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SYSTEMATIC REVIEW

Adult family carers' perceptions of their educational needs when providing end-of-life care: a systematic review of qualitative research [version 1; peer review: 3 approved with reservations]

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Abstract

Background: There is an increasing emphasis on the importance of the palliative and end-of-life care being provided in the community. Key to the success of this is the availability of information and educational support to facilitate carers in their role. The aim of the paper is to explore the educational needs of adult carers providing physical and other care to people at the end of life

Methods: A qualitative evidence synthesis was conducted using meta-ethnography. Five electronic databases were searched to January 2014, combining terms for: cancer, chronic obstructive pulmonary disease, neurodegenerative conditions, renal disease, heart failure and dementia, with terms for carers and education.

Results: A total of 35 papers were included in the review, reporting the experiences of over 900 carers. Throughout the illness trajectory carers were either enabled or hindered in their role by the nature and way information and education were provided. Enabling factors included: a sense of trust in health professionals; timely and accurate information delivered compassionately; access to professionals for information and support particularly during out-of-hours. Where carers experienced a lack of information or support this added to the strain of caring. Carers then felt the need to take on a more active role, acting both as an advocate and decision maker.

Conclusions: Carers express information and educational needs throughout the illness trajectory. The quality of health professionals' communication with carers was fundamental in ensuring carers felt confident and supported. Timely access to information and support from appropriately qualified health professionals should be made available to carers, including the out-of-hours period.

Keywords

Carers, education, end of life, qualitative evidence synthesis, meta-ethnography

Open Peer Review

Reviewer Status

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Introduction

Recent policy in the UK emphasises the importance of palliative and end-of-life care being provided in the community^{1,2}. Data published recently in England show that 60% of people would like to die in their own homes if circumstances allowed, with the rate much higher in some regions³. Key to the success of such policy initiatives and individual's preferences is the availability of family social support to care for people at home⁴. It is recommended that adult family carers of people requiring palliative care should be offered optimal support from health and social care professionals⁵.

The role that a family caregiver takes during the end-of-life trajectory is often a subtle transition of growing involvement—reflecting longstanding ties of family obligation—and the taking on of increasingly complex care⁶. The policies for end-of-life care now extend the planning and provision for end-of-life care beyond cancer to incorporate other life-limiting diseases such as heart failure, chronic obstructive pulmonary disease, liver and renal disease¹. The needs of patients with these conditions is wide ranging: those caring for them require information regarding a patient's illness, prognosis, symptom control; psychological, emotional, social and spiritual support; continuity of care and practical help⁷. Whilst much has been learnt about the care of patients with advanced cancer, these lessons are not always transferred to patients dying from other life-limiting diseases⁸.

Systematic reviews have evaluated the effectiveness of interventions to support family carers^{9–12}. These reviews have found mixed evidence for the effectiveness of interventions to support carers, with some benefit being identified in reducing psychological distress, caregiver burden, ability to cope and quality of life. Most studies included in these reviews focussed on carers of people with cancer. There is limited evidence in the reviews regarding carers of people with other advanced progressive illnesses. What is apparent is that little is understood about what

caregivers value in terms of the content, timing, and mode of delivery of educational interventions to support them in their role and what motivates them to accept support.

To improve the design of interventions to provide education for carers at the end of life, we need to understand the unique challenges carers face. In order to provide carers with the support they require, it is essential that carers needs are assessed separately and independently to those of the patient¹³. It is also important to recognise the difficulties associated with caregiving at the end of life, as family roles get blurred by providing physical care¹⁴. What emerges is a picture of complexity.

To begin to understand this complexity, qualitative research needs to be drawn together in a way that can create a cumulative body of evidence that builds and develops theory for practice in a way that examining individual studies will not¹⁵. Synthesising qualitative research allows maximum value to be gained from primary studies that have overcome problems in accessing and researching vulnerable populations such as carers. The aim of this paper is to gain insight into the educational needs of carers providing physical and other elements of care to people at the end of their lives through synthesis of qualitative research using meta-ethnography.

Methods

Data sources

Searches were pre-planned and developed with the assistance of an information specialist. They were run in five electronic databases, from their inception until January 2014: Medline, Cinahl, PsycInfo, Social Science Citation Index and EMBASE. Each strategy combined terms for each physical condition included in the review: cancer, chronic obstructive pulmonary disease, neurodegenerative conditions, renal disease, heart failure and dementia, with terms for carers, education and used a qualitative research filter (Table 1)¹⁶.

Table 1. Search strategy for Medline. Details of the search strategy used in Medline and which was the basis for adaptation for the other electronic databases searched.

| | |
|----|---|
| 1 | caregiv\$.ti,ab. (28478) |
| 2 | care giv\$.ti,ab. (3746) |
| 3 | carer\$.ti,ab. (6739) |
| 4 | informal care.ti,ab. (759) |
| 5 | befriending.ti,ab. (80) |
| 6 | caretak\$.ti,ab. (2957) |
| 7 | care taker\$.ti,ab. (118) |
| 8 | care taking.ti,ab. (181) |
| 9 | Caregivers/ (18609) |
| 10 | (child\$ adj2 (care or cares or caring or support or supports or supporting)).ti,ab. (17488) |
| 11 | ((son or sons or daughter\$ or friend\$ or partner\$ or spous\$) adj2 (care or cares or caring or support or supports or supporting)).ti,ab. (2809) |
| 12 | ((husband\$ or wives or wife or spouse\$ or grandparent\$ or grandchild\$ or neighbour\$ or neighbor\$ or relatives or relations or families or family or familial) adj2 (care or cares or caring or support or supports or supporting)).ti,ab. (13098) |

| | |
|----|--|
| 13 | ((parent\$ or mother\$ or father\$ or maternal or paternal or filial) adj2 (care or cares or caring or support or supports or supporting)).ti,ab. (9786) |
| 14 | ((peer or peers) adj2 (care or cares or caring or support or supports or supporting)).ti,ab. (1717) |
| 15 | 1 or 2 or 3 or 4 or 5 or 6 or 7 or 8 or 9 or 10 or 11 or 12 or 13 or 14 (83738) |
| 16 | exp Education/ (579225) |
| 17 | exp Educational Status/ (35911) |
| 18 | exp Self-Help Groups/ (8371) |
| 19 | exp self efficacy/ (10242) |
| 20 | exp Health Knowledge, Attitudes, Practice/ (63098) |
| 21 | exp Health Promotion/ (48263) |
| 2 | exp Life-Style/ (58080) |
| 23 | exp Rehabilitation/ (140274) |
| 24 | exp Communication/ (345676) |
| 25 | exp social support/ (46251) |
| 26 | exp Patient Participation/ (16376) |
| 27 | exp Patient Compliance/ (47996) |
| 28 | exp consumer participation/ (29531) |
| 29 | exp Counseling/ (30613) |
| 30 | exp Communication Barriers/ (4338) |
| 31 | (complianc\$ or adherenc\$).ti,ab. (124334) |
| 32 | (educat\$ or cultur\$ or instruct\$ or information\$ or program\$).ti,ab. (2122889) |
| 33 | (health knowledge\$ or rehabilitation\$ or communication\$).ti,ab. (217765) |
| 34 | (life style or life?style).ti,ab. (46519) |
| 35 | counsel\$.ti,ab. (61865) |
| 36 | (structured treatment\$ or teaching program\$).ti,ab. (2067) |
| 37 | (education\$ adj2 (patient\$ or program\$ or intervention\$ or meeting\$ or session\$ or strateg\$ or workshop\$ or visit\$)).ti,ab. (50785) |
| 38 | (behavio?r\$ adj2 intervention\$).ti,ab. (6493) |
| 39 | pamphlets/ (2954) |
| 40 | (leaflet\$ or booklet\$ or poster\$ or pamphlet\$).ti,ab. (212014) |
| 41 | ((written or printed or oral) adj information).ti,ab. (1338) |
| 42 | (information\$ adj2 campaign).ti,ab. (344) |
| 43 | (education\$ adj (method\$ or material\$)).ti,ab. (4216) |
| 44 | 16 or 17 or 18 or 19 or 20 or 21 or 22 or 23 or 24 or 25 or 26 or 27 or 28 or 29 or 30 or 31 or 32 or 33 or 34 or 35 or 36 or 37 or 38 or 39 or 40 or 41 or 42 or 43 (3354040) |
| 45 | cancer\$.ti,ab. (956107) |
| 46 | neoplasms/ (251472) |
| 47 | 45 or 46 (1069164) |
| 48 | 15 and 44 and 47 (3301) |
| 49 | exp heart failure/ (79006) |
| 50 | Heart failure, congestive/ (77558) |
| 51 | Pulmonary heart disease\$.ti,ab. (516) |
| 52 | Rheumatic heart disease\$.ti,ab. (3042) |
| 53 | Heart disease\$.ti,ab. (113826) |
| 54 | 49 or 50 or 51 or 52 or 53 (187969) |
| 55 | 15 and 44 and 54 (451) |
| 56 | exp Motor Neuron Disease/ (17851) |
| 57 | (motor adj2 neuron* adj2 disease).ti,ab. (3720) |
| 58 | (motorneuron* adj3 disease).ti,ab. (25) |

| | |
|-----|--|
| 59 | Mnd.ti,ab. (1258) |
| 60 | exp neuromuscular disease/ (234360) |
| 61 | (neuromuscular adj3 dis\$.ti,ab. (7837) |
| 62 | exp multiple sclerosis/ (40435) |
| 63 | Multiple sclerosis.ti,ab. (43391) |
| 64 | transverse myelitis.ti,ab. (1164) |
| 65 | demyelinating disease\$.ti,ab. (4214) |
| 66 | 56 or 57 or 58 or 59 or 60 or 61 or 62 or 63 or 64 or 65 (288800) |
| 67 | 15 and 44 and 66 (557) |
| 68 | exp kidney failure/ (113442) |
| 69 | Kidney failure, chronic/ (73662) |
| 70 | (kidney disease or kidney failure).ti,ab. (29273) |
| 71 | Chronic renal disease.ti,ab. (2422) |
| 72 | chronic kidney disease\$.ti,ab. (14565) |
| 73 | (chronic kidney failure\$ or chronic renal failure\$.ti,ab. (20812) |
| 74 | 68 or 69 or 70 or 71 or 72 or 73 (137473) |
| 75 | 15 and 44 and 74 (271) |
| 76 | Lung Diseases, Obstructive/ (17915) |
| 77 | exp Pulmonary Disease, Chronic Obstructive/ (19196) |
| 78 | emphysema\$.ti,ab. (18930) |
| 79 | (chronic\$ adj3 bronchiti\$.ti,ab. (9843) |
| 80 | (obstruct\$ adj3 (pulmonary or lung\$ or airway\$ or bronch\$ or respirat\$)).ti,ab. (50502) |
| 81 | COPD.ti,ab. (21395) |
| 82 | COAD.ti,ab. (182) |
| 83 | AECB.ti,ab. (209) |
| 84 | exp Bronchiectasis/ (7057) |
| 85 | bronchiet\$.ti,ab. (7) |
| 86 | bronchoect\$.ti,ab. (26) |
| 87 | kartagener\$.ti,ab. (726) |
| 88 | (ciliary adj3 dyskinesia).ti,ab. (760) |
| 89 | (bronchial\$ adj3 dilat\$.ti,ab. (394) |
| 90 | (interstitial\$ adj3 (lung\$ or disease\$ or pneumon\$)).ti,ab. (13263) |
| 91 | 76 or 77 or 78 or 79 or 80 or 81 or 82 or 83 or 84 or 85 or 86 or 87 or 88 or 89 or 90 (108267) |
| 92 | 15 and 44 and 91 (255) |
| 93 | cognition.ti. (6116) |
| 94 | dement\$.ti,ab. (62211) |
| 95 | alzheimer\$.ti,ab. (79641) |
| 96 | deliri\$.ti,ab. (7797) |
| 97 | ((cognit\$ or memory\$ or mental\$) adj3 (declin\$ or impair\$ or los\$ or deteriorat\$)).ti,ab. (57734) |
| 98 | (chronic adj4 cerebrovascular).ti,ab. (623) |
| 99 | (cerebr\$ adj3 deteriorat\$.ti,ab. (280) |
| 100 | (confusion\$ or confused).ab. (27348) |
| 101 | (Parkinson\$ disease dementia or PDD).ti,ab. (2249) |
| 102 | 93 or 94 or 95 or 96 or 97 or 98 or 99 or 100 or 101 (194915) |
| 103 | 15 and 44 and 102 (4651) |
| 104 | exp parkinsonian disorders/ (53372) |
| 105 | Paralysis Agitans.ti,ab. (177) |
| 106 | Hemiparkinsonism.ti,ab. (206) |
| 107 | shaking palsy.ti,ab. (34) |

| | |
|-----|--|
| 108 | basal ganglia disease.ti,ab. (75) |
| 109 | 104 or 105 or 106 or 107 or 108 (53492) |
| 110 | 15 and 44 and 109 (229) |
| 111 | qualitative.af. (109890) |
| 112 | findings.af. (1161545) |
| 113 | interviews.af. (99745) |
| 114 | 111 or 112 or 113 (1315002) |
| 115 | palliative care/ or terminal care/ or hospice care/ or respite care/ (55580) |
| 116 | ((palliat\$ or terminal or hospice* or respite or end of life) adj3 (care or caring)).ti,ab. (19660) |
| 117 | 115 or 116 (60163) |
| 118 | 48 and 114 and 117 (347) |
| 119 | 55 and 114 (120) |
| 120 | 67 and 114 (157) |
| 121 | 75 and 114 (59) |
| 122 | 92 and 114 (72) |
| 123 | 103 and 114 and 117 (99) |
| 124 | 110 and 114 (46) |
| 125 | 118 or 119 or 120 or 121 or 122 or 123 or 124 (848) |
| 126 | exp animals/ not humans.sh. (3785953) |
| 127 | 125 not 126 (848) |

Inclusion criteria

Studies were included if the following criteria were met: qualitative methods had been used that met the identified aims of the synthesis; the research was published in English.

'Carer' was operationalised in accordance with the Department of Health's definition¹⁷. Education was broadly conceptualised to capture both formal and informal education.

Data extraction and quality appraisal

Data extracted from each article provided a summary recorded in a specially developed data extraction table of (where reported): the aim of the research; type and number of participants; methodology; methods of data collection; methods of analysis; and key results.

Papers were appraised for quality by one reviewer and a sample of papers was checked by a second reviewer using a checklist developed for qualitative research¹⁸. Disagreements in scoring were discussed and resolved by consensus.

Methods for synthesis

The synthesis was conducted using meta-ethnography¹⁹. Meta-ethnography is an interpretative approach to research synthesis which enables conceptual translation between different types of qualitative research and occurs over four stages (Table 2) Atlas-ti Software 6.2 was used to manage the data²⁰.

Each study was read thoroughly to determine its position (phase 1) and then coded (phase 2), by a member of the research team (KF). The codes developed during phase 2 were compared and

provisionally grouped into broad areas of similarity (translations) during reciprocal translation analysis and discussed with the research team (KA, IW) (phase 3). The team then further examined the translations developed in phase 3 to determine which encompassed each other and could be further synthesised to form the final output of the review – the 'lines of argument' (phase 4).

The review is reported in line with the ENTREQ (Enhancing Transparency in reporting the synthesis of qualitative research) guidance^{21,22}.

Results

Studies identified

The searches identified a large set of papers (5507) of which 5440 on grounds of either title or abstract (Figure 1).

A total of 67 papers were deemed suitable for inclusion in the review. This is larger than any group of papers that has previously been included in a meta-ethnography. A more thorough review of the papers was undertaken that identified core papers which contained key concepts highly relevant to the review's aims; others provided more peripheral descriptive accounts. As a result, purposive sampling of the papers occurred, with inclusion limited to those papers which contained richer conceptual descriptions of the aims of the review. This is an approach advocated within meta-ethnography when the volume of papers is unfeasible to synthesise²³. For conditions which were less frequently researched (e.g. Parkinson's disease), all papers on that condition were included, even if the results contained less rich and more descriptive data. It was considered important that

Table 2. Phases of meta-ethnography (adapted from Noblit and Hare 1988)¹⁹. Describes each of the stages of meta-ethnography used in the synthesis.

| Phase of meta-ethnography | Processes involved |
|--|--|
| Phase 1 Reading the studies | Studies are read to develop an understanding of their position and context before being compared to others. Repeated re-reading of studies to identify key findings. |
| Phase 2 Determining how the studies are related | Determining the relationships between individual studies by compiling a list of the key findings in each study and comparing them with those from other studies |
| Phase 3 Translating the studies into one another | Determining the similarities and differences of key findings in one study with those in other studies and translating them into one another. The translations represent a reduced account of all studies. (First level of synthesis) |
| Phase 4 Synthesising translations | Identification of translations developed in Phase 3 which encompass each other and can be further synthesised. Expressed as a 'line of argument' (Second level of synthesis) |

different conditions should be included, capturing as many carer experiences as possible.

To determine if the sampling had been effective, after the initial coding of the 31 included papers, the papers not included were re-read. This was to explore whether either additional descriptions of concepts or new were provided in the non-sampled group of papers. This led to the inclusion of four additional papers, representing three studies, into the review. These papers were included as they provided additional data on carers' experiences of caring with a family member with a brain tumour²⁴, cancer cachexia²⁵ and on pain management at the end of life^{26,27}.

The quality scores for individual papers ranged from 20–27 (maximum score 36). We did not have an *a priori* quality threshold below which papers were excluded, but considered it important that a transparent and reliable assessment was made of the methodological quality of the papers. No papers were excluded as a result of the quality appraisal.

Study characteristics

The 34 included studies reported on the experiences of over 900 carers of individuals with advanced disease in six countries (Table 3). The majority of the studies (n=32) were conducted in the USA, UK, Canada & Australia. The gender of carers was reported in 26 of the 34 included studies, and in these studies 75% (n=462) of the carers were female. In the 21 studies (n=572) where the type of carer was described, 58% (n=330) were spousal carers. Other participant characteristics such as socio-economic status and ethnicity were insufficiently reported to draw meaningful conclusions. Data were predominantly collected in the primary studies through a mixture of interviews, focus groups and observations.

Results of the synthesis of the included studies

Following a careful reading of each study (phase 1), the data were coded in ATLAS.ti resulting in the formation of 111 codes (phase 2). The team examined how codes from the individual studies related to each other and generated a reduced set of codes (translations) that ensured that the essence of individual

study findings was retained (phase 3). In total, eight translations were identified that brought together carers' perceptions of their information needs across the disease types and the skills required to care, in addition to aspects that facilitated caring or caused difficulties:

- Information from the point of diagnosis and planning for the future course of disease
- Information to take on the caring role
- Management of symptoms, medicines & adverse events
- Information on acute exacerbations
- The processes around dying, bereavement and rebuilding their lives after the death of a patient
- Facilitators for being a carer
- Barriers to caring

The fourth phase focused on these 'translations'. We examined and compared translations to establish if some were able to encompass others to identify the common themes or 'lines of argument' - that ran through the studies. These lines of argument represent patterns running through family carers' perceptions of educational need that can be discerned when evidence from multiple studies is combined and compared. From the eight translations, two clear lines of argument emerged:

- The trajectory of information needs
- Enabling the carer

Together the two lines of argument represent the points during the disease trajectory that were identified by carers in which education and information are most valued and useful and how the carers were enabled, or not, to undertake their role. Participant quotes are used to illustrate particular points, with the disease group detailed. Where papers recruited carers of patients with mixed disease groups, the term 'mixed' is used.

The trajectory of information needs

Carers described information and educational needs that spanned the disease trajectory (Figure 2). Throughout the illness

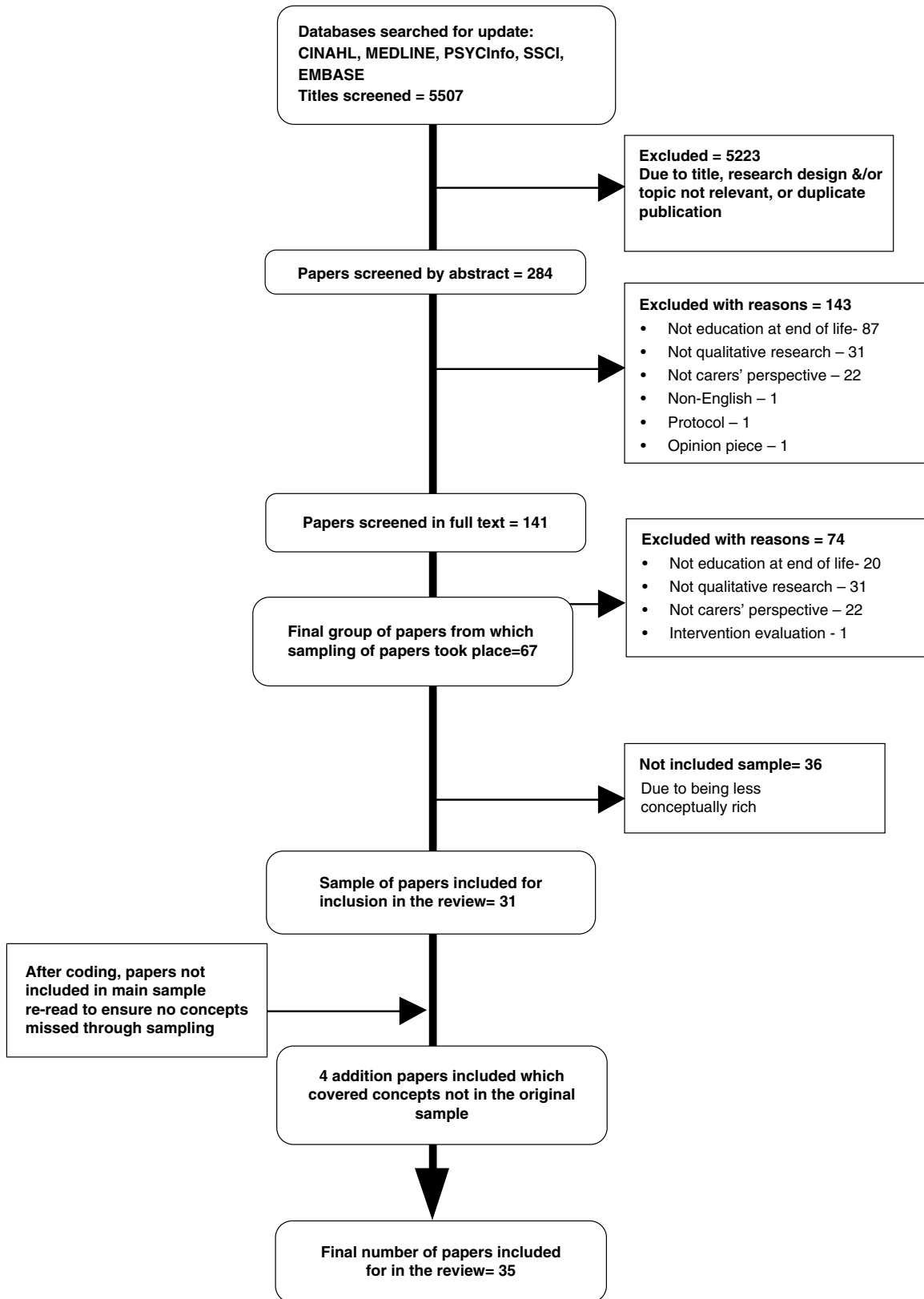


Figure 1. Flow chart of study inclusion. The numbers of studies identified through database searching, studies excluded (with reasons) and studies included in the review.

Table 3. Table of included studies. Included are details of the title, location, aim, population, methodology, type of analysis, key findings and overall quality appraisal score for all of the studies included in the review.

| Study/ location | Aim | Population | Methodology | Analysis | Key Findings | Quality score |
|---|---|--|---|--|--|---------------|
| Cancer papers | | | | | | |
| Carter (2011) ²⁸ USA | To understand the types of information carers need as well as the best method of delivering that information | 21 older female caregivers, living with and caring for a person with advanced cancer. Recruited by cancer care clinic nurses | 'Qualitative study' | Followed the principles of content analysis. | Caregivers' experience with regard to information needs. Paper predominantly deals with caregivers' negative experiences with information needs. 1. General cancer information 2. Specific patient cancer information survival prognosis 3. Individual caregiver information needs 4. Health care professionals sensitivity caregiver information needs 5. Information gatekeepers 6. Information falsehoods | 25 |
| Funk, Allan, Stajduhar (2009) ²⁹ Canada | To explore family caregiver accounts of their experiences within the health system and with individual providers | 31 current family caregivers of people with advanced cancer or were recently caring for someone and were now bereaved; from a prior study of coping in end of life cancer situations | Qualitative component of a mixed methods study | Thematic secondary analysis of qualitative data | Health professionals were seen as professional experts whom they could go to for information and guidance; sense of security was provided by time access to information from HPs and this was lacking when information giving was poor. Results have data on information needs on how to communicate with HPs, service and on rules and regulations | 26 |
| Hudson, Aranda, McMurray (2002) ³⁰ Australia | To obtain information to assist in the development of a nursing intervention to enhance the guidance and support provided to lay carers of people dying of cancer at home | 8 bereaved carers (7–14 months into bereavement), 6 current carers recruited from the community palliative care service | Qualitative research using 'focus group methodology' | The analysis process sought to gather specific content that would assist the development of a new intervention, rather than being interpretive | Four themes emerged each of which contained components of education 1. Factors that help caregivers manage their role 2. Obstacles to preparation for caregiving 3. Fundamental information for caregivers 4. The manner in which guidance and support should be offered. | 24 |
| Kimberlin, Brushwood, Allen, Radson, Wilson (2004) ³¹ USA | To examine the barriers and facilitators of effective communication regarding pain management issues from the perspectives of cancer patients and their family carers | Patients who were currently being treated for cancer and family carers who were either current carers or who had cared for someone who had died of cancer up to 5 years ago | Qualitative research using focus groups and personal interviews | Thematic analysis | Key themes with information component 1. Improve use of feedback from patients as a source of information eg carers mentioned keeping pain diaries to help communication with HPs. 2. Improve patient education efforts of providers ie carers wanted specific information to serve as a guide to decision make in pain management 3. Increase active participation of carer and caregiver in care process 4. Improve provider relationship building skills 5. Overcome time barriers 6. Addressing fears regarding use of pain management medications 7. Foster appropriate involvement of family and caregivers | 25 |

| Study/ location | Aim | Population | Methodology | Analysis | Key Findings | Quality score |
|--|--|--|--|--|--|------------------|
| Lau, Berman, Halpern, Pickard, Schrauf, Witt (2010) ³² USA | To explore factors that influence how informal caregivers manage medications as part of caring for hospice patients | 23 current carers assisting an elderly (60 + years) hospice patient (cancer=8, dementia=8, HF=3, other =4) 22 hospice providers also interviewed | Qualitative research using semi-structured open-ended interviews | Analysis consistent with grounded theory approach (little detail) | Findings address additional intervention points beyond knowledge and skill building that could be addressed to support caregivers in managing medications at home for palliative care patients | 26 |
| McConigley, Halket, Lobb <i>et al.</i> (2010) ²⁴ Australia | Caring for someone with high-grade glioma: a time of rapid change for caregivers | 21 carers (17 female) of patients with high-grade glioma 20 spousal 1 parent Aged 30-70+ years | Emergent qualitative design based on grounded theory using semi-structured interviews | Constant comparative method using open & axial coding | Caregiving was described as something that required numerous life role and life changes from the point of diagnosis. The speed of change and need for immediate information for carers appeared distinct to high grade glioma | 24 |
| Mehta, Cohen Carnvale <i>et al.</i> (2010a) ²⁶ Canada | Family caregivers of palliative cancer patient at home: the puzzle of pain management | 24 family caregivers (16 female), 'most involved with the management of pain at home' 16 spousal Mean age 69 years Mean length of caring experience 2.2 years (2weeks-20 years) | Grounded theory | Open coding, axial coding, selective coding | Family members need to be prepared by health professionals in order to optimise pain control and prevent detrimental effects on the family caregivers themselves | 27 |
| Mehta, Cohen Carnvale <i>et al.</i> (2010b) ²⁷ Canada | Strategizing a game plan. Family Caregivers of palliative patients engaged in the process of pain management | 24 family caregivers (16 female), 'most involved with the management of pain at home' 16 spousal Mean age 69 years Mean length of caring experience 2.2 years (2weeks-20 years) | Grounded theory | Open coding, axial coding, selective coding | Family carer involvement in pain management at home is complex and ongoing. Family caregivers accept responsibility for pain control, continuously seek new information and update their knowledge. | 27 |
| Reid, McKenna, Fitzsimons <i>et al.</i> (2009) ²⁵ UK | An exploration of the experience of cancer cachexia: what patients and their families want from healthcare professionals | 12 family members (10 female) of patients with cancer related cachexia, sampled from a regional cancer centre | Qualitative unstructured interviews | Primary thematic analysis, then interpretative Phenomenological Analysis | Family caregivers wanted three things from health professionals in response to cancer cachexia; the profound weight loss to be acknowledged, information about it and why it was happening and interventions to deal with it. | 25 |
| Rose (1999) ³³ UK | 'What is it like to care for a relative with cancer?' | 21 families were recruited; carers who were caring for an adult with cancer who was not expected to survive more than 6 months or who had recently died. No further detail on sample | 'Phenomenology' Longitudinal study with 55 interviews (1-5 per family) being carried out over an 18 month period. | Data were analysed qualitatively looking for recurring themes | Article favours carers 'negative accounts of their experiences relating to information, partly because those accounts were in the majority'. 1. Information needs in relation to illness itself 2. Information on prognosis 3. Information is individualised 4. Information on the process of dying 5. Who should be the recipient of information 6. False information | |

| Study/ location | Aim | Population | Methodology | Analysis | Key Findings | Quality score |
|---|---|---|--|--|---|---------------|
| Royak-Schaler, Gadalla, Lemkau, Ross, Alexander, Scott (2006) ³⁴ USA | To assess healthcare provider communication about EOL and hospice care with patients with terminal cancer and their families, from the perspective of the family members. | 24 bereaved carers | Qualitative research –two focus groups | Thematic analysis to inductively identify emerging themes, which were compared and contrasted across the two focus groups | Key factor was obtaining timely and accurate information about their status of patients and having the information conveyed effectively and empathetically by medical personnel. 1. Access to HPs in a timely fashion 2. Communication about disease progression and care options 3. Language, timeliness and sensitivity of communication 4. Communication about hospice care 5. Recommendations for improving communication | |
| Schumacher, Koresawa, West, Hawkins <i>et al.</i> (2002) ³⁵ USA | To describe the difficulties with pain management that patients and family caregivers bring to a nurse's attention during a teaching and coaching intervention | 33 family caregiver and 52 patients | Qualitative component of RCT teaching PRO-SELF pain control program. Audiotaped interaction of nurse/patient/carers interactions, nurses' field notes and telephone logs | A variation of content analysis termed 'clinical content analysis', ie data were generated in context of a clinical interaction not a research interview | Relevant findings: 1. Difficulty accessing information 2. Difficulty tailoring prescribed regimens to meet individual needs 3. Difficulty finding the optimal combination of medications 4. Difficulty finding optimal dose 5. Difficulty finding optimal timing for pain medication 6. Difficulty managing side effects 7. Difficulty cognitively processing complex information 8. Difficulty managing new or unusual pain 9. Difficulty managing multiple symptoms simultaneously | |
| Smith, Schonberg, Fisher, Pallin <i>et al.</i> (2010) ³⁶ USA | To better understand the experiences of acutely symptomatic patients seen in the ED | 7 family carers and 14 patients (most had cancer) | Grounded theory approach | Qualitative analyses conducted using an iterative process that followed standard grounded theory techniques | Most common reason for ED visit was pain: 1. Unprepared for managing symptoms at home – concern over excessive use of analgesia 2. Meaning of the symptoms and transition to palliative care | |
| Waldrop, Meeker, Kerr, Skretny <i>et al.</i> (2012) ³⁷ USA | Describe family caregivers accounts of the nature and timing of communication they had had with HPs during advanced stages of cancer and before hospice enrolment | 52 family carers 6-8 weeks post-bereavement | Exploratory descriptive design using semi-structured interviews | Iterative process of coding to categorise the nature and timing of family-provider communication. Theoretical analysis used concepts from the Sense of Coherence theory to develop a cross case analysis | The results are predominantly about communication with HPs, but this was found to be critical for helping family caregivers understand and manage the changes that accompany life threatening illness. This seemed key to enabling educational and information needs to be met | |

| Study/ location | Aim | Population | Methodology | Analysis | Key Findings | Quality score |
|--|--|--|---|--|---|---------------|
| Heart Failure (HF) papers | | | | | | |
| Harding, Selman, Beynon <i>et al.</i> (2008) ³⁸ UK | To generate guidance for appropriate information provision to CHF patients and their families | Eleven carers, 8 patients' wives 1 niece 1 daughter 1 son Carers reported a high rate of morbidity No other socio-demographic data provided 20 patients & six clinicians also interviewed | Cross-sectional qualitative methodology One off interviews | Constant comparison approach to formulate analytical categories or themes | 1. Patients and carers lacked understanding of CHF symptoms and management – this led to anxiety, concern and anger and was attributed to lack of time for health professionals to provide this information 2. No patients of carers has discussed with health professionals about disease progression or future care including end of life preferences 3. Patients and carers recommended that being given easily comprehensible information would improve communication, and where staff did this it was valued | 26 |
| Hupcey <i>et al.</i> (2011) ³⁹ USA | To describe the needs of spousal caregivers of patients of patients with HF being treated at a specialist centre | 45 spouses, 39 female, 6 male. Aged from 27–76 years (mean 60 yrs). Time since patient diagnosis of HF from 4 months – 20 years 'Major financial issues' were reported for 22 families as a result of illness induced early retirement. No other sociodemographic data reported | Grounded theory Aim was to conduct interviews monthly over 12-18 months (up to 12 interviews) Frequency ranged between one interview (2 carers) up to 12 times. | Data sets were analysed for identification of major needs reported by spousal caregivers | Four categories of overarching needs amenable to palliative care interventions were identified: informational financial, psychosocial and physical. These were constantly present but their significance during times of medical stability/ instability changed. This led to reprioritising of needs throughout the course of the illness. | 25 |
| Imes, Dougherty, Pyper <i>et al.</i> (2010) ⁴⁰ USA | To describe the experienced of living with severe HF from the perspective of the partner, including the role of advance directives in end of life care | 14 partners of patients with NYHA class 3 or 4 HF Mean age 64.85 93% married 93% white 50% retired 57% educated to high school 29% college degree 57% in good health | Qualitative descriptive naturalistic inquiry approach | Content analysis and comparisons between and among concepts | Three main themes: 1. My experience of HF in my loved one: impact on relationship, me & what helps me 2. Experience with health care providers: treatment, prognostic information, ways in which providers could help 3. Patient's experience of HF as perceived by the partner: patient symptoms, course & duration of HF, patients dying, patients future | 27 |
| Sanford <i>et al.</i> (2011) ⁴¹ USA | To examine how caregivers of family members with HF make decisions | 20 participants (15 female) 13 spouse 7 child 17 married 1 widowed 1 divorced 15 white 5 African American 8 unemployed 18 lived in same household Even distribution of low, middle and high income earners 5 caregivers from each of the 4 HF classifications | Grounded theory | Methods relating to grounded theory | Theoretical model of decision making by family carers. Phase two of the model relates to educational needs of carers: seeking information, input or support to aid decision making. | 27 |

| Study/ location | Aim | Population | Methodology | Analysis | Key Findings | Quality score |
|---|---|--|---|--|--|------------------|
| Neurological Papers | | | | | | |
| Dawson & Kristjanson (2003) ⁴² Australia | To determine the perceived needs of family carers in the late stages of motor neuron disease (MND) or muscular dystrophy (MD) | 16 carers 11 carers of patients with Duchenne MD ('some' were parents) 5 carers of patients with MND ('some' were spouses) 3 participants from each group were bereaved No other socioeconomic data | Exploratory qualitative methodology | Content analysis and constant comparison techniques | Three themes 1. Reactions and responses: grieving every day; fearing each crisis may mean the end; watching life in reverse 2. Health systems crossing points: getting lost on the system; living within limits; I want to know but who do I ask? 3. Reaching forward: holding onto the bigger picture; learning from other carers; needing help to plan the future; just getting on with it; don't forget the children | 26 |
| O'Brien <i>et al.</i> (2012) ⁴³ UK | To explore the views of current and former family carers of people with MND and identify their need for, and use of, support services | 18 current and 10 former family carers of people with MND <i>Current carers</i> had been caring for between 1 month and 7.5 years 11 male <i>Former carers</i> had been bereaved between 2 months and 7yrs 3 male | Qualitative study | Thematic framework approach | Carers described six aspects of caring: 1. Impact on carers of caring 2. The nature of their information needs 3. Accessing paid-for in-home care 4. Experiences of respite care 5. The role of formal counselling 6. Their own training needs | |
| Giles & Miyasaki (2009) ⁴⁴ Canada | What are the lived experiences of the health care system for persons and their family members who have lived with the palliative stage of Parkinson's Disease? | 3 patient carer dyads/triads Carers were daughter (2), spouse (2) | A qualitative cross-sectional exploratory phenomenological design | Phenomenological conceptual framework | Palliative care services need to be both multi-disciplinary and team based in order to provide comprehensive support to patients and families. | 20 |
| Hudson, Toye, Kristjanson (2006) ⁴⁵ Australia | To describe the experience of Parkinson's Disease and consider the relevance of palliative care for this population | 21 family care givers 19 spouses (5 male) 1 son 1 mother-in-law Aged 41–80 yrs Provided care for median 72 months (18–240 months) 5 early stage, 12 middle/late stage, 4 bereaved + 8 people with PD 6 health professionals | Qualitative descriptive study | Thematic analysis | Findings relating to the review: Having suitable supportive care interventions and appropriately skilled health professionals in a supportive care environment was important as PD progressed. | |
| Dementia papers | | | | | | |
| Gessert, Forbes, Bern-Klug (2001) ⁴⁶ USA | To develop an understanding of how family members currently experience their roles as end of life decision makers for elderly relatives with sever cognitive impairment | 28 individuals representing 26 families participated in 4 focus groups Relatives had moderate to advanced cognitive dementia | Qualitative methods | Analysis began following the first focus group, using content analysis | Findings relating to the review: Relatives had little understanding of the natural progression of dementia which impacted on their capacity to make decisions regarding specific issues. | 21 |

| Study/location | Aim | Population | Methodology | Analysis | Key Findings | Quality score |
|--|--|--|--|---------------------------------------|--|---------------|
| Thune-Boyle, Sampson, Jones, King, Lee, Blanchard (2010) ⁴⁷ UK | To define the end of life care needs of patients with advanced dementia and their carers following acute admission to general hospital as phase 1 of designing an intervention | 20 informal carers/relatives (13 female) of patients with advanced dementia admitted to an acute general hospital 8 relatives were full time carers, 12 were carers of patients in nursing/residential homes Aged 44–89 yrs 11 spouses (8 female) 5 children 3 niece/nephew 1 friend (additional demographics in paper) | Qualitative methods | Framework analysis | Carers' understanding of dementia and its likely progress was poor. Provision of information regarding the future was rare despite high information needs. | 23 |
| COPD papers | | | | | | |
| Hasson, Spence, Waldron <i>et al.</i> (2009) ⁴⁸ UK | To explore the palliative and end of life care needs and experiences of bereaved family members who cared for a person with advanced COPD at home | Nine bereaved carers (7 female) Age 25–65 8 cared for a parent 1 cared for a parent in law All cared for in patient's own home Interviewed 6–24 months after death | Descriptive qualitative design | Content analysis | Carers had difficulty comprehending the nature of the illness and its long term implications due to lack of information. Information from health and social services was sporadic. Carers educated themselves over. Increased support and help in decision making near the end of life was appreciated. | 24 |
| Hynes, Stokes, McCarron (2012) ⁴⁹ Ireland | To explore the experiences of informal caregivers providing care in the home to a family member with COPD | 11 carers (9 women) Aged 20–79 4 spouse, 7 daughter Living with care recipient 9 Years of caring 1–15 Working outside home - 4 Working outside home prior to caring role - 8 | Qualitative exploratory approach | Thematic analysis | Carers expressed frustration at not receiving fuller explanations from HCCPs of disease trajectory and management. Carers built up a high level of expertise, skill and tacit knowledge as a result of many years care-giving, despite formal support being almost entirely absent. This knowledge of the patients was not acknowledged by HCs and carers felt they had to watch over their relative during hospitalisations. | 26 |
| Spence, Hasson, Waldron <i>et al.</i> (2008) ⁵⁰ UK | To explore the specific needs of informal caregivers of patients with advanced COPD | 7 active family care givers (6 female) Married & aged 55–65 yrs (1 aged 30). Four caring for spouse, 2 for a parent, 1 for sibling Caring for 1->4 yrs | Descriptive qualitative methods design | Content analysis (Miles and Huberman) | Carers were unprepared to take on the caring role and did not initially understand the nature of COPD and its longer term implications Received sporadic information from health and social care professionals. There was lack of knowledge on how to access financial support | 24 |

| Study/ location | Aim | Population | Methodology | Analysis | Key Findings | Quality score |
|---|--|---|---|--|--|---------------|
| Mixed aetiology papers (or not stated) | | | | | | |
| Curtis, Engelberg, Young <i>et al.</i> (2008) ⁵¹ USA | To examine the perspectives of patients, family, physicians, & nurses, on the simultaneous need for supporting hope and discussing prognosis | <i>Relevant to this review:</i> 36 family members of patients with either advanced cancer or severe COPD Mean age 60 (18 female) Spouse - 20 Relative - 12 Friend - 4 | Qualitative Longitudinal interviews at baseline, 4-6 months (27 carers) & 12 months (10 carers) | A limited application of grounded theory | There was variability in the way patients and their family carers approach the interaction of wanting support for hope and prognostic information in response to being shown four diagrams modelling the interaction between hope and information. | 26 |
| Herbert, Schulz, Copeland <i>et al.</i> (2008) ⁵² USA | To determine what questions family caregivers want to discuss with health care providers in order to prepare for the death of a loved one | 33 carers of patients with cancer, COPD, cardiovascular disease, dementia and other 'terminal illnesses' Bereaved - 27 Female - 27 Spouse - 7 Child - 14 Other - 12 Mixed educational status from high school to degree African American - 15 White American - 18 | Ethnography: interviews and focus groups | 'Standard methods' | Carers need more than prognostic information in order to prepare for a patient's death. Carers may not ask important questions and unanswered questions may contribute to carers distress. | 26 |
| Herbert, Schulz, Copeland <i>et al.</i> (2009) ⁵³ USA | To determine the factors that family caregivers believe are important to preparing for death and bereavement | 33 carers of patients with cancer, COPD, cardiovascular disease, dementia and other 'terminal illnesses' Bereaved - 27 Female - 27 Spouse - 7 Child - 14 Other - 12 Mixed educational status from high school to degree African American - 15 White American - 18 | Ethnography: interviews and focus groups | Constant comparative method | Communication was the primary mechanism to manage caregiver uncertainty. Good communication included clear reliable information giving, combined with relationship centred health care. | 26 |
| Kalnins (2006) ⁵⁴ (Latvia) | To increase understanding of the experiences and needs of family caregivers of terminally ill persons in Latvia | 18 carers of people who had a diagnosis of cancer, stroke or other cardiovascular disease, who had been bereaved for at least a year Female - 16 Aged 29-80 Duration of care 1 week - 9 years Place of death, Home - 16 Hospital - 5 | A 'qualitative study' using semi-structured interviews | Interpretative phenomenological approach | Carers considered that the burden of caregiving would be eased with access to education, resources and ongoing skilled guidance in palliative care. | 23 |

| Study/location | Aim | Population | Methodology | Analysis | Key Findings | Quality score |
|--|---|---|---|---|---|---------------|
| Sherwood, Given, Doorenbos <i>et al.</i> (2004) ⁵⁵ USA | To explore the positive and negative aspects of providing care for someone with a primary malignant brain tumour (PMBT) | 43 carers of adults with PMBT Female – 40 Spouse – 27 Child – 8 Other – 8 Predominantly white American | Not reported | Content analysis of text from self-reported questionnaire | Carers took on responsibility for obtaining information about the PMBT and treatment options. Information on how to provide day-today care including symptom management was largely unavailable. | 23 |
| Stajduhar, Funk, Outcalt (2013) ⁵⁶ Canada | Explore how family caregivers describe learning to provide care to palliative patients | Total of 156 interviewees from 4 datasets. All provided palliative care to a family member | | Secondary analysis of data from four qualitative studies | Family carers use the following as ways of increasing their knowledge about care-giving: actively seeking needed information and guidance, applying knowledge and skills from previous experience, reflecting on current experience and trial and error | 25 |
| Teno, Casey, Welch <i>et al.</i> (2001) ⁵⁷ USA | To develop a conceptual model to determine what constitutes good end of life care by conducting qualitative research with bereaved family carers and a literature review. | 42 bereaved family members (3–12 months since death) who took part in 6 focus groups (acute care 2, nursing home 2, hospice/home help service 2). Mean age – 61 Female - 70% Included 14 spouses and 26 children or parents | Qualitative methodology | Grounded theory approach | One of the key features identified by bereaved family carers was that good quality end of life care should: educate the family carers so they feel confident in caring for their loved ones at home. | 26 |
| Waldrop (2006) ⁵⁸ USA | To determine the interrelationships between informal and formal care, and care-givers' perspectives about the salient features of professional help with terminal care | 69 caregivers (64 single interviews and 5 with two carers) of patients with cancer or another terminal illness & were using the hospice home care service Mean age 55.4 (21–83) 53 women 24 spouses 37 children (Interviews also conducted with 34 patients) | Qualitative study guided by concepts from the social care model | Analysis included initial coding of the transcripts, then a second phase in which genograms, & ecomaps of family care giving systems were developed. Each of these were analysed by constant comparative analysis | When caring for a relative who is dying, family carers value clear and straight forward communication, information, anticipatory guidance, alongside kindness and compassion, and a respect for self-determination. | 27 |

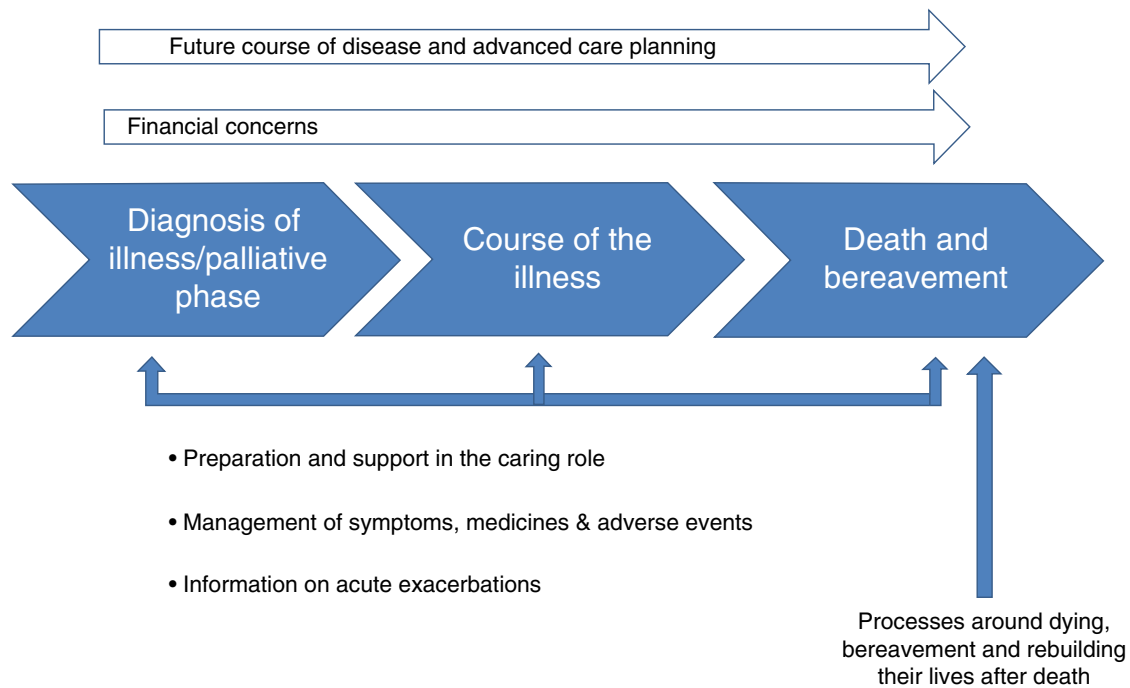


Figure 2. Trigger points for information. The way carers described their information and educational needs spanning across the disease trajectory is shown.

trajectory carers had concerns of a financial nature. Carers also identified their information needs changed over the course of the illness and increased amounts of caring were required as a person’s condition deteriorated.

Information from the point of diagnosis and planning for the future course of disease

Carers’ need for information arose both at the point of the diagnosis of the initial illness, or when the terminal stage was confirmed. Carers revealed how they struggled to obtain information regarding diagnosis and also as diseases progressed^{48,49}. Frustration was expressed with the quality of information given and what could be expected. Carers cited how health professionals were reluctant to use the word ‘dying’, discuss what was going to happen, or explain that the patient now had a limited time to live^{28,34,36–38,40,42,43,50}.

‘Nobody has actually told us what to really expect from the disease, and I feel myself, I am the carer... but I have had little guidance on what to expect.’⁴³ (Motor neurone disease)

Carers of people with dementia explicitly talked about the need to know about advanced decisions to refuse treatment^{46,47}. The complexity of decision making around issues such as resuscitation and antibiotic use was apparent, with many family members clearly struggling to know what to advocate for their relatives. When asked about information needs, a preference was expressed to know about the likely disease trajectory in order that planning could occur.

‘At least I will know what to expect. What the future will hold and how to prepare myself. Like a kind of preparation before something happens. It’s nice to know where you are. That is important.’⁴⁷ (Dementia)

Information to take on the caring role

Individuals talked about the kind of information and education that helped them prepare for the role and supported them through it. Preference was given to obtaining information as early as possible, allowing reflection and the opportunity for questioning⁴⁵. Carers prioritised information which addressed physical aspects of care^{24,43,56} and without this carers felt unsure about what advice to ask health professionals^{37,43,52,56}. Signposting and information about services was often poor, leaving carers with a limited understanding of how to access helpful services^{29,33,34,44,46,50,52}. Consequently carers recognised that developing their communication skills could enhance their ability as a carer, especially when negotiating with health professionals or through the ‘system’ of care.

‘We don’t even know enough to know what to ask . . . But why do I have to try to ask all these questions to get an answer. Haven’t they [healthcare professionals] done that before to be able to just tell us what to do?’⁵² (Mixed)

Whilst a range of learning styles was adopted, self-education was the most prominent way carers obtained information^{41,48,49,55,56,58}. Information from written and web based resources was often sought to supplement or validate that given by health profes-

sionals³⁰. Information was sought both proactively, in order to prepare for what was going to happen, or reactively, in response to a crisis. Much learning occurred through trial and error; an approach particularly adopted when there was a perceived lack of support of health professionals⁵⁶. As greater care and decision-making responsibility was assumed, so the carers need for information grew⁴¹.

Management of symptoms & medicines

Understanding and managing patients' symptoms was central to carers having the confidence to continue their caring role at home. Information about symptom recognition or exacerbations was preferred prior to events occurring^{27,29,56,58}.

'..when it's the end of life that you're dealing with, it's not a good time for surprises'⁵³ (Cancer)

Lack of information on medicines was a key concern, with carers feeling ill-prepared to take on the task of administering them^{31,36,52,55,57}. Complex medication regimens were felt to increase the burden on carers and contributed to anxiety associated with caring³². As a result carers developed techniques to help them monitor, record and report medicines administration^{31,32}. For others, uncertainty led them to request more input from health professionals in order to get reassurance that they were 'doing the right thing'³¹. Where carers felt well informed, they described an increased confidence in medicines management, which enhanced decision making^{26,27}.

Administration of analgesia was a common cause of concern, particularly with regard to stronger painkillers and the titration of doses in response to escalating pain^{31,36,47,54}. Central to this concern was the potential for causing harm by accidentally over-dosing a patient with analgesia.

'How much can I do [administer pain medications] without hurting [the patient]? I think if a health professional would tell the caregivers...you can give one drop every 4 hours..or give a few parameters...What is the minimum? What is the maximum?'³¹ (Cancer)

Whilst pain was the main symptom discussed, uncertainty over management of other symptoms such as breathlessness in patients with heart failure⁴⁰; concerns about choking for patients with Parkinson's Disease⁴⁵; seizures, hallucinations and psychotic episodes for those people experiencing brain tumours^{24,29,55,56}; understanding patients' emotions³²; managing artificial nutrition and cachexia^{25,52} were also reported.

Information on how to manage acute exacerbations of illness was also required. Carers talked of how they strove to maintain a sense of competency and coping, but described how each exacerbation eroded this⁴². Being prepared by health professionals in anticipation of exacerbations was welcomed and led to reduced contact with professionals for advice and acute presentations at hospital^{36,39,42,43}.

When an exacerbation did occur, carers stated that their information needs focussed on the immediacy of the moment, and the uncertainty around the reversibility of the event^{39,42}. Where

information on managing acute events had been given to carers they felt more confident in their ability to cope with the situation that unfolded before them⁴³.

The processes around dying, bereavement and rebuilding their lives after the death of a patient

As diseases progressed carers wanted information on the processes around dying and how to prepare for and manage bereavement and a life after caring. The importance of receiving information about what to expect during the dying phase was seen as crucial by carers, who believed it helped them overcome their fears^{45,52,56}.

'I would have been horrified if I hadn't been forewarned [about the dying phase]'²⁹ (Cancer)

Studies which involved interviews with bereaved carers included descriptions of information carers would have found helpful in preparation for bereavement^{45,48,53,55,57}. Generally carers described the hard work of grief and most felt that bereavement support should be offered to all. Their experiences of caring, both good and bad, stayed with them and shaped how bereavement progressed^{48,55,57}. Carers would have welcomed information, prior to death on the practical aspects associated with the death of a family member, such as funeral planning, registration of death and management of finances⁵³.

Carers were astute to how their lives would change once their caring role ceased once a patient died. Lives were put on hold whilst they adopted the role of carer, knowing this was for a finite period⁴². Where the interviewees were already bereaved, the difficult transition from active to bereaved carer was described, where feelings of being at a loss without caring were pronounced. Information on how to rebuild lives without their caring role was wanted^{42,48,54,55}.

Enabling the carer

Throughout the trajectory of illness some aspects of information giving and education enabled carers to manage their caring role, whilst others acted as barriers; commonly carers experienced both. Timely access to information and support appeared to enable carers to fulfil their role; lack of both added to the burden of caring.

Carers roles

The roles adopted by carers included being an advocate, decision maker, an expert carer, trainer and navigator of services. Carers did not generally take on these roles through choice *per se*, but because they sensed no one else was 'looking out' for the patient. Carers described a constant burden of advocacy, which was fuelled by fear that basic care needs would be neglected if they were not present with the patient^{47,49,57}.

'And you are there when she is calling for the nurse and the nurse doesn't respond. And you are thinking if they are not doing it while I am here, being the advocate, what are they doing when I'm not here?'⁵⁷ (Mixed)

In hospital, carers became the manager of patients' care because there were no perceived advocates. Staff seemed not to

understand patients' needs^{24,34,42,47,49,57}. Carers knew they had developed a high-level of expertise and tacit knowledge through their time as carers, and so felt best placed to be the patient's advocate^{26,49}. They also recognised the need to fight for the patient's best interest within the health care system, a fight which required persistence and energy^{29,31}.

*'Doctors are too busy, the nurses are too busy to be an advocate for a particular person, so the caregiver is the advocate and you've got to watch every single thing.'*³⁴ (Cancer)

At home, carers took on similarly watchful roles ensuring that visiting formal carers were able to care for the patient. Carers were often required to 'train' the formal carers, an onerous task due to the lack of continuity among staff and one which could ultimately cause a carer to refuse external care. In addition to caring for the patient, carers reported a wider role of being providers of information to wider family networks, a role which also required support and information from health professionals^{29,30,32,43,56}.

Carers commonly felt that they were forced into a role of negotiating access to services on behalf of the patient. Uncertainty over how to do this was compounded by a lack of knowledge of 'what to ask for'. Information seeking was time consuming and affected time spent in the caring role^{24,37,52,56}. Uncertainty regarding how access to services, confusion over the roles carried out by different health professionals and lack of availability of equipment such as hospital beds and hoists, added to carers sense of isolation and lack of support. Carers considered that the responsibility for negotiating on behalf of the patient was solely theirs^{29,39,48,49,42-44,54}.

The importance of professional relationships

The quality of the relationship between health professionals (either individually or as part of team) and the carer was a key influence on carers' perceptions of their caring experience. Positive relationships relieved the burden of caring. At the core of these relationships was good quality communication. Timely access to health professionals, particularly contact by telephone, provided a sense of security for carers, facilitating a more positive experience of caring (Funk *et al.* 2009, Royak-Schaler *et al.* 2006)^{29,34}. Alongside this, access to specialist services especially at short notice and when need was greatest, ensured carers felt supported in their caring role (Funk *et al.* 2009, Hudson *et al.* 2006, O'Brien *et al.* 2012)^{29,30,43}.

*'We've got two Parkinson's nurse-specialists who are absolutely brilliant....they would be the people I would go to, to help me through the maze of what to do; and I would be looking to them for leadership'*⁴⁵ (Neurological)

Proactive advice and help from health professionals, anticipating both patients' and carers' needs added to the sense of perceived support^{29,57}. Carers highlighted many ways in which this occurred, including anticipation of pain control, need for respite, the guidance of decision making and health professionals

making contact without prompting^{29,30,41,43,48,50,58}. Regular communication and information giving, through phone contact or quick 'check-ins', alongside more formal planned meetings were the most highly valued modes of communication^{52,58}.

Carers valued health professionals placing the whole family rather than the individual patient at the centre of care. This was achieved by giving time to answer questions, checking understanding, giving choice as to how information was communicated^{28,31,34,37,41,53,57}. Consistency and accuracy of information across all providers of care was also highly valued^{34,56}. Good communication of information underpinned the sense of trust that carers had in health professionals^{29,45,53}.

*'I think the key to me dealing with my father's death was the degree to which information was shared with me and the timeliness of the sharing, and perhaps the compassion with which that was communicated'*⁵⁷ (Mixed)

Overall, positive relationships with health professionals, facilitated through timely access, compassionate communication and pro-active support, relieved the burden of caring.

Equally, health professionals acted as barriers, restricting access to the information required by carers to carry out their role. Poor communication from professionals was central to this. Information given by health professionals needed to be easily comprehensible, delivered in a language and at a level appropriate for the recipient. If this did not occur, carers were left in a position of feeling un-informed and confused^{38,39,40,52,55}.

*'I'm sure [the house officer] is quite talented, but I understood nothing they said'*⁵⁵ (Mixed)

Carers described situations in which health professionals communicated insensitively^{28,31,33,34,37,40,46,48}.

*'He told me the [cancer diagnosis] on the phone and I asked him . . . what is multiple myeloma, and I remember him saying, 'ugh, if I explain it to you, I could be on the phone for an hour . . . you still wouldn't understand''*²⁸ (Cancer)

The impact of this was great and carers were left feeling isolated as the trust they had in health professionals was reduced as a result of poor or insensitive communication^{28,34,37,40,46,48}.

*'Doctors do not realise that one day your life is just normal and then this comes and smashes everything to bits, you know'*⁴⁰ (Heart failure)

Consistency of information was of central importance. It was vital that information given by professionals remained constant across all professional groups and that when care or treatment was proposed, it then happened^{28,34,52,56,58}. Inconsistent information left carers in a position of deciphering for themselves the best course of action to take^{29,56}.

'I have to say that the hospital staff were all very caring, but I felt that we got a lot of conflicting information and they didn't always do what they said they were going to do'³⁴ (Cancer)

Carers particularly spoke of receiving contradictory communication with regard to whether treatment was curative or palliative; leaving them struggling to comprehend the seriousness of the situation they were facing^{28,37}.

'This one is telling us this and that one was telling us something else. We're going to radiation every day to shrink it... if we shrink it enough he's ...going to do surgery and this nurse is saying "Oh no, we're just making him comfortable"'³⁷ (Cancer)

Experiences of a sense of power imbalance between carers and health professionals were described in a number of ways. Frustration was caused when carers had actively sought information and health professionals failed to respond to these requests in a timely way^{29,31,33,58}.

'...routine phone calls, I found that they were not really prompt in calling me back if I had a question. Like I called one Monday and the doctor called me back the next Monday'³¹ (Cancer)

Carers also described struggling to make themselves heard, repeatedly trying to bring concerns to the attention of medical staff which were ignored²⁹. It was considered that their role as carers was not always appropriately acknowledged by health professionals. The intimate and nuanced knowledge that a carer builds up through the course of caring, was often unrecognised within the hospital setting and carers became wary of asserting their knowledge for fear of reprisal^{31,49}.

'They should really treat you as someone other than the person who drove the car'³¹ (Cancer)

Carers additionally required education and support for the role they were undertaking. Often they did not see themselves as legitimate recipients of support; gentle persuasion by health professionals could help facilitate this. There was awareness among carers of the need for psychosocial support due to the emotional consequences of caring for someone who was dying^{39,40,42,43,45,54,55,57}. Many felt isolated by their caring role and had few opportunities to talk to others in similar situations. Carers needed to be signposted to group support and counselling by health professionals. Those who had accessed such support found it extremely helpful^{39,42,43,45,55}.

Discussion and conclusion

The review explored a rich seam of qualitative research, documenting the experiences of over 900 carers providing care at the end life to patients with a range of life limiting conditions. This has enabled insights to be developed to inform research, practice and educational policy. Whilst there were some occasional small differences between experiences of carers across conditions, the findings overwhelming represent common themes across the different illness types and across an international range of literature.

There were some limitations as to what could be achieved through the review. Both the inconsistency and quality of the reporting of demographic data in the primary studies and the lack of attribution of findings to different types of carers in the primary studies meant we were unable to determine whether information needs vary within different caring relationships, (i.e. spouse, adult child), or to establish whether age, gender, social class and ethnicity influence caring relationships and therefore require different educational interventions.

Where demographic data were reported in studies, carers were predominantly female and a high proportion was spousal. Data from the UK show this is broadly representative of the population of carers with 58% of all carers being female⁵⁹ and over a quarter of carers caring for a spouse or partner⁶⁰. Many of the findings seem to broadly apply irrespective of ethnic, social-economic or gender differences. A further limitation was the difficulty in distinguishing between professional groups in carers' descriptions. As a result the generic term 'health professional' was used throughout the findings.

The key insights that have been gained from the review are:

- Carers have information and educational needs at all points in the illness trajectory. These needs fluctuate as carers are required to adapt to the changes to their role caused by progressing illness
- Throughout the course of an illness carers experience health professionals acting as both barriers & facilitators to the provision of information and education, thereby affecting their ability to manage their caring role
- Timely access to information and support, particularly out of hours, from appropriately qualified health professionals facilitates carers to feel confident in managing care
- Information provision which is delivered compassionately, is consistent and accurate, facilitates a sense of control and coping
- Carers need support from health professionals to prioritise caring for themselves
- Lack of information and support, un-facilitated access to services and delayed responses to requests for information from health professionals add to the burden of caring
- Carers describe the burden of advocacy, initiated by experiences of low standards of care, coupled with feeling marginalised within formal health care settings

Implications for research

Whilst the review identified a large number of papers related to carers' experiences of caring for people with cancer, there were relatively few studies exploring heart failure, dementia, neurological conditions and renal failure. Whilst the findings from the review were consistent across disease types, more nuanced differences may have been identified if there had been greater representation. Due to limitations in reporting in the primary studies it was impossible to establish the influence of age, gender, social class and ethnicity on the expectations of caring

relationships. Priorities for research are therefore to: establish carers' experiences of caring for patients with conditions other than cancer and to determine the influence of demographic characteristics on the caring role. Additionally, future research looking at consistency between carers and "cared for" perspectives will help establish the how patients view the sharing of information, which is important for carers (e.g. prognostic information).

Implications for education

There are significant educational implications for the health care workforce arising from the review. The quality of health professionals' communication with carers and patients was fundamental in ensuring carers felt confident and supported in their role. Central to this is professionals having the confidence and skills to engage in end-of-life conversations with patients and carers. The findings resonate with recent policy advances which advocate that health care is provided by those who are capable of delivering effective, compassionate care. It is also emphasised that workforce education should reflect the central role that carers play^{61,62}. Additionally education and training in care of the dying should be given to all staff caring for dying patients, including communication skills training⁶³.

Implications for practice

Timely access to information and support for carers, including during the out of hours period, from appropriately qualified health professionals should be a priority for those developing and commissioning services. Further collaboration between carers' organisations and statutory services should occur to help identify, monitor and support patients during the last year

of life, whilst ensuring that these organisations have the skills to support carers at the end of life.

Carers of people with advanced progressive disease have extensive educational and information needs throughout the trajectory of illness. There are certain points during an illness at which information and education is particularly relevant. Health professionals variously act as facilitators to, or barriers against, effective information giving, which in turn enables or hinders carers in their role.

Data availability

All data underlying the results are available as part of the article and no additional source data are required.

Reporting guidelines

The paper is reported as per ENTREQ guidelines²¹. DOI: <https://doi.org/10.17605/OSF.IO/Q9N7K22>.

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References

- Department of Health: **End-of-life care Strategy – promoting high quality care for all adults at the end of life**. London, Department of Health, 2008. [Reference Source](#)
- Scottish Government Health Department: **Living and dying well: A national action plan for palliative and end of life care in Scotland**. Edinburgh, Scottish Government, 2008. [Reference Source](#)
- Gomes B, Calanzani N, Higginson IJ: **Local preferences and place of death in regions within England 2010**. London, Cicely Saunders International, 2011. [Reference Source](#)
- Currow DC, Burns C, Agar M, *et al.*: **Palliative caregivers who would not take on the caring role again**. *J Pain Symptom Manage*. 2011; 41(4): 661–672. [PubMed Abstract](#) | [Publisher Full Text](#)
- Davies E, Higginson I: **Better Palliative care for Older People**. Copenhagen, The WHO Regional Office for Europe, 2004. [Reference Source](#)
- Carter PA, Chang BL: **Sleep and depression in cancer caregivers**. *Cancer Nurs*. 2000; 23(6): 410–415. [PubMed Abstract](#) | [Publisher Full Text](#)
- Boyd K, Murray SA: **Recognising and managing key transitions in end of life care**. *BMJ*. 2010; 341: c4863. [PubMed Abstract](#) | [Publisher Full Text](#)
- Delamothe T, Knapp M, Richardson E: **We're all going to die. Deal with it**. *BMJ*. 2010; 341: c5028. [PubMed Abstract](#) | [Publisher Full Text](#)
- Sörensen S, Pinquart M, Duberstein P: **How effective are interventions with caregivers? An updated meta-analysis**. *Gerontologist*. 2002; 42(3): 356–72. [PubMed Abstract](#) | [Publisher Full Text](#)
- Harding R, Higginson IJ: **What is the best way to help caregivers in cancer and palliative care? A systematic literature review of interventions and their effectiveness**. *Palliat Med*. 2003; 17(1): 63–74. [PubMed Abstract](#) | [Publisher Full Text](#)
- Northouse LL, Katapodi MC, Song L, *et al.*: **Interventions with family caregivers of cancer patients: meta-analysis of randomized trials**. *CA Cancer J Clin*. 2010; 60(5): 317–39. [PubMed Abstract](#) | [Publisher Full Text](#) | [Free Full Text](#)
- Candy B, Jones L, Drake R, *et al.*: **Interventions for supporting informal caregivers of patients in the terminal phase of a disease**. *Cochrane Database Syst Rev*. 2011; (6): CD007617. [PubMed Abstract](#) | [Publisher Full Text](#)
- Grande G, Stajduhar K, Aoun S, *et al.*: **Supporting lay carers in end of life care: current gaps and future priorities**. *Palliat Med*. 2009; 23(4): 339–344. [PubMed Abstract](#) | [Publisher Full Text](#)
- Stajduhar KI, Davies B: **Variations in and factors influencing family members' decisions for palliative home care**. *Palliat Med*. 2005; 19(1): 21–32. [PubMed Abstract](#) | [Publisher Full Text](#)
- Flemming K: **The synthesis of qualitative research and evidence-based nursing**. *Evid Based Nurs*. 2007; 10(3): 68–71. [PubMed Abstract](#) | [Publisher Full Text](#)
- Flemming K, Briggs M: **Electronic searching to locate qualitative research: evaluation of three strategies**. *J Adv Nurs*. 2007; 57(1): 95–100. [PubMed Abstract](#) | [Publisher Full Text](#)
- Department of Health: **Caring for someone**. (June 2011, Accessed 1 September 2015). [Reference Source](#)
- Hawker S, Payne S, Kerr C, *et al.*: **Appraising the evidence: reviewing disparate**

- data systematically. *Qual Health Res.* 2002; 12(9): 1284–1299.
[PubMed Abstract](#) | [Publisher Full Text](#)
19. Noblit G, Hare R: **Meta-ethnography: Synthesising Qualitative Studies.** London, Sage Publications Inc. 1988.
[Publisher Full Text](#)
 20. Atlas-ti: **Atlas-ti Scientific Software Development GmbH.** Berlin, Germany. 2010.
 21. Tong A, Flemming K, McInnes E, et al.: **Enhancing transparency in reporting the synthesis of qualitative research: ENTREQ.** *BMC Med Res Methodol.* 2012; 12: 181.
[PubMed Abstract](#) | [Publisher Full Text](#) | [Free Full Text](#)
 22. Flemming K: **Adult Family Carers' Perceptions of Their Educational Needs When Providing End-of-Life Care: A Systematic Review of Qualitative Research.** *OSF Web.* 2018.
 23. Britten N, Pope C: **Medicine taking for asthma: a worked example of meta-ethnography.** In: Hannes K & Lockwood C (eds). *Synthesising Qualitative Research: Choosing the right Approach*, Oxford, BMJ Books/Wiley Blackwell, 2012; 41–57.
[Publisher Full Text](#)
 24. McConigley R, Halket G, Lobb E, et al.: **Caring for someone with high-grade glioma: a time of rapid change for caregivers.** *Palliat Med.* 2010; 24(5): 473–479.
[PubMed Abstract](#) | [Publisher Full Text](#)
 25. Reid J, McKenna H, Fitzsimons D, et al.: **An exploration of the experience of cancer cachexia: what patients and their families want from healthcare professionals.** *Eur J Cancer Care (Engl).* 2010; 19(5): 682–689.
[PubMed Abstract](#) | [Publisher Full Text](#)
 26. Mehta A, Cohen R, Carnevale FA, et al.: **Family caregivers of palliative cancer patients at home: the puzzle of pain management.** *J Palliat Care.* 2010; 26(2): 184–193.
[PubMed Abstract](#) | [Publisher Full Text](#)
 27. Mehta A, Cohen R, Carnevale FA, et al.: **Strategizing a game plan: family caregivers of palliative patients engaged in the process of pain management.** *Cancer Nurs.* 2010; 33(6): 461–469.
[PubMed Abstract](#) | [Publisher Full Text](#)
 28. Carter PA: **A not-so-silent cry for help. Older female cancer caregivers' need for information.** *J Holist Nurs.* 2011; 19(3): 271–284.
[PubMed Abstract](#) | [Publisher Full Text](#)
 29. Funk LM, Allan DE, Stajduhar KI: **Palliative family caregivers' accounts of health care experiences: the importance of "security".** *Palliat Support Care.* 2009; 7(4): 435–447.
[PubMed Abstract](#) | [Publisher Full Text](#)
 30. Hudson P, Aranda S, McMurray N: **Intervention development for enhanced lay palliative caregiver support - the use of focus groups.** *Eur J Cancer Care (Engl).* 2002; 11(4): 262–270.
[PubMed Abstract](#) | [Publisher Full Text](#)
 31. Kimberlin C, Brushwood D, Allen W, et al.: **Cancer patient and caregiver experiences: communication and pain management issues.** *J Pain Symptom Manage.* 2004; 28(6): 566–578.
[PubMed Abstract](#) | [Publisher Full Text](#)
 32. Lau DT, Berman R, Halpern L, et al.: **Exploring factors that influence informal caregiving in medication management for home hospice patients.** *J Palliat Med.* 2010; 13(9): 1085–90.
[PubMed Abstract](#) | [Publisher Full Text](#) | [Free Full Text](#)
 33. Rose KE: **A qualitative analysis of the information needs of informal carers of terminally ill cancer patients.** *J Clin Nurs.* 1999; 8(1): 81–88.
[PubMed Abstract](#) | [Publisher Full Text](#)
 34. Royak-Schaler R, Gadalla S, Lemkau J, et al.: **Family perspectives on communication with healthcare providers during end-of-life cancer care.** *Onc Nurs Forum.* 2006; 33(4): 753–760.
[PubMed Abstract](#) | [Publisher Full Text](#)
 35. Schumacher KL, Koresawa S, West C, et al.: **Putting cancer pain management regimens into practice at home.** *J Pain Symptom Manage.* 2002; 23(5): 369–382.
[PubMed Abstract](#) | [Publisher Full Text](#)
 36. Smith AK, Schonberg MA, Fisher J, et al.: **Emergency department experiences of acutely symptomatic patients with terminal illness and their family caregivers.** *J Pain Symptom Manage.* 2010; 39(6): 972–981.
[PubMed Abstract](#) | [Publisher Full Text](#) | [Free Full Text](#)
 37. Waldrop DP, Meeker MA, Kerr C, et al.: **The nature and timing of family-provider communication in late-stage cancer: a qualitative study of caregivers' experiences.** *J Pain Symptom Manage.* 2012; 43(2): 182–194.
[PubMed Abstract](#) | [Publisher Full Text](#)
 38. Harding R, Selman L, Beynon T, et al.: **Meeting the communication and information needs of chronic heart failure patients.** *J Pain Symptom Manage.* 2008; 36(2): 149–156.
[PubMed Abstract](#) | [Publisher Full Text](#)
 39. Hupcey JE, Fenstermacher K, Kitko L, et al.: **Palliative Needs of Spousal Caregivers of Patients with Heart Failure Followed at Specialized Heart Failure Centers.** *J Hosp Palliat Nurs.* 2011; 13(3): 142–150.
[PubMed Abstract](#) | [Publisher Full Text](#) | [Free Full Text](#)
 40. Imes CC, Dougherty CM, Pypser G, et al.: **Descriptive study of partners' experiences of living with severe heart failure.** *Heart Lung.* 2011; 40(3): 208–216.
[PubMed Abstract](#) | [Publisher Full Text](#) | [Free Full Text](#)
 41. Sanford J, Townsend-Rocchiccioli J, Madison J, et al.: **A process of decision making by caregivers of family members with heart failure.** *Res Theory Nurs Pract.* 2011; 25(1): 55–70.
[PubMed Abstract](#) | [Publisher Full Text](#)
 42. Dawson S, Kristjanson LJ: **Mapping the journey: family carers' perceptions of issues related to end-stage care of individuals with muscular dystrophy or motor neurone disease.** *J Palliat Care.* 2003; 19(1): 36–42.
[PubMed Abstract](#)
 43. O'Brien MR, Whitehead B, Jack BA, et al.: **The need for support services for family carers of people with motor neurone disease (MND): views of current and former family caregivers a qualitative study.** *Disabil Rehabil.* 2012; 34(3): 247–256.
[PubMed Abstract](#) | [Publisher Full Text](#)
 44. Giles S, Miyasaki J: **Palliative stage Parkinson's disease: patient and family experiences of health-care services.** *Palliat Med.* 2009; 23(2): 120–125.
[PubMed Abstract](#) | [Publisher Full Text](#)
 45. Hudson PL, Toye C, Kristjanson LJ: **Would people with Parkinson's disease benefit from palliative care?** *Palliat Med.* 2006; 20(2): 87–94.
[PubMed Abstract](#) | [Publisher Full Text](#)
 46. Gessert CE, Forbes S, Bern-Klug M: **Planning end-of-life care for patients with dementia: roles of families and health professionals.** *Omega (Westport).* 2001; 42(4): 273–291.
[PubMed Abstract](#) | [Publisher Full Text](#)
 47. Thune-Boyle ICV, Sampson EL, Jones L, et al.: **Challenges to improving end of life care of people with advanced dementia in the UK.** *Dementia.* 2010; 9(2): 259–284.
[Publisher Full Text](#)
 48. Hasson F, Spence A, Waldron M, et al.: **Experiences and needs of bereaved carers during palliative and end-of-life care for people with chronic obstructive pulmonary disease.** *J Palliat Care.* 2009; 25(3): 157–163.
[PubMed Abstract](#) | [Publisher Full Text](#)
 49. Hynes G, Stokes A, McCarron M: **Informal care-giving in advanced chronic obstructive pulmonary disease: lay knowledge and experience.** *J Clin Nurs.* 2012; 21(7–8): 1068–1077.
[PubMed Abstract](#) | [Publisher Full Text](#)
 50. Spence A, Hasson F, Waldron M, et al.: **Active carers: living with chronic obstructive pulmonary disease.** *Int J Palliat Nurs.* 2008; 14(8): 368–372.
[PubMed Abstract](#) | [Publisher Full Text](#)
 51. Curtis JR, Enegberg R, Young JP, et al.: **An approach to understanding the interaction of hope and desire for explicit prognostic information among individuals with severe chronic obstructive pulmonary disease or advanced cancer.** *J Palliat Med.* 2008; 11(4): 610–620.
[PubMed Abstract](#) | [Publisher Full Text](#)
 52. Herbert RS, Schulz R, Copeland V, et al.: **What questions do family caregivers want to discuss with health care providers in order to prepare for the death of a loved one? An ethnographic study of caregivers of patients at end of life.** *J Palliat Med.* 2008; 11(3): 476–483.
[PubMed Abstract](#) | [Publisher Full Text](#)
 53. Herbert RS, Schulz R, Copeland VC, et al.: **Preparing family caregivers for death and bereavement. Insights from caregivers of terminally ill patients.** *J Pain Symptom Manage.* 2009; 37(1): 3–12.
[PubMed Abstract](#) | [Publisher Full Text](#)
 54. Kalins I: **Caring for the terminally ill: experiences of Latvian family caregivers.** *Int Nurs Rev.* 2006; 53(2): 129–135.
[PubMed Abstract](#) | [Publisher Full Text](#)
 55. Sherwood PR, Given BA, Doorenbos AZ, et al.: **Forgotten voices: lessons from bereaved caregivers of persons with a brain tumour.** *Int J Palliat Nurs.* 2004; 10(2): 67–75; discussion 75.
[PubMed Abstract](#) | [Publisher Full Text](#)
 56. Stajduhar KL, Funk L, Outcalt L: **Family caregiver learning—how family caregivers learn to provide care at the end of life: a qualitative secondary analysis of four datasets.** *Palliat Med.* 2013; 27(7): 657–664.
[PubMed Abstract](#) | [Publisher Full Text](#)
 57. Teno JM, Casey LV, Welch CA, et al.: **Patient-focused, family-centered end-of-life medical care: views of the guidelines and bereaved family members.** *J Pain Symptom Manage.* 2001; 22(3): 738–752.
[PubMed Abstract](#) | [Publisher Full Text](#)
 58. Waldrop DP: **Caregiving systems at the end of life: How informal caregivers and formal providers collaborate.** *Fam Soc.* 2006; 87(3): 427–437.
[Publisher Full Text](#)
 59. Office for National Statistics: **Inequalities in the provision of unpaid care in England and Wales.** (2013, accessed 5 September 2015).
[Reference Source](#)
 60. The NHS Information Centre, Social Care Team: **Survey of Carers in Households 2009/10.** London, The Health and Social Care Information Centre, 2010.
[Reference Source](#)
 61. Department of Health: **Delivering high quality, effective, compassionate care: Developing the right people with the right skills and the right values: A mandate from the Government to Health Education England: April 2014 to March 2015.** London, Department of Health, 2014.
 62. Neuberger J: **More care, less pathway: A review of the Liverpool Care Pathway.** London, Department of Health, 2013.
[Reference Source](#)
 63. Royal College of Physicians: **National care of the dying audit for hospitals, England.** London, Royal College of Physicians, 2014.
[Reference Source](#)

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Emma Carduff

Marie Curie Hospice, Glasgow, UK

This well-written paper reports a meta-ethnography of qualitative evidence which described the educational needs of carers providing care to patients at the end of life. This is certainly a valuable area of study and the paper makes a valuable contribution to the overall body of evidence. Meta-ethnography is an appropriate methodology to address the question and the authors have described and justified the methods well. The literature searches are adequately reported and are replicable.

However, the searches are now 5 years old. The body of literature on caring at the end of life has grown rapidly over this time and there may be new themes and theories to include. This is an important area for research and the findings are directly applicable to practitioners. With this in mind, it would be very useful if the authors could update the literature search to include the most recent evidence. I also note that some of the quality scores are missing from table 3 - could the authors elaborate on why this is and what impact it may have on the findings.

Are the rationale for, and objectives of, the Systematic Review clearly stated?

Yes

Are sufficient details of the methods and analysis provided to allow replication by others?

Yes

Is the statistical analysis and its interpretation appropriate?

Yes

Are the conclusions drawn adequately supported by the results presented in the review?

Yes

Competing Interests: No competing interests were disclosed.

Reviewer Expertise: Palliative care - Caregivers of people at the end of life

I confirm that I have read this submission and believe that I have an appropriate level of expertise to confirm that it is of an acceptable scientific standard, however I have significant reservations, as outlined above.

Reviewer Report 03 June 2019

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Gunn Grande

School of Social Sciences, University of Manchester, Manchester, UK

This is a good quality review that synthesises a wide range of qualitative literature in a clear, accessible manner.

The search strategy seems very thorough, and is transparent and replicable. The selection of studies is very clear.

Some more explanation of how 'education' and 'educational needs' were defined would help, as these concepts are central to the aims of the review.

There may be a heading missing for 'Information on acute acerbations' on page 18(?)

The authors have done a good and comprehensive job of synthesising a vast amount of material into meaningful themes, although boundaries become a bit fluid at times and move beyond educational needs. However, this also reflects the complexity of carers' situation. I perhaps gained less insight than expected into carers' educational needs as such, but the paper clearly improves our understanding of the context and challenges relating to educational and information needs for carers in a broader sense.

A concern regarding the paper is that the review is limited to literature published in 2014 and earlier, so important literature from recent years may be missed. The authors may consider addressing this through an update or provide justification for this not being necessary.

Are the rationale for, and objectives of, the Systematic Review clearly stated?

Yes

Are sufficient details of the methods and analysis provided to allow replication by others?

Yes

Is the statistical analysis and its interpretation appropriate?

Not applicable

Are the conclusions drawn adequately supported by the results presented in the review?

Yes

Competing Interests: No competing interests were disclosed.

Reviewer Expertise: Palliative care research with focus on carers.

I confirm that I have read this submission and believe that I have an appropriate level of expertise to confirm that it is of an acceptable scientific standard, however I have significant reservations, as outlined above.

Reviewer Report 06 March 2019

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Nancy Preston 

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This is an interesting question and good choice of method.

This is a very good example of how to write up a review using meta-ethnography. The methods could have been improved by explaining how the quality score was used in the review except adding to the table (some of the quality scores are missing in the final column).

The main limitation of the paper is the search was conducted in January 2014 which makes it very out of date. Various relevant studies are been published since this date.

Clear conclusions and recommendations for practice.

Are the rationale for, and objectives of, the Systematic Review clearly stated?

Yes

Are sufficient details of the methods and analysis provided to allow replication by others?

Yes

Is the statistical analysis and its interpretation appropriate?

Yes

Are the conclusions drawn adequately supported by the results presented in the review?

Yes

Competing Interests: No competing interests were disclosed.

Reviewer Expertise: Palliative care

I confirm that I have read this submission and believe that I have an appropriate level of expertise to confirm that it is of an acceptable scientific standard, however I have significant reservations, as outlined above.
