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Published in:
Scandinavian Journal of Caring Sciences
DOI:
10.1111/scs.12855
Publication date:
2020
Document version
Final published version
Document license
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Citation for published version (APA):
Konradsen, H., Brødsgaard, A., Østergaard, B., Svavarsdóttir, E., Dieperink, K. B., Imhof, L., Luttik, M. L., Mahrer-Imhof, R., & García-Vivar, C. (2020). Health practices in Europe towards families of older patients with cancer: a scoping review. Scandinavian Journal of Caring Sciences. https://doi.org/10.1111/scs.12855

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

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Scand J Caring Sci; 2020

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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.

Submitted 24 October 2019, Accepted 17 March 2020

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
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

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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 deducted 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 care* or caregiv*)               |
| 2. exp Professional-Family Relations/       | S2 (MH “Professional-Family Relations”)     | or daughter* or families or family or husband* or     |
| 3. exp Social support/                       | S3 (MH “Counseling”)                        | “next of kin” or relatives or son or sons or spouse*  |
| 4. exp Counseling/                          | S4 (MH “Health Education”)                  | or wife or relatives) NEAR 5 (“clinical practice” or  |
| 5. Health Education/                        | S5 (MH “Health Care Delivery”)              | “community health” or counsel* or educat* or “general  |
| 6. Delivery of Health Care/                 | S6 (MH “Nursing Care+”)                     | practice” or geriatric* or “health care” or           |
| 7. Practice Patterns, Physicians’/          | S7 (MH “Nurses+”)                           | healthcare or “health practice” or “health visit” or  |
| 8. Practice Patterns, Nurses’/              | S8 (MH “Community Health Services”)         | “home care” or intervention* or medicine or “medical  |
| 9. exp Nursing Care/                        | S9 (MH “Community Health Nursing+”)         | practice” or nursing or nurse* or physician* or “primary  |
| 10. exp Nurses/                             | S10 (MH “Community Mental Health Services+”)| care” or “professional practice” or program* or       |
| 11. Nursing/                                | S11 (MH “Home Health Care+”)                | psychol* or psychotherap* or rehabilitation or “social  |
| 12. exp Nursing Process/                    | S12 (MH “Nursing Practice+”)                | care” or “social practice” or “social work” or        |
| 13. Community Health Services/              | S13 (MH “Medical Practice”)                 | support* or telenursing or telemedicine or therapi*) | ti,ab,kw OR (((family or |
| 14. exp Community Health Nursing/           | S14 (MH “Occupational Therapy Practice”)    | families) NEAR 2 (center* or focus* or health* or     |
| 15. Community Mental Health Services/       | S15 (MH “Practice Patterns”)*               | practice*)/(ti,ab,kw                                  |
| 16. Home Care Services/                     | S16 (MH “Primary Health Care”)              | #2 (“adult child* or carer* or caregiver* or daughter*  |
| 17. Home Health Nursing/                    | S17 (MH “Family Practice”)                  | or husband* or family or families or “next of kin” or  |
| 18. Home Care Services, Hospital-Based/     | S18 (MH “Physicians+”)                      | relatives or son or sons or spouse* or wife or        |
| 19. Home Nursing/                           | S19 (MH “Telehealth+”)                      | wives) or “home care” or “health care” or            |
| 20. Primary Health Care/                    | S20 (MH “Occupational Therapists”)          | “medical practice” or “home care” or intervention* or |
| 21. Health Services for the Aged/           | S21 (MH “Rehabilitation+”)                  | medicine or “medical practice” or nursing or nurse*   |
| 22. Family Practice/                        | S22 (MH “Social Work Practice”)             | or physician* or “primary care” or “professional       |
| 23. exp Physicians/                         | S23 (MH “Social Workers”)                   | practice” or program* or psychol* or psychotherap*    |
| 24. exp Telenedicine/                       | S24 (MH “Psychotherapy+”)                   | or rehabilitation or “social care” or “social practice” |
| 25. Occupational Therapists/                | S25 (MH “Psychologists”)                    | or “social work” or support* or telenursing or telемeđicine or therapi*) OR AB ( |
| 26. Cardiac Rehabilitation/                | S26 (MH “Psychotherapists+”)                | ((“adult child** or carer** or caregiv** or daughter**  |
| 27. Occupational Therapy/                   | S27 TI ( ((“adult child** or carer** or caregiv** or  |
| 28. exp Rehabilitation/                    |                                            | daughter** or families or family or husband** or     |
| 29. exp Social Work/                        |                                            | “next of kin” or relatives or son or sons or spouse*  |
| 30. Social workers/                         |                                            | or wife or wives) N5 (“clinical practice**” or “community  |
| 31. exp Psychotherapy/                      |                                            | health” or counsel* or educat* or “general practice**  |
| 32. ((adult child* or carer* or caregiv* or |                                            | or “health care” or healthcare or “health practice**  |
|     daughter* or families or family or       |                                            | or “health visit**” or “home care” or               |
|     husband* or next of kin or relatives or  |                                            | intervention* or medicine or “medical practice** or   |
|     son or sons or spouse* or wife or wives |                                            | nursing or nurse* or physician* or “primary care” or |
|     adj2 (clinical practice* or             |                                            | “professional practice” or program* or psychol* or    |
|     community health or counsel* or educat*  |                                            | psychotherap* or rehabilitation or “social care” or  |
|     or general practice* or                 |                                            | “social practice” or “social work” or support* or    |
|     geriatric* or health care or             |                                            | telenursing or telemedicine or therapi**) OR AB (  |
|     healthcare or health practice* or        |                                            | ((“adult child** or carer** or caregiv** or daughter** |
|     health visit* or home care or            |                                            | or families or family or husband** or “next of kin”  |
|     intervention* or medicine or             |                                            | or relatives or son or sons or spouse* or wife or    |
|     medical practice* or nursing or          |                                            | wives) N5 (“clinical practice**” or “community health” |
|     nurse* or physician* or primary care     |                                            | or counsel* or educat* or “general practice** or “    |
|     or professional practice* or             |                                            | geriatric* or “health care” or healthcare or “health  |
|     program* or psychol* or                  |                                            | practice** or “health visit**” or “home care” or    |
|     psychotherap* or rehabilitation or       |                                            | intervention* or medicine or “medical practice** or   |
|     social care or social practice* or       |                                            | nursing or nurse* or physician* or “primary care” or |
|     social work* or support* or telenursing  |                                            | “professional practice” or program* or psychol* or   |
|     or telemedicine or therapi**) ti,ab,kf   |                                            | psychotherap* or rehabilitation or “social care” or  |
| 33. ((family or families) adj2 (center* or  |                                            | “social practice” or “social work” or support* or    |
|     focus* or health* or practice*) ti,ab,kf |                                            | telenursing or telemedicine or therapi**)            |
| 34. or/1-33                                 |                                            | #3 (aged or aging or centenarians or elder* or nonagenarians |
| 35. Caregivers/                             |                                            | or octogenarians or old or older or senior*) ti,ab,kw |
| 36. Family/                                 |                                            | #4 (cancer* or carcinoma* or neoplasm* or tumor* or    |
|                                             |                                            | tumour*) ti,ab,kw                                     |
|                                             |                                            | #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 count*” 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  |

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Table 1 (Continued)

| Medline                                                                 | Cinaahl                                                                 | Cochrane library                                                                 |
|------------------------------------------------------------------------|------------------------------------------------------------------------|----------------------------------------------------------------------------------|
| 37. Adult Children/                                                    | 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*))) | 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 |
| 38. Spouses/                                                          | 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 | #6 #1 AND #2 AND #3 AND #4 AND #5 Limit to year 2008-2018 |
| 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. | S30 (MH “Caregivers”) OR MH (“Caregiver Burden”) |                                                                                   |
| 40. or/35-39                                                          | S31 (MH “Family”)                                                                                                           |                                                                                   |
| 41. exp Aged/                                                         | S32 (MH “Adult Children”)                                                                                                   |                                                                                   |
| 42. (aged or aging or centenarians or elder* or nonagenarians or octogenarians or old or older or senior*):ti,ab,kf. | S33 (MH “Spouses”)                                                                                                          |                                                                                   |
| 43. or/41-42                                                          | S34 (MH “Daughters”)                                                                                                       |                                                                                   |
| 44. exp Neoplasms/                                                    | S35 (MH “Sons”)                                                                                                            |                                                                                   |
| 45. (cancer* or carcinoma* or neoplasm* or tumor* or tumour*):ti,ab,kf. | 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) |                                                                                   |
| 46. or/44-45                                                          | S37 -S30 OR S31 OR S32 OR S33 OR S34 OR S35 OR S36 |                                                                                   |
| 7. exp Europe/                                                        | 38 (MH “Aged+”)                                                                                                            |                                                                                   |
| 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                                                          | 41 (MH “Neoplasms+”)                                                                                                       |                                                                                   |
| 50. 34 and 40 and 43 and 46 and 49                                    | S42 TI (cancer* or carcinoma* or neoplasm* or tumor* or tumour*):ti,ab,kf.                                               |                                                                                   |
| 51. limit 50 to (Danish or English or French or Norwegian or Spanish or Swedish) | S43 -S41 OR S42                                                                                                            |                                                                                   |
| 52. limit S1 to yr=“2008 -Current”                                    | 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
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 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 1 (Continued)

| Medline                  | Cnahl                              | 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 S42 AND S46 S48 Limiters - Published Date: 20080101-20181231 |
### Table 2: Characteristics of included studies

| Author (Year) | Title | Design | Aim | Participants and Data | Healthcare Context |
|---------------|-------|--------|-----|------------------------|--------------------|
| 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 |
| Author Title | Design | Aim | Participants and Data | Healthcare Context |
|--------------|--------|-----|-----------------------|-------------------|
| 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, Papadopoulos, & 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 | To gain understanding of the experience of care of men with prostate cancer and their partners. | Patients with cancer from UK. 35 patients | }
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

| Phase of illness | Family relationship to patient | Country | Context of care | Description of the actual health practice, and the experience of patients, carers or healthcare professionals of the actual practice |
|------------------|--------------------------------|---------|----------------|--------------------------------------------------------------------------------------------------|
| 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: • 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. 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. |
| 5 End-of-life care | Family carers | UK | Hospital | 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. |
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.

Table 3 (Continued)

| Phase of illness | Family relationship to patient | Country | Context of care | Description of the actual health practice, and the experience of patients, carers or healthcare professionals of the actual practice |
|------------------|--------------------------------|---------|----------------|-------------------------------------------------------------|
| 7 In treatment   | Not applicable                 | Cyprus  | Hospital       | Inpatient cancer care at major hospitals. The meaning of quality nursing care includes the following themes: 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. Being tested for or treated for prostate cancer within the last 6 months. Being cared for by nurses with clinical competencies. Having their religious and spiritual needs met by the nurse. |
| 11 Different stages in the treatment trajectory | Female partners | UK | Outpatient clinics at hospital | |
| 12 End-of-life care | Spouse Husband Wife Son Daughter Son | UK | Home | Hospice at home care. Having their religious and spiritual needs met by the nurse. |
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 their family caregivers to have to deal with multiple services and professionals that lead them to feel overwhelmed and lost (39).

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 Life-long 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 policymakers. 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’.

Acknowledgement

We thank information specialists Sabina Gillsund and Magdalena Svanberg, Karolinska Institutet University Library, for their supervision during the development of the search strategy.

Conflicts of interest

The authors have no funding or conflicts of interest to disclose.

Funding

No funding was received for this study.

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.
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