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The social and spiritual dimensions of parental experiences on end-of-life care of their child with cancer: A narrative review

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Abstract

Objective. Having a child with cancer is a burdensome experience for parents. Nurses need to better understand beliefs, hopes, and values of parents to holistically support them, which may have an impact on grief and depression. Thus, the aim of this paper was to highlight the social and spiritual dimensions of parental experiences on end-of-life care of their child with cancer.
Method. A narrative literature review was conducted by systematically searching databases (CINAHL Complete, Academic Search Elite, MEDLINE) for relevant literature. The contents of included studies were critically appraised regarding their methodological quality.
Results. Eleven studies were included. In terms of the social dimension, three categories emerged that are important for parents: Being a Parent, Being in Relationship with the Child, and Being in Relationship with Health Professionals. Parents tried to maintain normality and joy for their child, but also kept control over the situation. They wanted to protect their child from suffering but also felt the need to talk to them about dying. Parents had ambivalent experiences with helpful but also burdensome staff. The spiritual dimension comprised two main categories, Hope and Faith and a Unique Bond. Hope was found to be an important source of strength, while Faith was only mentioned by some parents. For parents the emotional connection with their child constituted a source of meaning as well as a foundation, on which they based their decisions on.
Significance of results. A therapeutic relationship and a supportive environment can be established by healthcare professionals by noticing, encouraging the unique bond between parents and their children, as well as by reflecting and addressing the parents' challenging situation.

Introduction

According to estimates more than 413,000 children and adolescents will suffer from childhood cancer by the end of 2020, whereof the global annual death rate is estimated to be 328,000 children and adolescents. Globally, this further implies that every 90 s, a child or adolescent dies from a malignant disease (Atun et al., 2020). The most common cancer types affecting children are leukemia, lymphomas, and tumors of the central nervous system. Symptoms most commonly mentioned include pain, poor appetite, and fatigue (Collins, 2004; Abu-Saad Huijer et al., 2013; Schulte et al., 2019) as well as nausea, lack of energy, hair, and weight loss (Olagunju et al., 2016). Children not only suffer physical symptoms but also experience psychosocial and spiritual distress (Sourkes, 2006; Lown et al., 2015). Yet, not only the sick child is affected by cancer but also the whole family (Björk et al., 2005; Cantrell and Conte, 2009; van Schoors et al., 2019). Parents have an unique role during the illness trajectory including the vulnerable end-of-life phase.

Studies showed that having a child with cancer depicted an everyday struggle, in which the familial environment was dramatically altered (Steele and Davies, 2006; Björk et al., 2009). Parents experienced changes in their daily work routines since caring for a child with cancer became a full-time job (Björk et al., 2005). A major burden rests on parents given the intense and very prolonged treatment processes (Lackner et al., 2000), the need to watch medication side effects as well as continuing their responsibilities within the entire family unit (Popp et al., 2015). Besides the changes in the family environment, parents suffer from emotional, physical, and spiritual distress as well as financial hardship (Steele and Davies, 2006; Roser et al., 2019).

Paediatric palliative care (PPC) is a concept for supporting children with life-limiting conditions and their families and is defined as the "active total care of the child's body, mind and spirit, and also involves giving support to the family" [World Health Organisation (WHO), 2018]. PPC starts at the point of the child's diagnosis and continues regardless of whether or not the disease is treated (WHO, 2018). In this narrative review, care that is provided during the palliative phase at the child's end of life is referred to "end-of-life care" and begins when curative treatment is no longer an option.

As PPC embraces physical, emotional, social, and spiritual elements for supporting families, we used the biopsychosocial–spiritual model for end-of-life care (Sulmasy, 2002) as a guiding framework. The model understands a person as "a being in relationship," which means human existence is based on relationships. In this model, illness disturbs intrapersonal (physical, mental) and extrapersonal relationships (social, spiritual). Spirituality according to this model of care may be defined as the person's connection to the transcendent and search for purpose and meaning in life. Although spirituality may be connected to a divine figure/religious faith, it significantly goes beyond religious affiliation (Rego et al., 2018). The social dimension encompasses relationships with others such as family, friends, and professionals, social roles, such as professional, familial, and community as well as participation in social activities. Following the biopsychosocial–spiritual model, the social and spiritual well-being domains are interrelated and connected through relationships with self, others, and transcendence (Prince-Paul, 2008).

Nurses play a key role in supporting families of a child with cancer at the end of life. Social and spiritual support are likewise important not only for the child himself/herself but also for the parents (Wolfe et al., 2000; Mu et al., 2015). In order to provide comprehensive care, nurses must understand the parents' beliefs, hopes, and values (Wolfe et al., 2000; Mu et al., 2015) as well as know the parent's spiritual and religious point of view (Desai et al., 2002; Penson et al., 2005; Robinson et al., 2006).

There is a need to better understand the social and spiritual experiences, and beliefs of parents. Therefore, the aim of this paper was to highlight the social and spiritual dimension of parental experiences on end-of-life care of their child with cancer, in order to develop strategies to provide the best possible care for the dying child and his/her family.

Methods

This narrative literature review was prepared as part of a PPC practice research carried out in 2017. A narrative literature review is a "comprehensive narrative synthesis of previously published information" (Green et al., 2006, p. 6) by integrating peer-reviewed literature. Due to time restraints, we purposely decided against a systematic review. Nevertheless, we used a comprehensive search approach aiming at increasing the quality of the search. The literature review was prepared by using the formal rating scale for quality assessment of narrative review articles (SANRA; Baethge et al., 2019). A structured literature search was conducted by two independent authors (MJ, PS) via EBSCO-Host in the electronic databases CINAHL Complete and Academic Search Elite as well as in MEDLINE via PubMed. In addition, Scopus was checked by combining the following keywords and synonyms by using the wildcard function: child, bereavement, palliative, end of life, terminal, cancer, parent, experience, social, and spiritual. Also, the berrypicking technique (Bates, 1989) was used to search for additional relevant sources. English as well as German publications from 2010 until 2016 were included. The population consisted of parents of a child with incurable cancer or a child who died of cancer. Parents had to be at least 18 years of age and were only considered if their child was under the age of 21 years. The chosen settings were hospitals, oncology centers, or the patients' homes. Included were parental experiences regarding social and spiritual dimensions, whereas experiences concerning any other dimensions of PPC were excluded. Initially, two authors (MJ, PS) identified a total of 210 studies. Removing duplicates ($n = 128$) left a total of 82 studies identified by searching databases. Together with publications identified by searching libraries and e-Journals ($n = 17$) as well as through the berrypicking technique ($n = 10$), a total of 109 studies appeared to be relevant. Seventy-three studies were eliminated by the two authors after abstracts were analyzed according to the inclusion and exclusion criteria, another 21 studies after reading the full texts. Reasons for discarding publications were shortcomings of inclusion criteria and irrelevant to answer the research questions. The remaining 15 studies were critically appraised regarding their methodological quality by using traffic light symbols (Figure 1). Risk traffic lights describe the quality of a study by using the colors red, yellow, and green. The red color stands for a problematic methodological quality, the yellow color depicts unclear methodological quality, and green represents adequate methodological quality (Panfil and Ivanovic, 2011).

Due to poor evaluation results, such as inappropriate sample characteristics and inconclusive methodology, four more studies were discarded leaving a total of eleven studies to be included in this narrative review. All steps of study selection as well as strengths and weaknesses of publications were discussed within the author team. Decisions on included studies were consensus-based. The systematic literature search is shown in Figure 2.

Results

Eleven studies, seven qualitative, three quantitative, and one mixed-methods study were included to answer the research question. Studies were conducted either in a European country (Netherlands, Sweden, UK, Germany), in the United States of America, or in Canada. Various research designs, like Grounded Theory, Phenomenology, qualitative retrospective, or inductive designs as well as cross-sectional designs, were used within the included studies. Seven of the included studies presented data that could be sorted to both, the spiritual and the social dimension (Kars et al., 2010, 2011a, 2011b; Zelcer et al., 2010; Cataudella and Zelcer, 2012; van der Geest et al., 2015b; Ljungman et al., 2016). Three studies contained data that only fit the social dimension (Robert et al., 2012; Kuhlen et al., 2014; van der Geest et al., 2014) and only one study simply presented data best fitting the spiritual dimension (van der Geest et al., 2015a). Within the studies, the parental role as well as parents' relationship with their child and healthcare professionals were particularly evident (social dimension). Regarding the spiritual dimension, parents' coping strategies such as staying hopeful and keeping faith, while also remaining an emotional bond in the sense of spiritual connection to their child were presented within identified studies (Tables 1 and 2).

All identified results were thematically grouped resulting in a total of three core categories for the social dimension and two core categories for the spiritual dimension. Sulmasy's biopsychosocial–spiritual framework (2002) guided the category building. Two authors (CK, MJ) independently labeled categories based on the results of the studies. The category building was then discussed within the author team until consensus regarding the

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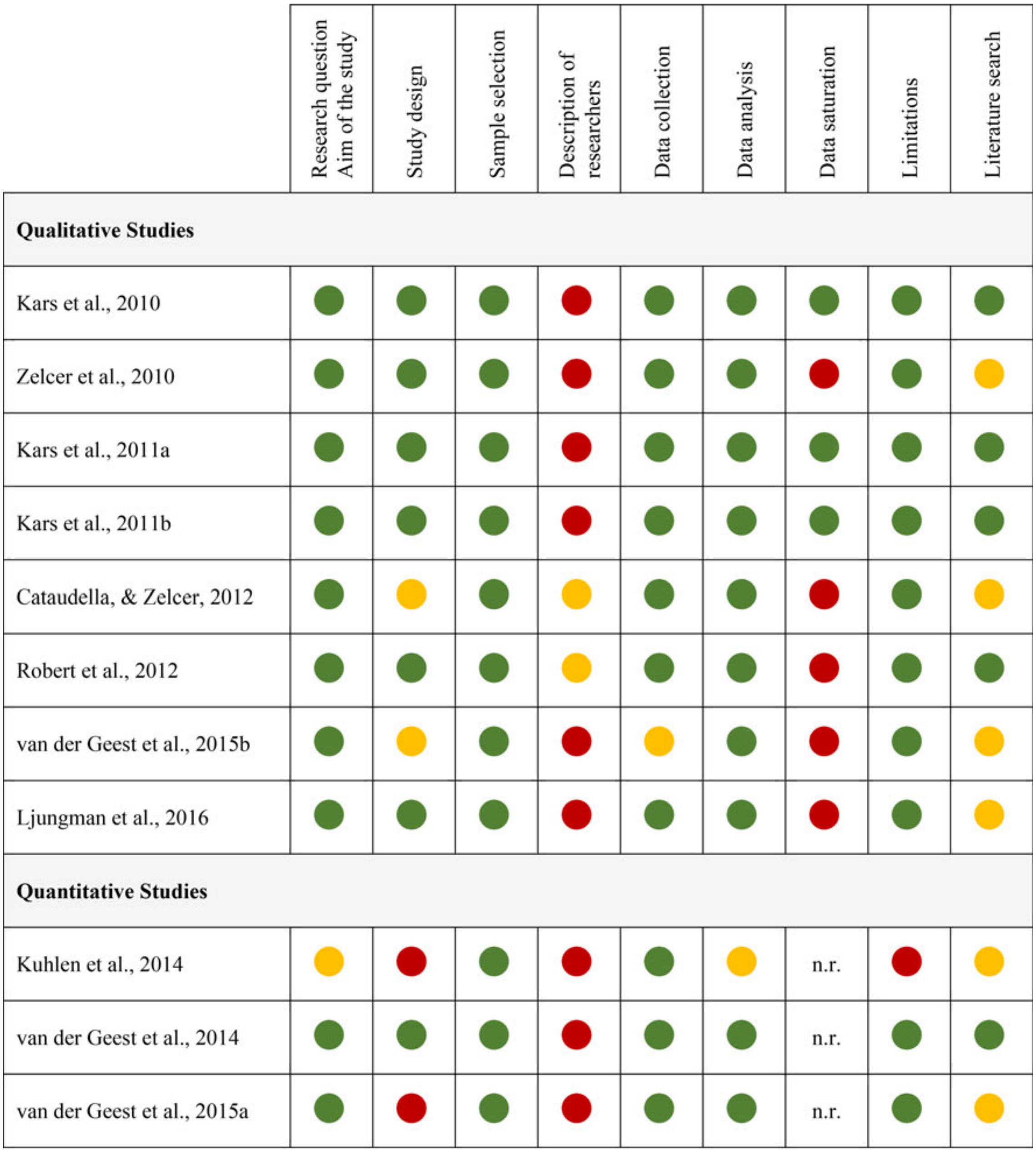

	Research question Aim of the study	Study design	Sample selection	Description of researchers	Data collection	Data analysis	Data saturation	Limitations	Literature search
Qualitative Studies									
Kars et al., 2010	🟢	🟢	🟢	🔴	🟢	🟢	🟢	🟢	🟢
Zelcer et al., 2010	🟢	🟢	🟢	🔴	🟢	🟢	🔴	🟢	🟡
Kars et al., 2011a	🟢	🟢	🟢	🔴	🟢	🟢	🟢	🟢	🟢
Kars et al., 2011b	🟢	🟢	🟢	🔴	🟢	🟢	🟢	🟢	🟢
Cataudella, & Zelcer, 2012	🟢	🟡	🟢	🟡	🟢	🟢	🔴	🟢	🟡
Robert et al., 2012	🟢	🟢	🟢	🟡	🟢	🟢	🔴	🟢	🟢
van der Geest et al., 2015b	🟢	🟡	🟢	🔴	🟡	🟢	🔴	🟢	🟡
Ljungman et al., 2016	🟢	🟢	🟢	🔴	🟢	🟢	🔴	🟢	🟡
Quantitative Studies									
Kuhlen et al., 2014	🟡	🔴	🟢	🔴	🟢	🟡	n.r.	🔴	🟡
van der Geest et al., 2014	🟢	🟢	🟢	🔴	🟢	🟢	n.r.	🟢	🟢
van der Geest et al., 2015a	🟢	🔴	🟢	🔴	🟢	🟢	n.r.	🟢	🟡

Fig. 1. Critically appraisal regarding methodological quality by using traffic light symbols (Panfil and Ivanovic, 2011).

category label was reached. Similarly, the authors together decided which finding best fits which category.

Figure 3 presents a graphical overview of the core and subcategories.

Hereinafter, the categories developed are presented separately for the social and spiritual dimension, each beginning with a brief introduction into the core category. Afterwards, subcategories are presented, which contain the direct findings from the included studies. The sources in parentheses indicate the origin of the result.

Social dimension

In terms of the social dimension, three categories emerged that are important for parents: Being a Parent, Being in Relationship with the Child, and Being in Relationship with Health Professionals.

Being a Parent

During a child's end-of-life phase, the parent's role became particularly evident. Parents were constantly challenged as they had to maintain normality, but also kept control over the ongoing situation. While striving for joy and comfort for their child, feelings of uncertainty, powerlessness, and fear accompanied them. Four subcategories highlight the parent's role at the end of life: Experiencing Different Stages, Creating Normality and Joy, Challenged Parenthood, and Being There for the Child Until Death.

Experiencing Different Stages. Parents described the end-of-life phase in four stages, from the moment of becoming aware of their child's imminent death until actually witnessing it (Kars et al., 2011b). Stage one ("Becoming aware of the inevitable

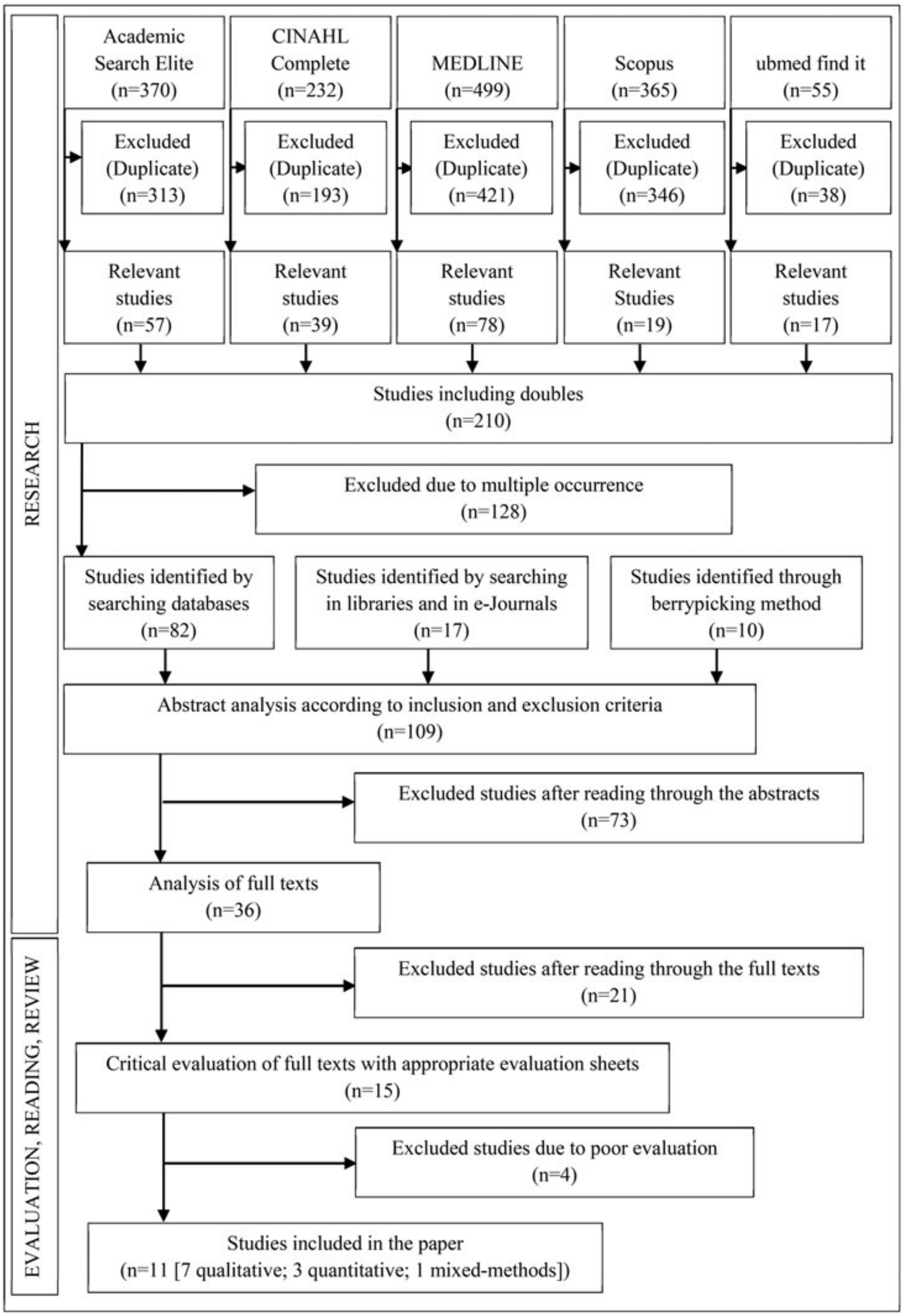

Fig. 2. Flowchart of the research process.

death") and two ("Making the child's life enjoyable") included learning about the incurability of the child's illness, the perception of the collapsing parenthood, and the wish for their child to enjoy life as much as possible. Parents described the last two stages ("Managing the change for the worse" and "Being with the dying child") as worsening of disease. They focused on their child's comfort and well-being, and needed to provide familiarity and safety. During those stages, parents dealt with factors leading either to preserving life, or to letting go (Kars et al., 2011a).

Creating Normality and Joy. For the sick children, it is important to be treated the same way as their healthy surrounding (Cataudella and Zelcer, 2012). Therefore, parents continued life for the sick child's happiness and joy as well as enabled their child to participate in school, meeting with friends and family, and plan special activities (Zelcer et al., 2010; Kars et al., 2011b; Cataudella and Zelcer, 2012). Yet, parents feared that if their child gave up on activities, death would soon approach (Kars et al., 2011a, 2011b). Seeing their child's happiness and joy helped parents forget about the threat of the disease (Kars et al., 2011b). Moments of joy were further mentioned to have occurred during hospital stays, when parents got to eat ice-cream in the hospital park or had Christmas dinner arranged by the hospital staff (Ljungman et al., 2016).

Challenged Parenthood. Parents mentioned that being told about their child's incurability felt as if their parenthood would collapse, suddenly having thoughts of not being a parent anymore once

Table 1. Overview of qualitative studies

Author, Year, Country	Research design Aim of the study	Sample Setting Ethics	Data collection Data analysis	Categories
Kars et al. (2010), Netherlands	Grounded Theory To describe the main aspects that affect parents in their decision to let their child die due to cancer	*Participants*: *n* = 44 (f = 21, m = 23) *Setting*: participants' home Ethical approval/ Informed consent	*Data collection*: Individual open interviews Duration: 1–2 h Survey period: 2005–2007 *Data analysis*: Interviews audiotaped and transcribed verbatim; coding and thinking theoretically (Morse et al., 2002); active coding (Charmaz, 2006); NVivo7 analysis computer software	Three core categories emerged 1. Factors leading toward preservation 2. Factors leading toward letting go 3. Factors leading in both directions
Zelcer et al. (2010), Canada	n.s. To gain an understanding of the end-of-life experiences of children suffering from brain tumors from a parental perspective	*Participants*: *n* = 25 (f = 9, m = 16) *Setting*: Children's Hospital, London Health Sciences Centre Ethical approval	*Data collection*: Semi-structured focus group interviews; detailed notes Duration: approx. 2 h *Data analysis*: Interviews audio- and videotaped; thematic analysis (Braun and Clarke, 2006); NVivo7 analysis computer software	Three core categories emerged 1. The dying trajectory 2. Parental struggles 3. Dying at home
Kars et al. (2011a), Netherlands	Grounded Theory To investigate parents' experiences of the processes they have to go through once being told that their child cannot be cured anymore and to examine the influences of these processes on parental decision making	*Participants*: *n* = 44 (f = 21, m = 23) *Setting*: participants' home Ethical approval/ Informed consent	*Data collection*: Individual in-depth open interviews Duration: 1–2 h Survey period: 2005–2007 *Data analysis*: Interviews audiotaped and transcribed verbatim; coding and thinking theoretically (Strauss and Corbin, 1998); researcher triangulation; NVivo7 analysis computer software	Three core categories emerged 1. Letting go and preservation in relation to loss 2. Letting go and preservation in relation to control 3. Letting go and preservation in relation to the child's condition
Kars et al. (2011b), Netherlands	Phenomenology To demonstrate parents' experiences of caring for an incurably sick child with cancer at home throughout the end-of-life phase and to illustrate how parents give their experiences meaning	*Participants*: *n* = 42 (f = 20, m = 22) *Setting*: participants' home Ethical approval/ Informed consent	*Data collection*: Individual in-depth open interviews Duration: 1–2 h Survey period: 2005–2007 *Data analysis*: Interviews tape-recorded and transcribed verbatim; inductive thematic data analysis according to the Giorgi method (Giorgi, 1997, 2005); NVivo 7 analysis computer software	Four core categories emerged 1. Becoming aware of the inevitable death 2. Making the child's life enjoyable 3. Managing the change for the worse 4. Being with the dying child
Cataudella and Zelcer (2012), Canada	Qualitative retrospective design To gain an understanding for the psychological experiences, children with brain tumors face in the end-of-life phase	*Participants*: *n* = 24 (f = 9, m = 15) R = 30–59[a] *Setting*: Local Focus Group Facility Ethical approval/ Informed consent	*Data collection*: Individual in-depth open interviews using focus group methodology, detailed notes Duration: approx. 2 h *Data analysis*: Interviews audio- and videotaped; audiotapes were transcribed verbatim; thematic analysis (Braun and Clarke, 2006)	Three core categories emerged 1. Intrapsychic changes 2. Interpersonal interactions 3. Posttraumatic growth
Robert et al. (2012), USA	Qualitative retrospective design To understand the experiences of parents, whose child died of cancer, regarding care of the child and palliative care	*Participants*: *n* = 14 (f = 7, m = 7) M = 51[a], SD ± 6[a] *Setting*: oncology centers Ethical approval/ Informed consent	*Data collection*: Three focus group sessions using sequences of open-ended, semi-structured questions Survey period: May 2008–June 2009 *Data analysis*: Discussions audiotaped and transcribed verbatim by professional transcriptionist; descriptive analysis; content analysis; ATLAS.ti Version 4	Four core categories were identified 1. Standards of care 2. Emotional care 3. Communication 4. Social support

(*Continued*)

Table 1. (*Continued.*)

Author, Year, Country	Research design Aim of the study	Sample Setting Ethics	Data collection Data analysis	Categories
van der Geest et al. (2015b), Netherlands, UK	Mixed-methods design To identify parental reasons for avoiding talking to their sick child with cancer about death or how they approached such conversations, and to find out how parents evaluate their decision	*Participants*: $n = 86$ (f = 32, m = 54) MD: 44[a] (R = 25–59[a]) *Setting*: Erasmus Medical Center-Sophia Children's Hospital Ethical approval/ Informed consent	*Data collection*: Questionnaire with additional open-ended questions (only open-ended questions were taken into account) *Data analysis*: Analysis using a framework approach (Gale et al., 2013)	Three core categories emerged (only qualitative data included) 1. Not discussing death 2. Discussing death 3. Parental evaluation of their decision
Ljungman et al. (2016), Sweden	Qualitative inductive design To investigate positive and negative experiences of parents whose child died of cancer	*Participants*: $n = 168$, thereof $n = 36$ bereaved (f = 16, m = 20) $n = 11$ (30.6%) < 40[a] $n = 16$ (44.4%) = 40–49[a] $n = 6$ (16.7%) ≥ 50[a] $n = 3$ (8.3%) = age not stated *Setting*: paediatric oncology centres Ethical approval/ Informed consent	*Data collection*: Telephone interview using open-ended, semi-structured questions Survey period: 2002–2004 *Data analysis*: Interviews simultaneously transcribed; content analysis (Graneheim and Lundman, 2004)	Seven core categories emerged, thereof: Four regarding negative experiences 1. Distressing events 2. Health care 3. Surrounding institutions 4. The fact that the child got cancer Three regarding positive experiences 5. Health care 6. Support systems 7. Unexpected joy

f, female; m, male; n.s., not stated; M, mean; SD, standard deviation; MD, median; R, range.
[a] years of age.

their child would die. They also mourned their future perspectives, which included experiencing the child's school entry, first love or becoming grandparents. In those moments, parents felt powerless and unable to provide comfort (Kars et al., 2011b). Mothers and fathers were afraid of witnessing their child's suffering and deterioration (Kars et al., 2010) thinking that the manifestation of symptoms and physical changes in their son or daughter posed a threat to their stability (Kars et al., 2011b). Therefore, to prevent themselves from breaking down, they used shielding mechanisms such as fragmentation by splitting up the child's symptoms into isolated complaints treating one at the time (Kars et al., 2010). Parents regarded control to be a requisite to fulfil their parental role; however, they sometimes lost sight of the reality causing a discrepancy between their perception and the actual situation (Kars et al., 2011a). Parents often felt caught in the midst of being their child's parent and being their child's "nurse." They experienced the task of taking over some nursing responsibilities, such as administering medication, as hindering in just being the child's mother or father (Zelcer et al., 2010). Since all the attention was paid to the child with cancer (Robert et al., 2012; Ljungman et al., 2016), many parents struggled with attending to their sick child's needs as well as taking care of other healthy children (Zelcer et al., 2010). For this reason, they not only neglected their parental role but also their responsibilities within the family unit (Robert et al., 2012). In contrast, parents deferred their own grief to care for the child with cancer as well as other family members (Kars et al., 2010).

Being There for the Child Until Death. Entering the later stage of end-of-life came along with parents' feelings of certainty that their child's approaching death was inevitable. The acceptance of the irreversibility was easier for parents who were told in advance that the child's previous treatment was the last one possible to try (Kars et al., 2010) and for those who were able to separate their needs from their child's needs (Kars et al., 2010, 2011a). In the study of Kuhlen et al. (2014), most parents felt prepared for the dying phase and death of their child. When the child's death was near, parents felt powerless since they realized that their child had to go through the process of dying alone (Kars et al., 2011b). Thereby, they found meaning in their parental role by providing their child an enjoyable and valuable life (Kars et al., 2010), adapting to the child's situation focusing on comfort and well-being (Kars et al., 2011b). Furthermore, parents explained the importance of being with their dying child during all his/her suffering at the end of life. They felt that nobody besides them was able to provide the desired comfort, safety, and sense of familiarity (Kars et al., 2011b). By the very end of their son's or daughter's life, parents narrowed the visitors to those being closest to the child and family (Robert et al., 2012). The child with cancer was either being surrounded by friends or shared intimate moments with their healthy siblings (Cataudella and Zelcer, 2012, p. 1194).

Being in Relationship with the Child

Parents mentioned the importance of a strong relationship with their sick child. They, on the one hand, wanted to protect their child from suffering, but, on the other hand, felt the urge to talk to them about dying. Losing the ability for interaction with their child was especially hard for parents. The importance of the relationship between parents and their sick child is revealed in three subcategories: Protecting the Child from Suffering, Talking about Death, and Losing Interaction.

Protecting the Child from Suffering. Parents could not bear to watch interventions hinder the quality of their child's life, which led some parents to be ahead of the actual situation,

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Table 2. Overview of quantitative studies

Author, Year, Country	Research design Aim of the study	Sample Setting Ethics	Data collection Data analysis	Results
Kuhlen et al. (2014), Germany	Cross-sectional design To examine the satisfaction of bereaved parents, whose child has been treated for cancer, regarding outpatient pediatric palliative care	*Participants*: n = 84 (f = 31 [36.9%], m = 46 [54.8%], o = 5 [6.0%], n.s. = 2 [2.4%]) n = 16 [19%] <40[a] n = 66 [78.6%] >40[a] n = 2 [2.4%] = n.s. *Setting*: participants' home Ethical approval/ Informed consent	*Data collection*: *Postal survey with a self-constructed questionnaire*, 87 items regarding general aspects, symptoms, symptom control, communication, psychosocial care, dying phase, and aftercare (combination of nominal scaled variables and numeric rating scales [1 = not at all; 4 = strong]) Survey period: October 2010–January 2011 *Data analysis*: descriptive statistics; $\alpha = 5\%$	*General aspects*: High satisfaction with: - the decision of domesticated palliative care (M = 3.93, SD ± 0.26) - the accessibility of the PPCT (M = 3.89, SD ± 0.31) - medical care (M = 3.89, SD ± 0.41), nursing care (M = 3.86, SD ± 0.44) - parental involvement in treatment (M = 3.77, SD ± 0.55), care (M = 3.93, SD ± 0.27) *Symptoms and symptom control*: Most common symptoms were pain (86.9%), fatigue (85.7%), depression (67.9%) and anxiety (63.2%) – regarding treatment: - high satisfaction: pain (M = 3.82, SD ± 0.38) - no satisfaction: anxiety (M = 3.37, SD ± 0.85), depression (M = 3.29, SD ± 0.82) *Communication*: n = 79 (94.0%) were satisfied regarding the communication with the PPCT (M = 3.73, SD ± 0.57) - very high satisfaction: communicating with a child (M = 3.84, SD ± 0.46), openness in conversations (M = 3.78, SD ± 0.57) and the devotion to the sick child (M = 3.80, SD ± 0.49) - medium satisfaction: scope of information given (M = 3.85, SD ± 0.57) *Psychosocial care*: n = 40 (47.6%) of parents talked about dying, n = 35 (41.7%) did not talk about death with the sick child - low satisfaction: psychosocial care of the sick child (M = 3.30, SD ± 0.93), the siblings (M = 3.08, SD ± 1.02), the parents (M = 3.20, SD ± 0.98) *Dying phase*: - prepared for the dying phase and death (M = 3.48, SD ± 1.07) - well supervised during dying process (M = 3.85, SD ± 0.90)
van der Geest et al. (2014), Netherlands, UK	Cross-sectional design To depict the experiences of parents whose child is suffering from cancer regarding interaction with healthcare providers, to portray symptom control during the child's end-of-life phase and to examine the impact on long-term parental grief	*Participants*: n = 89 (f = 33, m = 56) R_m = 25–59[a] (M = 42[a]) R_f = 31–55[a] (M = 45[a]) *Setting*: n.a. Ethical approval/ Informed consent	*Data collection*: *Questionnaire to collect data on parental experiences* (5-point Likert-type scale [disagree to agree]; 5 is most positive value); severity of physical and psychological symptoms (5-point Likert-type scale [symptom not present to a lot of suffering]; 5 is most negative value); extent to which symptoms were managed (5-point Likert-type scale [symptom completely managed to symptom completely not managed]; 5 is most negative value) *Data analysis*: SPSS 19.0; descriptive analysis; univariate analysis; $\alpha = 5\%$	*Interaction with Healthcare Professionals* 1. Communication ($p < 0.03$, M = 4.6, SD ± 0.6) 2. Continuity of Care ($p < 0.01$, M = 4.3, SD ± 0.6) 3. Parental Involvement ($p < 0.28$, M = 4.6, SD ± 0.7) *Symptoms at the End of Life* Child suffered at least one physical (88%) and one psychological (69%) symptom *Long-term Parental Grief and Impact of Care and Symptom Management* - Grief is lower, when ratings regarding communication and continuity of care are higher - Parental involvement in care has no influence on grief - Severity of symptoms are related to higher grief
van der Geest et al. (2015a), Netherlands, UK	Cross-sectional design To understand the importance of hope and faith during the end-of-life phase, to identify what sources parents use for coping and to demonstrate the impact of hope and faith on long-term parental adjustment	*Participants*: n = 89 parents (f = 37%, m = 63%) *Setting*: Erasmus Medical Center – Sophia Children's Hospital	*Data collection*: *ITG* to measure parental grief, 29 items (5-point Likert-scale [never to always]; 5 is most positive values; higher scores indicate more grief); *Depression subscale of the BSI* to measure parents' depression, 6 items (5-point Likert-scale [not at all to a lot]; 4 is most positive values; higher scores indicate more symptoms of depression); *Questionnaire designed for study to measure parents' experiences of end-of-life care* *Data analysis*:	*Faith and Hope* - Importance of faith during the end-of-life phase n = 19 (21%) - Faith was strengthened because of child's disease n = 13 (15%) - Hope for cure n = 30 (34%) - Hope for meaningful time with child n = 68 (76%) - Hope for a painless death n = 58 (65%) *Sources of Coping* - Factors mentioned the most are the sick child n = 70 (79%), healthcare professionals n = 46 (52%), family and friends n = 45 (51%) - Factors mentioned the least are prayers n = 12

(*Continued*)

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Table 2. (*Continued.*)

Author, Year, Country	Research design Aim of the study	Sample Setting Ethics	Data collection Data analysis	Results
			SPSS 21.0; descriptive analyses; unadjusted logistic regression analyses; $\alpha = 5\%$	(14%) and faith in God $n = 16$ (18%) *Long-term parental adjustment* Traumatic grief $n = 12$ (14%), symptoms of depression $n = 22$ (25%), both $n = 9$ (10%) *Impact of faith and hope* Faith (OR = 0.86, $p = 0.51$) and hope (OR = 1.07, $p = 0.71$) were not associated with increased long-term traumatic grief

f, female; n.s., not stated; m, male; M, mean; o, others; PPCT, pediatric palliative care team; R, range; SD, standard deviation; a, age; BSI, Brief Symptom Inventory; ITG, Inventory of Traumatic Grief; OR, odds ratio.
[a]years of age.

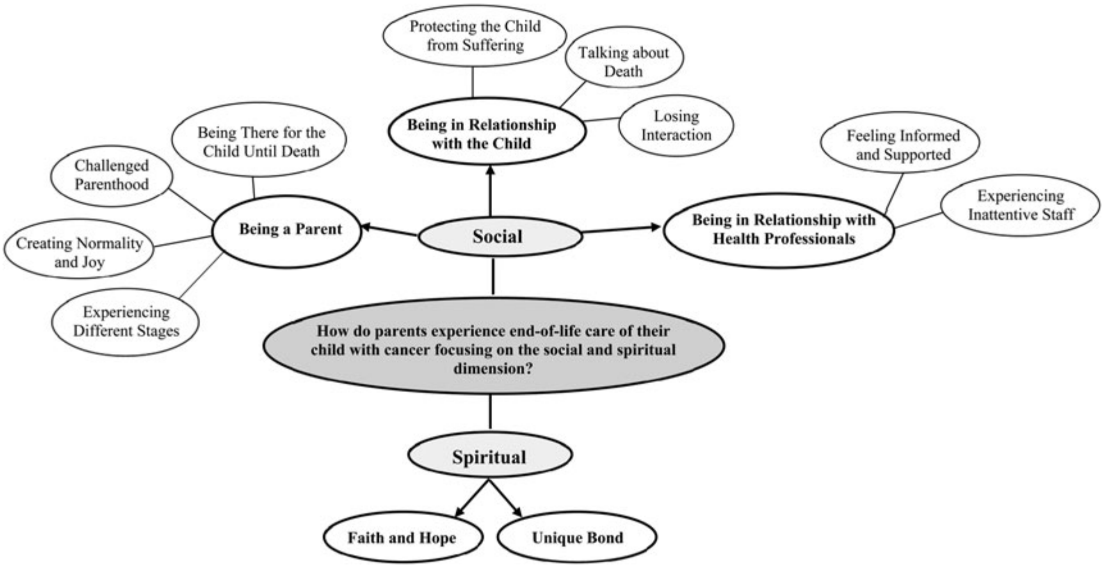

Fig. 3. Graphical presentation of core and subcategories.

waiting for death to step in although the moment was not there yet. This was illustrated in a parent's quote "My biggest fear is that he will suffer. […] if it's going to start now, then let it be over very quickly, just go to sleep now" (Kars et al., 2011a, p. 31). Some parents preferred to accelerate death in order to end their child's and their own suffering (Kars et al., 2011a). Mothers and fathers even encouraged their children to go, wishing them a peaceful death as they could not give any positive meaning to their child's pain and suffering (Kars et al., 2011b). Apart from that they often mentioned the dying child being the one saying goodbyes first (Zelcer et al., 2010). To prevent the child with cancer from being afraid of dying, parents explained to them what could be expected during and after death (Kars et al., 2011a).

Talking about Death. During the end-of-life phase, many parents considered engaging their child with cancer in conversations about dying and death but had fears about the impact this might have on their relationship with the child (Kuhlen et al., 2014; van der Geest et al., 2015b). In the study of Kuhlen et al. (2014), a total of 40 parents (47.6%) mentioned to have had such talks, whereas 35 mothers and fathers (41.7%) did not discuss these topics. Parents struggled with the way they should best approach conversations about dying and death (van der Geest et al., 2015b). Reasons cited by parents for not being able to discuss such difficult topics included being afraid of how their child would react emotionally and not wanting to be responsible if their child could not enjoy their remaining days (van der Geest et al., 2015b). Furthermore, parents mentioned being concerned that their child's personality was not strong enough or they were not old enough to talk about death (van der Geest et al., 2015b). Finally, parents feared that conversing about what happens at the end of life would result in them losing their child's trust, tearing the parent–child bond apart (Kars et al., 2011b). Healthcare professionals, on the one hand, advised parents not to talk to the child about its death (van der Geest et al., 2015b), but on the other hand encouraged them to honestly and openly discuss the impending death in consideration of the child's age and developmental stage (Kars et al., 2011b). Parents felt grateful if healthcare professionals assisted to ease the discussion between parents and their children (Cataudella and Zelcer, 2012).

It was important for parents that their child with cancer was in control over end-of-life conversations (Robert et al., 2012) and to talk about death since they thought that talking about death

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dispelled the child's fear of dying (van der Geest et al., 2015b). Mothers and fathers who approached conversations about dying and death described different strategies they used. These included symbolic stories or reading specific books, for example one parent stated "My child wanted to hear this story […]. At the end of the story, he would always start to cry, […] he really understood the message" (van der Geest et al., 2015b, p. 1323). A direct approach or waiting for the child to ask first were common strategies as well (van der Geest et al., 2015b).

Losing Interaction. Within the end-of-life phase parents noticed their child losing his/her abilities to communicate either verbally or non-verbally (Zelcer et al., 2010). Parents mentioned that as a result of the child not being able to verbalize himself/herself anymore none of the family members understood his/her needs, which further led to the child with cancer being angry and frustrated (Zelcer et al., 2010; Cataudella and Zelcer, 2012). For those parents, whose last contact to their child took place when the child was screaming or crying, loss of communication was especially hard (Kars et al., 2011b).

Being in Relationship with Health Professionals

Finally, parents mentioned their ambivalent experiences regarding their relationship with health professionals. The feeling of being well-informed and receiving support as well as shared decision-making was helpful. Ideally, a relationship of trust was built with health professionals. Negative experiences with stressed and insensitive staff were disempowering. Two subcategories (Feeling Informed and Supported and Experiencing Inattentive Staff) were created in order to strengthen the meaning this core category.

Feeling Informed and Supported. Healthcare professionals played an important role in parents' attitude toward preserving life or letting go (Kars et al., 2010). Parents appreciated healthcare professionals being supportive, honest, and fully devoted to the children, really caring about their patients' well-being. Parents positively mentioned the medical staff grieving with them after their child had died. Parents highly appreciated supportive services their child received during hospital stays. By joining their child in play therapy or hospital clowns, parents got the chance of meeting and talking to other parents in a similar situation (Ljungman et al., 2016). They highlighted the importance of maintaining friendships between parents in similar situations (Robert et al., 2012). Regarding the interaction with healthcare professionals, both communication and continuity of care showed significant results in the study of Kuhlen et al. (2014), whereas parental involvement was not regarded significant. Some parents ($n = 84$) only showed medium satisfaction with the scope of information given (Kuhlen et al., 2014). However, in the study of van der Geest et al. (2014), most parents felt clearly informed about the child's prognosis during the end-of-life phase and the exhaustion of curative options. In both studies, parents' ideas on how end-of-life care should be organized was respected well by healthcare professionals (Kuhlen et al., 2014; van der Geest et al., 2014). Thereby, parents ($n = 89$) highly rated the attention staff paid to their concerns and the shared decision-making process (van der Geest et al., 2014). Overall, care was considered ideal when healthcare staff and the child grew together, knowing and trusting each other well. This was quoted by a parent in this way: "At the funeral, the first two people who showed up were [hospital staff]. They came early and were thereafter. They grow to love these kids. They're not just patients" (Robert et al., 2012, p. 325–326).

Experiencing Inattentive Staff. Parents not always talked about healthcare professionals in a positive manner since some experienced unfriendly and stressed staff, who talked to the child with cancer in an insensitive and disrespectful way. Parents felt that this led to the children feeling unnecessarily distressed. They further complained about doctors talking about death in front of the affected child instead of taking the parents outside the room, as illustrated in a father's quote "When he [the doctor] said to me, out loud in front of the child: '[…] accept […], that she will die!' He […] could have asked me to follow him out" (Ljungman et al., 2016, p. 8).

Spiritual dimension

The spiritual dimension comprises two main categories, namely the meaning of Hope and Faith and the meaning of a Unique Bond.

Hope and Faith

Throughout the end-of-life phase, it was important for parents to keep-up their hope in order to deal with the situation. The type of hope changed over time, from the hope for healing to the hope for a peaceful death. For some parents, faith was their source of power, others reported that they also received their power from the courage and strength of their child.

Hope was reported as an important source of spiritual strength, not only for the child with cancer, but also for parents (Zelcer et al., 2010). Even knowing the predicted outcome, parents maintained their hope for a miracle (Zelcer et al., 2010) and that the disease would end positive for their child (Kars et al., 2010). Thereby, they never gave up hope for a cure (Zelcer et al., 2010; van der Geest et al., 2015a, 2015b). With the acceptance of the disease's incurability, hope for a positive outcome changed to hope for a short end-of-life phase and a quick, peaceful death (Kars et al., 2010). The study by van der Geest et al. (2015a) reported that mothers and fathers ($n = 68$ [76%]) wished for a meaningful remaining time with their dying child and 58 (65%) parents wished their son or daughter to suffer a painless death. For parents, staying hopeful was an effective way to postpone their confrontation with feelings of loss (Kars et al., 2010).

Whereas hope was regarded important, the study of van der Geest et al. (2015a) revealed that only 19 (21%) of the parents mentioned the necessity of faith. Furthermore, few mothers and fathers mentioned prayers ($n = 12$ [14%]) and faith in God ($n = 16$ [18%]) as helping spiritual sources of coping. A minority ($n = 13$ [15%]) felt as if their faith was strengthened by their child's disease. More than half of parents ($n = 45$ [51%]) disagreed on faith being important. Traumatic grief was found in 12 (14%) and depression in 22 (25%) parents; yet, no association was found between faith and hope for a cure with increased long-term grief (van der Geest et al., 2015a). Spiritual and religious beliefs were regarded as supportive factors if parents felt strongly about faith (Kars et al., 2010). Parents saw their child's dying from a religious point of view as being in god's hands. Some characterized a positive picture of heaven according to their religious belief in order to comfort their sick child. Other parents assured their child that a spiritual connectedness will remain after death (Kars et al., 2010).

Most parents ($n = 70$ [79%]) in the study from van der Geest et al. (2015a) viewed their sick child to be an important coping source during the end-of-life phase. Their child's ability to cope with the situation of suffering a life-threatening disease strengthened parents (Kars et al., 2011a, 2011b). The amazement of their son's or daughter's maturity of accepting their disease (Cataudella and Zelcer, 2012) and their ability to enjoy life made parents proud of their child (Kars et al., 2011a, 2011b). On the one hand, mothers and fathers expressed feelings of respect believing that they could not be as brave as their child if they were in the same situation (Zelcer et al., 2010); on the other hand, they reported about a changed self-awareness since they had proved themselves that they could handle more than they thought. Parents also viewed themselves as more empathetic after going through their child's illness trajectory wanting to help other families in similar situations. They also had new life perspectives and regarded their child's disease a wakening call showing them what was truly important (Ljungman et al., 2016).

A Unique Bond

For parents, the unique bond with their sick child, which went far beyond the "spoken," was particularly important. The emotional connection with their child was a source of meaning as well as a foundation, on which parents based their decisions regarding the child's end-of-life care or farewell on. Using various strategies parents even tried to preserve this connection beyond the child's death.

Once curative treatment was still the aim, parents considered the healthcare professionals' recommendations and treatment protocols in guiding their decision-making process. However, when they were informed about their child's incurability, they retook their parental responsibilities making end-of-life decisions on behalf of their parent–child relationship. The decision-making process was regarded as very tough as parents regarded treatment decisions as either "doing something" or "doing nothing." They equaled "doing nothing" to letting the child die, never forgiving themselves if they had not tried everything possible (Kars et al., 2011b). When death was near, many mothers and fathers withdrew from social life to be with the child during his/her last months. They distanced themselves completely from others except a few close people and started preparations for the funeral (Kars et al., 2011b). Some parents who were informed of the impending death were able to involve their child with cancer in his/her funeral planning. Thereby, they could respect their son's or daughter's wishes (Kars et al., 2011b; van der Geest et al., 2015b). Parents regarded taking memorabilia an option to keep something of their diseased child once he/she was gone (Kars et al., 2011b). In order to be with the child after his/her death, some parents chose to place the grave close to them. They thought this helps to maintain connection to their child (Kars et al., 2011b).

Discussion

The results emphasize the importance of social and spiritual dimensions for parents in end-of-life care of children with cancer. In terms of the social dimension, three categories emerged: Being a Parent, Being in Relationship with the Child, and Being in Relationship with Health Professionals. Parents tried to maintain normality and joy for their child, but also kept control over the situation, while their parenthood was challenged. They wanted to protect their child from suffering but were also urged to talk to them about dying. Parents had ambivalent experiences with helpful but also burdensome staff. The spiritual dimension comprised two main categories: Hope and Faith and a Unique Bond. Hope was found to be an important source of strength, while Faith was only mentioned by some parents. For parents, the emotional connection with their child was a source of meaning as well as a foundation, on which they based their decisions. According to Prince-Paul (2008), the social and spiritual well-being domains were interrelated and connected through relationships with self, others, and transcendence.

The study highlights the need for psychosocial interventions for parents supporting them in tackling the challenges they are facing in this challenging situation. Parents need information regarding prognosis and treatment options to best make end-of-life decisions (O'Shea and Kanarek, 2013; Wang et al., 2019). It is the healthcare professionals' task to inform parents about possible therapies in addition to support them by talking about how to spend the remaining time with their dying child (Hinds et al., 2009). Even though mothers and fathers are aware of their child's prognosis, several studies showed that most parents decide on cancer-directed treatment in order to prolong the child's life or to remain hopeful for a cure of the disease (Hinds et al., 2005; Bluebond-Langner et al., 2007; Wang et al., 2019). Tomlinson et al. (2011) revealed that remaining hopeful for a cure might be such a strong factor that parents oversee the impacts of treatment on the child's quality of life and survival. Hope could be regarded as a spiritual belief, thus being an important aspect in the caregiving process (O'Shea and Kanarek, 2013). In their study, Hinds et al. (2005) showed that the parents' need to avoid loss was tremendous; however, not all parents fought their child's death, but rather subordinated their own needs to their child's needs. A publication from Hinds et al. (1997) already brought to light that single parents who lack a supportive family structure were more likely to preserve their child's life at any cost. Darlington et al. (2018) highlight the importance of the social aspect of coping within the family.

Various studies in this review mention that parents either talk about the impending death with their child with cancer or avoid talking about death (Zelcer et al., 2010; Kars et al., 2011b; van der Geest et al., 2015b). Studies on that topic show that even though parents are afraid of bad news, they prefer receiving reliable and precise information (Kars et al., 2010; Nesbitt, 2019). Parents deal with an inner conflict as they on the one hand like to make their child's remaining life worthwhile and on the other hand feel responsible to support their child to cope with their death (Kreicbergs et al., 2004). Not talking to children about death seems to be a parental way of protecting their child, as Nitschke et al. (2000) stated. Mack and Joffe (2014) revealed that parental readiness to converse with a dying child about his/her death can be negatively influenced by feelings of guilt. Some parents show feelings of remorse for not having talked about death with their child with cancer (Kreicbergs et al., 2004).

The included studies demonstrate some limitations that hinder the generalizability of results. The most frequent limitation regarded sample characteristics. Data were gathered in one group only (White, Caucasian, Dutch) or just in a single institution (Kars et al., 2010, 2011a, 2011b). Furthermore, biases, such as a selection bias (Robert et al., 2012) and a recall bias (Cataudella and Zelcer, 2012; Robert et al., 2012; van der Geest et al., 2014, 2015a), limit the results. Recall biases of parents result in the time span from their child's death until the point of data gathering. A further limitation was that data saturation, setting information, and research design were not properly mentioned in all included studies. A weakness of this review is that only studies from 2010 to 2016 were included. This review was conducted as part of a practice project in 2017, however, time constraints led to the decision regarding the time period of included studies and to the decision to conduct a narrative review instead of a systematic review. More recent studies would possibly add depth to the findings. Nevertheless, we see the strength of the review in its grounding in Sulmasy's biopsychosocial–spiritual framework as well as in our comprehensive search strategy. This led to a comprehensive and in-depth description of the parents' social and spiritual experiences.

Conclusion and implications

This narrative review demonstrates the importance for nurses to consider the social and spiritual dimension of parental experiences when supporting parents of a child with cancer. The relationship between the child and the parents should be noticed and encouraged, and the parents' challenging situation should be reflected and addressed. Additionally, parents should be supported in talking to their child about dying and death. Hope and the unique bond between parents and their child can be a resource for the parents' purpose and meaning of life and may help them to cope with losing their child to cancer.

Nursing research should develop and validate concepts for the holistic support of parents by focusing the structure of relationships. The biopsychosocial–spiritual model could form a basis for future studies.

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