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# Nursing care and nurses' understandings of grief and bereavement among patients and families during cancer illness and death – A scoping review

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#### ABSTRACT

*Purpose*: Grief and bereavement is often present among patients and families during courses of cancer. Offering support for both patients and families is essential in the context of cancer nursing. Present scoping review offers an overview of existing knowledge, which can be used for inspiration in cancer-nursing. Hence, the objective of this study was to identify understandings of grief and bereavement, which is present in a cancer-nursing context and to develop insight on existing knowledge about nursing interventions targeted patients and their families' experiences of grief and bereavement due to cancer illness.

*Method:* The scoping review is conducted, inspired by the methodology of Joanna Briggs Institute. Sources of evidence are retrieved from a large number of databases and resources.

Results: Twenty-two studies are included in the scoping review. The studies are retrieved from eight different countries. Findings are mapped in nine categories. Eight categories related to nursing care targeted patients and/or families experiencing grief and/or bereavement; One category related to understandings of grief and/or bereavement targeted patients and families.

Conclusion: Nursing interventions to support patients and their families during grief and bereavement covers a broad spectrum of interventions. E.g. communication; using artwork; cultural and spiritual care; bereavement care; supporting coping strategies. Different models and theoretical understandings were identified. E.g. The dual process model of coping with bereavement; A Divorced Family-focused Care Model; Family Strengths-Oriented Therapeutic Conversation (Fam-SOTC); and understandings of children's grieving process.

#### 1. Introduction

Grief and bereavement are dominant phenomena among patients within the context of nursing cancer care (Madsen et al., 2019; Marcussen et al., 2019). According to the World Health Organization (WHO), cancer is a leading course of death worldwide with nearly 10 million deaths in 2020. Internationally, approximately 9 million people were diagnosed with a cancer illness in 2020 (World Health Organisation, 2022). The large amount of people and their families often need nursing care during the illness trajectory and hence underline the necessity of nurses having competencies to provide this support, when needed. WHO stress that palliative care takes a team approach to support patients and their families and the aim of palliative care is to

improve the quality of life among patients and their families – who are facing problems, e.g. related to be reavement and psychological and existential problems, associated with life threatening illness (World Health Organisation, 2020).

Bereavement and grief are two common emotions caused by losing something valuable in your life. The word "bereavement" is associated with experiencing the death of a person, with whom you had a close relation (Cambridge Dictionary, 2022a). The word "grief" is described as a very great sadness, especially experienced at the death of someone (Cambridge Dictionary, 2022b). In the context of palliative care – and hence nursing care - it is therefore important also to include an awareness that the support need a broader focus related to grief, as it may involve other areas in life than existential and psychological problems

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related to death. A theoretical perspective on loss, grief and bereavment, often used in nursing bereavement care, is the theories of Stroebe and Schut (Stroebe et al., 2008; Stroebe and Schut, 2015). According to Stroebe and Schut, loss is associated with grief and bereavement. The two phenomena, grief and bereavement, are the individual ways human being express their losses, depending on the meaning associated with the loss, and hence challenges, which this loss evokes. Bereavement is understood as a dual process of coping with the stressors of "the process of loss" and "the process of restitution", and a person's mental health is depending on the abilities to oscillate between these stressors (Stroebe et al., 2008; Stroebe and Schut, 2015).

In regards of bereavement care it is important to notice that the WHO has classified a new diagnosis "Prolonged grief disorder" (PGD), within their international classification of diseases (Deloitte & The Danish National Center for Grief, 2016; World Health Organisation, 2018). This diagnosis defines PGD as a disturbance including a persistent and pervasive grief response for a long period (at least 6 months) following a loss. (Deloitte & The Danish National Center for Grief, 2016; World Health Organisation, 2018). This new diagnosis underlines the necessity of developing nursing competences to prevent or identify and alleviate symptoms related to PGD – either in the context of nursing or initiate bereavement support in other professions related to the palliative care team approach.

From research it is identified, that both patients and families experience multiple losses during cancer illness and nursing care is often needed (Coyne et al., 2020; Madsen et al., 2018). Research has highlighted, that cancer influences both the person with cancer and their family equally with significant burden (Coyne et al., 2020). It is also well known that family caregivers are overburdened emotionally and physically, and some studies have demonstrated that this overload extends beyond the period of mourning (Ferrario et al., 2004). Family members are challenged in many ways throughout cancer and death, for instance: Parents must endure profound suffering in their bereavement following a child's death due to cancer (Denhup, 2017). Children experiencing parental cancer, are challenged in the lack of parents, well-being and the loss of daily routines (Elmose, 2011; Hauken et al., 2018; Lundberg et al., 2018). Also, double bereavement has been identified among children when a divorced parent dies (Marcussen et al., 2020). Both children and young adults losing a parent are found to be at risk for mental health problems, such as depression and distressing symptoms (Bugge et al., 2008; Marcussen et al., 2020). Research also stress, that siblings needs of support when a brother or sister dies from cancer (Nolbris and Hellström, 2005). Also, research has identified grandparents' challenged grieving in relation to childhood cancer (Moules et al.,

Young adults losing a divorced parent to death are found in research to have elevated risk of prolonged grief compared to losing a non-divorced parent (Marcussen et al., 2021) and a meta-analysis has found a prevalence of prolonged grief amongst bereaved adults to be 9, 8% (Lundorff et al., 2017). Although it is a common experience to experience an older spouse death, nearly one of four bereaved older spouses are challenged in the experience of prolonged grief or chronic depression (Davidow et al., 2022). Even though the loss of a close loved one to death is the most recognized kind of grief, it has to be noticed that grief emerges from many experiences of loss such as loss of family, home, function or ability (Shear, 2015). However, bereaved persons reactions related to grief and bereavement have to be seen in the perspective of the persons gender, age, personality, life conditions, vulnerability and the circumstances related to the loss (Marcussen et al., 2015; Mogensen and Engelbrekt, 2018; Nielsen et al., 2016b).

Experiencing a life situation dominated with grief and bereavement can be defined as a challenging transition. During this transition process the support from nurses, affect the outcome of wellbeing and mental health among family members (Madsen et al., 2019; Marcussen et al., 2019). Nurses' ability to identify challenging transitions and grief issues in families is an important competence in order to initiate support for

families – which implies caring on the levels of both individuals and as a family group (Nielsen et al., 2016a). For instance, research identified that spouses are challenged in balancing between 'deep grieving' and 'moving forward' in order to successfully create a new life without their partner (Holtslander et al., 2011), and other spouses' grief experiences involves transitions in regards of coping with own chaotic emotions and struggling to re-join with life after the death of a of their loved one (Madsen et al., 2018).

Although, it seems to be important for most nurses to provide bereavement and grief support towards different kind of families experiencing loss throughout cancer, some studies have identified a lack of professional care, when it was needed among families (Birtwistle et al., 2002; Marcussen et al., 2020; McCue and Bonn, 2003; Russell et al., 2018). Also, nurses can be uncomfortable offering support in fear of saying the wrong things or becoming emotional (Ruden, 1996). Nurses are also at risk of developing grief and bereavement themselves, while offering bereavement support for patients and families - and in its extreme consequence develop cumulative grief or compassion fatigue (Houck, 2014; Phillips and Welcer, 2017). Hence, when offering nursing care targeted grief and bereavement, nurses need the competence to recognize when assistance is needed (Houck, 2014; Phillips and Welcer, 2017).

Present scoping review strives to contribute to the development nursing care targeted grief and bereavement among patients and their families during cancer illness. Therefor this scoping review presents an overview by mapping existing knowledge of both nurses' understandings of grief and bereavement and existing knowledge of nursing care targeted patients and their families throughout the course of cancer illness and cancer death. Previously no reviews have taken this perspective in the context of cancer nursing.

#### 1.1. Aim and review questions

This scoping review aims to identify understandings of grief and bereavement, which is present in a cancer-nursing context and to develop insight on existing knowledge about nursing interventions targeted patients and their families' experiences of grief and bereavement due to the courses of cancer. Hereby this scoping review contributes with an overview of existing evidence, which can be used to develop nursing competences targeted patients and families, who experience grief and bereavement during cancer illness.

The scoping review explore the following research question: What kind of evidence about nursing care and nurses' understanding of grief and bereavement exists in research targeted patients and their families throughout grief and bereavement due to the course of cancer illness and death?

#### 2. Methods

#### 2.1. Design

A scoping review was conducted to address the identified research question, because this method is suitable, when you strive to create an overview of existing knowledge. The method is inspired by the methodology of Joanna Briggs Institute, and it aims to create an overview on existing knowledge (Khalil et al., 2016; Peters et al., 2015). This method is suitable for broad and complex research areas and consists of five stages: 1. Identifying the research question 2. Identifying relevant studies 3. Study selection 4. Presenting the data. This stage consists of charting the data in a tabular and narrative format. In a JBI scoping review the results may be presented as a "map" of the data in a logical, diagrammatic or tabular form, or in a descriptive format. The reviewers decide what rationally and clearly illustrate the results in terms of the object. For instance, the extracted results may be classified under main conceptual categories 5. Collating the results, which involves identifying the implications of the study findings for policy, practice or research

(Khalil et al., 2016). Due to the absence of the methodological quality appraisal in scoping reviews it may not be able to develop recommendations for practice. However, suggestions could be made based on the conclusions (Khalil et al., 2016; Peters et al., 2015). In present scoping review critical appraisal of the included studies was not conducted.

#### 2.2. Inclusion and exclusion criteria

Inclusion and exclusion criteria were used during the process of selecting studies for the scoping review. These are presented in Table 1.

#### 2.3. Search strategy

According to Khalil's second stage a search strategy was developed to identify relevant studies (Khalil et al., 2016). The aim of the search was to reveal both published and unpublished evidence. To ensure a wide search the following databases and resources were included: Cinahl Complete, Embase, SveMed+, APA PsycInfo, Scopus, Academic Search Premier, Bibliotek. dk, Den Danske Forskningsdatabase, Idunn. no, OpenDissertations, Open Access Thesis and Dissertations (OATD) and OpenGrey. These databases and resources cover both health science, more interdisciplinary areas, and grey literature. Searches were conducted in both Danish, Swedish, Norwegian and English databases and resources. The width of these, both international and national, was to ensure a comprehensive search and attempt to identify all of the available evidence (Khalil et al., 2016).

The review question was analyzed and divided into three aspects; bereavement, nursing, and cancer. To identify keywords to each aspect the first stage was a limited search of Cinahl Complete as the most relevant database (Aromataris and Riitano, 2014). Keywords and synonyms were then determined.

A search protocol was conducted. Block search as strategy was used as preferred method, when possible. In the resources where block searches were not supported, searches were conducted as systematic as possible. To build the search strategy the limited search were tested in Cinahl Complete including variations of text words and index terms based on the review question. This strategy was translated to reflect the rest of the resources. To specify the search string in the large databases

Table 1
Inclusion and exclusion criteria.

Participants: Nursing care for patients and families in all ages  Nursing care for all kinds of family structures  Context:  Cancer Nursing care  Cancer Nursing care  Concept:  Nursing care  Nursing care  Nursing care  Context:  Context:  Context:  Concept:  Nursing care  Context:  Concept:  Nursing care  Nursing care  Nursing care  Concept:  Nursing care  Nursing care  Concept:  Nursing care  Concept:  Nursing care  Nurses' experiences of caring for patients and/or families  Nursing interventions  Nurse' knowledge about grief and bereavement  Methods:	Inclusion	Exclusion
families in all ages  experiences of loss and bereavement not related to nursing care.  Nursing care for all kinds of family structures  Context:  Cancer  Nursing care  Cancer  Nursing care  Concept:  Nurses' own reactions and experiences of loss and bereavement in relation to care  Studies including a mix of health care professionals without a specific result related to nursing care  Cancer  Nursing care  Concept:  Nursing care  Cuntures or results not comparable with a western healthcare  Nurses' experiences of caring for patients and/or families  Nursing interventions  Nurse' knowledge about grief and bereavement in relation to care  Studies including a mix of health care  professionals without a specific result related to nursing care  Context:  Studies including other diseases than cancer  Cultures or results not comparable with a western healthcare  Not related to cancer nursing	Participants:	Participants
Nursing care for all kinds of family structures  Context:  Studies including a mix of health care professionals without a specific result related to nursing care  Cancer  Nursing care  Concept:  Nursing care  Concept:  Nursing care  Concept:  Nursing care  Cultures or results not comparable with a western healthcare  Nurses' experiences of caring for patients and/or families  Nurses' knowledge about grief and bereavement	Nursing care for patients and	Patients and families' describing own
Nursing care for all kinds of family structures  Context:  Studies including a mix of health care professionals without a specific result related to nursing care  Cancer  Nursing care  Concept:  Nursing care  Concept:  Nursing care  Cultures or results not comparable with a western healthcare  Nurses' experiences of caring for patients and/or families  Nurses' knowledge about grief and bereavement  Nurses' own reactions and experiences of loss and bereavement in relation to care  Studies including a mix of health care professionals without a specific result related to nursing care  Context:  Studies including other diseases than cancer  Cultures or results not comparable with a western healthcare  Not related to cancer nursing	families in all ages	-
family structures  Context: Studies including a mix of health care professionals without a specific result related to nursing care  Cancer  Nursing care  Concept: Nursing care  Concept: Studies including other diseases than cancer Cultures or results not comparable with a western healthcare  Nurses' experiences of caring for patients and/or families Nursing interventions Nurse' knowledge about grief and bereavement	Number of Control of the Asset	8
Context:  Studies including a mix of health care professionals without a specific result related to nursing care  Cancer  Nursing care  Concept: Nursing care  Cultures or results not comparable with a western healthcare  Nurses' experiences of caring for patients and/or families  Nursing interventions  Nurse' knowledge about grief and bereavement  Studies including other diseases than cancer Cultures or results not comparable with a western healthcare  Not related to cancer nursing		*
Professionals without a specific result related to nursing care  Cancer  Nursing care  Concept:  Nursing care  Cultures or results not comparable with a western healthcare  Nurses' experiences of caring for patients and/or families  Nursing interventions  Nurse' knowledge about grief and bereavement	*	
Cancer Nursing care  Concept: Nursing care  Concept: Nursing care  Cultures or results not comparable with a western healthcare  Nurses' experiences of caring for patients and/or families Nursing interventions Nurse' knowledge about grief and bereavement	<u>Gortesta</u>	9
Nursing care  Concept:  Nursing care  Cultures or results not comparable with a western healthcare  Nurses' experiences of caring for patients and/or families  Nursing interventions  Nurse' knowledge about grief and bereavement		•
Concept:  Nursing care  Nurses' experiences of caring for patients and/or families  Nursing interventions  Nurse' knowledge about grief and bereavement  Studies including other diseases than cancer  Cultures or results not comparable with a western healthcare  Not related to cancer nursing	Cancer	-
Nursing care  Cultures or results not comparable with a western healthcare  Nurses' experiences of caring for patients and/or families  Nursing interventions  Nurse' knowledge about grief and bereavement	Nursing care	Context:
western healthcare  Nurses' experiences of caring for patients and/or families  Nursing interventions  Nurse' knowledge about grief and bereavement		
Nurses' experiences of caring for patients and/or families Nursing interventions Nurse' knowledge about grief and bereavement	Nursing care	1
patients and/or families  Nursing interventions  Nurse' knowledge about grief and bereavement	Name of the Control o	
Nursing interventions Nurse' knowledge about grief and bereavement		Not related to cancer nursing
Nurse' knowledge about grief and bereavement		
and bereavement	e e	
Methods:	e e	
wictious.	Methods:	
Qualitative and quantitative	Qualitative and quantitative	
studies	studies	
Year:		
1995 to 2021		
Language:		
English, Danish, Swedish, Norwegian	•	

(Embase and Scopus) the searches were conducted only in the fields: title, abstract and keyword. The search terms were translated to Danish, Swedish and Norwegian for the databases and resources not in English.

The search strategy included studies published from 1995 and forward. The year 1995 was chosen, because around this year Stroebe and Schut presented a new thinking of bereavement understood as the dual process of coping with bereavement, in bereavement research (Stroebe and Schut, 1999). Studies were included due to those perspectives as well as other perspectives.

Studies published from 1995 and forward was identified from searches in all selected databases in the period of 28<sup>th</sup> of May to 30<sup>th</sup> of June 2020. The searches were updated the 1<sup>st</sup> of October to the 5<sup>th</sup> of October 2021 in following databases: Cinahl Complete, Embase, APA PsycInfo, Scopus, Academic Search Premier, Bibliotek. dk og Idunn. no. The remaining databases were either ceased (SveMed+, Den Danske Forskningsdatabase, and OpenGrey) or not available at the time searches were updated (OpenDissertations and Open Access Thesis and Dissertations (OATD)). Search limitations have been set in relation to year of publication and language, where it was possible. Table 2 presents two examples of search strings. The search strategy was conducted and discussed in the research team (in collaboration with a librarian).

#### 2.4. Study selection process

The selection process was, due to the update of the search, conducted twice

First in total 2149 hits were identified (June 2020) and after removing duplicates 1227 hits were screened based on title and abstract. 43 studies were read in full text and 21 met the inclusion criteria and were included in the scoping review. Second, the updated search (October 2021) revealed 146 new hits. 31 were duplicates and 103 were excluded at title and abstract level. After reading full text of the four studies, one was included in the scoping review.

When doubt occurred, the specific study was discussed among first and last author until agreement was obtained.

The flowchart is illustrated in Fig. 1.

#### 3. Extracting and charting the results

In present scoping review data is primarily mapped in tabular forms, when presenting the included studies and extracting central data related to the aim of present scoping review. However, data is charted in both tables and narrative format, when presenting main categories, study population groups and nursing interventions in regards of the study aim.

#### 3.1. Map of the research area

The 22 studies included in present scoping review origin from eight countries: U.S.A. (12), Canada (3), United Kingdom (2), Australia (1), Denmark (1), Finland (1), Hong Kong (1), Iceland (1).

To understand how nursing target patients and families experiences of grief and bereavement is provided, it is important to know about the different contexts of which the studies were conducted. The 22 included studies were placed in following contexts: 16 studies from cancer nursing/oncology nursing/cancer care/oncology nursing; 4 studies from pediatric oncology/pediatric intensive care unit/neonatal intensive care unit/pediatric bone marrow transplant unit/pediatric palliative care; 1 study from hospice and 1 study from a specialized palliative home care unit.

#### 3.2. Mapping of the included studies

The extraction fields of the included studies involve the authors, publication year, type of study, population and context. Furthermore the mapping of the 22 included studies are centered on extracted results related to grief and bereavement and interventions in nursing care

**Table 2** Examples of search strings.

Database	Search strings	Limits
Cinahl Complete Embase	(bereavement OR grief OR mourning OR chronic sorrow OR grieve OR mourn) AND (nurse OR nursing) AND (cancer OR neoplasm OR oncology) (bereavement:ti,ab,kw OR grief:ti,ab,kw OR mourning:ti,ab,kw OR 'chronic sorrow':ti,ab,kw OR grieve: ti,ab,kw OR mourn:ti,ab,kw OR 'bereavement'/de OR 'grief'/exp) AND ('nursing'/exp OR 'nurse'/exp OR nurse:ti,ab,kw OR nurses:ti,ab,kw OR nurses:ti,ab,kw OR neoplasm:ti,ab,kw OR oncology:ti,ab,kw OR 'malignant neoplasm'/exp OR 'oncology'/exp)	Published Date: 19950101-; Language: Danish, English, Norwegian, Swedish ([danish]/lim OR [english]/lim OR [norwegian]/lim OR [swedish]/lim) AND [1995–2021]/py

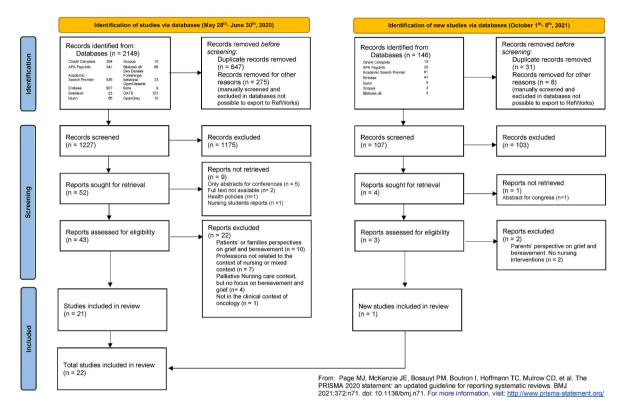


Fig. 1. Flow diagram

(Garrard, 2021). These extractions are presented in a tabular form (Table 3).

## 3.3. Mapping presented in relation to categories, populations groups, nursing care and understandings of grief and bereavement

Table 4 presents the nine categories developed based on the process of mapping studies in Table 3 and interpretation extracted findings within this table. This table also includes a mapping of each study representing these categories. The table shows that the first category "Communication" is the largest, represented by eight studies presenting knowledge on interventions in cancer nursing. Category two and three called "Bereavement care" and "Models and tools including interventions" are both represented with four studies. The fourth category "Art" is represented by two studies. Categories five to eight called "Art"; "Palliative Care"; "Complicated grief"; "Spiritual care"; "Cultural Care", are each represented with one study. Category nine called "Understandings of grief and/or bereavement" is represented by nine studies.

Table 5 presents a mapping of studies placed in relation to the identified categories. Within this mapping of each category it is possible to identify whether studies contribute to following three subcategories: Nursing care targeted bereavement and grief; Nursing care targeted grief; Nursing care targeted bereavement. Further, the table presents a

short overview of central content from each study contributing to each subcategories. Based on the mapping it is also possible to identify gaps of knowledge – as some of the subcategories are not represented by any studies.

Table 6 presents a mapping of populations groups represented in the included studies. The way of mapping studies shows that the largest amount of existing knowledge is related to the groups: "Children/parents" and "Family". Only three studies represent nursing care targeted "patients". Further, the table presents an overview of studies contributing with understandings of grief and/or bereavement in relation to the three population groups.

Table 7 presents a mapping of interventions in nursing care and understandings of grief and bereavement in nursing care. Herby this table presents an overview of extracted interventions in palliative nursing care mapped in relation to the nine identified categories. Within this table, it is possible to obtain knowledge in regards of specific interventions recommend within the included studies. In addition, the table maps theoretical understandings of grief and/or bereavement identified in nine included studies. All extracted text in the table origins from the twenty-two included studies.

Table 3
Extracted data from the included studies.

Study number	Author, year, country	Study type and population (P)	Context	Findings: Grief and bereavement	Findings: Nursing care and nursing interventions
	Ruden (1996)	Intervention study	Pediatric	Bereavement in families who	Bereavement follow-up program
	USA	P: Not available	Intensive Care Unit, Neonatal Intensive	have lost at child to cancer Mile's model of parental grief	Provide families with empathy
			Care Unit (NICU), and the Pediatric Bone Marrow Transplant Unit		Validate feelings
					Respect for children's memories Provide information about further support
2	Bailey (1997)	Review	Oncology Nursing	Enabling mourning and grieving through art and creative expression	Holistic care for patients and families
	USA	P: Journals, magazines, and personal experience		•	To be knowledgeable of the role of the arts and creative expression in care To incorporate art
3	Boyle (1998)	Descriptive	Cancer	Culture regarded grief, bereavement and mourning	Cultural nursing
	USA			outen tandar and anothering	Cultural awareness in the end of life care Being cultural sensitive Facilitating bereavement and grief Nursing guidelines
1	Kaunonen et al. (2000)	Intervention study	Oncology	Bereavement, mourning and grief	Oncology ward supportive telephone call after the death of a patient
	Finland	P; 95 Nurses			Evaluate the family's coping during phone calls.  Get feedback concerning the nursing care delivered  The call serves as a finishing analysis of the family nursing process
5	Leboeuf (2000)	Case study	Oncology nursing	Grief (Numerous losses)	Caring for patients with brain tumor and famil
	Canada	P: One family		Crisis (Chock, fear, powerlessness)	nursing Enhance coping strategies:  Using an Illness narrative approach. (Beliefs, perceptions)
5	Buxbaum and	Feature	Oncology	Anticipatory grief in children	Nursing care targeted children when a parent
	Brant (2001) USA	P: Literature		Grieving process	dies from cancer Assessment and interventions focusing on child's coping strategy; family environment; community resources
				Children' grieving process and reactions regarding age	
7	Walsh and Schmidt (2003)	Intervention study	Hospice	Bereavement and grief	Telecare
	USA	Pilot study		Intervention inspired by Hogan's Model of bereavement	Telephone conferences calls with caregivers provides support and education
		P: 14 caregivers			The intervention provide a mechanism for reaching small groups.
8	Rancour and Brauer (2003)	Literature review	Oncology	Grief as a normal process when loosing body parts and functions	Nurses can use letter writing as a means of assisting patients through the grief process associated with body image alterations
	USA	P: Numbers not available		Grief is not pathologic. Grief is the normal healing response to the loss of body parts and functions	
		Case study P: One female patient			
)	Devlin (2006)	Review of literature	Cancer and palliative care	Grief and distress expressed through artwork	Artwork from children
	United Kingdom	P: Numbers of studies not available	care	ough merion	Art as a valuable tool in the communication process Helping children and adult to express consciou and unconscious feelings
		Literature review	Oncology	Grief and bereavement process	Communicate with children and parents

Table 3 (continued)

Study number	Author, year, country	Study type and population (P)	Context	Findings: Grief and bereavement	Findings: Nursing care and nursing interventions
	Canada	Nursing narrative			Conversation guidelines
11	Foster et al. (2010) USA	Review P: Numbers of studies not available	Pediatric palliative care	Loss, grief bereavement, complicated grief	Caring for children with cancer and their families End-of-life issues in nursing:  Symptoms of cancer or its treatment Supporting hopefulness
					Supporting the process of trying to be a good parent in decision making Legacy making of ill children Family bereavement and continuing bonds
12	Tuffrey-Wijne et al. (2012)	Focus groups and face-to-face interviews	Cancer nursing	Grief and bereavement among adults with intellectual disability	Include persons with ID in the family unit
	United Kingdom	P: 21 adults with intellectual disability (ID) who had a relative with cancer now or in the past		, <b>,</b>	Ensure persons with ID are given adequate emotional support
					Be proactive in giving persons with ID information that is easy to understand Use functional stories
13	Gonzalez (2012)	Review	Cancer	Grief and the need to recognize and promote optimism among patients	Promoting optimism among oncology nurses involves:
	USA	P: Number of studies included not available			Assess own beliefs and attitudes towards optimism and cancer care Develop skills of listening, observing, communicating, Develop cultural competence, and provide culturally sensitive care
14	Darbyshire et al. (2013)	Individual interviews	Pediatric oncology unit	Bereavement and grief when losing a child	A telephone intervention program
	Australia	P: Six parents			Supporting bereaved parents in the years following their child's death Regular telephone contact from a familiar member of the child's treating team creates a more positive and supportive bereavement experience for parents
15	Chan et al. (2013)	Semi-structured interviews	Oncology Unit	Bereavement	Bereavement care
	Hong Kong	P: 15 nurses			Family members should be supported in involvement in the patient care, which could result in a positive impact on their grief and los experience
		10 bereaved family members			Nurses need more training on knowledge, skill and attitudes to improve their readiness and competencies of bereavement care
16	Rodgers et al. (2016)	Semi-structured telephone interview	Oncology Unit	Grief and bereavement	End of life care
	USA	P: 13 bereaved family members (18 years or older)		Postmortem	Postmortem care
					Bathing and honoring practice procedure after a loved one's death Supporting the initial grieving process
17	Holtslander et al. (2016)	Multi-method RCT with qualitative and quantiatative data	Oncology, advanced cancer	Bereavement	The finding balance intervention (FBI)
	Canada	P: 19 older adult family caregiver		Complicated bereavement	The FBI was easy to use, acceptable and of benefit.
				Dual Process Model of Coping with Bereavement	The FBI offered validation of emotions and ways to discover new ideas to find balance an moving forward on a unique journey through grief
18	Shore et al. (2016)	Review	Palliative care, oncology	Definition of anticipatory grief	Toolbox of Communication Skills Nurse Statements
	USA	P: Numbers of studies included not available Case study:		Assessment Tools for Anticipatory Grief	Assessment tools provides competences to identify those experiencing anticipatory grief Interventions to those experiencing anticipatory grief include:

Table 3 (continued)

Study number	Author, year, country	Study type and population (P)	Context	Findings: Grief and bereavement	Findings: Nursing care and nursing interventions
					Identifying physical and psychological symptoms. Treating them with pharmacologic and non-pharmacologic therapies Providing support and education to patients families, and caregivers Utilizing empathetic communication strategies
19	Tofthagen et al. (2017)	Review	Oncology nursing	Complicated grief among family caregivers	Early interventions: Prompt recognition and referrals to supportive care services and mental health professionals
	USA	P: Number of studies included not available			Family education during the cancer trajectory
20	Marcussen et al. (2019)	Interview	Cancer care	Grief and bereavement in relation to children living in divorced family/parental critical illness or death	Divorced family focused cancer care
	Denmark	P: 20 nurses		Double bereavement A Divorced Family-focused Care Model	Collect information about family structure Assess support needs
				The dual process model of bereavement	Initiate well-being support
					Coordinate and follow-up focusing on the child's well-being.
21	Petersen (2020)	Scoping review	Pediatric oncology	Grief, bereavement and end of life support	Nursing targeted parents whose children were diagnosed with cancer and who faced the end of life
	USA	P: 33 studies			Spirituality and spiritual care: Instilled hope Assisted in the search for meaning and purpose Guiding parents to develop continuing bonds with their child
22	Petursdottir et al. (2020)	Quasi-experimental design, a posttest comparing the intervention group and control groups receiving usual care	Specialized palliative home care unit	Grief and early bereavement	The Family Strengths-Oriented Therapeutic Conversation (FAM-SOTC) – a post loss intervention reduces psychological distress symptoms among bereaved family caregivers
	Iceland	P: 51 bereaved caregivers		The Range of Response to Loss Model (RRLM) The Adult Attitude to Grief (AAG) The Family Strengths-Oriented Therapeutic conversation (FAM-SOTC) Measuring grief reactions 3, 5, and 6 months after their close relative had died	

**Table 4** Identified categories and studies contributing to these categories.

Category number and name	Number of studies
1. Communication	8 (Study no. 4, 7, 8, 10, 12, 13, 14, 22)
2. Bereavement care	4 (Study no. 1, 15, 16, 17)
3. Models and tools including interventions	4 (Study no. 5, 6, 18, 20)
4. Art	2 (Study no. 2, 9)
5. Palliative care	1 (Study no. 11)
6. Complicated grief	1 (Study no. 19)
7. Spiritual care	1 (Study no. 21)
8. Cultural care	1 (Study no. 3)
9. Understandings of grief and/or	9 (Study no. 1, 6, 7, 8, 10, 17, 18, 19,
bereavement	20)

#### 4. Discussion

#### 4.1. Recommendations for cancer nursing

Present scoping review contributes with knowledge, which can be used for inspiration when developing cancer nursing – both regarding nursing interventions and theoretical understandings of grief and bereavement.

#### 4.1.1. Understandings of grief and bereavement in nursing care

The included studies all present understandings of grief or bereavement in cancer nursing. These studies can support the nursing care and include specific centered topics such as: The normal healing process to loss (Rancour and Brauer, 2003) and definitions of anticipatory grief (Shore et al., 2016). Other studies gave important knowledge related to children's grieving process and reactions regarding age (Buxbaum and Brant, 2001), general understandings of both grief and bereavement among children (Longfield and Warnick, 2009)and understandings of double bereavement among children losing a divorced parent to death (Marcussen et al., 2019). In addition, one study focused on the understanding of parental grief when losing a child (Ruden, 1996).

In relation to understandings of bereavement and coping with bereavement the dual process model by Stroebe and Schut was used, showing the importance of nursing interventions targeted both the loss and restitution of bereaved families (Holtslander et al., 2016; Marcussen et al., 2019; Stroebe and Schut, 2010). Also Hogan's bereavement model was represented targeted understandings of bereavement in nursing care, showing that social support impacts the personal growth of a bereaved person (Walsh and Schmidt, 2003). Altogether the studies present knowledge and interventions, which can support nurses, when caring for bereaved individuals and families during grief and bereavement; when caring for parents who have lost a child, and children who

**Table 5**Mapping studies in relation to the identified categories.

Categories	Nursing	g care targeted grief and bereavement		Nursing care targeted grief	Nursing care targeted bereavement
when commus impending de Including peo care and givin 12)		considerations and communication guidelines mmunicating with children about parent's ng death (study no. 10) g people with intellectual disabilities in family giving information easy to understand (study no.		Letter writing as a means of assisting patients through the grief process associated with body image alterations (study no. 8) Grief and promoting optimism among patients (study no. 13)	Supportive telephone call after the death of the patient to evaluate coping strategies among families and evaluate the nursing care delivered (study no. 4)  Tele-care via telephone conferences calls, which provide support and education to caregivers (study no. 7)
	interve	ng a family-oriented therapeutic conversation (FAM-SOTC) before and during bereave family cancer caregivers (study no. 22)			Nurse-led telephone support targeted bereaved parents when losing a child (study no. 14)
Bereavement care     No studies  3. Models and tools  Utilized to		s identified		No studies identified	Bereavement follow-up program for families who lost at child to cancer (study no. 1) Bereavement care from the perspectives of families and nurses (study no. 15) Postmortem care – a bathing and honoring practice support families' initial grieving (study no. 16) The finding balance Intervention (FBI) among older family caregivers (study no. 17)
including and Calg interventions nursing of brain tur approach Using "T		d the Calgary Family Assessment Model (CFAM) algary Family Intervention Model (CFIM) to guide g care targeted family during the course of malign umor. Family nursing by using the illness narrative ich to enhance coping strategies (study no. 5) "The Divorced Family–Focused Care Model" in the with children and families affected by double		Assessment tool for anticipatory grief and interventions to those experiencing anticipatory grief (study no. 18)  Assessment and interventions focusing on child's coping strategy (study no. 6)	No studies identified
4. Art	Artwor	k by patients and families can help nurses to v feelings and can be considered a valuable t nununication process (study no. 9)		Art and creative expressions among patients enable to mourn and grief (study no. 2)	No studies identified
5. Palliative care  End-of-life issues that can be anticipated by nurse pediatric palliative care (symptoms, hopefulness, to be a good parent, legacy making, bereavement artifamily and continuing bonds (study no. 11)		ing to	No studies identified	No studies identified	
6. Complicated grief	Complicated grief: Interventions to identify, prevent and support families (study no. 19)		No studies identified	No studies identified	
7. Spiritual care	Spiritual care targeted parents whose children faced the end of life (study no. 21)		No studies identified	No studies identified	
8. Cultural care Cultural sensitive care in the end of life care when facilitating bereavement and grief (study no. 3)			No studies identified	No studies identified	
Theme number and name Understandings of grief and bereavement in nursing care		Und	erstandings of grief	Understandings of bereavement	
		Grief and bereavement process among children (study no. 10)	Mile's model of parental grief (study no. 1)		The Hogan's Model of Bereavement (study no. 7)
			rega Grie (stue Anti	dren's grieving process and reactions rding age (study no. 6) f as a normal healing response to loss dy no. 8) cipatory grief (study no. 18) uplicated grief (study no. 19)	The dual process model of coping with bereavement (study no. 17,20) Double Bereavement – parental divorce and parental illness/death (study no. 20)

experience grief and bereavement. In future research we suggest that further research are conducted on the understanding of complicated grief (Mason et al., 2020; Shear, 2015), and prolonged grief (World Health Organisation, 2018) - and interventions in relation to these specific types of grief in the context of cancer nursing. To sum up the findings of multiple understandings of grief and bereavement existing in nursing care present that nursing care targeted people's loss experiences can be a demanding task for nurses, and therefor highlight a need of knowledge and competences development in both nursing practice and nurse education.

Other theoretical perspectives may also contribute with inspiration, when using theoretical understandings for inspiration to identify problems in regards of grief and bereavement among patients and families. For instance, the Swedish psychiatrist Loma Feigenberg developed a theory, which is often used in the context of nursing as it inspires nurses

to take a broad perspective to identify loss during terminal illness (Feigenberg, 1976). According to Feigenberg loss during terminal illness is related to five central areas in human life: 1) Loss of Body 2) Loss of Self-control 3) Loss of Identity 4) Loss of Social relations and 5) Loss of Life content (Feigenberg, 1976). This theoretical perspective could be further supplemented with Max Van Manen's theory about the four existentials in human life: The body; Social relations; Time; Room (van Manen, 1997). However, two of these existentials are already present in Feigenberg's theory (the body and social relations), but the perception of time and room can inspire nurses to take an even broader approach to identify grief and bereavement among patients and families in the context of cancer nursing. According to Van Manen the perception of time often change during illness - for instance life becomes abrupt and shorter than expected, waiting time may also occur. Futhermore, Rooms may change – e.g. losing the ability to stay at home, having problems

**Table 6**Mapping study populations regarded nursing care and understandings of grief and bereavement.

nd bereavement.		
Children and/or parents	Adult patients	Family
Nursing care: Impending death of a parent:	Nursing care: Impending death:	Nursing care: Anticipatory grief:
Using art as a way of expressing experiences and feelings among children (study no. 9)	Supporting letter writing and assisting a grieving process (study no. 8)	Assessing and interventions targeted anticipatory grief (study no. 18)
Communication guidelines targeted children (study no. 10)	Enabling grief and mourning through art and creative expressions (study no. 2, 9)	Coping strategies:
Using the family focused care model targeted double bereavement in divorced families (study no. 20)	Supporting grief and promoting optimism among patients (study no. 13)	Using CFAM, CFIM and the illness narrative approach (study no. 5)
End-of-life care:		Tele-care for caregivers (study no. 7)
Follow up program when losing a child (study no. 1)		Using art and creative expression to express feelings and experiences (study no. 9)
Issues in pediatric palliative care (study no. 11)		Including people with intellectual disabilities in family care and giving information easy to understand (study no. 12)
Bereavement:		Supporting older caregivers to find balance during caregiving (study no. 15)
Telecare for parents who have lost a child (study no. 14)		Postmortem care:
Spiritual care targeted parents who have lost a child (study no. 21) When a parent dies from cancer (study no. 6)		Initial grieving process – a bathing and honoring practice (study no. 16) <u>Bereavement:</u>
cancer (staal) not of		Telecare after death (study no. 4)
		Finding balance intervention for older adult bereaved family
		caregivers (study no. 17) Complicated grief: Identifying, preventing
		and supporting (study no. 19)
		Using the family focused care model targeted double bereavement in divorced families (study no. 20) Using interventions
		inspired by FAM-SOTC
Understandings of grief and/or bereavement: Mile's model of parental	Understandings of grief and/or bereavement Grief as a healing	(study no. 22) Understandings of grief and/or bereavement: The Hogan's model
grief (study no. 1)	response to loss (study no. 8)	normal of bereavement (study no. 7)
A child's coping strategies and understandings of grief and bereavement (study no. 6)		The dual process model of coping (study no. 17)
Grief and bereavement		Definitions of anticipatory grief (study

Double bereavement as a

parental divorce in

combination with the

(study no. 10)

consequence of

Table 6 (continued)

subsequent death of the parent or development of a parent's critical illness where death is imminent or expected (study no. 20)	Children and/or parents	Adult patients	Family
	parent or development of a parent's critical illness where death is imminent or expected		

feeling at home during hospitalization. But, Room also represents the inner room/mental health - e.g. existential struggles and thoughts related to one's life situation.

#### 4.1.2. Interventions targeted grief and bereavement in cancer nursing

Present scoping review revealed a large amount of nursing interventions in Table 7, which can be used when caring for patients and families during experiences of grief and bereavement in cancer nursing. Especially studies targeted communication and ways of asking, initiation and conduction conversations appear in the scoping review (Darbyshire et al., 2013; Gonzalez, 2012; Kaunonen et al., 2000; Longfield and Warnick, 2009; Petursdottir et al., 2020; Rancour and Brauer, 2003; Tuffrey-Wijne et al., 2012; Walsh and Schmidt, 2003). But also studies, which described nursing interventions from a broader perspective in regards of bereavement care, were identified (Chan et al., 2013; Holtslander et al., 2016; Rodgers et al., 2016; Ruden, 1996). Further different models which can facilitate grief and bereavement care were identified (Buxbaum and Brant, 2001; Leboeuf, 2000; Marcussen et al., 2019; Shore et al., 2016). A smaller group of studies focused on palliative care, art, spiritual care, cultural care and complicated grief (Bailey, 1997; Boyle, 1998; Devlin, 2006; Foster et al., 2010; Petersen, 2020; Tofthagen et al., 2017). Due the small amount of studies and hence guidance for nursing interventions, these areas call for further research. In addition, gaps in knowledge were identified in relation to the newly implemented diagnosis of prolonged grief disorder. No studies have yet contributed with knowledge targeted nursing interventions targeted patients or families experiencing this specific kind of grief.

#### 4.2. Critical reflections and limitations

The search strategy involved a broad search in relevant databases and resources in order to identify existing knowledge on the topic of present scoping review. However, it is possible that some studies or documents were not identified in the search. This may be a limitation of the study. However, in present scoping review we have strived to ensure a high quality of the search strategy when planning, conducting and updating searches. Most of the included studies have been peerreviewed. However, when conducting a scoping review a critical appraisal of the included studies is not required (CASP UK Critical Appraisal Skills Programme, 2022; Peters et al., 2015). Meanwhile the research team chose to do a critical reflection in relation to the quality of the conducted studies, when they found that it was needed during the selection process. However, when implementing extracted findings from present scoping review in nursing care it is important to reflect on the potential need for critical assessment of the original studies.

Present scoping review has a mono-disciplinary perspective. The review contributes with an overview and mapping of existing knowledge targeted cancer nursing in relation to grief and bereavement, and understandings of grief and bereavement in cancer nursing. However, palliative care is also a multidisciplinary discipline and involves various professions. Some of the excluded studies in present scoping review covers the multidisciplinary and other mono-disciplinary professions which nursing care could seek inspiration from in order to improve the quality of cancer nursing care. These studies are e.g. targeted: Bereavement programs (Morris and Block, 2015); bereavement groups (Näppä et al., 2016) and music therapy (Hilliard, 2003; Magill, 2009).

anticipatory grief (study

Complicated grief (study

no. 18)

no. 19)

#### Table 7

Mapping interventions targeted on cancer nursing and understandings of grief/

Nursing care targeted grief and/or bereavement

#### Category 1: Communication

Caring for children of parents who are dying: (Study no. 10)

General considerations:

Talk early; Be honest, Don't be afraid to say "I don't know"; Children grieve in chunks. Conversation guidelines:

Create the environment; Explain that there are medicines for comfort; Ask the child
if he/she wants to be told what changes to expect in the parent during the dying
proces; Check in with the child frequently; Encourage children to ask questions;
Encourage families to grieve together.

Caring for people with intellectual disability: (Study no. 12)

- Cancer nurses should ensure that people with ID in their patients' social circle are included in the family unit and receive adequate emotional support.
- They should be proactive in giving them information that is easy to understand.
- Using fictional stories can be particularly helpful in eliciting questions and concerns Offering a theory-driven FAM-SOTC intervention for bereaved family caregivers:

  (Study no. 22)
- Supporting the cognitive, affective, and behavioral domains of the family member's illness experience.
- The nurse creates a calm and trusting environment and space for the bereaved caregiver to talk about his/her concerns.
- The nurse organizes and uses the therapeutic questions during the conversation depending on the bereaved caregivers' experience/situation, concerns, and difficulties.
- The nurse acknowledges emotions expressed by the bereaved caregiver and offers hope
- The nurse provides information about resources available from the community and the health care system.
- The nurse uses each opportunity during the conversation to affirm the strengths and potential resources of the bereaved caregiver

Caring (letter writing) for female patients with breast cancer who have lost a breast and grieve due to body alterations: (study no. 8)

- Nurses can use letter writing as a means of assisting patients through the grief process associated with body image alterations
- The process begins with identification of the body part that will be lost or changed.
   Once the patient has expressed his or her feelings about the upcoming treatment, he or she is instructed to write a letter (as homework) to the affected body part, describing his or her reactions to its impending loss.
- When the patient returns for the next session, he or she is asked to read the letter out loud to the healthcare provider. This creates an additional opportunity for catharsis.
   At the end of the session, the patient is given another homework assignment. This time, the threatened part or function "writes" back to the patient.
- At the next meeting, the patient is encouraged to read the letter from the body part
  to the therapist. This way, an active dialogue is set up between the patient and the
  removed or altered body part. This letter writing between the patient and the
  affected body part continues until the patient has diverged from his or her previous
  physical sense of self and is forming a new, more holistic identity.

Promoting optimism among patients: (Study no. 13)

- Nurses will need to give themselves permission to be optimistic, and to care with a
  good sense of humor. Being happy, grateful, even laughter, may help patients feel
  that they are in an optimistic environment.
- Assess patients verbal and nonverbal expression of optimism
- Optimism must be promoted, not imposed

Supportive telephone calls for bereaved family members: (Study no. 4)

- · A telephone call a months after the death of the significant other
- Meeting the needs of the bereaved family member from the time of death and 1
  month after the death.
- Help the bereaved family member to gain knowledge about grief reactions; available bereavement support; Gain knowledge about the illness and death of their loved one
- Listening and answering questions asked
- Completing the relationship between the bereaved family member and nurse Tele-care via telephone conferences: (Study no. 7)
- Guided by the Hogan's Model of Bereavement to provide care and education
- Care of self/social support; Stress reduction
- Nourishing one's body and spirit
- Communication with health care providers, visitors and patient. Pain control.
- Life planning

<u>A telephone intervention program for pediatric oncology targeted bereaved parents:</u> (Study no. 17)

- Parent focused objectives included that the program would help maintain parents' sense of connectedness with the hospital
- Making contact in the lead-up to particularly difficult anniversaries or 'special days' would be especially appreciated

#### Table 7 (continued)

Nursing care targeted grief and/or bereavement

- A call reminder system individualizing each child's special dates was developed to assist nurses planning bereavement care.
- The designated nurse, representing the oncology team, attended the child's funeral and subsequently telephoned the family at appropriate times until 13 months after the child's death.
- They would also send personalized cards at special times such as the child's birthday.
- The program linked with other support groups, health professionals, resources and services as necessary.

#### Category 2: Bereavement Care

Bereavement care for families who has lost a child: (Study no 1)

- Numbness and shock. Examples of nursing care behavior: Genuine empathy and respect; Active listening, touching; Validation of normalcy of feelings
- Intense grief. Examples of nursing interventions: Patience and support for unhurried
  grieving; Give telephone number of unit and invite parent(s) to calf; Remind family
  they will be contacted again; Give bereavement literature; Provide list of support
  groups; Inquire about diet, sleep, exercise; Invite expressions of feelings or
  experiences

What to say to the bereaved:

It must be hard for you; Would you like to talk? I'll listen; You have a right to your
feelings; You will have good days and bad days and it's okay not to feel guilty for
having a good day; Grief is a process that takes as long as you need it to; There is no
right way to grieve and everyone grieves differently – trust your own process

Inappropriate to say in nursing care:

I know just how you feel; It's such a blessing that he/she died; it was Gods will; You
can always have more children; Be strong for your family; Don't cry; Look how well
he/she is doing; You will get over this in time; It's been six months, a year, etc. You
must be over it by now.

Nurses' perspective towards bereavement care: (Study no. 15)

 Elements of good bereavement care: Providing good nursing care to the dying patient; Informing progress/prognosis on time and regularly providing updated information on a patient's condition; Providing physical comfort to the bereaved

 $\underline{\text{Postmortem care}-\text{support for families' in the initial grieving:}} \ (Study \ no. \ 16)$ 

To aid the family in the grieving process

- Immediately after death, it is very important that the nurse express sympathy toward family. A simple statement, such as, "I am sorry for your loss," is all that is necessary.
- Assure the family that they may take as much time as needed to be with their deceased loved one and say their goodbyes.
- Explain to the family what will happen now that their loved one has died
- Ask the family if there is anything that is important in their family or culture to do at the time someone dies.
- Invite family members to participate in the bathing if they want to. Assure hesitant
  family members that you will lead the way and show them what to do.
- During the bathing: If it seems appropriate, invite family members to share memories and stories from the person's life
- Read aloud the nondenominational honoring words or simply pause to honor the
  person's life and death, perhaps by saying, "We pause a moment to honor [patient
  name]'s life and to acknowledge her/his transition.

Finding balance interventions (FBI) for older adults: (Study no. 17)

- The Findings Balance Interventions (FBI) is a self-administered writing tool, theoretically inspired by the Dual Process Model (DPM). The FBI describes three processes of finding balance, with specific examples from others in similar situations and writing exercises to encourage reflection, expression of emotions, and personal and creative ways to find balance in each person's unique journey
- Deep Grieving consists of activities that address the emotional aspects of grief: The
  grieving person is asked to write down "my emotions today", balanced with a
  planned "time out" activity that works for them; Another activity in this section is to
  create a support system, listing supportive people their phone number, and how
  they are most helpful
- Walking a Fine Line, consists of planning specific activities that address ways to find
  a balance between the two extremes of grieving and looking forward; Specific
  suggestions for maintaining a balance of daily life include using a weekly calendar
  to schedule three activities a week for connecting with the outside world and three
  different ways to take quiet time for themselves.
- Moving Forward involves taking time to thoughtfully reflect on their caregiving story, and how what they have been through may also have made them stronger.
   Suggestions include making a list of activities that give them inner strength, reflecting on their experience of caregiving and loss and how this story and the lessons they have learned might help others

#### Category 3: Models and tools including interventions

Family-centered approach in the context of nursing care targeted patients living with malign brain tumor: (Study no. 5)

(continued on next page)

#### Table 7 (continued)

#### Nursing care targeted grief and/or bereavement

 The Clinical Nurse Specialist (CNS) uses a family approach inspired by The Calgary Family Assessment Model (CFAM) and The Calgary Family Intervention Model (CFIM)

Examples of interventions that the CNS can utilize:

- Storying the illness experiences, drawing forth strengths and resources between family members
- Giving information and emotional support and suggesting certain behaviors and tasks.
- · Using different types of circular questions and metaphors:
- Difference questions e.g. What is your best and the worst advice that you had received from the health care professional since your admission?
- Behavioral effect question e.g. In your opinion, which member of your family is the most affected by the illness?
- Dyadic question e.g. What do you feel is the most frustration for your spouse?
- Triadic question: What does your sister do to help your mother relieve her anxiety?
- Hypothetical question e.g. If your children were here today, what would be their main concern regarding your hospitalization?
- Future oriented questions e.g. Do you think that you can develop skills that will help you cope with the effects of the illness?
- The use of metaphors serves to stimulate reflection and modify the individual's
  perception of the situation by using the same wording as that of the individuals
  involved

Using "The Divorced Family–Focused Care Model": A Nursing Model to Enhance Child and Family Mental Health and Well-Being of Doubly Bereaved Children - Following Parental Divorce and Subsequent Parental Cancer and Death: (Study no. 20)

- · Phase 1: Collecting information about family structure:
- Step 1: Knowledge of parental collaboration, resources and other involved professionals
- Step 2: Mapping the family divorced family structure and resource persons;
   Content to access the child
- Phase 2: Assessment of support needs:
  - Step 1: Knowledge of child's well-being, future and relationships to divorced family structure (parents, step-parents, and grandparent)
- Step 2: Involve the child and divorced family; Assess needs of professional support
- Phase 3: Initiation of well-being support
- Step 1: Provide knowledge and support on age, reactions, signs of problems;
   Provide support possibilities
- Step 2: Gather divorced family and network (ex-partner, grand parents, school; Establish support
- Phase 4: Coordination and follow-up
- Step 1: Divorced family focused care; Provide information and support throughout illness, death, and bereavement
- Step 2: Designate a primary coordinator responsible for coordinating well-being support for the relative-child; Follow-up

Anticipatory Grief: An Evidence-Based Approach: (Study no. 18)

The anticipatory grief tools that can be utilized with patients and family members:

- Preparatory Grief in Advanced Cancer Patients Scale (PGAC): 31-Item selfassessment scale that measures anticipatory grief in Greek patients with advanced cancer
- Anticipatory Grief Scale (AGS): 27-Item self-administered scale that measures the bereavement experience of female spouses of dementia patients
- Marwit-Meuser Caregiver Grief Inventory: 50-Item self-report scale that measures grief response of family caregivers of people with Alzheimer disease

Managing the anticipatory grief: Toolbox of Communication Skills Nurse Statements.

A framework of communication which focuses on recognizing, responding and validating emotional responses

- N: Name the emotion; "I see you are very frustrated"
- U: Understand the emotion; "It sounds like this has been a long, hard journey for you and your family"
- R: Respect what the patient, family, or caregiver tells you; "Your love and devotion to your children and family have been so evident to the staff"
- S: Support the patient, family, and caregiver; "You don't need to do this alone. Our team will be here to help you along the way"
- E: Explore the patient, family, or caregiver concerns; "Can you tell me more about what worries you?"

<u>Nursing care targeted children - when a parent dies of cancer:</u> (Study no. 6) Guiding parents and caring adults:

- Receive adequate information. Their fears and anxieties must be addressed, and
  they must be reassured that they are not to blame; Are carefully listened to. Their
  feelings must be validated and they must have help with overwhelming feelings;
  Have opportunities for involvement and inclusion in death rituals, have healthy
  grief behaviors modeled to them, and have opportunities to remember; Continue
  with their routine activities
- Although the family may meet some or all of these needs, such as allowing the children to participate in planning the funeral, more formalized interventions, such

#### Table 7 (continued)

Nursing care targeted grief and/or bereavement

as grief groups and counseling, may better meet the children's needs. Interventions can and often should be initiated prior to the parent's death

Recommendations for school personnel:

- Take time to reflect on your own feelings about illness and death.
- Familiarize yourself with death and dying theory; incorporate death and dying into the curriculum.
- Be available and caring; listen to students and their worries.
- Offer hugs when you can be assured they are appropriate; know that hugs can cause tears
- Boost self-esteem, which can be lowered after a parent's death; boost the healthy coping mechanisms that children do have.
- Be aware of anniversary dates and the grief behaviors that accompany the dates.
- Keep in contact with family members who can provide information about the child's functioning at home, as well as that of other family members.
- Know your limits; you may be prepared to deal with normal grief reactions but be aware of red flags that indicate complicated grief and make the appropriate referrals
- Practice self-care. You can't appropriately care for anyone else if you don't take care
  of yourself

#### Nursing care:

- Nurses interact with bereaved children in a variety of settings. They can be supportive by providing information about grief reactions and anticipatory grief.
   They can prepare family members for feelings of anger, isolation, and anxiety, and they can help individuals develop healthy coping mechanisms.
- Hospice nurses have an opportunity to care for a dying parent and the family as much as six months prior to the death and for months following the death. Hospice nurses often provide continuity of care and work to meet the children's grief and bereavement needs.
- Like hospice nurses, home health nurses work in the home environment and have
  opportunities to provide care, counseling, and referrals for bereaved children.
- Oncology nurses should consider the needs of the children of their dying patients, whether they work in inpatient or outpatient settings.
- Nurses in outpatient settings can provide suggestions to adults for care of the children, even though they might never meet the children of the patient. These nurses have opportunities for follow-up with the adults.
- Nurses in inpatient settings may see their patient's children during visits and can
  provide direct education and counseling to the children.
- School nurses have access to bereaved children and have the opportunity to focus
  on children without interruption from competing needs of other family members.
   School nurses and other school personnel can provide informal services as well
- Regardless of the practice setting, nurses can access a variety of bereavement resources to assist with the children's grief process

#### Category 4: Art

Using drawings in nursing care: (Study no. 9)

- It is evident from the literature that art can have a valuable role in cancer and
  palliative care. It has been used with success in helping children and adults to
  express conscious and unconscious feelings. The emphasis must not be on artistic
  skill, but rather on the process itself.
- Patients should be encouraged to explain their drawings if they wish. Assumptions
  regarding the work must not be made. However, analysis by a qualified therapist IS
  invaluable where patients are unable to articulate what they are experiencing, or
  where it is felt there are hidden issues
- Individual or group artwork may be used depending on the specific needs of individuals. The environment must be supportive and those engaged in conducting the art session non-directive. This is crucial in order that the patients or clients can express their true feelings freely.
- Not only may insight be gained in relation to thoughts and feelings, but also there is
  the potential for the development of the creative domain, with the possibility of
  enhancement of self-esteem at a time when morale is often at a low point

Using art in nursing interventions: (Study no. 2)

- Assess patients' spiritual needs, interests, and tastes. Learn what has brought comfort and joy in the past and what they have had fun doing. Suggest resuming these activities
- Provide space to display patient and family artwork in the clinical setting
- Develop a library of literature, poetry, quotations, art prints, photography, music tapes, and videos to support patients as well as families and staff.
- Discover the patient's favorite color and/or flower. Bring in flowers as appropriate
- · Keep plants and fresh flowers around the patient's bedside, when appropriate
- Assess the patient's environment noting what is in it as well as what is not. For
  example, note if the bulletin board is bare or filled with family pictures. Some
  patients are comforted by meaningful or symbolic objects, (ie, a "shrine). Create
  space for this.
- · Schedule a "pet visit" if the patient is an animal lover.
- Establish a collection of art materials, including blank books for writing that can be available to patients and staff at all times

(continued on next page)

#### Table 7 (continued)

#### Nursing care targeted grief and/or bereavement

• Discover the patient's favorite song or piece of music. Sing or play it for them, or find musicians who can. When possible, use live music, for there is always a special rapport that evolves between the performer and the listener that engenders a new creation that cannot be duplicated by recorded music.

#### Category 5: Palliative care

Nursing Care Strategies for Care of Family Members: (Study no. 11)

Help families regain control:

- · Encourage ill child to attend school (at hospital or regular school) as clinically possible. Even attending for a short time or sporadic attendance may facilitate social networking and increase sense of continuing the "work of childhood."
- · Encourage healthy sibling to visit ill child at hospital.
- · Encourage parent to consider taking sick leave or family leave from work, if
- Encourage parents to maintain discipline for ill and healthy children.
- · Promote family members to feel safe and secure

Promote family members to feel safe and secure:

- · Establish trusting relationships with parents
- · Encourage siblings to remain close to peers, teachers, and ill child.
- Encourage parents to spend time with healthy children.
- Encourage parents to spend time alone with each other.
- Provide honest answers to ill and healthy children's questions.

No regrets from family members:

- Help guide parents in decision-making process by providing adequate resources.
- Reassure families in their decisions (e.g., whatever decision is made, it is the right one for them).
- · Encourage families to spend and cherish time together.

Decrease sibling loneliness and isolation:

Include healthy siblings in conversation.

Provide opportunities for siblings to express their thoughts and concerns and

- Help inform healthy sibling of the ill child's status and changing goals of care.
- Offer suggestions to involve healthy sibling in care of ill child (eg, make a special gift, read a story, help make a meal, help pick out clothes).

#### Category 6: Complicated grief

Complicated grief interventions in oncology nursing: (Study no. 19)

- Recognize the risk factors associated with complicated grief (CG) to ensure that family caregivers receive prompt interventions.
- Support family caregivers experiencing CG by offering condolences for their loss, providing referrals to grief counseling or supportive services, and allowing family caregivers to express their feelings about the loss.
- Provide efficient palliative care, symptom management, and patient and family education during the cancer trajectory to help prevent experiences of CG in family

#### Category 7: Spiritual care

Spiritual care for parents whose children with cancer face the End of Life: (Study no.

Providing support:

- · Relationships provided comfort (the supportive presence of staff, friends, and family members)
- · Spiritual care provided by nurses. Friends and family provided comfort and support. Enhance coping:
- The most important source of strength for parents who are caring for a dying child; strength was specifically found through God, hope, faith, and prayer. Parents also stressed the importance of maintaining a positive attitude and finding meaning in the death of the child
- · Faith was central to parents' ability to cope and make meaning of child's death; faith sustained and comforted parents.
- Most frequently employed coping mechanism: Increasing spiritual practices and searching for meaning

Instilling hope:

- Spiritual belief in afterlife provided hope
- · Finding meaning and purpose:
- · Assisted parents to find meaning and purpose in child's death

Developing continuing bonds:

- Religious beliefs allowed parents to maintain a bond with child after death. Building the child's legacy important to parents
- · Keeping the memory of the child alive was a key factor for parents to successfully move forward in life
- Parents identified spiritual resources that helped them get through their child's death, including belief in the transcendent nature of the relationship with the child

Cultural care in cancer nursing: (Study no. 3)

#### Table 7 (continued)

Nursing care targeted grief and/or bereavement

Guidelines for patient/family assessment with culturally diverse populations coping with end of life care:

- · Assess the language used to discuss this patient's illness and disease, including the degree of openness in discussing the diagnosis, prognosis and death itself
- Determine whether decisions are made by the patient or a larger social unit, such as the family
- · Consider the relevance of religion beliefs, particularly about the meaning of death, the existence of an afterlife, and belief in miracles
- Determine who controls access to the body and how the body should be approached after death
- · Assess how hope for a recovery is negotiated within the family and with health care professionals
- Assess the patient's degree of fatalism versus an active desire for the control of events into the future
- Consider issues of generation or age, gender, and power relationships, both within the patient's family and in interactions with the health care team
- Take into account the political and historical context, particularly poverty, refugee status, past discrimination, and lack of access to care
- To aid the complex effort of interpreting the relevance of cultural dimensions of a particular case, make use of available resources, including community or religious leaders, family members, and language translator

#### 9. Understandings of grief and/or bereavement

Understanding grief and bereavement among children of parents who are dying from dying: (Study no. 10)

· Children of different developmental levels have varying abilities to understand concepts involving cancer and death. Yet, children are of all ages react to the separation of a parent and benefit from having cancer and death described to them in clear, concrete language. Regardless of age, some children will want more information than others.

Nursing care and understandings of bereavement among children, when a parent dies of cancer: (Study no. 6)

Children's common responses to parental bereavement:

- 0-3 months: The infant grieves for loss of nurturance and can be soothed by a
- · 4 months to 2 years: The child grieves the loss of a specific person and will search for that person, eventually giving up the search. He or she may feel despair and lose interest in previously enjoyable activities.
- 21/2- 5 years: The child's grief expressions are intermittent, but grief feelings are persistent. The child's behavior may regress, becoming clingy and dependent and repeatedly asking for the deceased person. Feelings of anger may be directed toward the living parent. The child may think obsessively about the deceased parent
- 5-8 years: The child uses denial to deal with loss, appearing as if nothing is wrong. The child may fantasize about the deceased, feel guilt, and fear for the health and well-being of other family members. The child may appear self-reliant.
- $\bullet~8\text{--}12$  years: The child may fear sharing feelings of grief for fear of appearing childish. Angry feelings may manifest as irritability and may be punished or ignored by caretakers. He or she may have difficulty accepting the finality of death. The child may act grown up in an attempt to identify with the deceased parent, denying his or her helplessness. The child may become a caretaker or control the behavior of others
- · Adolescence: The child is expected to act adult-like but may feel childish, frightened, powerless, and dependent. Anger may be expressed; anger may feed depression and punishment of self and others. The child may be resistant to communicating with adults and concerned about acceptance of his or her grief behaviors. Guilt may lead to complications, including withdrawal, depression, and acting out

Range of common grief manifestations in children and adolescents:

- NORMAL OR VARIANT BEHAVIOR: Shock or numbness; Crying; Sadness; Anger; Feeling guilty; Transient unhappiness; Keeping concerns inside; Increased clinging; Disobedience; Lack of interest in school; Transient sleep disturbance; Physical complaints; Decreased appetite; Temporary regression; Being good or bad; Believing deceased is still alive; Adolescent relating better to friend than family; Behavior lasts days to weeks
- SIGN OF PROBLEM OR DISORDER: Long-term denial and avoidance of feelings; Repeated crying spells; Disabling depression and suicidal ideation; Persistent anger; Believing guilty; Persistent unhappiness; Social withdrawal; Separation anxiety; Oppositional or conduct disorder; Decline in school performance; Persistent sleep problems; Physical symptoms of deceased; Eating disorder; Disabling or persistent regression; Being much too good or bad; Persistent belief that deceased is still alive; Promiscuity or delinquent behavior; Behavior lasts weeks to months

Miles' model for parental grieving: (Study no. 1)

• The model identified four stages of grief according to 1) a time frame: 2) numbness, 3) yearning and protest, 4) disorganization, and reorganization

The understanding of anticipatory grief: (Study no. 18)

· Grief is a normal and expected reaction to loss

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#### Table 7 (continued)

#### Nursing care targeted grief and/or bereavement

- Anticipatory grief is an emotional response that is experienced before a true loss.
   Other terms for this prescient state include preparatory grief or premature grief.
- Anticipatory grief is a symptom that can be experienced by caregivers and patients, especially those coping with advanced disease. Frequently, symptoms of anticipatory grief are disguised as depression, anxiety, or pain.

#### The understanding of complicated grief in oncology nursing: (study no. 19)

- Manifestations of CG include (a) intense longing; (b) loneliness, emptiness, or lack
  of meaning in life; (c) recurring thoughts of wanting to join the deceased; and (d)
  intrusive thoughts about the deceased that interfere with functioning.
- Individual signs and symptoms of CG also may include feelings of guilt over the
  death; constantly replaying the circumstances of the death in their mind; imagining
  that they could have somehow prevented the death if they had done something
  differently; and feeling numb, shocked, or in disbelief over the death. The nature of
  the relationship to the deceased, personality traits, coping style, psychiatric history
  and comorbidities, and socioeconomic factors all contribute to the risk of CG.

#### The Hogan's Model of bereavement - 10 phases: (Study no. 7)

- 1. Getting the diagnosis: a) Shock b) Calculating the odds
- Dedicating ressources: a) Family being there for the patient b) Accommodating care
- 3. Negotiation treatment: a) Fighting for life b) Enduring stress c) Shutting it out
- 4. Losing the battle: a) Seeing the obvious b) Ending the suffering

#### Death occurs

- 5. Finding out about the death
- 6. Facing realities of the death
- 7. Becoming engulfed with suffering a) Missing, longing, yearning: Enduring hopelessness, existing in the present, reliving the past. B) Making sense: Aching with physical pain, Getting through the day
- 8. Emerging from the suffering/embracing hope
- 9. Getting on with life
- 10. Experiencing personal growth
- The dual proces model: (study no. 17, 20)
- The Dual Process Model (DPM) of coping with bereavement describes everyday life
  experiences of adaptive coping as a back and forth oscillation between both loss
  (including grief work, denial, and intrusion of painful emotions) and restoration
  processes (including doing new things, distraction and seeking new identities). The
  essence of adaptive grieving is found in accommodating the loss while also
  engaging in activities to promote restoration

#### The understanding of double bereavement: (Study no. 20)

In this article, we use the term—double bereavement to refer to the double loss and
grief experienced as a consequence of parental divorce in combination with the
subsequent death of the parent or development of a parent's critical illness where
death is imminent or expected.

To further explore and identify even more existing knowledge on interventions and understandings of grief and bereavement relevant for nursing care the context could be expanded also to include multidisciplinary studies and other mono-disciplinary professions in palliative cancer care. Also it can be expanded to include patients and families perspectives about nursing care targeted their grief and bereavement experiences (Kim et al., 2013). In 2018 the new diagnosis prolonged grief disorder were presented by WHO (World Health Organisation, 2018). There was a lack in this study identifying knowledge about prolonged grief. Meanwhile there will be a need in the future to investigate, how nurses should both prevent this in patients and family's life and how to target support towards people with this diagnosis.

#### 4.3. Implication for clinical practice

This scoping review contributes with an overview and mapping of existing evidence targeted nursing care in relation to patients and families experiencing grief and/or bereavement during cancer illness and death. Thus, it presents an overview of understandings of the two concepts – grief and bereavement – in the context of cancer nursing. Results from present scoping review can be used to develop nursing knowledge about understandings of grief and bereavement when caring for patients and their families during cancer illness. Also, results can contribute to develop nursing, when caring for patients and their families, who experience grief and bereavement within their trajectory of cancer illness. Present scoping review can also contribute with relevant knowledge and inspiration for nursing interventions in contexts beyond

cancer nursing – where findings are found transferable to other life threatening and/or chronic illnesses. Also researches can use this scoping review to identify gaps of knowledge and hence areas which also calls for further research to be conducted in order to ad evidence to these knowledge gaps.

#### 5. Conclusion

Present scoping review aimed to explore existing knowledge on nursing care and nurses' understandings of grief and bereavement targeted patients and their families throughout the course of cancer illness. Twenty-two studies were included in this scoping review published in the period of 1995-2021. The mapping of findings revealed eight categories targeted interventions to support patients and families during grief and bereavement. These covers a broad spectrum of interventions in relation to e.g. communication, using artwork, including cultural and spiritual care, bereavement care after the loss of a loved one and supporting coping strategies. Also the mapping included studies presenting models for identifying needs and interventions to support families during grief and bereavement. Moreover, a 9th category was identified related to understandings of grief and/or bereavement in nursing care. This covers e.g. the dual process model of bereavement, the Hogan's model of bereavement, anticipatory grief, double bereavement and understanding the grief and bereavement proces among children. These categories can be used as inspiration, when developing nursing care for patients and families targeted grief and bereavement. Furthermore present scoping review map the population groups within the included studies: 1) Children/parents, 2) Patients and 3) Family. This revealed a gap of knowledge in regards of studies focusing on nursing care targeted grief and understandings of grief among patients. In addition, gaps of knowledge were identified related to the nine developed categories. Further, gaps where identified in the discussion, when reflecting on nonexisting categories in nursing care, e.g. using music when caring for patients of families experiencing grief or bereavement.

#### Declaration of competing interest

None to declare.

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