

Health practices in Europe towards families of older patients with cancer: a scoping review

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Abstract

Introduction: In Europe, cancer is one of the predominant causes of mortality and morbidity among older people aged over 65. A diagnosis of cancer can imply a negative impact on the quality of life of the older patients and their families. Despite research examining the impact of cancer on the family, it is unclear what kind of information is available about the types of clinical practice towards older patients with cancer and their families. The aim is to determine the extent, range and variety of research in Europe describing health practices towards families of older patients with cancer and to identify any existing gaps in knowledge.

Methods: Scoping review.

Results: A total of 12 articles were included, showing that family interventions are generally based on end-of-life care. Most studies used a qualitative approach and involved different types of family member as participants. Most studies were conducted in the UK.

Conclusions: Review findings revealed limited knowledge about health practices in Europe towards families with an older patient with cancer. This review indicates a need to increase family-focused research that examines health practices that meet the needs of families of older patients with cancer. Seeing cancer as a chronic disease, there is an urgent need for the implementation of family-focused interventions.

Keywords: cancer, ageing, Europe, professional practices, review.

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Background

According to the 2018 Ageing Report by the European Commission (1), Europe's population continues to age significantly. The number of persons aged 65 and above in the European Union (EU) is projected to increase by 10 percentage points, from 19% in 2016 to 29% in 2070 (1). The projected changes in the population structure in

Europe show health challenges and a need for new strategies for sustainability of long-term care due to the increase in chronic diseases, particularly in the elderly (2). According to CHRODIS PLUS – Joint Actions on Chronic Diseases, a 3-year initiative (2017–2020) funded by the European Commission and the participating partner organisations to share best practices to alleviate the burden of chronic diseases, 65% of people over 65 are affected by multimorbidity. This number rises to 85% for the 85-year-old group (<http://chrodis.eu>).

Among the older population, cancer is one of the predominant causes of mortality and morbidity (3,4), and disease and treatment can imply a negative impact on

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the quality of life of the elderly (5). In addition to the physical and psychological repercussions, a diagnosis of cancer in an older person has an impact on the health experiences and functioning of their family (6-8). This is because an illness such as cancer is a family affair and families engage in collaborative efforts throughout the life course, especially in the old age due to the natural changes in this stage (9,10). These families might need additional education and support interventions from healthcare professionals in order to manage the healthcare situation on a daily basis (11). The diagnosis of cancer in combination with ageing (physical and psychological changes) (12) can imply changes in the family dynamics and roles and a mutual state of suffering: patients suffer because of the physical and emotional impact of cancer and its treatments and family members suffer from seeing their relative being afflicted. Furthermore, often older patients with cancer live at home and depend on their caregivers for support with cancer treatment, the management of chronic diseases and activities of daily living (13). Therefore, caring for their frail relative may add to the experience of distress. Kehoe et al. (14) conducted a cross-sectional study of baseline data from nationwide research of older patients with advanced cancer aged 70 and older and their family caregivers, to evaluate the relationships between the geriatric assessment which includes validated test to assess domains of health (cognitive, functional, etc.) for older patients with advanced cancer and the quality of life of caregivers. Their findings supported that patient impairments were associated with poorer emotional health and lower quality of life of caregivers.

There is a wealth of research examining the importance of family for patients and on the impact of illness on family members (6,8,10,11). However, often these studies do not assume the family as a unit. That is why some authors question: 'Who will care for the caregivers of older patients with cancer?' (15). Or, rather, who is going to approach the family as the unit of care? (16).

The importance of family health has a global interest. A recent paper reviewing the systematic reviews on family involvement in adult chronic disease care, including cancer, showed that when the intervention focused on the family the outcomes showed more often decreased depressive symptoms for the patient and family members (17). Furthermore, the authors encouraged the development of interventions for specific patient groups which take into consideration the context in order to increase intervention effectiveness. The review above took a global perspective; however, we also have to consider that the healthcare practice and the role of health professionals are patterned and consistent with how the countries or regions healthcare system is organised, financed and managed. Furthermore, family caregivers, who are family members and friends who provide care to their loved one

with a chronic illness or long-lasting healthcare need such as cancer, have different caring experiences according to their social and cultural contexts. Therefore, it is important also to examine specific contexts of care such as the healthcare practice of families with an older member suffering from cancer from a European perspective that has not been explored so far.

Eurocarers – the European Association Working for Carers – in joint collaboration with the European Cancer Patients Coalition (ECPS) published in 2017 a White Paper that presented recommendations for a strong policy framework supporting cancer caregivers (18). Besides, this White Paper emphasises the need for specific care towards the needs of cancer carers in Europe. Multicomponent interventions for caregivers are needed, given their crucial role for cancer patients.

Furthermore, European guidelines to improve comprehensive cancer care are committed to inclusion of family in patient care (19). However, it is unclear what kind of information is available in the literature about the type of clinical practices put in place for older patients with cancer and their caring family members. Therefore, this paper aimed to determine the extent, range and variety of research in Europe describing health practices towards families of older patients with cancer, as well as to identify any existing gaps in knowledge. By health practice, we refer to the clinical practice in which nurses, doctors, psychologists and social workers develop assessment, information seeking, diagnosis, planning and intervention with older people with cancer and their families (20).

Materials and methods

Type of review

A scoping review was developed to determine the coverage of the literature published on health practices in Europe towards families of older patients with cancer and to map the existing studies on this topic (21). This type of review was considered the most appropriate to respond to the aim of this study, since the evidence on the examined topic is emerging and there are no specific questions that can be posed and valuably addressed by a more precise systematic review (22).

The review was conducted by European researchers from the FAMily health in Europe – Research in Nursing group (FAME-RN) (23). The method followed the recommendations for the conduct of scoping reviews from the Joanna Briggs Institute (24), updated in 2017 (21), based on earlier work by Arksey and O'Malley (25). To facilitate complete and transparent reporting and to improve the quality of the research, the Preferred Reporting Items for Systematic reviews and Meta-Analyses extension for Scoping Reviews (PRISMA-ScR) (26) checklist was used. Methodologically, this meant including the following

steps: identifying the research question, identifying relevant studies, study selection, charting data, summarising and reporting of results. As this scoping review did not aim to produce a critical appraisal of the results of the studies, and rather aimed to provide an overview and map of the evidence, an assessment of methodological quality of the studies was not performed (22).

Research question

What are the health practices in Europe towards the families of older patients with cancer?

Electronic searches

PubMed, CINAHL and Cochrane databases were used to identify publications until October 2018, using a combination of the following key terms: 'family', 'health practice', 'older adults', 'Europe' and 'neoplasm'. To ensure the best possible support to identify relevant studies, help was sought from research librarians who supported the development of the search protocol (see Table 1). The review was limited to available full-text articles describing primary research. Grey literature (i.e. unpublished, policy documents and expert opinion) was excluded from this review. Furthermore, papers were only included if they were written in English, German, Spanish, Danish, Norwegian, Swedish or French as these languages were read and understood by the research team. Studies which were not more than 10 years old, so as to include the most recent knowledge, were included. No limitation was used in relation to study design, but studies reporting findings from a feasibility study were excluded, as this was not considered an actual occurring practice.

Criteria for considering studies for this review

The following inclusion criteria were applied:

- Had to be conducted in a European country
- Patients having a mean age of 65 years or above, if no mean age was described the median age had to be above 65 or the range of age had to have its maximum above 65
- Patients diagnosed with cancer or if studies include patients with complex illness diagnoses, this would have to also include patients with cancer
- Had to include a type of healthcare practice. In this review, health practice is based on clinical and education activities: (i) delivered in any health or social setting (hospital, the community, home, etc.); (ii) aimed at any of the following domains: physical, psychological, social, spiritual, economic or environmental; and (iii) based at any of stages of 'The Cancer Control

Continuum' defined by the National Institute of Cancer (27), that is prevention, early detection; diagnosis and treatment, survivorship or end-of-life care.

- The health practice had to have a family health approach.

The exclusion criteria were as follows:

- Studies published in European journals but reporting results or experiences of health practices in other countries outside of Europe (i.e. the United States, Brazil and Japan)

Data extraction and management

The results of the literature search, having deduced duplicated findings, were sent from the librarians to the researchers. Publications were then inserted into Zotero, a software program that enables the online sharing of papers. Six of the researchers divided themselves into three groups, who in pairs assessed the title, abstract and keywords of the papers. Each group assessed the assigned papers and divided them into the following three groups: A, highly recommended to include, B, not clear subject for discussion and C, exclude.

The whole group met twice online and discussed at the first meeting the papers in group B and decided in which group to place the paper, and in the second meeting, the group discussed the final selection of papers. No manual search for documents was done.

After the final list of included papers was agreed upon (see Table 2), the first author extracted data and presented them in a matrix (see Table 3). The extracted data were first discussed with the last author. Then, the whole group of researchers met at a face-to-face European two-day seminar in Denmark, discussed extracted data and drew 15 random papers from the excluded list to once again validate the selection process. See Figure 1 for the selection process.

Data analysis and synthesis

The analysis and synthesis of findings was done narratively, inspired by Pedersen et al. (28). This meant that we build a thematic construction, listed extracted data in the construction and discussed them in the research group which consisted of experts in the field and as such findings were continuously synthesised.

The thematic construction of the matrix was the phase of illness of the family member with a cancer illness, design of study, which family member(s) contributed in the study, which countries the study was conducted in, context of care and description of the actual health practice, and the experience of patients, family members or healthcare professionals of the actual practice.

Table 1 Search protocol, keywords and search strategy

Medline	Cinahl	Cochrane library
1. Family Nursing/	S1 (MH "Family Nursing")	#1 (((("adult child*" or carer* or caregiv* or daughter* or families or family or husband* or "next of kin" or relatives or son or sons or spouse* or wife or wives) NEAR/5 ("clinical practice*" or "community health" or counsel* or educat* or "general practice*" or geriatric* or "health care" or healthcare or "health practice*" or "health visit*" or "home care" or intervention* or medicine or "medical practice*" or nursing or nurse* or physician* or "primary care" or "professional practice*" or program* or psychol* or psychotherap* or rehabilitation or "social care" or "social practice*" or "social work*" or support* or telenursing or telemedicine or therap*)):ti,ab,kw OR (((family or families) NEAR/2 (center* or focus* or health* or practice*)):ti,ab,kw
2. Professional-Family Relations/	S2 (MH "Professional-Family Relations")	#2 ("adult child*" or carer* or caregiver* or daughter* or husband* or family or families or "next of kin" or relatives or son or sons or spouse* or wife or wives):ti,ab,kw
3. exp Social support/	S3 (MH "Counseling+")	#3 (aged or aging or centenarians or elder* or nonagenarians or octogenarians or old or older or senior*):ti,ab,kw
4. exp Counseling/	S4 (MH "Health Education")	#4 (cancer* or carcinoma* or neoplasm* or tumor* or tumour*):ti,ab,kw
5. Health Education/	S5 (MH "Health Care Delivery")	#5 (Europe or Andorra or Austria or Balkan or Belgium or France or Germany or Gibraltar or "Great Britain" or England or Scotland or Wales or Greece or Ireland or Italy or Liechtenstein or Luxembourg or Monaco or Netherlands or "Nordic countr*" or Portugal or Denmark or Finland or Iceland or Norway or "San Marino" or Scandinavia* or Sweden or Spain or Switzerland or "United Kingdom" or Albania or Baltic or Estonia or Latvia or Lithuania or Bosnia or Herzegovina or Bulgaria or Croatia or Czech or Hungary or Kosovo or Macedonia or Moldova or Montenegro or Poland or Belarus or Romania or Russia or Serbia or Slovakia or Slovenia or Ukraine) OR AB (Europe or Andorra or Austria or Balkan or Belgium or France or Germany or Gibraltar or "Great Britain" or England or Scotland
6. Delivery of Health Care/	S6 (MH "Nursing Care+")	
7. Practice Patterns, Physicians'/	S7 (MH "Nurses+")	
8. Practice Patterns, Nurses'/	S8 (MH "Community Health Services")	
9. exp Nursing Care/	S9 (MH "Community Health Nursing+")	
10. exp Nurses/	S10 (MH "Community Mental Health Services+")	
11. Nursing/	S11 (MH "Home Health Care+")	
12. exp Nursing Process/	S12 (MH "Nursing Practice+")	
13. Community Health Services/	S13 (MH "Medical Practice")	
14. exp Community Health Nursing/	S14 (MH "Occupational Therapy Practice")	
15. Community Mental Health Services/	S15 (MH "Practice Patterns")	
16. Home Care Services/	S16 (MH "Primary Health Care")	
17. Home Health Nursing/	S17 (MH "Family Practice")	
18. Home Care Services, Hospital-Based/	S18 (MH "Physicians+")	
19. Home Nursing/	S19 (MH "Telehealth+")	
20. Primary Health Care/	S20 (MH "Occupational Therapists")	
21. Health Services for the Aged/	S21 (MH "Rehabilitation+")	
22. Family Practice/	S22 (MH "Social Work Practice")	
23. exp Physicians/	S23 (MH "Social Workers")	
24. exp Telemedicine/	S24 (MH "Psychotherapy+")	
25. Occupational Therapists/	S25 (MH "Psychologists")	
26. Cardiac Rehabilitation/	S26 (MH "Psychotherapists+")	
27. Occupational Therapy/	S27 TI ((((("adult child*" or carer* or caregiv* or daughter* or families or family or husband* or "next of kin" or relatives or son or sons or spouse* or wife or wives) N5 ("clinical practice*" or "community health" or counsel* or educat* or "general practice*" or geriatric* or "health care" or healthcare or "health practice*" or "health visit*" or "home care" or intervention* or medicine or "medical practice*" or nursing or nurse* or physician* or "primary care" or "professional practice*" or program* or psychol* or psychotherap* or rehabilitation or "social care" or "social practice*" or "social work*" or support* or telenursing or telemedicine or therap*))) OR AB ((((("adult child*" or carer* or caregiv* or daughter* or families or family or husband* or "next of kin" or relatives or son or sons or spouse* or wife or wives) N5 ("clinical practice*" or "community health" or counsel* or educat* or "general practice*" or geriatric* or "health care" or healthcare or "health practice*" or "health visit*" or "home care" or intervention* or medicine or "medical practice*" or nursing or nurse* or physician* or "primary care" or "professional practice*" or program* or psychol* or psychotherap* or rehabilitation or "social care" or "social practice*" or "social work*" or support* or telenursing or telemedicine or therap*)))	
28. exp Rehabilitation/		
29. exp Social Work/		
30. Social workers/		
31. exp Psychotherapy/		
32. ((adult child* or carer* or caregiv* or daughter* or families or family or husband* or next of kin or relatives or son or sons or spouse* or wife or wives) adj5 (clinical practice* or community health or counsel* or educat* or general practice* or geriatric* or health care or healthcare or health practice* or health visit* or home care or intervention* or medicine or medical practice* or nursing or nurse* or physician* or primary care or professional practice* or program* or psychol* or psychotherap* or rehabilitation or social care or social practice* or social work* or support* or telenursing or telemedicine or therap*)):ti,ab,kf.		
33. ((family or families) adj2 (center* or focus* or health* or practice*)):ti,ab,kf.		
34. or/1-33		
35. Caregivers/		
36. Family/		

Table 1 (Continued)

Medline	Cinahl	Cochrane library
37. Adult Children/ 38. Spouses/ 39. (adult child* or carer* or caregiver* or daughter* or husband* or family or families or next of kin or relatives or son or sons or spous* or wife or wives).ti,ab,kf. 40. or/35-39 41. exp Aged/ 42. (aged or aging or centenarians or elder* or nonagenarians or octogenarians or old or older or senior*).ti,ab,kf. 43. or/41-42 44. exp Neoplasms/ 45. (cancer* or carcinoma* or neoplasm* or tumor* or tumour*).ti,ab,kf. 46. or/44-45 7. exp Europe/ 48. (Europe or Andorra or Austria or Balkan or Belgium or France or Germany or Gibraltar or Great Britain or England or Scotland or Wales or Greece or Ireland or Italy or Liechtenstein or Luxembourg or Monaco or Netherlands or Nordic countr* or Portugal or Denmark or Finland or Iceland or Norway or San Marino or Scandinavia* or Sweden or Spain or Switzerland or United Kingdom or Albania or Baltic or Estonia or Latvia or Lithuania or Bosnia or Herzegovina or Bulgaria or Croatia or Czech or Hungary or Kosovo or Macedonia or Moldova or Montenegro or Poland or Belarus or Romania or Russia or Serbia or Slovakia or Slovenia or Ukraine).ti,ab,kf. 49. or/47-48 50. 34 and 40 and 43 and 46 and 49 51. limit 50 to (Danish or English or French or Norwegian or Spanish or Swedish) 52. limit 51 to yr="2008 -Current"	S28 -TI (((family or families) N2 (center* or focus* or health* or practice*)) OR AB (((family or families) N2 (center* or focus* or health* or practice*))) S29- S1 OR S2 OR S3 OR S4 OR S5 OR S6 OR S7 OR S8 OR S9 OR S10 OR S11 OR S12 OR S13 OR S14 OR S15 OR S16 OR S17 OR S18 OR S19 OR S20 OR S21 OR S22 OR S23 OR S24 OR S25 OR S26 OR S27 OR S28 S30 (MH "Caregivers") OR MH ("Caregiver Burden") S31 (MH "Family") S32 (MH "Adult Children") S33 (MH "Spouses") S34 (MH "Daughters") S35 (MH "Sons") S36 TI ("adult child*" or carer* or caregiver* or daughter* or husband* or family or families or "next of kin" or relatives or son or sons or spous* or wife or wives) OR AB ("adult child*" or carer* or caregiver* or daughter* or husband* or family or families or "next of kin" or relatives or son or sons or spous* or wife or wives) S37 -S30 OR S31 OR S32 OR S33 OR S34 OR S35 OR S36 38 (MH "Aged+") S39 TI (aged or aging or centenarians or elder* or nonagenarians or octogenarians or old or older or senior*) OR AB (aged or aging or centenarians or elder* or nonagenarians or octogenarians or old or older or senior*) S40 -S38 OR S39 41 (MH "Neoplasms+") S42 TI (cancer* or carcinoma* or neoplasm* or tumor* or tumour*) OR AB (cancer* or carcinoma* or neoplasm* or tumor* or tumour*) S43 -S41 OR S42 S44 (MH "Europe+") S45 TI (Europe or Andorra or Austria or Balkan or Belgium or France or Germany or Gibraltar or "Great Britain" or England or Scotland or Wales or Greece or Ireland or Italy or Liechtenstein or Luxembourg or Monaco or Netherlands or "Nordic countr*" or Portugal or Denmark or Finland or Iceland or Norway or "San Marino" or Scandinavia* or Sweden or Spain or Switzerland or "United Kingdom" or Albania or Baltic or Estonia or Latvia or Lithuania or Bosnia or Herzegovina or Bulgaria or Croatia or Czech or Hungary or Kosovo or Macedonia or Moldova or Montenegro or Poland or Belarus or Romania or Russia or Serbia or Slovakia or Slovenia or Ukraine) OR AB (Europe or Andorra or Austria or Balkan or Belgium or France or Germany or Gibraltar or "Great Britain" or England or Scotland or Wales or Greece or Ireland or Italy or Liechtenstein or Luxembourg or Monaco or	or Wales or Greece or Ireland or Italy or Liechtenstein or Luxembourg or Monaco or Netherlands or "Nordic countr*" or Portugal or Denmark or Finland or Iceland or Norway or "San Marino" or Scandinavia* or Sweden or Spain or Switzerland or "United Kingdom" or Albania or Baltic or Estonia or Latvia or Lithuania or Bosnia or Herzegovina or Bulgaria or Croatia or Czech or Hungary or Kosovo or Macedonia or Moldova or Montenegro or Poland or Belarus or Romania or Russia or Serbia or Slovakia or Slovenia or Ukraine):ti,ab,kw #6 #1 AND #2 AND #3 AND#4 AND #5 Limit to year 2008-2018

Table 1 (Continued)

Medline	Cinahl	Cochrane library
	Netherlands or "Nordic countr*" or Portugal or Denmark or Finland or Iceland or Norway or "San Marino" or Scandinavia* or Sweden or Spain or Switzerland or "United Kingdom" or Albania or Baltic or Estonia or Latvia or Lithuania or Bosnia or Herzegovina or Bulgaria or Croatia or Czech or Hungary or Kosovo or Macedonia or Moldova or Montenegro or Poland or Belarus or Romania or Russia or Serbia or Slovakia or Slovenia or Ukraine) S46 -S44 OR S45 S47 -S29 AND S37 AND S40 AND S43 AND S46 S48 Limiters - Published Date: 20080101-20181231	

Results

This section is structured in three subsections: 'description of the included studies' that presents the methodological characteristics and contexts of the studies; 'type of healthcare practices towards families of older cancer patients' that includes the different clinical practices of health professionals with families of older patients with cancer; and 'experiences of families with older cancer patients' that refers to the perceptions and experiences of families with the care they received from professionals in the different phases of the cancer trajectory.

Description of the included studies

From over 1602 results in the selected databases, a total of 12 studies were included in the review. Of these studies, 11 had a qualitative design and one had a quantitative design. Six studies focused on patients with cancer (29-34), and six included patients with a diagnosis of multiple illness including cancer (35-40). Most studies (nine) included patients and families who were in the end-of-life care (29-30,32,35-40), one study included patients in different stages of illness (34), one study included patients undergoing inpatient cancer treatment (31), and one study included patients during survivorship (33). In the majority of studies, the relationship of family members as participants was spouses or partners, although other relationships such as children, sibling, son-/daughter-in-law, friend and carer were also described (Table 3).

Studies used a variety of data collection methods, either as the only source of data or in a combination of different methods: individual interviews with patients (nine) (30-31,34-40), individual interviews with family members (six) (30,34,37-40), individual interviews with healthcare professionals (three) (30-31,37), family interviews (one) (32), observations (one) (30), questionnaires

sent to relatives (one) (29) and interviews with key advocates from cancer organisations (one) (31). The context of care was in eight studies at the hospital (29,31-34,36-37,39), one study at home (40), two studies at the hospice (29,35), one study in district care (30), and two studies were conducted across sectors (32,38). Eight studies were conducted in the UK (29-30,34-37,39,40), one in Denmark (33), one in Norway (32), one in Cyprus (31), and one study included data from five different European countries (38).

Type of healthcare practices towards families of older cancer patients

Only limited information and not well-described healthcare practices were presented in the included papers. In a study from the UK (30), district nurses, patients who all had advanced cancer and their caregivers were interviewed and support visits at home were observed. The early support visits predominately included extensive assessment of patients' physical symptoms (over 50 symptoms were assessed in total, with pain, breathlessness, loss of appetite, nausea and tiredness assessed most). Besides, activities of daily living (mobility, eating and drinking, sleeping, selfcare and continence) and review of medications, dosage and side effects of treatment were assessed. The support visits also included the evaluation of the need for practical help such as mobility equipment and wheelchairs. Giving information to patients and family caregivers was also a key type of healthcare practice provided by district nurses. Giving information included a range of activities: providing general information about social services or Macmillan Nursing services, among others; explaining about treatments given in hospital, effects of chemotherapy on the patient's immune system or side effect of constipation with pain medication; and educating family members on medications, moving and handling the patient. Finally, enabling

Table 2 Characteristics of included studies

	<i>Author Title</i>	<i>Design</i>	<i>Aim</i>	<i>Participants and Data</i>	<i>Healthcare Context</i>
1	(Addington-Hall & O'Callaghan, 2009) A comparison of the quality of care provided to cancer patients in the UK in the last three months of life in inpatient hospices compared with hospitals, from the perspective of bereaved relatives: results from a survey using the VOICES questionnaire	Quantitative study	To compare hospice inpatient care and hospital care for cancer patients, from the perspective of bereaved relatives.	A total of 40 bereaved relatives to 40 persons who had died of cancer in the UK during 2002. Just under a third of the deceased had been above 80 years of age, a third had been above 70 years of age, and a fifth were below 60 years of age. Data: Questionnaires sent to informants who reported the death of a person with cancer.	Admission in the last 3 months of life to a hospice versus a hospital
2	(Griffiths, Ewing, & Rogers, 2013) Early support visits by district nurses to cancer patients at home: A multi-perspective qualitative study	Qualitative study	To present the findings of a multi-perspective study that explored how district nurse early support visits are both described and carried out.	Patients with advanced cancer from UK. Age range 53-85, median 72. Data: District nurses (focus group interviews, individual interviews and observation visits). Observations and interviews with patients and carers.	Early support visits from district nurses
3	(Payne et al., 2017) Enhancing integrated palliative care: what models are appropriate? A cross-case analysis	Qualitative study	Investigate accounts of hospice integration with local healthcare providers, to determine how service users and healthcare professionals perceived palliative care services and the extent of integration experienced and to investigate practices associated with care as experienced by patients, family carers and health professionals which promote or limit integration.	Patients from the UK, mean age 66 with a diagnosis of cancer, COPD or heart failure. Data: Interviews with patients (twice at two timepoints) and interviews with patients and carers combined.	Integrated palliative care
4	(Lowson et al., 2013) From 'conductor' to 'second fiddle': older adult care recipients' perspectives on transitions in family caring at hospital admission	Qualitative study	Explore the meaning of family caring for care recipients by drawing on older adults' perspectives about the impact of hospital admission on established family caring relationships.	Patients from the UK diagnosed with heart failure or lung cancer, mean age 79 years. Data: Interviews with patients.	Hospital admission
5	(Bailey, Hewison, Karasouli, Staniszewska, & Munday, 2016) Hospital care following emergency admission: a critical incident case study of the experiences of patients with advanced lung cancer and Chronic Obstructive Pulmonary Disease	Qualitative study	Explore experiences of patients with advanced COPD and lung cancer, their carers and healthcare professionals following emergency admission to hospital.	Patients diagnosed with COPD or lung cancer, mean age 72 years. Data: Interviews with patients, carers and healthcare professionals.	Emergency admission

Table 2 (Continued)

	<i>Author Title</i>	<i>Design</i>	<i>Aim</i>	<i>Participants and Data</i>	<i>Healthcare Context</i>
6	(den Herder-van der Eerden et al., 2017) How continuity of care is experienced within the context of integrated palliative care: A qualitative study with patients and family caregivers in five European countries	Qualitative study	Examine how relational, informational and management continuity of care are experienced by patients with advanced diseases and their family caregivers receiving care from several integrated palliative care initiatives in five European countries.	Patients with cancer, COPD or heart failure from the UK, Hungary, the Netherlands, Germany or Belgium, mean age 68 years. Data: Interviews with patients and relatives.	Palliative care
7	(Charalambous, Papadopoulou, & Beadsmoore, 2008) Listening to the voices of patients with cancer, their advocates and their nurses: a hermeneutic-phenomenological study of quality nursing care	Qualitative study	To investigate the views of patients with cancer and to explore their experiences in relation to the quality of nursing care in the Cyprus National Health and Insurance Scheme (private and public). In the light of the patients' views, the views of the nurses providing the service to these patients and the views of key advocates from the cancer associations were explored.	Patients from Cyprus with cancer, age range 21 to 68 years. Data: Interviews with patients, nurses, focus group interview with patients and key advocates from the cancer associations.	Cyprus National Health and Insurance Scheme
8	(Mason et al., 2016) 'My body's falling apart.' Understanding the experiences of patients with advanced multimorbidity to improve care: serial interviews with patients and carers	Qualitative study	Experiences and perceptions of people with advanced multimorbidity to inform improvements in palliative and end-of-life care.	Patients from the UK with multiple conditions including lung cancer, average age 76 years. Data: Interview with patients and family carers.	Acute admission
9	(Fjose, Eilertsen, Kirkevold, & Grov, 2018) 'Non-palliative care' – a qualitative study of older cancer patients' and their family members' experiences with the healthcare system	Qualitative study	Explore what older home dwelling cancer patients in the palliative phase and their close family members, as individuals and as family, experience as important and difficult when facing the health services.	Patients with cancer from Norway, mean age 79 years. Data: Family group interviews.	Norwegian health services
10	(Ledderer, la Cour, & Hansen, 2014) Outcome of supportive talks in a hospital setting: insights from cancer patients and their relatives	Qualitative study	To qualitatively assess the outcome of supportive talk from the pairs' perspective and to provide a nuanced understanding of psychosocial support offered to pairs in a hospital setting in Denmark.	Patients with cancer from Denmark, age of patients ranged from 54 to 81 years. Data: Interviews with pairs of patients and relatives.	Psychosocial support in a hospital setting
11	(Sinfield, Baker, Agarwal, & Tarrant, 2008) Patient-centred care: What are the experiences of prostate cancer patients and their partners? (17a70,13a55and70and5a55). Data: Interviews with patients and partners.	Qualitative study Testing or treatment for prostate cancer	To gain understanding of the experience of care of men with prostate cancer and their partners.	Patients with cancer from UK. 35 patients	

Table 2 (Continued)

Author Title	Design	Aim	Participants and Data	Healthcare Context
12 (Jack, Mitchell, Cope, & O'Brien, 2016) Supporting older people with cancer and life-limiting conditions dying at home: a qualitative study of patient and family caregiver experiences of Hospice at Home care	Qualitative study	To explore patients' and family caregivers' experience and perception of Hospice at Home care.	Patients with life-limiting conditions, principally cancer, from the UK. Aged 2 from 61 to 70, 3 from 71 to 80 and 11 from 81 to 90 years of age. Data: Interview with patients and caregivers.	Hospice at Home care

discussion between the district nurses and the patients and families was found an important practice for liaison, facilitation and referral. As described by the authors '*an example of liaison was a when a district nurse told the family she would contact the GP about an infected lymph node; facilitation was exemplified when a district nurse informed the family, she would arrange delivery of medications by the pharmacy. Referral was shown when a district nurse contacted another service, such as a specialist palliative care team*' (30, p. 353). These healthcare practices were described as valuable and supportive by patients and their caregivers, although district nurses reported to have difficulty in articulating the content of the early support visits.

In the context of hospice care, a study from UK investigated how hospices integrate with local healthcare providers (35) and described a support and supplementation and that some hospices provide inpatient facilities, home care, day care, outpatient clinics and bereavement support. However, the study did not present any specific information on the characteristics of these practices.

Communication was not described as a specific type of practice in the studies, but it was argued to be fundamental and critical for the effective practice and delivery of health care (29,37,39).

Experiences of older families with health care

Findings are also limited in relation to older patients' and families' experiences of the actual practices. In a study on hospice inpatient care, families were more satisfied with information in the hospice setting than in the hospital setting (29). In the acute care setting in hospitals, a study from the UK found that older patients had positive experiences in the acute phase, but lacked attention and experienced poor communication in the recovery phase (38). Receiving relevant information, experiencing effective communication with oneself as well as one's family, was in focus, and thereby viewed by patients from Cyprus as characteristics of quality nursing care (31). Across countries, the importance of information and communication was classified as informational continuity

and exemplified by patients not having to repeat their stories (37,38). In a Norwegian study characterised as effective communication (32) and in a Danish study characterised as supportive talk, the findings showed that the older patients and families valued the focus on inter-family relations (33).

With regard to care at the end of life, the experiences of the patients from the UK were that the family was responsible for care when the patient was in their own home, whereas the healthcare professionals were responsible during hospitalisation (36). In relation to interacting with healthcare professionals, the older patients and family within the context of integrated palliative care valued continuity of care (38) expressed as meeting a small number of healthcare professionals or relational continuity. In contrast, patients and carers struggled to cope with multiple care systems, services and staff. Lack of care coordination among the many service providers led to feelings of impersonal care (39).

Finally, being cared for by nurses who were clinical competent healthcare professionals was valued by patients treated for prostate cancer and their families in the UK (34) and valued by cancer patients from Cyprus (31). The characteristics of competencies were described as seeing the patients as a person with multidimensional needs by patients from different countries (38), meeting religious and spiritual needs by patients from Cyprus and the UK (31,40), and providing emotional support by patients from Norway (32).

Discussion

This scoping review reports findings identified through a systematic literature search, focusing on healthcare practices towards older patients with cancer and their families. In this review, few studies met our inclusion criteria, so, in general, we found a limited amount of research aimed at older patients and their families published in the Continent of Europe.

The scoping review displayed a limited productivity of research within Europe, and most of the studies were

Table 3 Data and findings in included papers

	<i>Phase of illness</i>	<i>Family relationship to patient</i>	<i>Country</i>	<i>Context of care</i>	<i>Description of the actual health practice, and the experience of patients, carers or healthcare professionals of the actual practice</i>
1	End-of-life care	Spouse, children, sibling, son-/daughter-in-law, friend, other relative	UK	Inpatient hospice and hospital	Hospice inpatient care. Relatives were more satisfied with information, communication and nursing care in the hospice setting, and there were no significant differences in feeling involved in decision-making or symptom control.
2	End-of-life care	Spouses or daughters	UK	District care	In early support visits, the following actions were undertaken by healthcare professionals <ul style="list-style-type: none"> • Assessment of physical care needs • Assessment and delivery of practical help • Information giving • Enabling talk Nurses found it difficult to articulate the actual practice.
3	End-of-life care	Carers	UK	Hospice	Hospices in Northern England provide support and supplement other providers. Patients and carers experience the provision as a supplement to the care received by the general practitioner and primary care integration with local health providers.
4	End-of-life care	Spouses, relatives, friends	UK	Hospital	Hospital admission as part of end-of-life care. Care recipients perceived family carers as 'conductors' when the patient was in their own home, as the carer then took responsibility for the coordination of care received and for the patient's well-being. When being in another care setting, the care recipient perceived the family carer as 'second fiddle' to paid staff, while still maintaining the carer relationship.
5	End-of-life care	Family carers	UK	Hospital	Emergency admission to acute care hospital. The patients had positive accounts of the care received in the acute phase. In the recovery phase, patients felt a lack of attention, lack of recognition of expert family, poor communication around care planning towards patients and relatives, and lack of continuity of care.
6	End-of-life care	Partner, parent, child or other	Netherlands, UK, Germany, Belgium, Hungary	Integrated palliative care initiatives (across sectors)	Integrated palliative care, where the initiative is an established local palliative care collaboration, at least two different organisations, direct patient care is provided, and healthcare professionals have a multidisciplinary background. Patients and carers experienced continuity of care as having relational continuity with a small number of healthcare professionals. Informational continuity when healthcare professionals were well informed and not having to repeat their stories. Management continuity when seen as a person with multidimensional needs and not a medical subject.

Table 3 (Continued)

	<i>Phase of illness</i>	<i>Family relationship to patient</i>	<i>Country</i>	<i>Context of care</i>	<i>Description of the actual health practice, and the experience of patients, carers or healthcare professionals of the actual practice</i>
7	In treatment	Not applicable	Cyprus	Hospital	Inpatient cancer care at major hospitals. The meaning of quality nursing care includes the following themes <ul style="list-style-type: none"> • Being treated for cancer in easily accessible services • Being cared for by nurses who provide emotional support and effective communication with them and their families • Being given health-related information by nurses • Being cared for by nurses with clinical competencies • Having their religious and spiritual needs met by the nurse • Being cared for by nurses who promote shared decision-making • Promoting family presence and involvement in care
8	End-of-life care	Family carers	UK	Hospital, outpatient and primary care	Acute hospital admission. Being treated for cancer in easily accessible services.
9	End-of-life care	Wife Husband Son Daughter Son-in-law Daughter-in-law Grandchildren Sister	Norway	Hospital and community	Living at home and receiving palliative care. Being cared for by nurses who provide emotional support and effective communication with them and their families.
10	Survivorship	Spouse Daughter	Denmark	Hospital	Psychosocial cancer rehabilitation targeting interpersonal communication between patient and carer and 5-day residential rehabilitation course. Being given health-related information by nurses.
11	Different stages in the treatment trajectory	Female partners	UK	Outpatient clinics at hospital	Being tested for or treated for prostate cancer within the last 6 months. Being cared for by nurses with clinical competencies.
12	End-of-life care	Spouse Husband Wife Daughter Son	UK	Home	Hospice at home care. Having their religious and spiritual needs met by the nurse.

conducted within only one European country (UK). The studies included a variety of different family members as participants and used different methods of data collection, for example, both individual and family interviews and interviews with healthcare practitioners and with key advocates from cancer organisations. Thus, the studies were primarily qualitative and descriptive, showing limited knowledge in the effectiveness of the health

interventions towards older patients and families. Therefore, there is a strong need within Europe to conduct family-focused intervention development and research among older patients with cancer to meet their needs for healthcare services, especially regarding the effectiveness of family nursing interventions within the cancer trajectory and to develop clinical guidelines that can be applied within European healthcare settings.

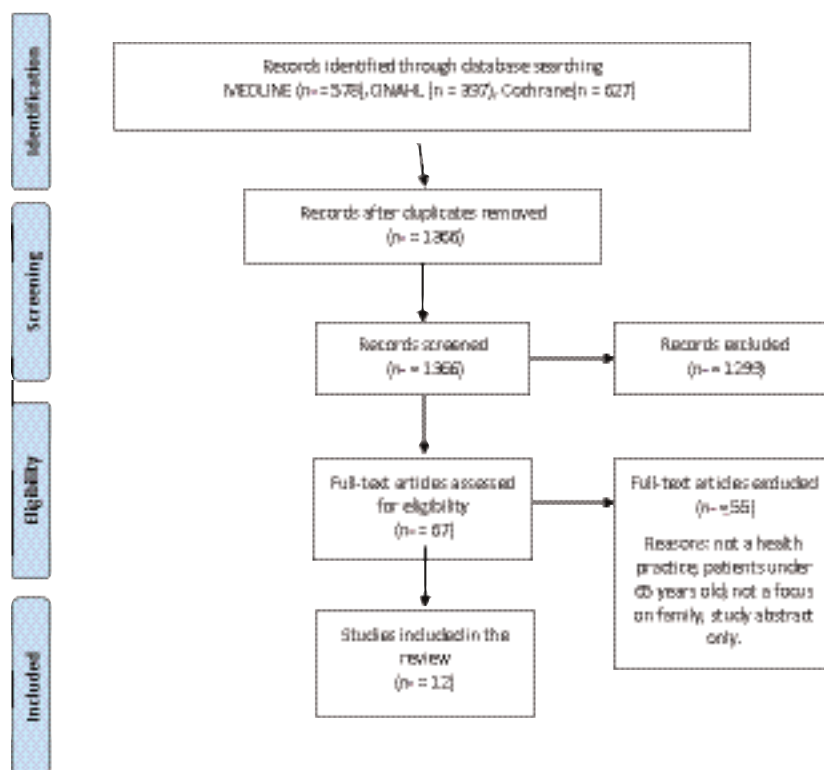


Figure 1 Prisma chart illustrating selection process.

Within the context of oncology, health practices are getting increasingly complex but needed, since cancer patients are living longer and are often dealing with several severe chronic illnesses at the same time (3). Cancer treatment is also getting more complex, with different treatment modalities including surgery, chemotherapy, hormonal therapy, immunotherapy and radiotherapy. Older patients are especially likely to experience complications (41), which demands qualified healthcare professionals and practices. Furthermore, this review showed that older patients with cancer and their family caregivers have to deal with multiple services and professionals that lead them to feel overwhelmed and lost (39). Family members reported physical and emotional exhaustion and felt undervalued by professionals (39). This might be because the role of family caregivers is still poorly understood (45). Therefore, it might be useful that centralised practices are being targeted at older patients and families with higher support needs, so to bring more family-centred support rather than service-centred support. Greater awareness of the needs associated with living with cancer in the older age and the coping strategies adopted by the patients and carers is needed, together with more centralised access to appropriate cancer care.

This review showed that most of the healthcare practices were based on the hospital or hospice environment where assessment and interventions focused on the

physical needs of the patients. When healthcare practices were based at home (30), other practices were carried out such as the assessment of family resources for care or education about symptoms management and daily living activities such as moving or handling the patient. Although these types of practices are relevant and necessary for quality care for the older patient with cancer, there is still a gap to meet the needs of both the patient and family members during the different phases of cancer. Geriatric assessment is increasingly being recognised as a good way to assess the functioning of the individual older patient (43), but systematic assessment of family functioning requires skills which may not always be present (44).

The caregiver burden is commonly experienced by family caregivers of older patients with cancer, particularly if the caregivers provide assistance with patients' activities of daily living (8). This burden impacts the health and quality of life of these caregivers, which may negatively impact the support that these caregivers are able to provide to the patient. Therefore, health practices are important to address the family as a unit of care. Family-focused perspectives including information and psychosocial support were valued characteristics of good health care in this review. This is in line with the results from a review on caregiver-mediated interventions, which showed that patient outcomes were improved through caregiver-mediated interventions focusing on

education and practical support, and caregiver outcome increased by the activation of the caregiver role and related information (48).

Nurses play a central role in the care of patients with cancer and cancer-nursing interventions can be delivered across all stages of the cancer continuum (46). Therefore, nurses have a central role in the development of health-care practices, which is also supported by a meta-analysis of intervention studies directed towards family caregivers of patients with cancer across the age spectrum (47).

The family structure in societies in Europe has changed over the last few decades, and relatives may or may not have a strong relationship with the older person with cancer (42), and this implies that the strength and resources in the families must be assessed when planning health care. In other words, it is essential to explore the family structure and to understand the family experience of living with cancer, so that professionals can have valuable knowledge to support families to deal with the responsibility of caring for their old relative with cancer.

European countries have developed numerous training programmes supported by the European Commission Lifelong Learning Programme targeted at family health nurses recognised as generalised nurses, which can make available support to families in their homes (49). However, this is primarily a development project and limited research has been conducted about the practice of teaching family-focused care outside the United States. Only a few nursing education programmes in Europe have included didactic and clinical learning skills on how to assess, plan, implement and evaluate family-focused interventions, which might explain the lack of family system focus within European healthcare institutions (49).

Strengths and limitations

We undertook a broad electronic search of studies covering all main health specialties (nursing, medicine, psychology, social work). We conducted a comprehensive search including different languages (English, German, Spanish, Danish, Norwegian, Swedish or French). However, we did not include publications from grey literature and snowballing, so it is possible that some studies may have been missed. Furthermore, we did not critically appraise included literature following recommendations from the Prisma Guidelines (PRISMA-ScR) (26), as the aim of this scoping review was to synthesise a variety of research evidence to gain an overview of the topic under study.

This review covered the different stages of the cancer trajectory and included studies with different designs and methods to map the existing literature on the topic. In spite of this, the studies found were poorly contextually described and there was no clear evidence of the types of health practices that are carried out in European countries with ageing families that live with cancer and beyond.

Conclusion

This scoping review shows that knowledge about health practices in Europe towards families affected by cancer is limited beyond the focus on descriptive data of older patients and family experiences and hence the limited health practices described are based on diverse conceptualisation of professional support to families.

Recommendation to practice based on review findings

Based on the findings from this review, we are not able to provide any recommendations for practice or policy-makers. Thus, the findings underline the importance of conducting future research that examines the types of practices that health professionals should develop and implement to meet the needs of ageing families living with and beyond cancer. In this new era of the conceptualisation of cancer as a chronic disease, and ageing as a factor of multi-pathology, we should focus on the implementation of family-focused care, which prevents the physical and psychological suffering of older patients with cancer and that promotes family functioning and quality of life during the different stages of cancer. However, in line with recommendation 7 of the White Paper on Cancer Carers (2017: 6), '[there is a need to] introduce a robust carer [family caregiver] support programme including training, psychological support and financial support, as well as access to health and care public services, and the inclusion in a patients' care team'.

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Author contribution

The study was initiated by all authors. HK, ES, KBD, RM, and CG assessed manuscripts for inclusion in the review. HK and CG wrote the initial manuscript. All authors read and approved the final manuscript.

References

- 1 European Commission. The 2018 Ageing Report: Economic and Budgetary Projections for the EU Member States (2016-2070). 2018. Report No.: Vol 8014.
- 2 Busse RBM, Scheller-Kreinsen D, Zentner A. Tackling chronic disease in Europe. Strategies, interventions and challenges. 2010, http://www.eurowho.int/_data/assets/pdf_file/0008/96632/E93736pdf. (last accessed 04 April 2020)
- 3 Jorgensen TL, Hallas J, Friis S, Herrstedt J. Comorbidity in elderly cancer patients in relation to overall and cancer-specific mortality. *Br J Cancer* 2012; 106: 1353–60.
- 4 Moller H, Flatt G, Moran A. High cancer mortality rates in the elderly in the UK. *Cancer Epidemiol* 2011; 35: 407–12.
- 5 Esbensen BA, Osterlind K, Hallberg IR. Quality of life of elderly persons with cancer: a 3-month follow-up. *Cancer Nurs* 2006; 29: 214–24.
- 6 Lund L, Ross L, Petersen MA, Groenvold M. Cancer caregiving tasks and consequences and their associations with caregiver status and the caregiver's relationship to the patient: a survey. *BMC Cancer* 2014; 14: 541.
- 7 Esbensen BA, Thome B, Thomsen T. Dependency in elderly people newly diagnosed with cancer—a mixed-method study. *Eur J Oncol Nurs* 2012; 16: 137–44.
- 8 Ge L, Mordiffi SZ. Factors associated with higher caregiver burden among family caregivers of elderly cancer patients: a systematic review. *Cancer Nurs* 2017; 40: 471–8.
- 9 Utz RL, Berg CA, Butner J. It's a family affair: reflections about aging and health within a family context. *Gerontologist* 2017; 57: 129–35.
- 10 Esbensen BA, Thome B. Being next of kin to an elderly person with cancer. *Scand J Caring Sci* 2010; 24: 648–54.
- 11 Wright LM, Leahey M. *Nurses and Families: A Guide to Family Assessment and Interventions*, 6th edn. 2013, F. A: Davis Company, Philadelphia, PA.
- 12 Estape T. Cancer in the elderly: challenges and barriers. *Asia Pac J Oncol Nurs* 2018; 5: 40–2.
- 13 Jeong A, Shin D, Park JH, Park K. what we talk about when we talk about caregiving: the distribution of roles in cancer patient caregiving in a family-oriented culture. *Cancer Res Treat* 2019; 51: 141–9.
- 14 Kehoe LA, Xu H, Duberstein P, Loh KP, Culakova E, Canin B, Hurria Arti, Dale W, Wells M, Gilmore N, Kleckner AS, Lund J, Kamen C, Flannery M, Hoerger M, Hopkins JO, Liu JJ, Geer J, Epstein R, Mohile SG. Quality of life of caregivers of older patients with advanced cancer. *J Am Geriatr Soc* 2019; 67: 969–977.
- 15 Huang LW, Smith AK, Wong ML. Who will care for the caregivers? Increased needs when caring for frail older adults with cancer. *J Am Geriatr Soc* 2019; 67: 873–876.
- 16 García-Vivar C. Family-centered care: a necessary commitment to address chronicity. *Metas de Enfermería* 2019; 22: 4.
- 17 Gilliss CL, Pan W, Davis LL. Family involvement in adult chronic disease care: reviewing the systematic reviews. *J Fam Nurs* 2019; 25: 3–27.
- 18 Eurocarers. White paper on cancer carers. Finding the right social response to give people with cancer and their carers a proper quality of life. Eurocarers and European Cancer Patient Coalition. <https://eurocare.org/publications/joint-white-paper-on-cancer-carers-with-ecpc/2017>. (last accessed 04 April 2020)
- 19 Albrecht T, Kiasuwa R, Van Den Bulcke M. European Guide on Quality Improvement in Comprehensive Cancer Control. 2017, <http://www.cancerbe.be>. (last accessed 04 April 2020)
- 20 Mendes MA, da Cruz DA, Angelo M. Clinical role of the nurse: concept analysis. *J Clin Nurs* 2015; 24: 318–31.
- 21 Peters MDJ, McInerney P, Baldini Soares C, Khalil H, Parker D. *Scoping Reviews*. 2017, Joanna Briggs Reviewer's Manual. Adelaide: Joanna Briggs Institute, Adelaide.
- 22 Munn Z, Peters MDJ, Stern C, Tufanaru C, McArthur A, Aromataris E. Systematic review or scoping review? Guidance for authors when choosing between a systematic or scoping review approach. *BMC Med Res Methodol* 2018; 18: 143.
- 23 García-Vivar C, Astedt-Kurki P, Brodsgaard A, Dieperink KB, Imhof L, Kon L et al. Prioritizing family health of older people in Europe: Current state and future directions of family nursing and family focused care. *J Fam Nurs* 2019; 25: 163–9.
- 24 Peters MD, Godfrey CM, Khalil H, McInerney P, Parker D, Soares CB. Guidance for conducting systematic scoping reviews. *Int J Evid Based Healthc* 2015; 13: 141–6.
- 25 Arksey H, O'Malley L. Scoping studies: Towards a methodological framework. *Int J Soc Res Methodol* 2005; 8: 19–32.
- 26 Tricco AC, Lillie E, Zarin W, O'Brien KK, Colquhoun H, Levac D, Moher D, Peters MDJ, Horsley T, Weeks L, Hempel S, Akl EA, Chang C, McGowan J, Stewart L, Hartling L, Aldcroft A, Wilson MG, Garrity C, Lewin S, Godfrey CM, Macdonald MT, Langlois EV, Soares-Weiser K, Moriarty J, Clifford T, Tunçalp Ö, Straus SE. PRISMA extension for scoping reviews (PRISMA-ScR): checklist and explanation. *Ann Intern Med* 2018; 169: 467–73.
- 27 National Cancer Institute. Cancer Control Continuum. 2017, <https://cancercontrol.cancer.gov/od/continuum.html>. (last accessed 04 April 2020)
- 28 Pedersen B, Delmar C, Lorincz T, Falkmer U, Gronkjaer M. Investigating changes in weight and body composition among women in adjuvant treatment for breast cancer: a scoping review. *Cancer Nurs* 2019; 42: 91–105.
- 29 Addington-Hall JM, O'Callaghan AC. A comparison of the quality of care provided to cancer patients in the UK in the last three months of life in in-patient hospices compared with hospitals, from the perspective of bereaved relatives: results from a survey using the VOICES questionnaire. *Palliat Med* 2009; 23: 190–7.
- 30 Griffiths J, Ewing G, Rogers M. Early support visits by district nurses to cancer patients at home: a multi-perspective qualitative study. *Palliat Med* 2013; 27: 349–57.
- 31 Charalambous A, Papadopoulos IR, Beadsmoore A. Listening to the voices of patients with cancer, their advocates and their nurses: A hermeneutic-phenomenological study of quality nursing care. *Eur J Oncol Nurs* 2008; 12: 436–42.

- 32 Fjose M, Eilertsen G, Kirkevold M, Grov EK. "Non-palliative care" - a qualitative study of older cancer patients' and their family members' experiences with the health care system. *BMC Health Serv Res* 2018; 18: 745.
- 33 Ledderer L, la Cour K, Hansen HP. Outcome of supportive talks in a hospital setting: insights from cancer patients and their relatives. *Patient* 2014; 7: 219–29.
- 34 Sinfield P, Baker R, Agarwal S, Tarrant C. Patient-centred care: What are the experiences of prostate cancer patients and their partners? *Patient Educ Couns* 2008; 73: 91–96.
- 35 Payne S, Eastham R, Hughes S, Varey S, Hasselaar J, Preston N. Enhancing integrated palliative care: what models are appropriate? A cross-case analysis. *BMC Palliative Care* 2017; 16: 64.
- 36 Lowson E, Hanratty B, Holmes L, Addington-Hall J, Grande G, Payne S, Seymour J. From 'conductor' to 'second fiddle': older adult care recipients' perspectives on transitions in family caring at hospital admission. *Int J Nurs Stud* 2013; 50: 1197–205.
- 37 Bailey C, Hewison A, Karasouli E, Staniszevska S, Munday D. Hospital care following emergency admission: a critical incident case study of the experiences of patients with advanced lung cancer and Chronic Obstructive Pulmonary Disease. *J Clin Nurs* 2016; 25: 2168–79.
- 38 den Herder-van der Eerden M, Hasselaar J, Payne S, Varey S, Schwabe S, Radbruch L, Van Beek K, Menten J, Busa C, Csikos A, Vissers K, Groot M. How continuity of care is experienced within the context of integrated palliative care: A qualitative study with patients and family caregivers in five European countries. *Palliat Med* 2017; 31: 946–55.
- 39 Mason B, Nanton V, Epiphaniou E, Murray SA, Donaldson A, Shipman C, Daveson BA, Harding R, Higginson IJ, Munday D, Barclay S, Dale J, Kendall M, Worth A, Boyd K. 'My body's falling apart'. Understanding the experiences of patients with advanced multimorbidity to improve care: serial interviews with patients and carers. *BMJ Support Palliat Care* 2016; 6: 60–5.
- 40 Jack BA, Mitchell TK, Cope LC, O'Brien MR. Supporting older people with cancer and life-limiting conditions dying at home: a qualitative study of patient and family caregiver experiences of Hospice at Home care. *J Adv Nurs* 2016; 72: 2162–72.
- 41 Naeim A, Aapro M, Subbarao R, Balducci L. Supportive care considerations for older adults with cancer. *J Clin Oncol* 2014; 32: 2627–34.
- 42 Montoro-Gurich C, Garcia-Vivar C. The family in Europe: structure, intergenerational solidarity, and new challenges to family health. *J Fam Nurs* 2019; 25: 170–189.
- 43 Wildiers H, Heeren P, Puts M, Topinkova E, Janssen-Heijnen MLG, Extermann M, Falandry C, Artz A, Brain E, Colloca G, Flamaing J, Karnakis T, Kenis C, Audisio RA, Mohile S, Repetto L, Van Leeuwen B, Milisen K, Hurria A. International Society of Geriatric Oncology consensus on geriatric assessment in older patients with cancer. *J Clin Oncol* 2014; 32: 2595–603.
- 44 Coyne E, Dieperink KB. A qualitative exploration of oncology nurses' family assessment practices in Denmark and Australia. *Support Care Cancer* 2017; 25: 559–66.
- 45 Davidson PM, Abshire MA, Paull G, Szanton SL. Family caregivers: Important but often poorly understood. *J Clin Nurs* 2018; 27: 4242–4.
- 46 Charalambous A, Wells M, Campbell P, Torrens C, Östlund U, Oldenmenger W, Patiraki E, Sharp L, Nohavova I, Domenech-Climent N, Eicher M, Farrell C, Larsson M, Olsson C, Simpson M, Wiseman T, Kelly D. A scoping review of trials of interventions led or delivered by cancer nurses. *Int J Nurs Stud* 2018; 86: 36–43.
- 47 Northouse LL, Katapodi MC, Song L, Zhang L, Mood DW. Interventions with family caregivers of cancer patients: meta-analysis of randomized trials. *CA Cancer J Clin* 2010; 60: 317–39.
- 48 Fiest KM, McIntosh CJ, Demiantshuk D, Leigh JP, Stelfox HT. Translating evidence to patient care through caregivers: a systematic review of caregiver-mediated interventions. *BMC Med* 2018; 16: 105.
- 49 Martin P, Duffy T, Johnston B, Banks P, Harkess-Murphy E, Martin CR. Family health nursing: a response to the global health challenges. *J Fam Nurs* 2013; 19: 99–118.