

A qualitative meta-synthesis examining spirituality as experienced by individuals living with terminal cancer

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Abstract

This review aimed to examine and synthesise literature on spirituality as experienced by individuals living with terminal cancer. Six databases were systematically searched for studies with qualitative findings relevant to spirituality and terminal cancer. Thirty-seven studies were included and thematic synthesis was used to identify themes. Analytical themes included: making sense of dying; living with dying; feeling connected; and being reflective. This review highlights how the experience of spirituality can positively impact the lives of terminal cancer patients. Further, these findings suggest that spirituality can be a transformative experience that allows individuals to experience peace at end of life.

Keywords

cancer, spirituality, qualitative methods, systematic review, health psychology

Introduction

Due to factors such as global population growth and aging, the incidence of cancer and mortality rate are rising rapidly (Bray et al., 2018). By 2030, the number of cancer related deaths is predicted to increase to 13 million deaths annually (Fidler et al., 2018). A cancer diagnosis, its further progression and end of life phase can be causes of significant distress and suffering for individuals (Martins and Caldeira, 2018). Specifically, living with terminal cancer may be regarded as a particularly stressful experience (Chang et al., 2013). Distress may be experienced by such individuals in all dimensions (World Health Organisation, 2021); physical (such as physical pain), psychological (depression or anxiety), social (loneliness or feelings of isolation), and spiritual (meaning, purpose and relationships) (Puchalski, 2002). The awareness of a reduced life expectancy may become a turning point by which individuals with terminal cancer begin to reflect on their own spirituality, relationships with others and God and to resolve spiritual issues within (Leung et al., 2006).

While religion is based on a shared set of practices and beliefs within a social institution (Dyson et al., 1997),

spirituality is more individual in nature and is associated with transcendence, connection with a higher power and relationships that provide meaning and purpose (Siddall et al., 2015). Transcendence may be described as a feeling of connection with something which is greater than oneself (Breitbart, 2002). The International Consensus Conference on Improving the Spiritual Dimension of Whole Person Care defined spirituality as “a dynamic and intrinsic aspect of humanity through which persons seek ultimate meaning, purpose, and transcendence and experience relationship to self, family, others, community, society, nature, and the significant or sacred. Spirituality is expressed through beliefs, values, traditions and practices” (Puchalski et al., 2014: 646). Spirituality is a dynamic process that exists within an individual as they search for the sacred in their lives (Pargament, 1999). Both religion and spirituality have

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been found to have a positive impact on cancer patients' emotional wellbeing (Salsman et al., 2015), to help patients find meaning in their illness, to cope with existential issues and to elicit support from others within their social community (Jim et al., 2015). More specifically, religion and spirituality have also both been reported to play an important role in the wellbeing of individuals with terminal cancer (Bovero et al., 2016).

A spiritual perspective may be defined as "an expansion of personal boundaries through experiences such as prayer, forgiveness, belief in a power greater than oneself, and, for many, belief in a form of life after physical death" (Coward and Reed, 1996: 281). The adoption of a spiritual perspective helps individuals to make sense of their lives based on the belief in, and a feeling of transcendence or connection with, a power greater than self (Haase et al., 1992). While spirituality is considered innate in all humans, a spiritual perspective differs among individuals in terms of the awareness that they may have of their own spirituality. Pivotal life events may be the precursor to individuals developing a spiritual perspective (Haase et al., 1992). A spiritual perspective helps individuals to frame these life events and determine their significance (Mohan and Uys, 2006). Viewing life from a spiritual perspective may enable an individual to understand the process of personal growth, cope with adversity and to find meaning and purpose in life (Mohan and Uys, 2006). Research has shown that the adoption of a spiritual outlook by those living with a life threatening illness helps them to find meaning, strength and comfort (Albaugh, 2003). A spiritual perspective has also been associated with self-transcendence in terminally ill patients and has been reported by medical professionals as having a significant and positive impact on patient wellbeing (Coward and Reed, 1996).

Following a terminal diagnosis, cancer patients often encounter psychological, social and spiritual distress (Adler and Page, 2008). Research has shown that their primary spiritual concerns at this point in the cancer trajectory are love, their relationships with others, their own life purpose (Ferrell et al., 2013) and their search for meaning as they attempt to make sense of a terminal diagnosis (Selby et al., 2016). A scoping review examining spiritual distress found that individuals living with terminal illness experienced a spiritual struggle, resulting in spiritual issues with others, within themselves and their own faith and with feelings of abandonment and anger with God (Roze des Ordons et al., 2018). Caldeira and colleagues (2014) in their study of elderly patients living with cancer, found that many individuals experience spiritual distress as they face the prospect of their death. This distress may manifest further as spiritual pain (Vasudevan, 2003), where feelings of meaninglessness, loss, hopelessness and despair can occur as patients live with terminal illness (Chen et al., 2018). The opportunity of spiritual growth may occur through the

suffering of an illness (Tu, 2006). Through spiritual coping, research from other contexts has found that spiritual transformation can take place, resulting in a reformed view of an individual and their world and having a greater sense of purpose in their lives (Pargament et al., 2013).

Previous qualitative reviews have synthesised spirituality, the spiritual care needs and spiritual perspectives of patients at end of life (Clyne et al., 2019; Edwards et al., 2010; Williams, 2006). Other reviews have investigated spirituality as an aspect of the terminal cancer experience (Willig and Wirth, 2018). Previous meta-syntheses have also been conducted in the area of spirituality focused on the needs of family caregivers (Benites et al., 2021; Lalani et al., 2018) but none have focused specifically on terminal cancer patients. To our knowledge, this is the first meta-synthesis specifically examining spirituality in terminal cancer patients. For the purpose of this review, we operationally defined terminal cancer as advanced cancer with a prognosis of less than a year. We chose to do this in line with current definitions, due to the interchangeability of terms such as advanced cancer, end of life cancer and terminal cancer in the literature (Cordeiro et al., 2020). Each of these terms refer to cancer that is incurable. However, while advanced cancer may be responsive to life-prolonging treatment, this is not the case in terminal cancer. The focus of treatment for terminal cancer is symptom control and palliative care (Kim et al., 2016). Dittus and colleagues (2017) asserted that many individuals with advanced cancer may live well for several years, although they have been diagnosed with a life-limiting illness. In contrast, a scoping review conducted by Cordeiro and colleagues (2020) identified that terminal illness specifically refers to an illness that is no longer amenable to curative treatment and has a prognosis of less than 12 months. Additionally, end of life may refer to a more specific period of time that is shorter than a year but could be hours, weeks or months (Cordeiro et al., 2020; Hui et al., 2014).

The aim of this review was to examine and synthesise evidence on spirituality as experienced by individuals living with terminal cancer. This specific patient population has been identified as being important as a terminal cancer diagnosis has been widely documented to have the potential to trigger psychological, social and spiritual concerns for patients as they move closer towards death. Understanding the experience of spirituality among individuals living with terminal cancer can inform the type of compassionate end of life care and support that is needed to help individuals live while dying.

Method

Meta-syntheses are integrations that give new interpretations of discoveries and are more than the sum of their parts (Thorne et al., 2004). These interpretations are not present in

any one study; rather, they are conclusions drawn from a sample of studies as a whole (Thorne et al., 2004). They provide a more thorough and holistic understanding of a certain event or experience (Sandelowski, 2012; Thorne et al., 2004). This systematic review and qualitative synthesis was conducted and reported in conformity with the requirements set out by the Enhancing Transparency in Reporting the Synthesis of Qualitative Research Statement (Tong et al., 2012) (See [Supplementary File A](#)). This review has been registered with PROSPERO (Registration no. CRD42021237406).

Search strategy

The search strategy drew upon search terms which were identified by the reviewers from an initial scoping search relating to definitions of spirituality and spiritual perspectives. Search terms were grouped into three categories; spirituality; terminal cancer; and qualitative. The search strategy consisted of a combination of controlled vocabulary (e.g. MeSH) and free-text terms (See [Supplementary File B](#) for search strategies). Boolean terms “OR” and “AND” were utilised to combine terms within and between the specified categories. The strategy was then adapted for each of six databases (PubMed, PsycINFO, CINAHL, Embase, Medline and Web of Science). The first database search was conducted on the 26th March 2020. Updated searches were completed on the 22nd March 2021 and 12th March 2022. The first two searches were screened by LH and EB. The screening for the final search was carried out by LH and AD as EB was unavailable.

Selection criteria

This review included empirical studies published between March 2009 and March 2022. Articles were selected for inclusion within the systematic review if they (1) were empirical studies published in English; (2) included adults of 18 years of age or older with a terminal cancer diagnosis; (3) included qualitative data relating to patients’ perspectives on spirituality, spiritual perspectives or related concepts such as meaning making, existential distress, transcendence, religious perspective, sacred connections and personal growth. These concepts were drawn from the definition of spirituality from the International Consensus Conference on Improving the Spiritual Dimension of Whole Person Care (Puchalski et al., 2014), and from an initial scoping search relating to definitions of spirituality and spiritual perspectives. Mixed methods, intervention or quantitative studies with open-ended questions were included if qualitative data were reported separately. For the purpose of the review, we defined terminal cancer as advanced cancer with a prognosis of less than a year, where there is an explicitly stated terminal diagnosis or where it

can be inferred by a paper that participants are approaching end of life with advanced cancer.

Screening and full text review process

Following the exporting of searches from each database and subsequent removal of duplicate studies in Zotero™, the remaining titles and abstracts were imported by the first reviewer (LH) into systematic review software Covidence™. A two-stage screening and full text review process was undertaken. In the first stage, pairs of reviewers screened the titles and abstracts of included studies independently. LH and EB screened the studies for the first and second round of searches. LH and AD screened the studies for the final round as EB was unavailable. In the second stage, papers deemed as eligible from stage 1 were sourced as full texts and independently assessed for inclusion by LH and EB or AD.

Any disputes or discrepancies relating to the above were resolved through consensus between LH and EB or AD. Two other independent reviewers (SD, PG) were available for discussions to resolve any conflicts that were unable to be resolved. The reasons for exclusion for full text articles were recorded by the reviewers (LH, EB, AD) (See [Figure 1](#) which highlights the review process and provides a summary of these reasons).

Data extraction

The following data was extracted for each included study: author(s); country of study; aims of study; sample size; age range; setting; data collection method; and analytical approach. Data was extracted by LH and cross-checked by SD.

Quality appraisal

The Critical Appraisal Skills Programme (CASP) was adhered to by the reviewers when appraising the methodological quality of the included studies. All included studies were individually assessed by LH and EB or AD using the qualitative checklist examining methodological quality across 10 items including; results; methodology; research design; recruitment strategy; data collection; ethical considerations; and data analysis. Reviewers screened and rated each study using yes, no or can’t tell based on each checklist item (Critical Appraisal Skills Programme, 2018). Any disputes or discrepancies were resolved through consensus. Two other independent reviewers (SD, PG) were available to help resolve any conflicts that arose during this process.

Qualitative meta-synthesis method

The portions of the results and findings sections of the included studies that were relevant to the aims of this

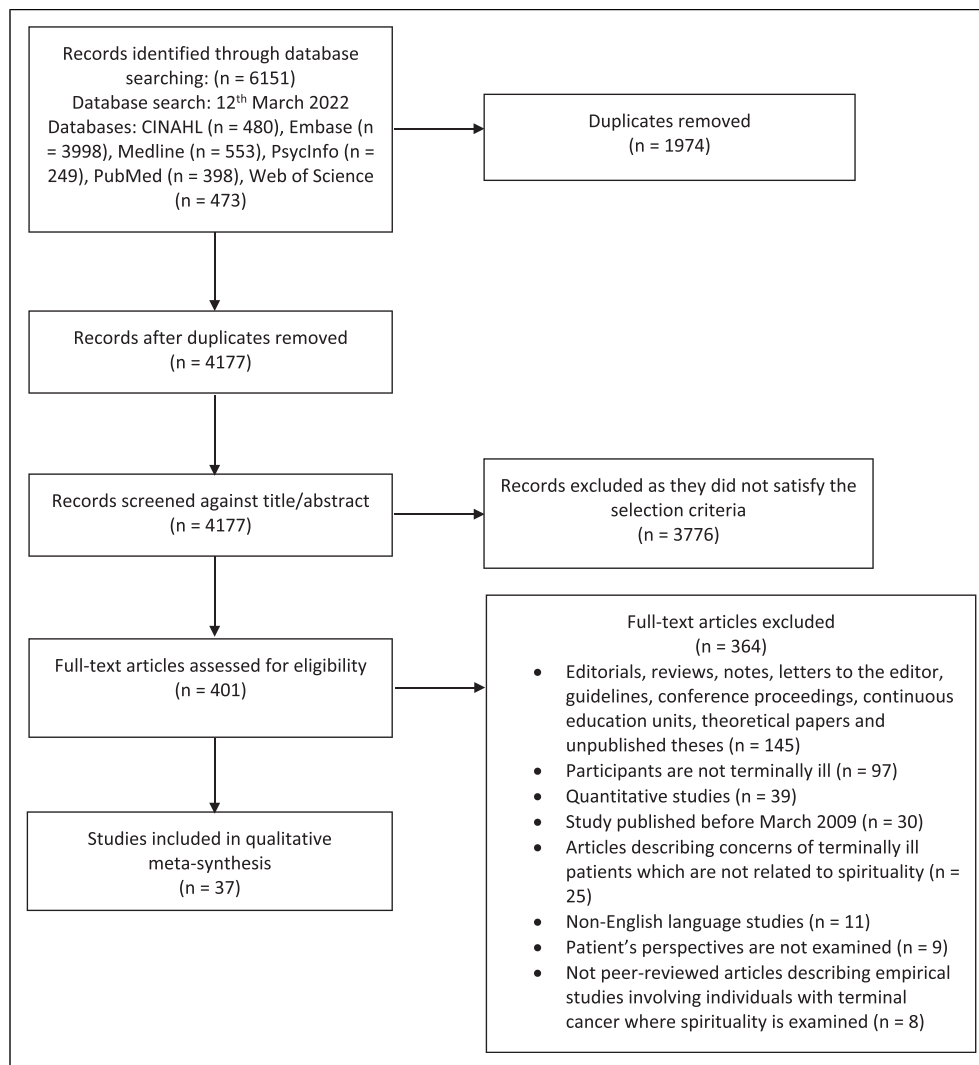


Figure 1. PRISMA flow diagram.

review were extracted by the first reviewer (LH) and entered into NVivo 12 software for data analysis. Thematic synthesis (Thomas and Harden, 2008) was utilised by the first reviewer (LH) in this qualitative meta-synthesis. The data was thematically synthesised using a three-stage framework; firstly, the line-by-line coding of relevant data; secondly, descriptive themes which remain close to the themes identified in the primary studies were developed according to patterns across the codes; and lastly, the development of analytical themes which go beyond the themes identified in the primary studies to produce a superior level of conceptual understanding and identify new concerns or recommendations relating to the topic being studied (Barnett-Page and Thomas, 2009). Each of the codes, descriptive themes and analytical themes were identified by the first author (LH) and validated by two further authors (SD, PG).

Results

The systematic search yielded 6151 articles. Following removal of duplicates by the first reviewer (LH), this left 4177 articles for title and abstract screening. Following title and abstract screening by the first and second reviewers (LH, EB, AD), 3776 of these articles were excluded as they did not satisfy the selection criteria. The remaining 401 full text articles were screened and 364 were removed as they did not satisfy the inclusion criteria. Following this screening, 37 articles were included in the review (See Figure 1).

Characteristics of included studies

Studies originated from the United States ($n = 9$), the United Kingdom ($n = 4$), Australia ($n = 2$), New Zealand ($n = 2$),

Table 1. Characteristics of included studies.

Author (Year)	Country	Aim of study	Sample (gender)	Age	Type of cancer	Setting	Data collection method	Analytical approach	Patient classification
Adorno and Brownell (2014)	USA	This exploratory study examined the perceptions of QOL from older veterans who were living with late-stage lung cancer	12 (12m)	55–87	Late-stage lung cancer	Hospital	Semi-structured interviews	Grounded theory	Advanced cancer with a prognosis of <12 months
Alcorn et al. (2010)	USA	This study sought to inductively derive core themes of religion and/or spirituality active in patients' experiences of advanced cancer to inform the development of spiritual care interventions in the terminally ill cancer setting	68 (37f, 36m)	Mean = 60, SD = 11.9	Not specified	Not stated	Scripted interviews	Grounded theory	Advanced cancer with a prognosis of <12 months
Aoun et al. (2016)	Australia	This study describes the lived experiences of older people coping with terminal cancer and living alone, focusing on how they face challenges of the biographical life changes from their disease progression	43 (22f, 21m)	52–91	Lung, colorectal, breast, prostate, bladder, ovarian stomach and lymph nodes	Home	Semi-structured interviews	Thematic analysis	Terminal cancer
Bentur et al. (2014)	Israel	This pilot study focused on identifying the coping strategies for existential and spiritual suffering at the end of life of secular Jews suffering from advanced-stage cancer	22 (14f, 8m)	39–76	Breast, lung, skin, stomach, pancreas, colon and neuro-blastoma	Hospital and home	In-depth interviews	Phenomenology	Advanced cancer with a prognosis of <12 months
Best et al. (2014)	Australia	This study aimed to explore the nature of spiritual support for a group of Australian patients with advanced cancer, and ascertain their preferences regarding the role of doctors in helping them cope as they experience terminal illness	15 (10f, 5m)	41–87	Stage IV pancreas, lung, prostate, Breast, colorectal, cervix and bladder	Hospital	Semi-structured interviews	Grounded theory	Advanced cancer with a prognosis of <12 months
Bruun Lorentsen et al. (2019)	Norway	The primary aim of this study is therefore to explore the patients' experiences of bodily changes in relation to dignity. The secondary aims are as follows: • What are the patients' experiences of the bodily changes? • How do the patients' experiences of bodily changes give insight into the phenomenon of dignity?	13 (9f, 4m)	53–83	Not specified	Hospital	In-depth interviews	Ontological hermeneutics	Cancer patient at end of life
Cao et al. (2020)	China	This study aimed to investigate the meaning of aftermath concerns in the process of preparing for dying among terminal cancer patients	25 (13f, 12m)	36–84	Not specified	Hospital and Home	Semi-structured interviews	Thematic analysis	Terminal cancer
Chikhladze et al. (2018)	Georgia	This study aimed to compare the attitudes, needs, and requirements at the end of life of the groups of patients with cancer and elderly individuals	50 (34f, 16m)	Not stated	Not specified	Cancer centre	Semi-structured interviews	Thematic analysis	Advanced cancer with a prognosis of <12 months
Chittem et al. (2022)	India	This study aimed to understand Indian cancer patients' hopes and beliefs about the end of life, particularly focusing on how this informed their preferences regarding end-of-life treatment	25 (7f, 18m)	27–72	Lung, stomach, colorectal, prostate, breast, non-hodgkin lymphoma, acute lymphoblastic leukemia, cervix, endometrium, tongue cancer	Hospital	Semi-structured interviews	Interpretative phenomenological analysis	Advanced cancer with a prognosis of <12 months

(continued)

Table 1. (continued)

Author (Year)	Country	Aim of study	Sample (gender)	Age	Type of cancer	Setting	Data collection method	Analytical approach	Patient classification
Cronfalk et al. (2009)	Sweden	The purpose of this study was to explore how patients in palliative home care perceive physical touch in the form of soft tissue massage, when they are dying	22 (14f, 8m)	41–76	Not specified	Home	In-depth interviews	Hermeneutic analysis and interpretation	Advanced cancer with a prognosis of <12 months
Duggieby et al. (2010)	Canada	The purpose of this study was to explore the current societal discourse on hope as well as the hope of older terminally ill cancer patients, their significant other, and their primary nurse	3 (2f, 1m)	62–82	Not specified	Home	Qualitative interviews	Critical discourse analysis	Advanced cancer with a prognosis of <12 months
Egan et al. (2017)	New Zealand	This study aimed to investigate people's understanding of spirituality and spiritual care practices in New Zealand (NZ) hospices	24	Not stated	Not specified	Not stated	Semi-structured interviews	Thematic analysis	Advanced cancer with a prognosis of <12 months
Ellis et al. (2015)	UK	To explore the concept of suffering and distress by eliciting what individual patients with advanced cancer perceived as suffering and how they utilised their own resources to manage suffering	49	31–89	Advanced breast, colorectal and lung cancer	Home and palliative care day centre	Narrative interview	Thematic analysis	Advanced cancer with a prognosis of <12 months
Elser et al. (2012)	India	To investigate psychosocial and spiritual problems of terminally ill patients in Kerala, India	37 (22f, 15m)	26–65	Terminal breast and head-and-neck cancer	Home	Semi-structured interviews	Thematic analysis	Advanced cancer with a prognosis of <12 months
Eun et al. (2017)	Korea	The purpose of the current study was to gain insight into the perceptions of terminally ill cancer patients and their family members regarding a patient's end-of-life status and their need for palliative sedation using qualitative, in-depth interviews	13 (5f, 8m)	32–81	Not specified	Healthcare facility	In-depth interviews	Thematic analysis	Terminal cancer
Ginter (2020)	USA	The aim of this qualitative study was to seek to understand the lived experiences of young women with metastatic breast cancer; in particular, the essence of their quality of life following their diagnosis	9 (9f)	28–40	Metastatic breast cancer	Home	Semi-structured interviews	Phenomenology	Terminal cancer
Harmon (2019)	USA	This auto/ethnography sought to exhibit the simple importance of a dog to the meaning making process for someone coming to terms with their mortality	1 (1f)	71	Breast and lung	Outdoor - Marina	Ethnography	Autoethnography	Cancer patient at end of life
Hughes et al. (2015)	New Zealand	The aim of the study was to explore how people who had been diagnosed with a terminal illness perceived and made meaning of palliative care, taking culture into account	8 (4f, 4m)	30s–70s	Not specified	Hospital and home	Ethnography/Semi-structured interviews	Grounded theory/thematic analysis	Terminal cancer
Lee and Ramaswamy (2020)	Singapore	The study examined and described the perspectives of people living with advanced cancer and the changes over time in their needs and experiences	11 (6f, 5m)	58–76	Not specified	Home	Semi-structured interviews	Interpretative phenomenological analysis	Advanced cancer with a prognosis of <12 months
Lee et al. (2013)	Singapore	This study examined the perceptions of dignified palliative care by a local population in Singapore?	4 (3f, 1m)	39–55	Advanced breast, thyroid and corpus uteri cancer	Home	Semi-structured interviews	Thematic analysis	Advanced cancer with a prognosis of <12 months

(continued)

Table 1. (continued)

Author (Year)	Country	Aim of study	Sample (gender)	Age	Type of cancer	Setting	Data collection method	Analytical approach	Patient classification
Li et al. (2014)	Taiwan	The purpose of this study was to explore the conceptualization of patients' dignity in the context of end-of-life care in Taiwan from both patients' and healthcare professionals' perspectives	9 (5f, 4m)	29–77	Not specified	Hospital and home	In depth interviews	Hermeneutic interpretive analysis	Terminal cancer
Liu et al. (2021)	China	This study aimed to explore the meaning of patient dignity at the end of life in traditional Chinese culture from perspectives of advanced cancer patients and their family members	15 (6f, 9m)	26–78	Myeloblastoma, liposarcoma, peritoneal cancer, Glioma, rectal, cardia, liver, Breast, stomach, colon, pancreatic cancer and chondrosarcoma	Hospital	Semi-structured interviews	Thematic analysis	Advanced cancer with a prognosis of <12 months
Maiko et al. (2019)	USA	To better understand the spiritual and religious strengths and distress of adults with advanced cancer	21 (14f, 7m)	Not stated	Not specified	Cancer centre	Semi-structured interviews	Thematic analysis	Advanced cancer with a prognosis of <12 months
McTiernan and O'Connell (2015)	Ireland	To explore how individuals with terminal cancer make sense of their dying experience within an Irish context	8 (6f, 2m)	36–68	Not specified	Home and Hospice	Semi-structured interviews (from public broadcasts)	Interpretative phenomenological analysis	Terminal cancer
Meisenholder et al. (2016)	USA	To describe this young college student's experience of prayer in coping during a life-threatening illness	1 (1f)	19	Abdominal rhabdomyosarcoma	Not stated	Case study: Journal entries	Case study analysis	Cancer patient at end of life
Mok et al. (2010)	Hong Kong	The aim of this study was to explore the phenomenon of spirituality and spiritual care among terminally ill Chinese patients	15 (8f, 7m)	53–89	Not specified	Hospital	In-depth interviews	Interpretative phenomenological analysis	Terminal cancer
Nedjat-Haiem et al. (2020)	USA	This study examined the data using a guide developed from the concepts related to distress of a multifactorial unpleasant experience of a psychological, social, spiritual, and/or physical nature from a veteran's perspective	27 (27m)	66–75	Not specified	Outpatient cancer clinic	In-depth interviews	Phenomenology	Advanced cancer with a prognosis of <12 months
Nilmanat et al. (2015)	Thailand	The objective of this study was to explore how Thai persons with advanced cancer move beyond suffering at the end of their life	15 (11f, 4m)	30–72	Cervical, urogenital, lung breast, head-and-neck and colon cancer	Hospital and home	Case study: structured interview	Thematic analysis	Advanced cancer with a prognosis of <12 months
Peoples et al. (2018)	Denmark	The purpose of this study was to gain a deeper understanding of the ways in which people with advanced cancer who live at home perceive quality of life and any possible association with different dimensions of belonging	9 (5f, 4m)	57–85	Colon, breast, prostate, and endometrial cancer	Home	Semi-structured interviews	Thematic analysis	Advanced cancer with a prognosis of <12 months
Reeve et al. (2012)	UK	The aim of this study is to analyse these accounts from the perspective described in Illich's medical Nemesis (1974) to see whether it offers any new insights into understanding and dealing with distress when living with terminal illness	27 (16f, 11m)	40s–80s	Breast, lung, gastrointestinal, haematological, head/neck, tongue, gynaecology, liver, urological	Hospital and home	Semi-structured interviews	Thematic analysis	Terminal cancer
Reeve et al. (2010)	UK	To explore how well biographical theory supports the understanding of individual lived experience with terminal cancer	19 (11f, 8m)	40s–80s	Respiratory, haematological, gastrointestinal, urological, gynaecology, breast, and soft tissue	GP	Semi-structured interviews	Holistic form analysis	Terminal cancer

(continued)

Table 1. (continued)

Author (Year)	Country	Aim of study	Sample (gender)	Age	Type of cancer	Setting	Data collection method	Analytical approach	Patient classification
Sherman et al. (2018)	USA	The current qualitative study sought to deepen our understanding of preparedness for EOL care, from the perspective of patients themselves	13 (6f, 7m)	Mean 63.8	Breast, lymphoma, prostate, lung, melanoma, head/neck, bladder, osteosarcoma, lipo-sarcoma	Not stated	In-depth interviews	Thematic analysis	Advanced cancer with a prognosis of <12 months
Thompson et al. (2009)	Canada	To identify the impact of prognostic acceptance or nonacceptance on the physical, psychological, and existential well-being of patients with advanced cancer	38 (21f, 169m)	Not stated	Lung, breast, genitourinary, gynaecologic, gastrointestinal and others	Palliative care unit	Semi-structured interviews	Thematic analysis	Cancer patient at end of life
Tuck et al. (2012)	USA	The threefold purpose of the study is to (a) explore the acceptability and feasibility of implementing the PATS (presence, Active listening, touch, sacred story) intervention, an approach to narrative storytelling developed by the first author/principal investigator, and the administration of spiritual Health Inventory (SHI; Highfield, 1992) in a sample of people who have a terminal diagnosis of cancer; (b) explore the experience of living with a terminal illness as expressed in the narratives of the sacred stories of the study participants that results from PATS; and (c) analyse the sacred stories for the presence and nature of spirituality and healing	7 (3f, 4m)	Mean 59.5	Not specified	Hospital and home	Narrative interview; sacred story	Narrative analysis	Terminal cancer
Voertmann et al. (2022)	Denmark	The purpose of this study was to investigate how spiritual matters are communicated both verbally and non-verbally in the interaction between patient and HCP in two Danish hospices	12 (8f, 4m)	Mean 61	Not specified	Hospice	Semi-structured interviews	Interpretative phenomenological analysis	Terminal cancer
Willig (2015)	UK	This article has 2 aims. The first is to demonstrate how the application of an innovative qualitative methodology generated novel insights into the experience of living with advanced cancer. The article's second aim is to challenge the idea that the identification of shared themes provides the researcher with access to the meaning and significance of the experience of "living-with-dying."	3 (3f)	Mid 30s -early 80s	Not specified	Cancer centre and Home	Semi-structured interviews	Hermeneutic phenomenological analysis	Advanced cancer with a prognosis of <12 months
Yoon Sun Kim (2021)	Korea	The purpose of this study was to examine the life-sustaining treatment decisions of terminal cancer patients	10 (4f, 6m)	61-75	Liver and biliary tract cancer, lung cancer	Healthcare facility	In-depth interviews	Phenomenological analysis	Terminal cancer

Table 2. Overview of analytic and descriptive themes.

Analytic themes	Descriptive themes
Making sense of dying	Spiritual distress Meaning making Maintaining a sense of purpose Changing identity
Living with dying	Finding acceptance Living with hope Living in the present
Feeling connected	A feeling of connection to self Feeling connected with family and friends Feeling connected with nature and animals Feeling connected with a higher power
Being reflective	Life review and legacy Reflecting on the transformation journey

Canada ($n = 2$), Singapore ($n = 2$), Denmark ($n = 2$), China ($n = 2$), India ($n = 2$), Korea ($n = 2$), Hong Kong ($n = 1$), Thailand ($n = 1$), Israel ($n = 1$), Norway ($n = 1$), Georgia ($n = 1$), Sweden ($n = 1$), Taiwan ($n = 1$), and Ireland ($n = 1$). There was a combined total of 1046 participants and of the 37 studies included, 35 provided a gender breakdown of participants (54% female and 46% male). Data collection methods included interviews ($n = 34$), ethnography ($n = 1$), a combination of interview and ethnography ($n = 1$) and a case study of journal entries ($n = 1$). Studies were classified into whether patients were at end of life ($n = 4$), patients had terminal cancer ($n = 13$), or patients had advanced cancer with a prognosis of less than 12 months ($n = 20$). General characteristics of the included papers are included in Table 1.

CASP quality appraisal

Supplementary File C provides the results of the CASP quality appraisal. All included studies ($n = 37$) yielded a yes rating for criteria relating to research aims, appropriateness of methodology, research design, recruitment strategy, data collection, research findings and value of the research. Where studies reported insufficient information regarding a specific criterion, they received a cannot tell rating. Criteria receiving cannot tell ratings included: relationships between the researcher and participants ($n = 18$), whether data analysis was sufficiently rigorous ($n = 1$) and ethical considerations ($n = 1$). However, this may have been a reporting feature within a given article rather than a lack of research quality. On this basis, studies were deemed of a medium to high quality when they did not receive any no ratings (indicating a low quality) and were therefore included in the meta-synthesis.

Thematic synthesis findings

Four analytical themes relating to an individual's experience of spirituality while living with terminal cancer were

generated: making sense of dying, living with dying, feeling connected and being reflective. Analytical and associated descriptive themes are presented in Table 2. Illustrative quotes are presented in Table 3.

Making sense of dying. Many participants across the included studies reported initial feelings of spiritual distress as they attempted to live with dying. As participants endeavoured to make sense of dying, spirituality was found to help them find new meaning and appreciation of life while living with terminal illness, to live with purpose and to live with a changed identity.

Spiritual Distress. The experience of spiritual distress was identified by participants of several included studies, as they attempted to make sense of dying. When faced with the reality of living with terminal illness, participants in four studies struggled with being confronted with their mortality (Chittem et al., 2022; Ellis et al., 2015; Willig 2015; Yoon Sun Kim, 2021) and in another study, participants suffered from existential angst (Egan et al., 2017). Some participants from other included studies also experienced feelings of injustice at the unfairness of having a terminal illness, with questions of 'why me?' and 'why now?' (Egan et al., 2017; McTiernan and O'Connell, 2015; Reeve et al., 2010; Reeve et al., 2012; Thompson et al., 2009).

Many participants in included studies feared suffering associated with death (Eun et al., 2017; Sherman et al., 2018). Participants of several studies not only experienced a fear of dying, but also feared and grieved leaving behind family members and friends (Cao et al., 2020; Chittem et al., 2022; Egan et al., 2017; Liu et al., 2021; Maiko et al., 2019; Thompson et al., 2009; Tuck et al., 2012; Yoon Sun Kim, 2021). Feelings of loneliness and loss were experienced by participants in further studies, which they perceived as difficulties experienced with family members (Maiko et al., 2019; Thompson et al., 2009; Tuck et al., 2012) and friends

Table 3. Overview of analytic themes, descriptive themes and illustrative quotes.

Analytic themes	Descriptive themes	Illustrative quotes
Making sense of dying	Spiritual distress	<p>"They don't even want to hear ... if I talk positive, they are pretty good, but if I talk negative, they don't want to hear that other outcome, what it could be or whatever. They refuse to listen to it and that angers me some too because I'm trying to prepare them and prepare myself too." (Adorno and Brownell, 2014: 139)</p> <p>"Seeing my family suffer looking at me. not being able to be in control of my own destiny" (Ellis et al., 2015: 204)</p> <p>"One thing I dread is being on my own. I am not frightened to die, but I am frightened of dying, I don't want to go through all this pain." (Egan et al., 2017: 227)</p> <p>"If I am destined to die, please let me die without suffering." (Eun et al., 2017: 1013)</p> <p>"The only thing is, I don't know what the future's going to be. Do I want to know? ... Maybe I'm a coward and I don't want to know yet. Just take every day as it comes. And that's, really that's all you can do isn't it? ... I've got it, what can I do about it? Get on with it ... I'm no special person. I'm one of many. I'm a pinhead in the universe ... I am a fatalist you know. I believe what has to be, will be ... I feel quite peaceful. It's there. I can't do anything about it." (Reeve et al., 2010: 186)</p> <p>"We need a good farewell. We all know the truth, but no one wants to openly talk about it and just wait until the last minute. Some families even didn't get a chance to say goodbye" (Liu et al., 2021: 4)</p> <p>"All my priorities and my perspective on life changed, I say those who haven't been there don't even understand what life is... I think people these days are too busy with material things and confuse the unimportant things with the essence." (Bentur et al., 2014: 4)</p> <p>"It's made me completely and utterly totally change my outlook, my philosophy, my way of life, my behaviours, to some extent my morals as well has changed." (Reeve et al., 2012: 149)</p> <p>"I'm saying there's nothing stronger than the power of daily routine. For me, managing to keep the routine going, waking up in the morning with the kids and putting them to bed, sending them off to kindergarten with a smile, reading them a story ... [is] supreme bliss. Supreme." (Bentur et al., 2014: 4)</p> <p>"I have that feeling [the feeling of meaninglessness]. After the diagnosis I felt like that. Before that I didn't feel like that because I earned more and we had a lot of fish and money. When I fall I can recognize the fall of my family also" (Elsner et al., 2012: 1185)</p> <p>"I don't want to talk about it all the time. I don't want to be the girl that has cancer. It is mine, I wear it, I accept it. But, I'm not a side-show." (Sherman et al., 2018: 461)</p> <p>"I have started to think that my body is my house and that I still am situated in my body. I try to imagine nice pictures of my body. A house is a good place where you are happy, safe and taken care of. It is a place filled with warmth and love.... I have started painting. I feel that is important for my identity now... By doing this I feel that I have moved into new rooms deeper in my body." (Bruun Lorentsen et al., 2019: 1167)</p> <p>"Why can't it be somebody else?" (McTiernan and O'Connell, 2015: 644)</p>
	Meaning making	
	Maintaining a sense of purpose	
	Changing identity	

(continued)

Table 3. (continued)

Analytic themes	Descriptive themes	Illustrative quotes
Living with dying	Finding acceptance	<p>"This growing acceptance of life as it is, with all the sorrow, the pain, the suffering and the tragedy, has brought me a kind of peace" (Mok et al., 2010: 364)</p> <p>"I want to be prepared for death, so I need to face the reality that I'm not going to live" (Hughes et al., 2015: 177)</p> <p>"I just keep thinking that God has a plan, and if this is it, I'm accepting" (Maliko et al., 2019: 582)</p> <p>"Adopting the Buddhist teaching on the truth of life helped the informants move on and be at peace with themselves. Just think that as a human being, birth, aging, sickness, and death are there. I We can't escape from it (death) the poor die, so do the rich. This is the same world for everyone. We were once born, and we will once die. This is how I tamjai. We have to accept the way things are." (Nilmanat et al., 2015: 227)</p> <p>"And it [death] had a lot of focus for me in the beginning. I may have gotten use to it by now, I think. Although it doesn't make it better, though. I think I have gotten use to it. A little bit of everyday life has come into it" (Voetmann et al., 2022: 3)</p> <p>"I hope that it would go quietly, peacefully, with as little pain as possible ..." (Duggleby et al., 2010: 364)</p> <p>"The day you lose hope is the day you start to die. I'm not ready to give up my hope yet." (Ginter, 2020: 429)</p> <p>"To me, hope keeps my mind alive, and inspires my will to live." (Nilmanat et al., 2015: 228)</p> <p>"You've got to have faith and a positive outlook because it is going to help you last longer." (Alcorn et al., 2010: 583)</p> <p>"At least right now, our end result really isn't really going to be a cure. It's more about long-term coping and maintenance and how long can we run with it. And I feel like the longer we hold on to our hope, the better we are going to be." (Ginter, 2020: 429)</p> <p>"It's not about cancer...it's not, it's not...anything else. It's your day-to-day life. If you don't have hope, you don't have life" (Chittam et al., 2022: 2519)</p> <p>"...Anyway, I will get over this. So I don't think yet I am losing this battle. I still think I will win. I will not lose hope" (Yoon Sun Kim, 2021: 104)</p>
	Living in the present	<p>"I really just am living day to day right now ... and not so much focusing on planning for the future. It makes it a lot easier to sort of cope with having, you know, a quote unquote, 'terminal disease' or whatever." (Ginter, 2020: 428)</p> <p>"I am living my life, not my death." (McTiernan and O'Connell, 2015: 645)</p> <p>"I need to be in harmony with myself and the universe. I don't know what will happen tomorrow, but I will try to be happy today." (Mok et al., 2010: 364)</p> <p>"It teaches you to live for today" (Reeve et al., 2012: 149)</p> <p>"What we need to do is to resign ourselves to our fate, just let it be." (Li et al., 2014: 2925)</p>

(continued)

Table 3. (continued)

Analytic themes	Descriptive themes	Illustrative quotes
Being connected	A feeling of connection to self	<p>"The bodily changes have helped me calm down and become aware of what is important in life." (Bruun Lorentsen et al., 2019: 1166)</p> <p>"I am in a very difficult situation the massage helped me to gain strength." (Cronfalk et al., 2009: 1205)</p> <p>"[Yoga] was cathartic, giving me that quiet time with my mind, just being able to be thankful for what I did have, you know, the life that was there." (Ginter, 2020: 426)</p> <p>"In the past, I was scared of some things. Like, it never would've occurred to me ever to get a tattoo in a million years. But I feel like at this point, it's a way of being able to control my body and taking sort of ownership of something. And at this point, I figured, you know, my body's been through so much. I have scars. I have all sorts of stuff. Why not add a tattoo? You're only going to live once." (Ginter, 2020: 427)</p>
	Feeling connected with family and friends	<p>"I believe in human strength, in human contact. Not as a cliché, on a true level... I think that now, around the illness, I have succeeded in reaching levels with people that are so much deeper than just the written word." (Bentur et al., 2014: 3)</p> <p>"People say death is a most personal and lonely journey. However, I have found that when there is a connected relationship with me, in the journey of dying, it gives me a lot of courage and encouragement" (Mok et al., 2010: 364)</p> <p>"Well, [cancer] weeded out the superficial friendships and enhanced the lifelong friendships that are the ones that are really meaningful. Most people, if they don't experience things like this, it's kind of like a filter that weeds out, like I say, the superficial friends and the true friends, are the cream that come to the top" (Maiko et al., 2019: 578)</p>
	Feeling connected with nature and animals	<p>"I enjoy the seasonal change in my garden. I see it as the meaning of life that things grow and perish. It's the same with us, we grow up and then we die. It just takes us a bit longer" (Peoples et al., 2018: 206)</p> <p>"I can't live without my dog. I wouldn't be happy without my dog." (Aoun et al., 2016: 361)</p> <p>"I prefer to remain at home with family and animals" (Aoun et al., 2016: 361)</p> <p>"It has to do with the meaning of life, that there is something that is bigger than oneself. Maybe that is why I'm so comfortable in nature." (Peoples et al., 2018: 206)</p>
	Feeling connected with a higher power	<p>"I don't know if I will survive this cancer, but without God it is hard to stay sane sometimes. For me, religion and spirituality keeps me going." (Alcorn et al., 2010: 584)</p> <p>"I've been more spiritually hungry now than I was on my first diagnosis. Because... I knew was going to survive. Which is why I didn't really bother. And now, it's like, well, maybe I should reconsider this." (Ginter, 2020: 428)</p> <p>"You believe in God, you got everything." (Best et al., 2014: 1335).</p> <p>"I think it's important, but especially important in the situation I'm in. It would be very difficult if I didn't have any sense of spirituality." (Egan et al., 2017: 226)</p> <p>"Through the years I've turned my back on my God. Tried to do things on my own. Since my illness I've called on him to help me through this." (Maiko et al., 2019: 579)</p> <p>"Religion is SO important...it's important to have a relationship that, to know or to believe that it's not the end. And that, that is the most comforting thing you can have." (Sherman et al., 2018: 461).</p> <p>"God will show me the way," (Tuck et al., 2012: 76).</p> <p>"They had a song – the queen song 'I don't want to live forever', at the end, and I said 'That's my song', but I'm going to have 'I want to break free' at the beginning...and I don't want them to cry, it's not sad. They should be happy that I'm relieved...released you know." (Aoun et al., 2016: 361).</p> <p>"Keeping faith in God that's it, and taking treatment, after all...it is God's decision. There is nothing in our hands. Getting this disease is not in our hands, so, we need to be strong" (Chitem et al., 2022: 2520).</p> <p>"I don't want to be in pain when I die. However, I feel comfortable when I am beside God. So I am not afraid of dying. You wouldn't imagine the power of faith" (Yoon Sun Kim, 2021: 104)</p>

(continued)

Table 3. (continued)

Analytic themes	Descriptive themes	Illustrative quotes
Being reflective	Life review and legacy	<p>"I had a few things that I always said I wanted to be a part of, and I achieved that, and everything is alright now... You want to see your children settled and financially secure ...that their lives will be fine. I wanted a grandson, and he's coming." (Bentur et al., 2014: 4)</p> <p>"I have regrets in things that I did wrong, which I don't have the opportunity to put right, and I wish to goodness I had." (McTiernan and O'Connell, 2015: 645)</p> <p>"I have completed my responsibilities as a father as I have worked hard and supported the family." (Mok et al., 2010: 364)</p> <p>"When a person gets a death sentence, it makes me look back how I have lived, and I tend to think more" (Yoon Sun Kim, 2021: 103)</p>
	Reflecting on the transformation journey	<p>"It's a transformative experience to have an illness such as this, and when you have that you have to re-evaluate all you've done in life, who you are, and who you're going to be." (Alcorn et al., 2010: 584)</p> <p>"People who knew me before I was ill can't believe the transformation that I've gone through. I'm much calmer, less het up" (Reeve et al., 2012: 149)</p> <p>"This cancer has really changed me. I used to be really hard, now I'm softer. I want to just live every day I have now, not thinking about when I'll die, but just live each moment" (Hughes et al., 2015: 175)</p> <p>"You feel black. You feel 'why me?' And you can't do things. I was angry, very angry - extremely angry... 'I don't know. I mean I'm happy as Larry now. I still have my down days. I still get down... And I think now, well heh hey so it's a house! Why do you need to be rushing? I don't run for buses anymore! You know - if I miss a bus. Well ok, there'll be another in a few minutes. As long as the lads have got clothes on their back. Meals in the house. That's it.' (Reeve et al., 2010: 189)</p>

who were fearful of their illness and ceased the friendships (Aoun et al., 2016). For participants of some included studies, the ultimate loss was perceived as experiencing the sadness and suffering of their loved ones (Cao et al., 2020; Ellis et al., 2015; Maiko et al., 2019; Thompson et al., 2009).

In five studies, participants reported that they experienced difficulties in communicating their grief about a future that they would no longer share with families (Adorno and Brownell, 2014; Bentur et al., 2014; Elsner et al., 2012; Ginter 2020; Liu et al., 2021). The inability of some family members to accept and speak about the impending death of their loved ones contributed to the suffering of participants in further studies (Adorno and Brownell, 2014; Eun et al., 2017; Sherman et al., 2018).

Meaning Making. Spirituality contributed to participants finding meaning within their illness and to cope in their daily lives. During the course of their illness, participants in two studies found that their perspective on life had changed and this was reflected in what gave life new meaning (Alcorn et al., 2010; Lee et al., 2013). For participants in three further studies, this was found in the routine of everyday life and time spent with the family (Bentur et al., 2014; McTiernan and O'Connell, 2015). Connection with family and friends and the strengthening of relationships provided powerful meaning for participants in one study (Mok et al., 2010). In this study, meaning was also found through participants acknowledging the good that they had done in their lives and having no regrets (Mok et al., 2010). In another study, meaning was found also through spiritual practices such as meditation, prayer and daily rituals (Egan et al., 2017). In two further studies, meaning was also experienced in the transience of nature, which reflected the natural flow of life, where things grow, flourish and then die (Mok et al., 2010; Peoples et al., 2018). In one study, participants struggled with the existential challenge of finding meaning in their lives as they attempted to live while dying (Willig, 2015). Through learning to live with uncertainty of the future, participants in another study found new meaning in their approach to life and their appreciation of it (Reeve et al., 2012).

Maintaining a Sense of Purpose. Living with a sense of purpose was found to be of significance to participants as they attempted to make sense of dying. This was achieved through keeping a sense of purpose or in some cases, finding new purpose through connection with others. Participants in one study wished for continuity and routine in their daily lives as a means of maintaining purpose (Reeve et al., 2010). Adorno and Brownell (2014) found that the physical symptoms of late-stage cancer prevented participants from partaking in activities which helped them cope with stress in life and which provided them with purpose and a sense of

identity, of 'who I am.' For participants in another study, lack of purpose led to a sense of uselessness and meaninglessness (Elsner et al., 2012). Being able to contribute to the lives of others, such as supporting friends and family members, enabled participants in three further studies to live with a sense of purpose (Bentur et al., 2014; Peoples et al., 2018; Thompson et al., 2009). Being perceived by others as a good person was reported by participants as being an important aspect of ones' life purpose in another study; the sense of connection, respect and value that it created was an important inner spiritual resource when living with terminal illness (Mok et al., 2010).

Changing Identity. The diagnosis of terminal illness also led to changes in identity participants' perceptions and experiences of their identity in three studies (Lee et al., 2013; McTiernan and O'Connell, 2015). In one study, while a number of participants experienced a loss of their own identity, others began to perceive themselves in a more spiritual light (Maiko et al., 2019). Participants in two further studies commented on the change in their identity and were concerned with the stigma associated with it (Reeve et al., 2012; Sherman et al., 2018).

Living with dying. As participants attempted to live with the knowledge of their shortened life expectancy, they began to accept they were dying. In many cases, such acceptance was found through spirituality, such as connection with oneself and ones' inner strength, connection with others, spiritual beliefs and transcendence. Hope was identified as an important resource to maintain positivity during illness in the face of death. Previous hopes for a cure were replaced with hope for comfort and a peaceful death, without suffering. Living in the present moment helped participants to live with dying, instead of worrying about the future.

Finding Acceptance. Spirituality was found to help participants to find acceptance of living with the knowledge that their cancer was terminal. As participants lived with the reality of the terminal status of their illness, they moved towards acceptance of their shorter life expectancy. For instance, in Maiko and colleagues' study (2019), participants used acceptance through positive thinking and accessing their own inner sources of strength as they attempted to live with the reality of their terminal illness. Aoun and colleagues (2016) found that many participants accepted their death through 'biographical closure' where death was normalized as they approached the end of their lives without fear. The finding of acceptance through the normalization of death was also found by authors in seven further studies (Hughes et al., 2015; Liu et al., 2021; Maiko et al., 2019; Thompson et al., 2009; Tuck et al., 2012; Voetmann et al., 2022; Yoon Sun Kim, 2021). Acceptance of dying was found through many means, including feeling

love and support from family and friends (Adorno and Brownell, 2014; Lee et al., 2013; Thompson et al., 2009), spiritual beliefs, faith and practices and a belief in the afterlife (Alcorn et al., 2010; Maiko et al., 2019; Thompson et al., 2009). In some cases, participants experienced difficulties in finding acceptance due to fears of leaving loved ones behind (Adorno and Brownell, 2014) and worries of becoming a burden on family (Aoun et al., 2016; Elsner et al., 2012; Lee et al., 2013; Liu et al., 2021; Yoon Sun Kim, 2021). Participants in another study moved towards a greater acceptance of their imminent death through surrendering control of their lives to a transcendent power (Mok et al., 2010). When participants accepted death as a part of the process of life, it helped to create a sense of peace within them (Mok et al., 2010; Nilmanat et al., 2015; Tuck et al., 2012). Professional spiritual support through palliative services was also reported as an important component of facilitating acceptance (Thompson et al., 2009).

Living with Hope. Living with hope was found by the authors of some studies to be an aspect of spirituality which assisted participants in living with terminal cancer. Hope was noted by the authors of some studies as an important inner resource used by participants to help themselves to keep positive throughout the course of their illness. In five studies, participants continued to ‘keep fighting’ in the hope of overcoming their illness, despite knowing the prognosis (Bentur et al., 2014; Chittam et al., 2022; Hughes et al., 2015; Tuck et al., 2012; Yoon Sun Kim, 2021). Participants in further studies expressed the need for faith and positivity in the hope of living longer (Adorno and Brownell, 2014; Alcorn et al., 2010; Eun et al., 2017). In two studies, participants hoped that medication would either stop the growth of the cancer or extend the length of their lives (Hughes et al., 2015; McTiernan and O’Connell, 2015). Participants in other studies held out hope for a cure, despite knowing their terminal condition (Alcorn et al., 2010; Lee and Ramaswamy, 2020; Nilmanat et al., 2015; Thompson et al., 2009). Where suffering increased, participants in two studies hoped for a peaceful death without suffering (Eun et al., 2017; Lee and Ramaswamy, 2020). Others hoped for an afterlife (McTiernan and O’Connell, 2015). The continuation of treatment meant hope for participants, while the end of treatment was associated with death in one further study (Adorno and Brownell, 2014). During the progression of their illness, participants’ hopes of being cured were replaced with hopes for comfort and peace for themselves and their families at the end of life in two studies (Duggleby et al., 2010; Meisenhelder et al., 2016). Hope was shifted from recovery and finding a cure to focusing on maintaining a better quality of life during the remaining course of their illness in a further study (Lee et al., 2013). In one study, participants reported that they moved between hope and a sense of hopelessness as they struggled to live with dying (Lee and Ramaswamy, 2020).

Living in the present. Living in the present, by being mindful of the present moment, is an aspect of spirituality which was identified by participants in many studies as helping them to live with dying. In one study, many participants decided to live in the present, rather than plan for the future, as a means of living with their terminal illness (Ginter, 2020). While a terminal illness diagnosis was identified by Reeve and colleagues (2010) as a ‘biographical disruption’ in participants’ lives, continuity in the flow of life was achieved through living life in the present, where participants found comfort in completing daily activities. McTiernan and O’Connell (2015) found that participants lived with dying by focussing on living life, rather than dying. Living life on a daily basis and deciding to maintain a positive approach to life were important factors in helping participants to live with their prognosis (Bentur et al., 2014; Liu et al., 2021; Maiko et al., 2019; Nedjat-Haiem et al., 2020; Thompson et al., 2009; Tuck et al., 2012; Voetmann et al., 2022). Through living in the present, participants reported an increased appreciation of what they found to be meaningful in their lives (McTiernan and O’Connell, 2015). Li and colleagues (2014) found that living life to the full during their illness helped participants to maintain their dignity. Through continuing to live their lives instead of worrying about their prognosis, participants of another study recognised the importance of living each moment of every day as they lived with dying (Hughes et al., 2015). Lee and Ramaswamy (2020), however, found that while living in the present was reported by many participants in the earlier stages after diagnosis helped them to continue with their lives, for participants whose health physically deteriorated, this was replaced by a sense of meaninglessness as the disease progressed.

Feeling connected. Spirituality was experienced by participants in included studies through experiences of feeling connected to oneself, others, animals, nature, transcendence and God or a higher power. Connection to self was reported by participants as helping to reduce physical discomfort, while connections with friends and family members were identified as an important source of spiritual support as participants lived with terminal cancer. A connection to nature and animals was considered to have a positive impact on participants’ wellbeing. Connection with God or a higher power facilitated participants to find spiritual strength and comfort while living with terminal cancer. Engaging in spiritual practices provided participants with comfort, distraction from physical symptoms and a sense of calm.

A feeling of connection to self. The experience of a harmonisation of self, through integrating one’s physical, emotional and spiritual health was identified by participants as being of significant benefit to their wellbeing while living with terminal cancer. Specifically, three studies found that,

where the integration of spiritual, mental and emotional wellbeing was experienced, participants found it easier to cope with physical difficulties (Bentur et al., 2014; Ginter, 2020; Nilmanat et al., 2015). Some practices to facilitate such an integration were found in two studies and these included yoga, meditation, mindfulness, hypnosis (Ginter, 2020) and massage (Cronfalk et al., 2009). Bruun Lorentsen and colleagues (2019) found that some participants equated the physical changes in their body to an 'existential journey' through the course of their illness. Also, in this study, participants reported visualizing and connecting with their body in a new light as a means of maintaining dignity and preserving their identity (Bruun Lorentsen et al., 2019). The experience of integration and harmonisation of the self through mind, body and spirit was found to provide existential respite for participants in one study, where feelings of meaninglessness were replaced with a sense of existential wellbeing and reduced anxiety and loneliness (Cronfalk et al., 2009). Through this connection, participants in another study gained a sense of control and ownership of their bodies and became more comfortable within themselves (Ginter, 2020). Through connection with their body, participants in a further study realized for themselves that death was near (McTiernan and O'Connell, 2015).

Feeling connected with family and friends. Several included studies reported the importance of meaningful relationships with family members and with friends. Here, connections with friends and family were found to be an important source of spiritual support. The experience of living with terminal cancer enabled participants to move away from superficial relationships and to deepen the more meaningful relationships in their lives in four studies (Adorno and Brownell, 2014; Hughes et al., 2015; Lee et al., 2013; Maiko et al., 2019). In three studies, participants reported a strengthening of connections with family and close friends following a terminal diagnosis and a deeper sense of meaning being created between themselves and their loved ones (Lee et al., 2013; Maiko et al., 2019; Willig, 2015). Participants in four further studies reported a strong need to feel connected with others and this connection provided them with an increased sense of wellbeing (Bentur et al., 2014; Chikhladze et al., 2018; Lee and Ramaswamy, 2020; Peoples et al., 2018); in one of these studies, this was especially the case for family members, whose happiness and wellbeing were deeply connected to that of their own (Bentur et al., 2014). Relationships with family and friends were also reported as being important factors in providing meaning in life for participants in two studies (Bentur et al., 2014; Lee and Ramaswamy, 2020). Li and colleagues (2014) reported that being loved by others had a substantial impact on participants' ability to maintain their dignity. For most participants in Adorno and Brownell's (2014) study, their 'greatest worry' was for their family members.

Participants also prepared themselves to be reunited with their loved ones after death (Aoun et al., 2016). Relationships with family and friends were regarded as sources of spiritual strength or support in five studies (Best et al., 2014; Lee et al., 2013; McTiernan and O'Connell, 2015; Mok et al., 2010; Nilmanat et al., 2015). In Tuck and colleagues' study (2012), connections with others enabled participants to talk about their prognosis and to search for answers.

Feeling connected with nature and animals. Spirituality as experienced through a connection with animals and nature was reported by participants as having a positive impact on their wellbeing in many included studies. In three studies, a connection to pets (Aoun et al., 2016; Harmon, 2019; Thompson et al., 2009) was reported by participants as providing comfort to them, as they lived with terminal illness. Participants of three studies also experienced comfort through spending time in nature (Aoun et al., 2016; Elsner et al., 2012; Peoples et al., 2018). Spending time in nature with animals was found to help participants' in coming to terms with their own mortality in two studies (Aoun et al., 2016; Harmon, 2019). In Harmon's (2019) study in particular, dogs were found to provide therapeutic support through a meaningful connection and their relationship with people. Aoun and colleagues (2016) reported that the company of animals was a factor in participants' decisions to remain living at home and in maintaining independence; participants in this study also reported that a spiritual connection to nature influenced where they chose to die. Thompson and colleagues (2009) found that participants experienced difficulty in facing the prospect of leaving their pets behind in distress following their death. Nature provided participants with the opportunity to feel a sense of existential belonging and spiritual connection and to reflect upon the transience of life in a further study (Peoples et al., 2018). For those who were unable to spend time in nature, a deep sense of disconnection from the world was experienced by participants in one study (Elsner et al., 2012).

Feeling connected with a higher power. The experience of feeling a connection to a higher power was found to be an important way of finding meaning in illness, in gaining acceptance and finding peace within among participants in included studies. This feeling of a connection to a higher power through religious and spiritual beliefs had a significant influence on how participants lived with their illness across many included studies (Alcorn et al., 2010; Aoun et al., 2016; Best et al., 2014; Chittem et al., 2022; Egan et al., 2017; Ellis et al., 2015; Elsner et al., 2012; Ginter, 2020; Lee and Ramaswamy, 2020; Lee et al., 2013; Li et al., 2014; Liu et al., 2021; Maiko et al., 2019; McTiernan and O'Connell, 2015; Meisenhelder et al., 2016; Mok et al., 2010; Nedjat-Haiem et al., 2020; Nilmanat et al., 2015;

Reeve et al., 2012; Sherman et al., 2018; Tuck et al., 2012; Yoon Sun Kim, 2021). In three studies, participants reported initial feelings of anger and disappointment for being let down or abandoned by God (Maiko et al., 2019; McTiernan and O'Connell, 2015; Reeve et al., 2012), while in another study, participants reported that they were being tested by God (Nilmanat et al., 2015). In three studies, participants reported that a terminal diagnosis resulted in an increased connection with God (Elsner et al., 2012; Ginter, 2020; Maiko et al., 2019). Maintaining a relationship with, and faith in, God was acknowledged by participants as an important aspect of living with terminal illness in six studies (Alcorn et al., 2010; Aoun et al., 2016; Egan et al., 2017; Lee et al., 2013; Nedjat-Haiem et al., 2020; Tuck et al., 2012). In further studies, a relationship with God or a transcendent being was reported as being a source of spiritual strength for participants (Alcorn et al., 2010; Best et al., 2014; Liu et al., 2021; Meisenhelder et al., 2016) and as a means of coping emotionally (McTiernan and O'Connell, 2015). In five studies, participants reported that a relationship with God provided them with an important source of comfort during their illness as they prepared for end of life (Alcorn et al., 2010; Ellis et al., 2015; Lee and Ramaswamy, 2020; Sherman et al., 2018; Yoon Sun Kim, 2021). Religious beliefs were reported by participants of further studies to help participants to live with terminal illness (Alcorn et al., 2010; Chittem et al., 2022; Lee et al., 2013; Maiko et al., 2019) and to find peace within (Mok et al., 2010). 'Having faith in God's will' assisted participants of one study to gain peace of mind in the face of death (Nilmanat et al., 2015). 'Resignation to God's will' was reported by participants of two studies as a means of maintaining dignity at the end stages of terminal illness (Lee et al., 2013; Li et al., 2014). The belief in an afterlife was reported by participants of further studies to provide comfort (Alcorn et al., 2010; Ginter, 2020) and peace (Mok et al., 2010).

Religious and spiritual practices were used by participants as a means of connecting with a higher power while living with their illness in two studies (Alcorn et al., 2010; Meisenhelder et al., 2016). Participants of five studies reported that engaging in prayer and meditation were used as a positive means of coping (Alcorn et al., 2010; Ginter, 2020; Hughes et al., 2015; Meisenhelder et al., 2016; Tuck et al., 2012). In one study, participants reported that prayers were not only intended for cancer survivors themselves, but also for their families (Alcorn et al., 2010). In further studies, prayer was reported by participants as providing them with a sense of comfort (Aoun et al., 2016), distraction and relaxation (Elsner et al., 2012). Talking to God was reported by Lee and colleagues (2013) as providing a sense of calm, in helping participants sleep and to be effective in managing pain. In addition, participants of two studies felt comforted

by the prayers from their spiritual community (Elsner et al., 2012; Maiko et al., 2019) and participants of another study reported that they appreciated the practical assistance that the community offered (Sherman et al., 2018).

Being reflective. Reflecting on one's mortality, the life that was lived and the meaningful connections created with others were identified by participants in included studies as important aspects of spirituality at the end of life. Through this reflection, many of these participants identified the need to heal unresolved wounds with others from the past, create legacies to connect with future generations and to prepare for death with their loved ones. As participants reflected on their illness and their shortened life expectancy, many reported a transformation in their outlook towards life, in their meaning of life and in finding peace and acceptance in dying.

Life review and legacy. In many included studies, spirituality, as experienced by those living with terminal cancer, involved reflecting on one's own mortality, re-evaluating one's life history, appreciation of life (Alcorn et al., 2010; Mok et al., 2010; Yoon Sun Kim, 2021) and previous life choices and decisions (Hughes et al., 2015; McTiernan and O'Connell, 2015). Time was identified as a facilitator for participants of one study, which enabled them to complete essential life tasks and make pivotal decisions (Voetmann et al., 2022). Participants of four studies reported having 'unfinished business' with others, such as organizing personal affairs (Tuck et al., 2012), and saying goodbye to loved ones and dealing with relationships (Hughes et al., 2015; McTiernan and O'Connell, 2015; Sherman et al., 2018). Unresolved issues, such as regrets over previous wrongdoings and worries about leaving family members, resulted in the experience of suffering among participants in two studies (Egan et al., 2017; McTiernan and O'Connell, 2015). In one study, participants reflected on the future generations that they would not have an opportunity to meet and created several types of legacy documents for family members as gifts and memories, including DVDS, photographs, journals and films (McTiernan and O'Connell, 2015). In other studies, creating keepsakes, memoirs and gifts for great-grandchildren, created a sense of connection with future generations of family and existential hope for the future among participants (Hughes et al., 2015; Peoples et al., 2018). Saying goodbye to close friends and family members, sharing personal belongings with loved ones, making a will and planning funeral arrangements were means by which some participants of further studies found closure to their lives as they prepared for death (Aoun et al., 2016; Bentur et al., 2014; Ginter, 2020; Hughes et al., 2015). In one study with Chinese participants, the preparing of a shroud in which to be buried was used to help participants to create a sense of togetherness with family, to

prepare for death and to serve as a spiritual support for participants as they prepared for death (Cao et al., 2020).

Reflecting on the transformation journey. Through reflection on their mortality and the re-evaluation of their lives as they journeyed towards death, some participants in included studies identified a transformation in their outlook towards life, their experience of meaning of life and their peaceful acceptance of death. Participants in one study reported that they found their illness to be a transformative experience (McTiernan and O'Connell, 2015), while participants of two further studies reported that this experience changed how they viewed the world in a meaningful way (Alcorn et al., 2010; Reeve et al., 2010). Ellis and colleagues (2015) found that, through their suffering, participants experienced a spiritual transformation, which enabled them to gain a deeper understanding of themselves and a greater ability to cope with their illness. Transcendence, a feeling of being connected with something which is greater than oneself, was reported by participants of one study as being an important spiritual need at end of life (Chikhladze et al., 2018). In another study, transcendence occurred as a transformation in the way participants connected with their family (Hughes et al., 2015) and in a further study, transcendence was experienced by participants in their renewed outlook on life (Reeve et al., 2012). For participants of another study, transcendence was achieved through finding peace, harmony and serenity within. Transcendence was gained by participants through connection with self, others and God and in finding meaning and acceptance of death (Mok et al., 2010). Nilmanat and colleagues (2015) found that faith and trust in God, being hopeful and being surrounded by the love and care of family enabled participants to move beyond and transcend distress and suffering and to achieve peace.

Discussion

This qualitative meta-synthesis examined the available recent literature to provide an insight into spirituality as experienced by individuals living with terminal cancer. To our knowledge, this is the first meta-synthesis specifically examining spirituality in terminal cancer patients. An operational definition of terminal cancer has been provided to address the lack of clarity surrounding the difference between advanced cancer and terminal cancer, and to provide a basis for this meta-synthesis. This specific population has been identified as being important as a terminal cancer diagnosis may potentially trigger psychological, social and spiritual concerns for patients as they move closer towards death. Understanding the experience of spirituality among individuals living with terminal cancer can inform the type of compassionate end of life care and support that is needed to help individuals live while dying.

Four analytical themes relating to an individual's experience of spirituality while living with terminal cancer were generated. These included making sense of dying, living with dying, feeling connected and being reflective. These findings demonstrate the difficulties experienced by those suffering from spiritual distress and highlight how the experience of spirituality could positively impact an individual's life through one's sense of meaning, purpose and identity. The findings also show that individuals living with terminal cancer can continue to live their lives despite knowledge of their finitude through acceptance, hope and living in the present moment. The findings also suggest the potentially transformative impact of self-reflection on one's outlook on life and on dying; specifically, these aspects of spirituality were reported by participants as being beneficial in living while dying, to help in overcoming suffering, finding a deeper understanding of self and meaning in life, gaining acceptance of illness and death, and achieving inner peace.

While previous reviews in the area of spirituality highlight the importance of meeting the spiritual care needs for patients at end of life (Clyne et al., 2019; Edwards et al., 2010), this meta-synthesis offers a unique contribution to literature in the area as it specifically examines the recent literature on spirituality as experienced by terminal cancer patients. Further, it demonstrates the transformation that an individual may experience in dealing with increased distress and finding peace of mind. This meta-synthesis suggests that spirituality may act as a catalyst in experiencing this transformation from suffering to peace. In addition, the findings of this meta-synthesis highlight the tension that exists between the distress of meaninglessness and the spiritual comfort that may be achieved through personal growth. In some studies included in this meta-synthesis, this transformation was referred to by participants as an existential or a transformational journey. In existing research, this has been referred to as a spiritual journey (McGrath, 2004).

The findings of the review also demonstrate how individuals may struggle to make sense of the situation that they are in and its consequential meaning following a terminal diagnosis. Individuals living with terminal illness may experience feelings of fear, anxiety, hopelessness, frustration and desperation due to uncertainty about their future (Tarbi and Meghani, 2019; Wang et al., 2018). While previous research indicates that religion or spirituality may not always have a positive effect on individuals with terminal cancer (King, 2012), this review identifies spirituality as a means through which an individual may navigate through the uncertainty of their cancer journey and it highlights how transcendence from suffering may occur through transformation of self. Previous literature has identified spirituality as a means of helping individuals to make sense of a terminal diagnosis (Ford et al., 2012), to

live with the uncertainty of their cancer journey (Balboni et al., 2007) and to find meaning within their lives (Guerrero-Torrelles et al., 2017; Visser et al., 2010; Young et al., 2015). Although none of the articles examined in this review specifically reported on the use of spiritual perspectives for participants to find meaning and purpose while living with terminal cancer, the findings suggest that viewing one's life through the lens of spirituality may prove to be very beneficial for individuals as they engage in reflection towards the end of one's life.

Our findings also demonstrate the potential that spirituality has to enable individuals to find meaning and purpose in their lives. The findings highlight that spirituality may act as a catalyst in facilitating individuals with terminal cancer to experience strengthened relationships with the self, family, society, nature, and a higher power. It highlights the importance of relationships and connections in the process of meaning making at end of life. The findings of this meta-synthesis are similar to previous literature in terms of the focus of spirituality being on meaning and significant relationships, however these studies did not exclusively focus on terminal cancer patients (Breitbart, 2002; Gijssberts et al., 2019). The findings also support previous studies which noted that relationships play a pivotal role in meaning making and finding acceptance (Rego et al., 2018; Sand et al., 2009).

Our findings indicate that hope and living in the present may be used by individuals as means of coping and as ways of living with dying. Individuals may retain a sense of hope, despite knowing that there is no cure available. Previously held hopes for the future may be replaced with the creation of new hopes which are deeper and more fulfilling. Hopes may include the strengthening of relationships, leaving a legacy behind and being well remembered (Ferrell and Coyle, 2010). Furthermore, hope may play a pivotal role in enabling people with terminal cancer to live their lives in a more meaningful manner. Living in the present may enable an individual to accept the inevitability of terminal cancer and to live life in a meaningful way, despite difficulties that may be experienced. This corresponds with studies in other contexts which have shown that completing everyday activities such as undertaking chores offers individuals a sense of purpose and enables them to show their capability and competence despite being ill (La Cour et al., 2009). Living in the present, while maintaining a sense of purpose, allows individuals to feel they are not just a patient nor defined by their illness and there are other aspects to their lives beyond dealing with their symptoms (Breitbart, 2002).

This meta-synthesis highlights the important role of relationships in the experience of spirituality in the lives of those living with terminal cancer. Relationships and meaningful connection with self, others, nature and God are identified as significant dimensions of spirituality.

Individuals may utilise the connection between themselves and others, nature, animals and a higher power as a means of living with the reality of their impending death. Previous research suggests that the existential isolation experienced by individuals with terminal cancer motivates them to value the relationships they have in their lives (Strang et al., 2001). The findings suggest that connections with family, friends and religious communities have been valuable sources of emotional support at end of life, in line with findings of previous reviews (Edwards et al., 2010; Weathers et al., 2016). Our findings indicate that individuals who maintain a relationship with God may feel a sense of comfort and feel less lonely. Individuals utilise their relationship with a higher power as a source of strength, support and comfort. This finding is supported by previous research (Scott et al., 2014; Sulmasy, 2006).

End of life is identified as an important time of reflection of one's values, relationships and a search for meaning. The findings of this meta-synthesis suggest that the process of reflection offers individuals living with terminal cancer the opportunity to consider their lives and their relationships with others. This review highlights a common wish for individuals at end of life to resolve all unfinished business or unresolved disputes within one's life in order to move towards living with a sense of peace at end of life. Previous studies on advanced cancer patients suggest that individuals wish to resolve these issues to minimise any negative ultimate outcomes such as guilt, regret and remorse (Masterson et al., 2018).

The findings of this meta-synthesis highlight the need for interventions and programmes that promote the wellbeing of those with terminal cancer. Evidence suggests that individualised interventions are necessary to match the specific needs of terminal cancer patients to help them cope with their illness, manage symptoms and find meaning in their lives (Teo et al., 2019). Further, previous research suggests that there is need for the integration of person-centred spiritual care into healthcare services (Selman et al., 2018). Studies have shown that there is a requirement for basic spiritual care training for all palliative care staff with more advanced levels of spiritual care to be offered by more highly skilled professionals (Selman et al., 2018). This review supports these findings due to the individualised and dynamic nature of both spirituality and suffering as experienced by individuals with terminal cancer. Additionally, these findings may inform the type of compassionate end of life care and support that is needed to help individuals live while dying.

There are several strengths and limitations of the current review. As indicated above, this qualitative meta-synthesis provides a unique contribution to existing literature in the areas of spirituality and terminal cancer as it highlights that spirituality can be a transformative experience that helps individuals to experience peace at end of life through

acceptance, hope and living in the present. It also highlights the importance of relationships in meaning making and living well at end of life which may result in increased wellbeing in terminal cancer patients. The use of the CASP quality assessment helped the authors to maximise the quality and reliability of the studies included. Based on the CASP quality assessment, each of the 37 studies were identified as being of medium to high quality. The authors of this review, however identified a recurring issue relating specifically to whether the relationship between the researcher and participants had been adequately considered. In 18 studies the nature of the relationship was not sufficiently addressed to answer this question. It is proposed by the authors that future studies should provide adequate information regarding the relationship between the researcher and participants. A potential limitation associated with this meta-synthesis was the lack of clarity surrounding the difference between the terms ‘advanced’ and ‘terminal’ cancer in relevant literature; in response to this, we focused on the perspectives of terminal cancer patients with less than 12 months prognosis in our inclusion criteria. As such, this review is limited to describing results of individuals from this group only; additional studies addressing the perspectives of other patients, caregivers and healthcare professionals who may have ‘advanced cancer’ with a longer projected prognosis were not included during the screening stage of this review. In future research, it would be beneficial for authors to clearly define the meaning of advanced cancer and to include whether participants have been explicitly advised if they have entered the terminal phase or not. This is an important issue to consider as the terms are currently used interchangeably which causes a lack of clarity within the literature. Further research in this area would be beneficial in providing a holistic understanding of the perceived spiritual needs of patients at end of life from alternative perspectives; however, focusing on patients is valuable because their perspectives are provided from those living with terminal cancer and can provide a deeper insight into their spiritual and existential needs as they live with the knowledge of their reduced life expectancy.

Conclusion

The findings of this qualitative meta-synthesis highlight how the experience of spirituality can positively impact the lives of terminal cancer patients. The findings demonstrate the multi-dimensional and dynamic nature of spirituality as individuals attempt to live with dying. They provide evidence that spirituality can be a transformative experience that allows individuals to experience peace at end of life through acceptance, hope and living in the present. Meaning in life may be found through relationships and connections with self, family, friends, nature, animals and God or a higher power. Through finding meaning in life and

connection, participants experience increased wellbeing. These findings may inform the type of compassionate end of life care and support that is needed to help individuals live while dying.

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Supplemental Material

Supplemental material for this article is available online.

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