with advanced cancer. Participants were followed from the point of referral at the hospital to their death at home or in hospital. An inductive qualitative analysis was applied.	Patients move beyond their suffering by: connecting with their religious faith (all participants identified as Buddhist or Muslim), being surrounded by the love and care of the family (all participants were cared for by, and lived with, family members), and being hopeful.
Rujs et al. (2009)	Netherlands	64 Patients. All participants had advanced cancer.	To develop a tool that will measure unbearable suffering.	Quantitative study. Participants completed 69 questions related to five domains in the SOS-V.	The State-of-Suffering (SOS-V) is a validated tool that measures unbearable suffering across five domains: (i) Medical signs and symptoms, (ii) Loss of function, (iii), Personal aspects (e.g., feeling lonely, helpless, loss of control); (iv) Aspects of social environment (e.g., feeling insufficiently supported by family/friends, insufficient availability of care, etc.); (v) Nature and prognosis of disease (e.g., fear of future suffering, fear of no longer being able to bear suffering, etc.).
Rujs et al. (2012)	Netherlands	76 Patients. All participants had advanced cancer and prognoses of 6 months or less.	To investigate the various aspects of unbearable suffering at the end of life for patients with advanced cancer.	Mixed methods study. Cross-sectional study. Structured interview using the SOS-V scale followed by qualitative questions at the end of the interview.	For patients, half of their experience of unbearable suffering stemmed from medical symptoms such as weakness, tiredness, pain, loss of appetite and not sleeping well, and the other half stemmed from psychological, social and existential dimensions (e.g., feeling dependent, not being able to do important things, trouble accepting the situation, being bedridden and loss of control). Love and support helped patients the most to bear their suffering. One quarter of all participants experienced unbearable suffering.

(Continued)

Table 3. (Continued.)

Article	Country	Population/Setting	Study Aims	Methods	Key Findings
Rydahl-Hansen (2005)	Denmark	12 Patients admitted to a palliative care unit. All participants had advanced cancer. Participants had been ill for between 3 months and 5 years and had lived with the knowledge that their illness was incurable for between 1 week and 4 years.	To describe the characteristics of suffering experienced among hospitalized patients with advanced cancer.	Qualitative study. Phenomenology. Three thematically structured interviews and two observations with each participant.	'Suffering' as experienced by hospitalized patients with advanced cancer has the following characteristics: increasing powerlessness, increasing loneliness and isolation, and "an eternal and with time unconquerable struggle to maintain or regain control." Powerlessness was related to feeling unable to express their social, psychological or existential suffering to healthcare providers due to multiple barriers (e.g., lack of space and time in the clinical environment).
Sacks and Volker (2015)	United States	22 Hospice nurses employed in a hospice setting for at least 3 months. Years of nursing experience ranged from 2 to 45 years.	To develop an inductive theory describing the process that hospice nurses use to identify and respond to their patients' suffering. In addition, the study sought to describe the coping strategies that hospice nurses used when working with patients they considered to be suffering.	Qualitative study. Grounded theory. Semi-structured interviews.	Participants responded to their patients' suffering within a 4-phase process of the nurse-patient relationship: observation; issue assessment; labeling the suffering; and intervention. In addition to signs of physical suffering, the participants identified other aspects of patient suffering: role losses, fear of the impending death, aloneness, and feelings of guilt or regret. Participants also identified suffering experienced by the family; family members experience their own suffering and there is also a shared or "communal" experience suffering. Participants acknowledged the importance of self-care, but had difficulty naming strategies used to cope with patient suffering.
Sacks and Nelson (2007)	United States	18 Hospice patients. Participants had advanced cancer and noncancer (e.g., end-stage heart disease, multiple sclerosis)	To uncover participants' experiences of nonphysical suffering and what was helpful during this time.	Qualitative study. Grounded theory. Semi-structured interviews.	Participants identified "difficulty trusting" as central to the suffering experience because advanced illness had forever changed participants' worlds. Uncertainty about the future was also a feature of suffering for many participants, as were multiple losses, and participants' fears and worries about their own death.
Schroepfer (2007)	United States	96 Patients accessing palliative care/hospice care either in home, as an inpatient, or as an outpatient.	To understand what "critical events" in the dying process lead to/result in physical and psychosocial suffering.	Qualitative study. In-depth, face-to-face interviews.	Critical events in the dying process that contribute to physical and/or psychosocial suffering include: dying in a distressing environment, which includes lack of time and attention from staff in hospital environments; the unacknowledged emotional toll of treatments such as chemotherapy; and unbearable physical pain.

Tan et al. (2016)	Malaysia	20 Palliative care inpatients. All participants had advanced cancer.	To understand the psychological processes underpinning patients' experiences of suffering at the end of life.	Qualitative study. Thematic analysis. Semi-structured interviews.	Participants identified family stress, dependence on others, loss and changes, disease and dying, healthcare interactions, and hospital stays as sources of suffering. The psychological processes underpinning and fuelling patients' experiences of suffering were: (i) the perception of an unpleasant event; (ii) the negative appraisal of the event; (iii) hope and the struggles with acceptance; (iv) the arising of unpleasant emotions; (v) appraising or not accepting the event; and (vi) clinging by means of rumination and worrying.
Tang et al. (2016)	Taiwan	325 Patients. All participants had advanced cancer.	To explore whether there is an association between prognostic awareness/acceptance and psychological distress, existential suffering, and quality of life in individuals living with advanced cancer.	Quantitative study. Longitudinal. Participants were surveyed and longitudinally followed until death. Psychological distress was measured by anxiety and depressive symptoms, which were assessed by the Hospital Anxiety and Depression Scale (HADS); Spiritual/existential suffering was assessed by the 10-item Self-perceived Burden Scale (SPBS); and overall QOL was measured by a 13-item modified version of the McGill Quality of Life Questionnaire (MQOL).	After controlling for identified confounders and time proximity to death, accurate prognostic awareness does not increase the likelihood of patients experiencing severe anxiety or depressive symptoms in their last year of life but precipitates their high self-perceived sense of burden to others and worse quality of life.
Terry and Olson (2004)	Australia	100 Hospice patients (patients admitted for respite, symptom management, or for end-of-life care). 92 participants had advanced cancer.	To ask patients one question about their suffering, and see what kind of responses were elicited.	Qualitative study. Interviews — single question asked as part of regular hospice admission interview.	35 Patients identified their suffering as physical pain and 30 patients identified their suffering with physical symptoms other than pain. 28 patients identified their suffering as entirely emotional in origin (e.g., losses and fears), and 7 patients identified their suffering as both physical and emotional in origin. The simple question used in this study — “In what way are you suffering?” could allow access to important areas of patient concern not readily predictable from other clinical information.
White et al. (2004)	Australia	9 Nurses working with palliative care patients in hospice, hospital or community setting. Average years of nursing experience: 11	To describe the impact of unrelieved patient suffering on nurses working with palliative care patients.	Qualitative study. Semi-structured interviews.	Participants spoke of two types of suffering: physical and “the other,” the latter included emotional, psychological, existential, metaphysical, and spiritual aspects of patients' suffering (e.g., loss of self, loss of body image, facing mortality, unresolved family dynamics, and lack of meaning at the end of life). The impact of unrelieved suffering is uncomfortable, difficult, and a situation participants want to avoid. Participants were more comfortable with physical suffering because it was easier to treat than the other types of suffering.

(Continued)

Table 3. (Continued.)

Article	Country	Population/Setting	Study Aims	Methods	Key Findings
Williams (2004)	United States	33 Patients in an outpatient setting. All patients had advanced cancer. Time since diagnosis ranged from 6 weeks to 10 years.	To describe the experience of existential suffering among low-socioeconomic (SES) patients dying from cancer.	Qualitative study. In-depth interviews.	Dying “off time” in the life course, being exposed to the illness trajectories of others, and experiencing social isolation contribute to existential suffering. The effects of social isolation are particularly pronounced among individuals with low SES, as they have less access to social resources. Attending to the social component of existential suffering is important, because being a poor, young person with an advanced illness differs in many ways from the white, middle-class experience dominating current understandings of suffering at the end of life.
Wilson et al. (2007)	Canada	381 Palliative care patients. All participants had advanced cancer and a prognosis of less than 6 months. Participants either had received palliative consultations with a palliative care specialist, or had been admitted to a palliative care unit.	To investigate the causes and correlates of suffering among patients with advanced cancer.	Mixed Methods Study. Face-to-face semi-structured interviews Questionnaire: 22-item version of the Structured Interview of Symptoms and Concerns.	Physical problems accounted for just under half of patient reports of suffering, with psychological, existential, and social concerns (e.g., loss of identity, uncertainty, feeling like a burden to others, leaving loved ones) accounting for just over half of patient reports of suffering. Those who reported higher levels of suffering were younger, more highly educated, and had lower PPS scores than were participants with lower levels of suffering. No difference in suffering was noted between settings (e.g., inpatients vs. other settings).

Theme 5: Requests for hastened death

Four of the 30 studies in the scoping review reveal requests for hastened death as a feature of patients' nonphysical suffering. In particular, increasing dependency on others and associated burdensome feelings can be sources of nonphysical suffering that may lead a patient to request a hastened death (Daneault et al., 2004; Nilmanat et al., 2010). Additionally, "Not being able to assess the duration of anticipated suffering may be conducive to wishes for an accelerated death" (Daneault et al., 2004, p. 10). One study reveals that sources of nonphysical suffering are just as likely to contribute to a patient's experience of "unbearable suffering," and therefore consideration of hastened death, as are physical sources (Rujs et al., 2012, p. 1). Another study finds that lack of attentive care from healthcare providers and feeling unsupported by one's clinical team or family around treatment decisions contribute to "psychosocial suffering" that may lead a patient to consider a hastened death (Schroepfer, 2007, p. 143).

Theme 6: Family suffering

While the majority of research on nonphysical suffering within palliative care focuses on the individual living with an advanced illness, that their family members and/or caregivers (including chosen family) suffer, too, is also evident. Two of the 30 studies reveal that family caregivers experience nonphysical suffering in a variety of ways: (i) witnessing their ill family member experience pain and other symptoms, which can evoke both worry and empathy that can feel like suffering (Bruce et al., 2011; Beng et al., 2013); (ii) witnessing the dying process can contribute to family suffering; (iii) and anticipating both the imminent death of their ill family member, and a future without them, are also sources of suffering for family caregivers (Bruce et al., 2011; Beng et al., 2013). Family caregiver suffering is described as "silent" or "disenfranchised," because it "is often unacknowledged by healthcare providers or by [family caregivers] themselves" (Beng et al., 2013, p. 487). Another study reveals that the helplessness and frustration parents experience when they feel they cannot help their terminally ill child engenders within the parents a deep sense of suffering (Montoya-Juarez et al., 2013b).

Theme 7: Clinician suffering

The impact of witnessing patients' nonphysical suffering on the palliative care clinician is highlighted in three of the 30 studies, two of which focus specifically on nurses. Across the three studies, clinicians describe feeling helpless and like a failure in the face of patients' nonphysical suffering (White et al., 2004; Bruce et al., 2011; Sacks and Volker, 2015), particularly "given the underlying philosophy of palliative care" (White et al., 2004, p. 442). Clinicians experience feelings of distress, vulnerability, frustration, sadness and overwhelm when they are unable to relieve patients' nonphysical suffering, and are much more comfortable working with patients' physical suffering because it is easier to treat than suffering that is nonphysical in nature (White et al., 2004). One study notes that palliative care providers need to learn to "be okay with not being okay ... [and] that it is okay to feel inadequate when faced with existential questioning of dying persons" (Bruce et al., 2011, p. 6).

The impact of patients' nonphysical suffering on clinicians' personal lives is also noted in the research. Strategies clinicians employ to cope with this aspect of the work include taking time

away from work, seeking professional help, and "chang[ing] patients" (White et al., 2004, p. 442). Clinicians can feel isolated in their work with patients' nonphysical suffering, and finding or seeking support from friends or family can be difficult (White et al., 2004). The research also reveals that "educational programs, build[ing] supportive environments, and develop[ing] policies to support their staff" (Sacks and Volker, 2015, p. 490) are integral to helping palliative care clinicians cope with patients', and their own, suffering. In particular, work environments where the suffering of clinicians can be openly and safely discussed are imperative (White et al., 2004).

Discussion

This scoping review confirms that there is much variability in terms of how suffering is studied within the field of palliative care. To be included in this scoping review, studies had to consistently use methods to assess nonphysical 'suffering,' rather than 'pain' or 'distress.' Studies that used these terms interchangeably and whose methods did not specifically explore 'suffering' were excluded (e.g., Duggleby, 2000; Strang et al., 2004). While 'suffering' is consistently conflated with 'distress' (White et al., 2004; Krikorian et al., 2012; Smith et al., 2014) and physical pain (Cassell, 2004; Morrissey, 2011) within the palliative care literature, there are also important distinctions. Suffering is thought to be a more all-encompassing, enduring, and intense experience than 'distress' (Chapman and Gavrin, 1993; Rodger and Cowles, 1997; Cassell, 2004; Krikorian et al., 2012; Beng et al., 2017), which is considered to be more of a "transient or fleeting experience" (Chapman and Gavrin, 1993, p. 6). Related to its enduring nature, there is thought to be a temporal element to 'suffering' (Cassell, 1982; Strang et al., 2004; Fishbain et al., 2015); that is, "in order for a situation to be a source of suffering it must influence the person's perception of future events" (Fishbain et al., 2015, p. 1058). Pain and suffering are also not synonymous (Baines and Norlander, 2000; Cassell, 2004; Morrissey, 2011); an individual can experience pain without suffering, and suffering in the absence of pain (Chapman and Gavrin, 1993; Baines and Norlander, 2000; Morrissey, 2011). This review, therefore, highlights the importance of language in the study of 'suffering,' vs. 'distress' and/or 'pain' that is nonphysical in nature.

While Saunders' and Cassell's longstanding and important conceptualizations of 'suffering' as an integrated, multidimensional experience encompassing both physical and nonphysical elements are widely used throughout the palliative care literature, this scoping review reveals that suffering can also be a fragmented experience. For example, suffering is fragmented in the design of studies in this scoping review: studies by Sacks and Nelson (2007) and Bruce et al. (2011) specifically ask participants about their experiences with 'nonphysical suffering'; the study by Schroepfer (2007) seeks to understand sources of 'psychosocial suffering' vs. 'physical suffering'; and the Baines and Norlander study (2000) examines patients' ratings of suffering in three distinct categories: physical, spiritual, and personal or family. Suffering is also fragmented in several studies' findings in this scoping review, with patient participants explicitly differentiating their experiences of suffering into physical and nonphysical elements [e.g., studies by Kuuppelomaki and Lauri (1998), Daneault et al. (2004), Terry and Olson (2004), Wilson et al. (2007), Nilmanat et al. (2010), Rujs et al. (2012) and Sacks and Volker (2015)]. Additionally, when suffering has a physical element, research findings show that palliative care providers know better what to

‘do’; whereas when suffering does not have a physical component, palliative care providers feel inadequate and helpless in their abilities to relieve suffering that is nonphysical in nature (e.g., studies by White et al., 2004 and Blondeau et al., 2005). This scoping review demonstrates, then, that researchers, patients and clinicians distinguish physical from nonphysical aspects of suffering. Suffering may be multidimensional and integrated, and it may also not be; both exist, rather than one or the other. This is an important finding from this scoping review, as it expands palliative care’s understanding of suffering beyond current conceptualizations. It is imperative for patients, families, and clinicians to understand and appreciate that suffering may manifest physically, it may have both physical and nonphysical elements (as per ‘total pain’), or it may be suffering that is solely nonphysical in nature.

One of the most significant outcomes of this review is that losses, fears, and worries are primary sources of patients’ nonphysical suffering. These aspects of nonphysical suffering are consistently noted across the research studies, despite cultural and geographic diversity — a significant finding that lies in contrast to palliative care’s discourse that describes suffering as complex, multifaceted, subjective, and affecting each individual uniquely (Chapman and Gavrin, 1993; Daneault et al., 2006; Sacks and Nelson, 2007; Montoya-Juarez et al., 2013b; Ellis et al., 2015). Historically, psychosocial interventions to relieve patients’ nonphysical suffering have focused on facilitating meaning-making and fostering personal growth (Saunders, 1966; Cassell, 1982; Byock, 1994; Cherny, 2015). While meaning- and growth-oriented interventions continue to play a significant role in addressing suffering, how might understanding nonphysical suffering as losses, worries, and fears affect the way we might additionally conceive of psychosocial interventions to address this type of suffering? Approaches that support and acknowledge patients’ profound and varied losses, worries, and fears require further exploration and integration into front-line clinical care.

That patients struggle to express their nonphysical suffering to healthcare providers, and the reasons why, is another key finding from this review; much nonphysical suffering remains unshared due to multiple barriers. How, then, can barriers to nonphysical suffering’s expression be reduced and/or removed in the provision of palliative care? This review reveals efforts to quantitatively capture patients’ experiences of nonphysical suffering; how might these and other approaches help to facilitate the expression of nonphysical suffering within the constraints of clinical environments? While it is common practice in palliative care to ask patients about pain, nausea, anxiety, and more, what could be learned from asking patients whether they are suffering (Cassell, 1982), and in what ways (Terry and Olson, 2004)?

This review reveals that patients can effectively cope with and minimize their nonphysical suffering by opting to perceive their situation in a positive, hopeful, and accepting way — an idea that is pervasive within the palliative care discourse (Chapman and Gavrin, 1993; Mount, 2003; Byock, 2009). While this will be an effective approach for some, care must also be taken to validate and support the patients for whom grief, worry, and fear may persist, and may understandably not be amenable to a change in one’s perception.

The multilayered, isolating nature of nonphysical suffering experienced by family caregivers and palliative care clinicians is another key outcome of this review. While the suffering of clinicians and family members are noted in the palliative care discourse (Klagsburn, 1994; Witt Sherman, 1998; Rushton, 2001;

Sudore et al., 2010; Krikorian et al., 2012; Cherny, 2015), they remain under-researched. How might psychosocial interventions aimed at addressing family members’ nonphysical suffering be conceptualized? Might family members, like patients, benefit from being asked specifically about their own suffering? The research also reveals that palliative care clinicians feel helpless and inadequate in the face of nonphysical suffering, and are much more comfortable addressing physical suffering. How might clinicians, then, be differently trained and supported to address nonphysical suffering? And in what ways can work environments create safety and space for clinicians’ own suffering to be expressed and normalized?

The sensitive and contentious interplay between nonphysical suffering and both palliative sedation and requests for hastened death is also revealed in this scoping review, highlighting the long-standing and unique struggle that nonphysical suffering — and specifically existential suffering — presents within the provision of palliative care (Cherny et al., 1994; Rousseau, 2001, 2005; Bruce and Boston, 2011; Karsoho et al., 2016; Bozzaro and Schildmann, 2018; Rodrigues et al., 2018). And finally, the scoping review reveals that palliative care’s understanding of nonphysical suffering is primarily informed by the adult advanced cancer experience, as nearly all research participants have advanced cancers. While limited research currently exists (Montoya-Juarez et al., 2013b; Smith et al., 2014), further research is needed on whether and how the experience of nonphysical suffering may differ for individuals with other life-limiting illnesses beyond cancer, as well as for pediatric populations.

Conclusion

Palliative care is a discipline dedicated to the prevention and relief of suffering, both physical and nonphysical (WHO, 2021). Nonphysical suffering — suffering that is emotional, psychological, existential, spiritual, and/or social in nature — is a central part of palliative care provision, yet existing research on this topic is not well known. This is the first scoping review to map palliative care’s research specific to suffering that is social, emotional, spiritual, psychological, and/or existential in nature. To date, research on nonphysical suffering within palliative care has focused on: (i) patients’ experiences of nonphysical suffering; (ii) patient coping mechanisms; (iii) efforts to measure nonphysical suffering; (iv) palliative sedation; (v) requests for hastened death; (vi) family suffering; and (vii) clinician suffering. The review’s results increase our understanding of nonphysical suffering within palliative care and have significant implications for front-line clinical care and future research.

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