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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

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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 regions[3]. Key to the success of such policy initiatives and individual's preferences is the availability of family social support to care for people at home[4]. It is recommended that adult family carers of people requiring palliative care should be offered optimal support from health and social care professionals[5].

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 care[6]. 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 disease[1]. 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 help[7]. 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 diseases[8].

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 patient[13]. It is also important to recognise the difficulties associated with caregiving at the end of life, as family roles get blurred by providing physical care[14]. 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 not[15]. 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 diseas$.ti,ab. (516)
52	Rheumatic heart disease$.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 definition[17]. 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 research[18]. Disagreements in scoring were discussed and resolved by consensus.

Methods for synthesis

The synthesis was conducted using meta-ethnography[19]. 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 data[20].

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 synthesise[23]. 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 tumour[24], cancer cachexia[25] 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 or 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 bought 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
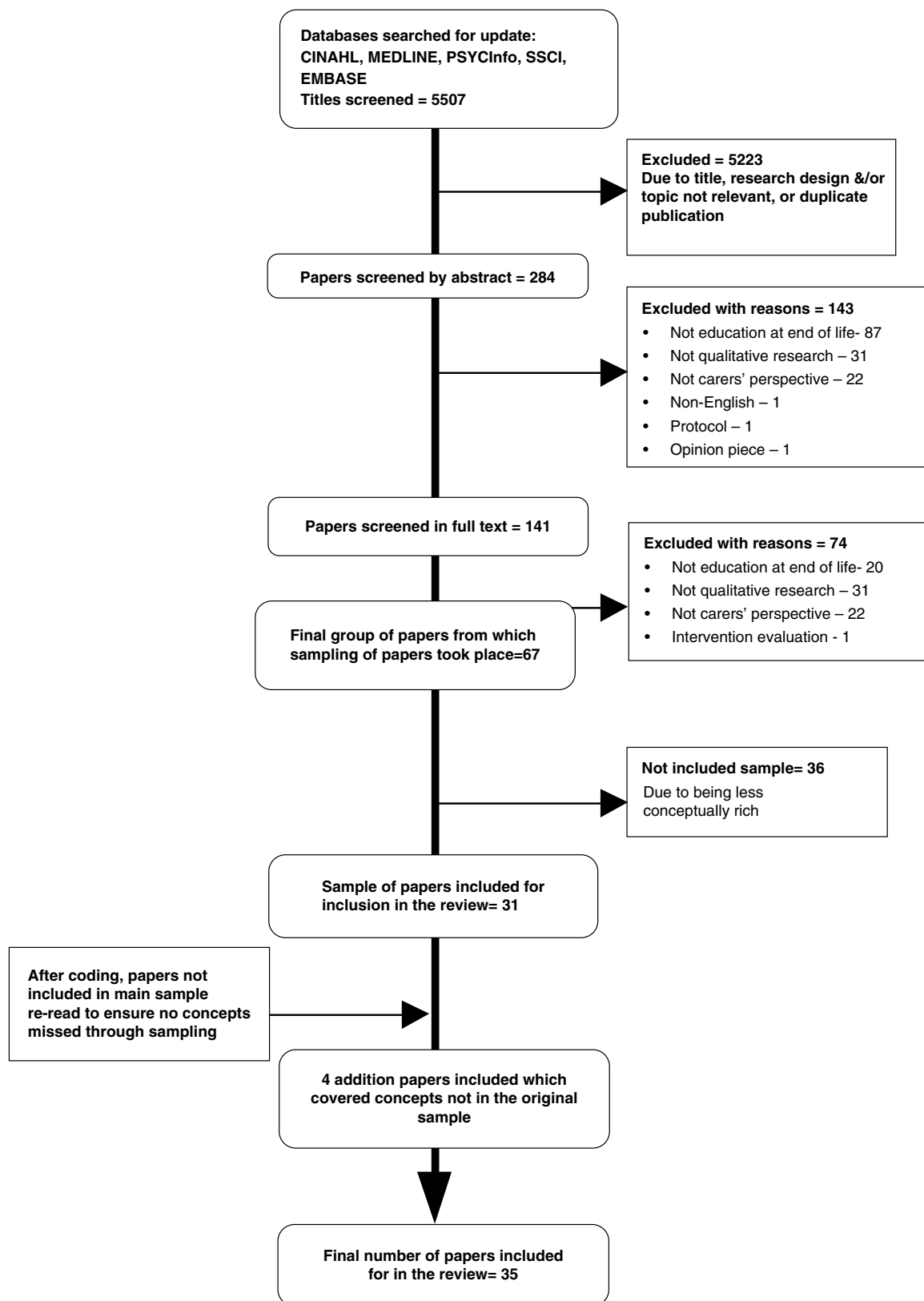
Figure 1. Flow chart of study inclusion. The numbers of studies identified through database searching, studies excluded (with reasons) and studies included in the review.

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 et al. (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 et al. (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 et al. (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 et al. (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 form 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 *et al.* (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. Difficultly 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 *et al.* (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 *et al.* (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 carers6-8 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 et al. (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-demongraphic 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 et al. (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 et al. (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 et al. (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 *et al.* (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 *Current carers* had been caring for between 1 month and 7.5 years 11 male *Former carers* 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 *et al.* (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 HPs and carers felt they had to watch over their relative during hospitalisations.	26
Spence, Hasson, Waldron *et al.* (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 *et al.* (2008)[51] USA	To examine the perspectives of patients, family, physicians,& nurses, on the simultaneous need for supporting hope and discussing prognosis	*Relevant to this review:* 36 family members of patients with either advanced cancer or severe COPD Mean age 60 (18 female) Spouse - 20 Relative – 12 Friend - 4	Qualitative Longitundinal 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 *et al.* (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 *et al.* (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 *et al.* (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 *et al.* (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
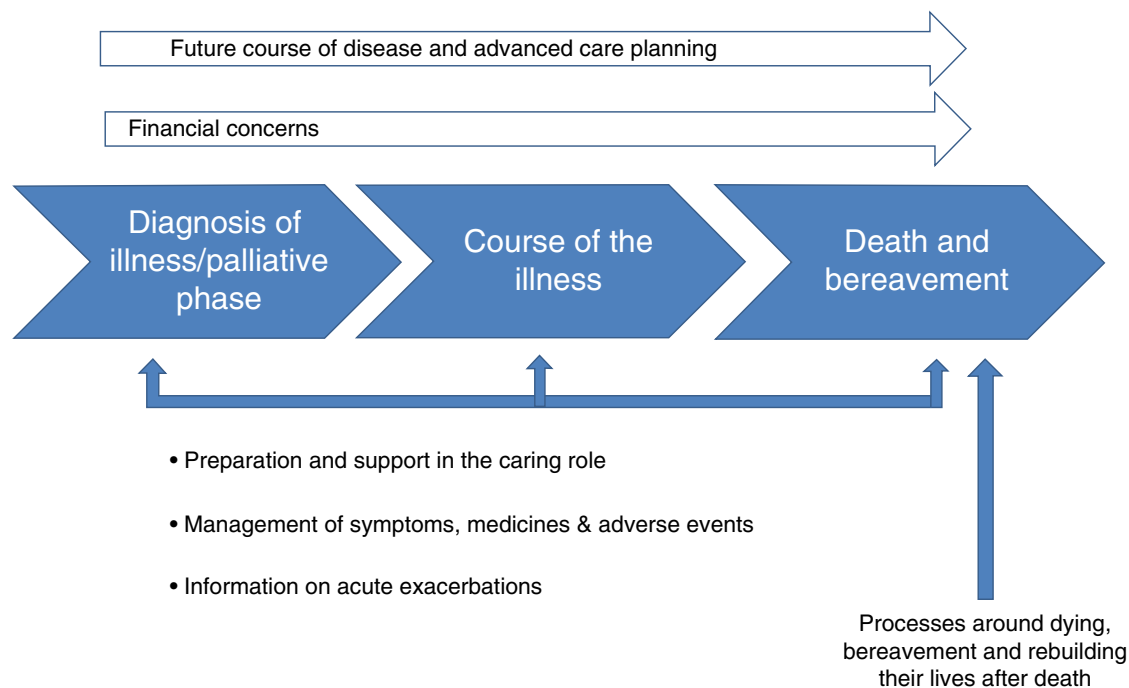
Figure 2. Trigger points for information. The way carers described their information and educational needs spanning across the disease trajectory is shown.

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 questioning[45]. 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-

sionals[30]. 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 professionals[56]. As greater care and decision-making responsibility was assumed, so the carers need for information grew[41].

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 caring[32]. 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 failure[40]; concerns about choking for patients with Parkinson's Disease[45]; seizures, hallucinations and psychotic episodes for those people experiencing brain tumours[24,29,55,56]; understanding patients' emotions[32]; 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 this[42]. 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 them[43].

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 finances[53].

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 period[42]. 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 ignored[29]. 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 female[59] and over a quarter of carers caring for a spouse or partner[60]. Many of the findings seem to broadly apply irrespective of ethnic, social-economic of 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 training[63].

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 guidelines[21]. DOI: https://doi.org/10.17605/OSF.IO/Q9N7K[22].

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Open Peer Review

Current Peer Review Status: ❓ ❓ ❓

Version 1

Reviewer Report 24 June 2019

❓

Emma Carduff (iD)

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

https://doi.org/10.21956/amrcopenres.13921.r26402

? **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

https://doi.org/10.21956/amrcopenres.13921.r26300

?   **Nancy Preston** iD

International Observatory on End of Life Care, Faculty of Health and Medicine, Lancaster University, Lancaster, UK

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.