Psycho-Oncology
Psycho-Oncology **24**: 977–986 (2015)
Published online 9 March 2015 in Wiley Online Library (wileyonlinelibrary.com). **DOI**: 10.1002/pon.3795

Review

Conceptual analysis of suffering in cancer: a systematic review

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Abstract

***Objective*: Patient suffering is a neglected area of care, partly because of poor definitions. The aim of this study was to distill what is currently known about suffering in the health literature in order to generate a conceptual basis for further research.**

***Methods*: A systematic review focusing on suffering across all cancers was undertaken. The search included peer-reviewed English articles published between 1992 and 2012 in MEDLINE, Embase, PsycINFO and the Cochrane Library databases focusing on conceptualisation of suffering in adult cancer patients. Seminal theoretical articles conceptualising suffering more generally were also eligible. To ensure identification of a sufficiently broad range of conceptualisations of suffering in cancer, the search strategy was drafted iteratively. Study findings were subjected to conceptual analysis using the evolutionary method.**

***Results*: One hundred twenty-eight studies were identified, which discussed definitions or conceptualisations of suffering. In terms of its attributes, suffering is defined as 'an all-encompassing, dynamic, individual phenomenon characterized by the experience of alienation, helplessness, hopelessness and meaninglessness in the sufferer which is difficult for them to articulate. It is multi-dimensional and usually incorporates an undesirable, negative quality.' Surrogate terms, antecedents and consequences of suffering are described.**

***Conclusions*: The systematic review revealed that suffering includes holistic suffering, which is multidimensional, oscillating, individual and difficult for individuals to express. Opportunities should be provided for patients to express their suffering. The potential for suffering to be transcended needs to be recognized and facilitated by healthcare staff.**

Received: 6 August 2014
Revised: 11 February 2015
Accepted: 11 February 2015

Background

Relief of suffering is integral to healthcare, but topics beyond physical suffering have been overlooked in much of the cancer literature. There is no clear definition of non-physical suffering, and the existing literature is scattered through a number of genres. In 1997, it was observed that lack of conceptual definition for human suffering was a barrier to recognition and understanding of the experience [1]. This is the case at present.

Historically, the most commonly cited discussions around suffering are from Victor Frankl, Cicely Saunders and Eric Cassell. Frankl was an Austrian psychiatrist who proposed, as a result of his internment at Auschwitz during World War II, that suffering could be endured if one saw meaning in life [2]. He called the process of discovering meaning in life and its associated personal growth 'transcendence'. While this term is used in modern philosophy to connote 'climbing or going beyond', whether it be with regard to human knowledge or relationships, Frankl's use refers to the spiritual pathway which can enhance meaning in life and well-being, even when other pathways to well-being are not available [3]. It is thus possible to be 'healed' even in the face of physical deterioration. He proposed that, in unavoidable suffering, one has the responsibility to choose one's attitude towards it, and that only the individual can discover his own personal meaning.

Cicely Saunders, acknowledged as the founder of the modern hospice movement, used the term 'total pain' to describe the suffering of dying patients. She reported patient narratives identifying physical, psychological, social, emotional and spiritual elements of suffering and a need to seek meaning in it [4]. She advocated an individual, patient-centred approach to help the patient endure their suffering, with excellent symptom control and inclusion of the family unit as basic aspects of care [5]. She referred to Frankl's work and the spiritual nature of the struggle involved.

Eric Cassell argued that suffering is experienced by persons, not merely by bodies, and 'has its source in challenges that threaten the intactness of the person as a complex social and psychological entity' [6]. He criticised the approach to medical care that focuses on the physical

and downplays the mind/spirit/person domains. He attributed the current medical paradigm to Cartesian dualism, which has influenced medicine since the 17th century, and suggested that patient suffering would only be overcome when the separation of body and mind was rejected. He recognized the need to see suffering persons in their wholeness to understanding the perceived meaning of suffering for the individual.

These references indicate that what is being described in the literature is a phenomenon which involves more than physical distress. Multiple reviews illustrate that our understanding of what is meant by the term 'suffering' has progressed slowly [1,7–10]. Although the extent of pain and/or psychological distress and suffering in a patient are obviously related, direct associations are too simplistic. Pain and suffering are not the same thing, and the meaning that the individual brings to the experience has to be taken into account [7]. The reviews also reflect the paucity of research available and a lack of consistency in how suffering is defined and understood [1].

This illustrates our need to explore suffering beyond the physical sense and to draw together strands of literature, which have investigated suffering in parallel, in order to provide a more nuanced understanding of the phenomenon. In an area where research is limited, it is important to review all available discussion to ensure that all lines of enquiry are pursued. Our study uses a systematic approach to conceptualise suffering in cancer survivors as well as at the end of life.

The aims of this systematic review were as follows:

1. Identify and synthesise conceptualisations of suffering in health literature
2. Identify surrogate terms for suffering
3. Identify antecedents of suffering
4. Describe the consequences of suffering

Methods

The concept of suffering was analysed using the evolutionary method [11]. This method aims to achieve conceptual clarity by inductively generating a definition and the contexts in which a phenomenon is used from a systematic search of the literature. The development of an adequate conceptual foundation assists in further exploration of the topic [1]. According to this method, concepts are dynamic and our understanding of them alters with a growth in knowledge. When concepts are clearly defined, they also contribute to the development of knowledge by improving our level of understanding. According to evolutionary concept analysis, variations in the definition can be introduced as the phenomenon is clarified by further research. The literature on suffering spans many healthcare disciplines and has multiple historical influences. Use of the evolutionary method of concept analysis incorporates all of these. Its attention to methodological rigour increases reliability of results.

Search

The inclusion criteria for our systematic search were: cancer diagnosis; adults (aged 18 years and older); outcome of interest, that is, conceptualisation of suffering in cancer patients. Research conducted with caregivers was included where the focus of the paper was the outcome of interest. Seminal theoretical articles conceptualising suffering more generally were also eligible.

Exclusion criteria were: studies focusing on suffering of parents of children with cancer, or other caregivers of patients with cancer, or adult survivors of childhood cancers; studies focusing on suffering in patient groups where cancer was not specifically separated out; books or book chapters and dissertation and conference abstracts.

In the MEDLINE database, 'suffering' is indexed only under the thesaurus heading 'Stress, Psychological' and the term 'suffering from' is frequently used as an equivalent to 'diagnosed with'. Therefore, 'suffering' was not useful as a search term. To ensure a sufficiently broad range of conceptualisations of suffering were covered by this review, the search strategy was drafted using an iterative process. Results from preliminary searches were used to develop a list of concepts synonymous with suffering or 'symptoms' of suffering and their antonyms (Table 1). Papers using the term 'suffering' to denote 'diagnosed with' were discarded as irrelevant. Only papers exploring a negative response to suffering were included in the review. The databases searched were: Medline, EMBASE, PsycINFO and the Cochrane Library. Search terms are listed in Table 2.

The final results were then limited to the English language, year of publication 1992–2012 and peer-reviewed journal articles.

Both L. A. and M. B. then examined the title and abstract of each reference for relevance according to the inclusion criteria while continually discussing search rules until consensus was reached. Full copies of all relevant references were obtained and examined, resulting in a final set of relevant articles. The reference list of the final articles and review articles were perused to identify papers missed by the database search. EPPI-Reviewer 4 software was used to organise and manage articles. See Figure 1.

Data extraction

Information was extracted by L. A. and M. B. It comprised the author, year of publication, description of article and surrogate terms for the phenomenon under review. Verbatim quotes were extracted for each of the specific categories required by the method used, namely attributes, antecedents, consequences, references, surrogate terms

DOI: 10.1002/pon

Table 1. Synonyms and symptoms of 'holistic suffering' and their opposites

Concept
Suffering
Existential distress
Existential suffering
Existential pain
Spiritual distress
Spiritual suffering
Spiritual pain
Psycho-spiritual distress
Psycho-existential suffering
Total pain
Demoralisation
Hopelessness, despair
Loss of meaning
Sense of meaning/finding meaning
Sense of coherence
Purpose in life
Hope
Dignity
Transcendence
Spiritual well-being
Peace
Faith

Table 2. Search terms

Suffering	Cancer
Existentialism	Neoplasm
Meaning	Hopelessness
Purpose	Faith
Transcendence	Peace
Spirituality	Sense of coherence
Hope	Demoralisation
Total pain	Dignity

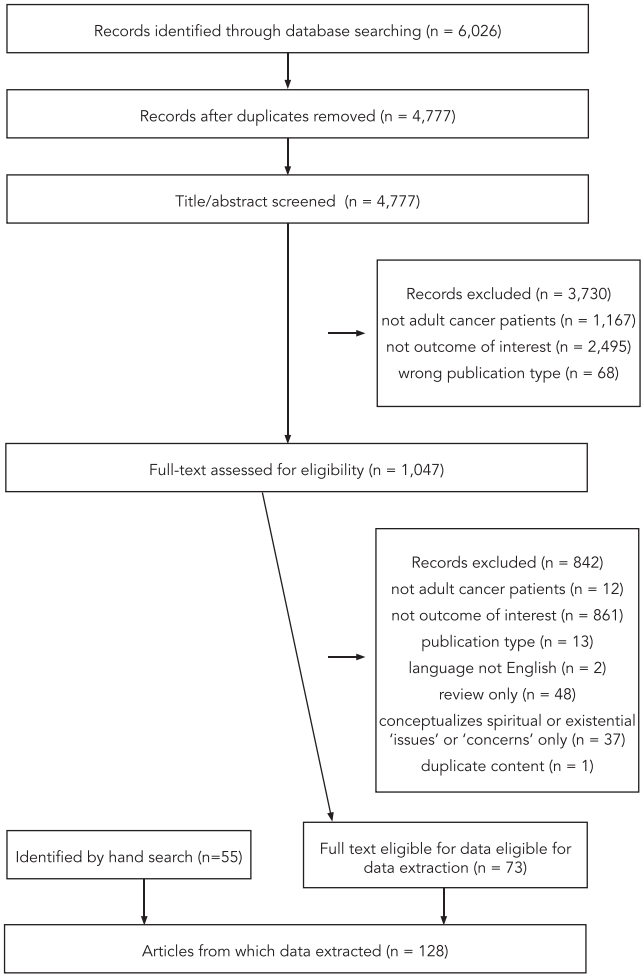

Figure 1. Literature search

and related concepts and recorded in tabulated form [11]. According to the evolutionary method, the attributes constitute the main characteristics of the concept; antecedents and consequences provide the context in which suffering occurs; while surrogate terms position the concept in the literature.

Data analysis

Levels of evidence were not assigned to individual studies as the goal was to distill definitions and concepts in studies of any type.

We inductively built a bank of free codes allowing the translation of concepts between studies and began synthesis. Similarities and differences between codes were identified to allow grouping them into descriptive themes. All researchers then considered the implications of these themes, first independently and then as a group, to identify the analytical themes that contributed to the final definition of suffering by clarifying the contextual features. As required by the analytic method used, verbatim quotes were maintained throughout this process. Results are reported according to AMSTAR guidelines.

Results

One hundred twenty-eight papers were identified through the systematic search that described conceptualisation of suffering. Quantitative and qualitative studies and theoretical papers were included. For characteristics of included papers, see supplemental Appendix A.

The findings from this conceptual analysis constitute a list of the surrogate terms used for the concept under investigation and related concepts identified in the literature, attributes, antecedents and consequences.

Surrogate terms and related concepts

Concept analysis relates to the philosophical position that a concept may be expressed in different ways and so investigates the surrogate terms used. By examining related concepts, we can better comprehend the context in which it is placed in the literature [11]. An important feature in

DOI: 10.1002/pon

this review was the confusion regarding the use of the word 'pain' as a surrogate for 'suffering' [1,10]. It is also necessary to highlight the interchange of meanings for the term 'suffering' between response to a noxious stimulus in an individual human dimension and the all-encompassing phenomenon, which is the focus of this review [1]. This breadth of experience is reflected in the large number of surrogate terms identified.

Synonymous terms for the phenomenon under investigation were identified by the similarity of descriptions. They include: spiritual distress, spiritual pain, spiritual suffering, spiritual angst, spiritual despair, spiritual problem, spiritual disintegration, spiritual struggle, spiritual turmoil, spiritual chaos, spiritual crisis, existential fear, existential suffering, existential crisis, existential distress, existential anxiety, existential pain, existential angst, existential despair, psychosocial–spiritual pain, psychosocial–spiritual suffering, psycho-existential suffering, anguish, demoralisation, total pain, death anxiety and distress at the end of life.

Suffering and its synonyms were often discussed in relation to breakdown of the ability to cope because of a depletion of coping resources [8,12–15], which could be associated with a feeling of subjective incompetence [16]. Suffering was noted to be a common human experience [13], the expression of which is hampered by the medicalization of death [17].

Attributes

Despite the number of papers and the diversity of genres included, there was remarkable consistency in the findings. Attributes and verbatim examples of their underlying themes are in Table 3. They are itemised in the succeeding sections, and have been separated from the symptoms of suffering such as anxiety, fear, anger, grief, depression and a desire for hastened death, which are beyond the scope of this paper.

Table 3. Themes within the concept of holistic suffering and example verbatim quotes

Themes	Verbatim quotes
Individual	Subjective experience, intensely personal [12,23,24]
	Historically, culturally and socially located [15]
	Unique to each individual [22]
Alienation	Feeling alone, separated from themselves, and from others [10]
	Separated from personal source of comfort and strength [30]
Helplessness	Perceived helplessness [8,34,41,42]
	Subjective incompetence [34]
Hopelessness	Loss of hope for improvement or recovery [31]
	Feelings of fighting an unending battle [14]
Meaninglessness	Pointlessness, loss of purpose [31]
	Loss of meaning [28,34]
Difficult to articulate	No vocabulary to express her deepest feelings [32]
	Unable or not wanting to express distress [37]
Multidimensional	What affects one dimension will affect the others [43]
	Includes spiritual, physical, cognitive, psychological, social, functional, existential and mental elements [14,18,24,39,41,57,62]
Negative	Undesirable affective quality [25]
	Negative meaning, perceived threat [48]
	Aversive experience [9]
Dynamic	Oscillating [39,42]
	Intensity of suffering varied [25]
All-encompassing	Encompasses all areas of life [19]
	Pervades a person's entire being [20]

All-encompassing

In the literature, suffering is described as all-encompassing [18,19], a disruption that pervades a person's entire life [20,21].

Individual

Suffering was described as 'individual' for several reasons. It is an intensely personal experience, unique to each sufferer [1,12,17,22–25]. Many authors noted the importance of context, including cultural, historical, economic and social factors, that impact on the meaning an individual gives to an experience [13–15,19,20,26]. For example, the stress of suffering as a result of a cancer diagnosis may be made worse for a young person if there are cultural expectations of caring for parents, such as in Asian families. Previous experience of suffering can colour the current understanding of suffering, and resources from the past can now help [1,17,22,27]. Whether a given situation is experienced as suffering depends on its interpretation by and significance to the patient [28,29]. The antecedents of suffering are therefore unlimited [22].

Alienating

Suffering was characterised as alienating [14,30,31]; an objective physical and social isolation and sense of loneliness [8,12,31–34] and a subjective sense of aloneness [35,36]. Suffering may be increased, created and alleviated in relationship to other persons as well as within oneself [32]. Suffering persons feel separated from or abandoned by their source of comfort and strength, be it important others or a transcendent being [30]. Patients may lose community and a sense of connectedness because of hospitalisation [12,25], be avoided by others who are embarrassed by them, or withdraw from society because of fear of stigmatisation or if their body image is distorted by treatment or disease [14,19,24,31,37]. They are further separated from their loved ones if physical problems limit physical

DOI: 10.1002/pon

contact, by a sense of irrelevance as they lose their social role, and by realising they are no longer a part of the family's future plans [19,38,39]. Melin-Johansson *et al.* described a period close to death when patients took 1 day at a time that contributed to a sense of imprisonment [39]. Cessation of curative treatment and the sense of 'being given up on' exacerbated the sense of loneliness [40]. Younger suggested that alienation is not an absence of connection but a state of negative connectedness in all relationships [10].

Helplessness

Suffering persons as represented in the literature experience a sense of perceived helplessness and subjective incompetence [8,34,37,41,42]. They feel powerless with regard to their physical incapacity and inability to influence the progress of their disease, or to find meaning and purpose in their experience [12,28,36,41,43]. The concept of demoralisation is one expression of a breakdown in coping associated with subjective incompetence [36].

Loss of hope and meaning

Suffering persons experience a loss of hope [34,44,45]. Hope is lost for improvement or recovery and the sufferer has a sense of fighting an unending battle [14,31] or of having no future [46]. Chochinov found that hopelessness, and not actual degree of physical dependency, was predictive for burden to others [47]. Pessimism is a feature [30,48]. Some writers have identified oscillation between hope and despair [49], which they suggest represents a transition from unbearable 'unipolar' hopelessness to a bearable 'bipolar' state [50].

A core dimension of suffering is a loss of meaning for the sufferer [24,28,30,31,33,34,51]. Some authors suggest that rather than being an attribute of suffering, loss of meaning *is* suffering [38,52].

Difficult to articulate

According to the literature, the suffering person finds it difficult to articulate what they are experiencing [10,28,41] either because of the inability or lack of desire to express distress [12,37]. The suffering person may have no vocabulary to express their deepest feelings [32] and others are often unwilling to discuss them [40]. Discussing feelings may be difficult for loved ones because of their own distress or for cultural reasons [53]. Healthcare workers may not be able or want to acknowledge a patient's existential distress [18,54] because of the use of the biopsychosocial paradigm in medicine that ignores the spiritual dimension. This means healthcare workers do not recognise suffering [27,32,46,54]. Staff may fail to respond to suffering even if they recognise it [55], perhaps because of their own death anxiety [10,22]. Joviality can replace expression of grief on the ward, suppressing the patient's experience [56]. It could be that patients wait for a cue that never eventuates, or just think that the staff are too busy to listen [57]. Some sufferers described the lack of a 'safe space' in which to discuss their fears [14]. The sufferer may feel the need to protect others from their suffering and suppress it consciously. This has been called 'doubled suffering' [56]. They may avoid the topic because of fear that they will not be able to cope with the subsequent conversation [14]. Suffering increases when it remains concealed [27]. Assistance may be needed to voice the conflict [44], which is beneficial for the sufferer [44,58]. Some patients find it easier to talk to others who understand because they have had a similar existential experience [59].

Multidimensional

Suffering is described as multidimensional and experienced by the whole person [25,32], to whose integrity it poses a threat [6,56]. Unity of mind, body and spirit are such that what affects one will affect the others [43,46]. Suffering should be considered when a patient's physical symptoms are puzzling or emotional responses seem disproportionate to loss [60]. Distress incorporates spiritual, physical, cognitive, psychosocial, functional and existential elements [14,18,23,39,41,57,61,62].

Negative

Suffering is usually perceived as a negative, aversive experience in response to an event that is assigned an intensely negative meaning [1,8,9,25,26,48]. This can be reduced if suffering is perceived as penance.

Dynamic

Suffering is experienced as a dynamic process according to the studies included in this review, with the intensity oscillating during its course [25,39,46,55]. The dynamic nature of suffering can also be understood in terms of the trajectory, where the patient moves from despair through the suffering [58].

Definition

The primary finding in evolutionary conceptual analysis constitutes a definition of suffering expressed in terms of its attributes, which were identified in the data. According to this process, suffering is defined as 'an all-encompassing, dynamic, individual phenomenon characterized by the experience of alienation, helplessness, hopelessness and meaninglessness in the sufferer which is difficult for them to articulate. It is multidimensional and usually incorporates an undesirable, negative quality'.

Antecedents

The overwhelming majority of examples given in the literature with regard to antecedents can be summarised as

DOI: 10.1002/pon

examples of real, perceived or impending loss [8,35,44,61–63]. This can take many forms.

Diagnosis of cancer is recognized as a common precedent to suffering [22–24,26,28,30,35,46,49], and is recognized as a trigger for the raising of existential questions, which require the patient to seek meaning in their experiences [15,20,27,64]. Cancer as a phenomenon contains overtones of death for many people [40,54], which become stronger with recurrent or progressive disease [41,49], thus these are also recognized antecedents [28,30,63]. Suffering is not restricted to cancer but can be precipitated by any illness [1,18,46]. Awareness of impending death may not occur at diagnosis but can be the trigger for suffering and asking existential questions whenever it occurs [24,25,28,29,36,38,42,43,48]. The arrival of awareness of death may be associated with the dissolution of denial, but the timing is not well understood [65].

Any threat or perceived threat to the self may result in suffering [8,14,22,27,28,30,35,38,40,52,63]. This is often expressed as a disconnection with the person one once was [42]. In cancer, this can occur as a result of the many interpersonal losses faced [41], especially when the self is identified with the physical body during a period of embodied deterioration [46].

The losses experienced by a patient with cancer can be felt in every human dimension [49]. They include illness-related losses such as those of health, sexuality, hair, body parts, attractiveness, energy, loss of sense of control over the disease and hope concerning prognosis and will to live [14,49,63]; social losses, such as those of the capacity to maintain professional activities, and loss of employment, housing, or income [1,49]; concrete losses such as pets or material belongings [30]; or relational losses, such as involuntary social isolation due to embarrassment or estrangement [52] and loss of roles and responsibilities in the family [12,19,38,41]; personal losses such as those of control, dignity, autonomy, integrity, power and even humanity [1,13,24,39,46,52]; existential losses such as those of meaning, purpose, hope [13,29,31,33,36,38,48,62]; and loss of the future, with its dreams and aspirations [33,52,66]. Loss of autonomy and control of self-care with increased dependency can be associated with fear of being a burden [19,38,67], another antecedent of suffering.

Many patients reflect on their spirituality in their last days, often considering questions of human existence and the meaning of life and death [13,36,38,39,60,67] or reevaluating their relationships with a higher being or the sacred [24,46]. There is a desire to take a moral and spiritual inventory of one's life [13], some wondering if their illness is a type of punishment [38]. Suffering can be experienced as a lack of freedom [21]. Patients may feel guilt or have regrets that increase their suffering [21,30,48] and there may be issues of forgiveness and reconciliation [30].

Pain is often listed as a cause of suffering, and indeed is strongly associated with physical suffering [1,19,39,42], but pain itself is rarely sufficient to precipitate multidimensional suffering [8]. In the instance of suffering as an all-encompassing experience, the degree of suffering may not be proportionate to the amount of nociceptive pain [1,10,14,68], although it should be noted that patients who are very sick and/or experiencing cognitive impairment may use a physical language to express all aspects of suffering [69]. Some patients may have significant nociceptive pain but little pain expression, depending on the meaning they attribute to their symptoms [70]. Pain can be accompanied by existential consequences, for example metastatic spread can remind the patient of the cancer's active nature, causing spiritual distress [43]. Pain without meaning can also become suffering [24]. Physical symptoms and suffering are bidirectional in nature, each able to exacerbate the other [30,60]. Uncontrolled pain can increase fear of the future [13,57] and any source of physical distress can precipitate suffering [18,25,42,63], particularly if it interferes with function [19]. Control of pain and other troubling symptoms is important for the relief of suffering from any cause, allowing the patient to devote energy to their existential questions [20,41,46,69].

Existential concerns are common in the cancer community, but significant distress is less common. Existential issues may not result in suffering if the patient is resilient and retains a sense of spiritual well-being [28,58]. Yang and colleagues reported from their study of cancer patients that those who accepted their finitude or consciously denied the life-threatening nature of their illness and focused on recovery, did not experience an existential crisis [28].

Consequences

According to the literature, two possible pathways follow the onset of suffering – an experience of transcendence or continued suffering. It is also possible to oscillate between the two. Transcendence of suffering is achieved through personal growth, authentic living, new relationships and a sense of peace.

Transcendence [62] can result from the experience of suffering, involving personal transformation as one finds new meaning through reevaluating oneself [10,26,28,42,52,63]. The experience of suffering is therefore considered by some to be a necessary part of human development [45] and the opportunity to re-examine life may be seen as a benefit of cancer [33]. New skills may be learnt [64], which leads to higher levels of self-esteem and well-being [28,30,63,64], spiritual growth that might not have otherwise been possible [1,30,44,45], acceptance of life and death, integrating the disease into one's life story and moving on [49,64]. Enhanced relationships with God, other higher beings or union with nature can be experienced [29]. It is described as a form of healing [26,44,49].

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The proximity of death can give a new appreciation for life [33] and the ability to live in an authentic fashion [32]. This is characterised by new priorities and making changes in life, which are aligned with the new understanding [1,28,35,42,49,64]. It is living life to the full with new strength [64] and enjoying the small things [40,45].

This is associated with new relationships, as there is an increased awareness of interpersonal dependency [29,35,45,63]. There is an increased empathy for others and a desire to help them [49,64], as well as openness to receiving help from others [26,33,64]. Many cancer survivors volunteer for advocacy work or research [35,42].

Transcendence and the meeting of spiritual needs is characterised by a sense of inner peace [29,48], harmony and security [44], which eases the fear and pain of loss [64], although 'moments of darkness' may still occur [42].

Some people are overwhelmed by the losses that precipitate suffering [62] and are unable to move beyond suffering [32,64]. This state may be characterised by a false sense of hope or the inability to maintain hope, withdrawal, increased somatic complaints and increased physical distress [12,30].

In the case of cancer survivors, it may not be until after treatment has ended that they are ready to process the losses experienced at which time former supports may have withdrawn [10].

Listing exacerbating factors [12] and the spiritual care which can help modify the development of spiritual distress [61] is beyond the scope of this paper.

Discussion

We used concept analysis [1] to provide a systematic means of defining suffering within the health literature. Key elements of the definitions for suffering and its synonyms extracted from papers included in this review were synthesised. It is interesting to note from supplemental Appendix A that a significant proportion of the discussion of suffering took place in the absence of any explicit definition of the phenomenon. Instead, it was discussed in a way that inferred a definition or assumed a common understanding. Lindholm found in her study of nurses that they tended to discuss the 'why' of suffering rather than the 'what', concluding that the essence of suffering was 'remote' and 'intangible' [21]. Authors who attempted to explore a more tangible 'what' of suffering are included in this synthesis.

Synonymous terms identified in the literature were numerous and often used without definition. This correlates with the finding of Rodgers and Cowles [1] that there is a tendency to 'talk around' the topic of suffering rather than to confront it directly. The intensity of the experience under investigation is reflected in many of the terms, such as angst, despair and crisis. The multidimensional nature of suffering is recognized by the breadth of approaches used to understand it, although the spiritual/existential dimension predominates. This distinguishes the all-encompassing phenomenon of suffering from its less complex counterpart (single-focus distress). The frequent relationship of suffering with the end of life is reflected in terms referring to death and its discussion in relationship to the setting of death.

Accumulation of losses for the cancer patient is inherent to the disease experience [14]. Given the isolating and alienating nature of suffering, there is a perceived loss of interpersonal relationships for the patient just when they are most needed, compounding the distress of the individual [17]. The trajectory of suffering does not appear to be linear. Oscillations occur, during which unintentional isolation is relieved and hope is regained [25,39]. Although some patients appear to 'deny' the life-threatening nature of their illness as they focus on cure [28], in fact, it is more likely to be a 'postponement' of suffering until after they have completed treatment, at which time they may also experience withdrawal of support and pressure to join in the celebration of remission. This can inhibit healing [10].

The related topic of the pervasive presence of suffering underlines the importance of addressing this topic [13]. Its discussion in relation to the medicalization of death points to one of its exacerbating factors [18,23,27,54,71]. As pointed out by Cassell [6], the biomedical model, with its focus on more specific and/or objective concerns, contributes to the difficulty of recognising suffering holistically [17,57,64,71,72]. Related to this is the focus on the physical domain, rather than the multidimensional nature of suffering, and difficulty disentangling the different dimensions of distress [66]. Many authors highlight the danger of focusing on pain or symptoms in isolation, or reducing suffering to single constituent elements [17,44,64], rather than treating the 'whole person' who is suffering. Acknowledging the holistic nature of pain – and in particular the spiritual dimension of suffering – is argued to protect patients from misinterpretations and missed problems, and avoids exposing them to futile, inappropriate and burdensome treatment [6,44,69]. Ultimately assessment and care must be multidimensional to be effective [9,51,66,67,72]. In view of the fact that it is always experienced differently for each individual, it also needs to be personalised. The individual and subjective nature of suffering should be included in any conceptualisation of suffering and is reflected in the variety of case study reports included in this review.

Given the confusion between all-encompassing suffering and distress from a single cause, and given the large number of surrogate terms identified in the literature, further research would benefit from agreement on a single term for the phenomenon analysed here. Furthermore, the multiple meanings given to the word 'suffering' in the vernacular, as well as in healthcare, suggests that a qualifier is needed. We propose the term 'holistic suffering' be used

DOI: 10.1002/pon

to reflect the multidimensional causation as well as the recommended approach to care.

Assessment and treatment of holistic suffering will require engaging with the spiritual health of the patient, where spirituality is defined to mean the way people find meaning and purpose, and how they experience their connectedness to self, others, the significant or sacred [73]. Those familiar with the spirituality literature will realise that spirituality incorporates a far broader concept than religion [73]. Spirituality has been identified as an independent component of quality of life in cancer patients [74] and holistic suffering is a real and distressing phenomenon. It cannot be ignored. Opportunities to assist suffering patients are already being missed [54]. If we do not address the spiritual well-being of our patients, we will continue to do so.

By acknowledging the association between the phenomenon of holistic suffering and patient spirituality, we also note the prominence given to existential meaning in life during its experience, and give reference to Saunders [75] and Cassell's [6] work regarding the complexity of suffering and Frankl's [76] work regarding the potential path through it.

An important issue raised by this review is how we should manage holistic suffering in cancer patients. The literature suggests two possible approaches, namely prevention, by supporting the patient's spiritual well-being [77], or therapeutic, facilitating the articulation of holistic suffering by cancer patients and, where possible, assisting them on the road to transcendence [78]. In conceptualising suffering, however, it is important not to focus excessively on its transformative aspects. It has been argued that this risks bypassing, glossing over and/or diminishing the experience of suffering by privileging its potential positive consequences [64].

Obviously, there will be challenges in recognising holistic suffering if cancer patients are known to consciously hide it from caregivers [14,56], but maintaining the possibility of holistic suffering as a differential diagnosis allows the possibility of specific interventions [67]. In order to care for the suffering patient, staff must come to terms with their own mortality [10,22], and the biomedical model needs to be replaced with a more holistic view of the patient [27]. Providing space for cancer patients to articulate their suffering will be a new experience for many and require education and support for healthcare workers [79]. Symptom control remains a keystone of treatment [36].

The analysis produced a portrait of a phenomenon that has previously been considered intractable. Identifying suffering as a syndrome which can be recognised and potentially treated, will improve the care of cancer patients [51]. Our definition has highlighted some of the challenges that will be inherent in the recognition of suffering. The introduction of routine spiritual screening is a necessary part of this process [80], and will be welcomed by patients [68].

Our study did not reveal cultural or religious differences in the essential components of holistic suffering [15], although their expression may be influenced by cultural patterns of relationship, such as expectations of children and parents [53].

This study was restricted to papers that investigated suffering in the context of cancer patients. A wider study may identify further characteristics. Longitudinal studies would be helpful in exploring the natural trajectory of holistic suffering in cancer patients.

Conclusions

In this literature review and concept analysis, we defined holistic suffering according to its' attributes. Antecedents of holistic suffering are multiple and generally involve some type of loss. Examination of the consequences of suffering suggests that the course of holistic suffering can be influenced by healthcare workers. Further effort is needed to educate the staff who care for cancer patients in their understanding of this phenomenon in order to facilitate its recognition and improve care for the patients involved.

Acknowledgements

This project received funding from the Australian Government through Cancer Australia.

Conflict of interest

The authors have declared no conflicts of interest.

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DOI: 10.1002/pon